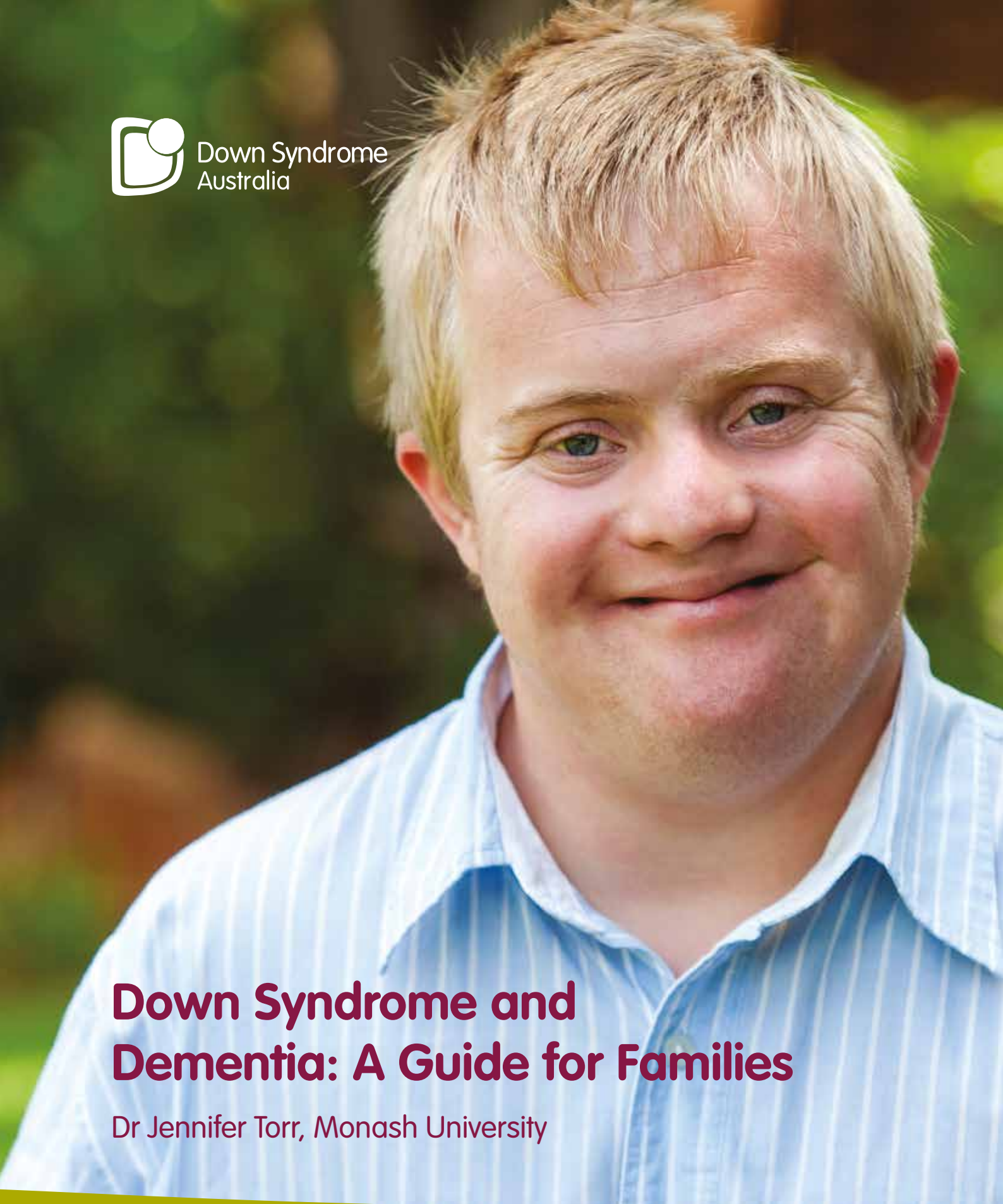

Down Syndrome Australia

Down Syndrome and Dementia: A Guide for Families

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This publication was developed through funding received from Dementia Australia

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Introduction

People with Down syndrome are living longer and healthier lives than ever before. In Australia most people with Down syndrome can now expect to live on average to 60 years of age, and more than one in ten adults with Down syndrome will live to 70 years. As we get older we are all prone to age related health conditions. Older adults with Down syndrome experience some age-related conditions at a younger age and more often than people in general.

Many people are not aware that there is a link between Down syndrome and dementia. People with Down syndrome are more likely to get dementia and on average at a younger age than other people in the population. While this may be confronting to know, it is also helpful to understand the links between health and lifestyle so that you can take action to reduce the risk of dementia, recognise the signs of dementia, and do what you can to support a person with Down syndrome if they do develop dementia.

This resource has been developed to inform and empower people supporting a person with Down syndrome to:

- Understand the links between lifestyle, health and dementia
- Promote healthy active living
- Support a person with Down syndrome and dementia
- Advocate for appropriate services and informed care.

Down Syndrome and Alzheimer's Disease

What is the Life Expectancy for a Person with Down Syndrome?

People with Down syndrome are living longer than ever before. One hundred years ago the life expectancy of a baby born with Down syndrome was about 10 years. As a result of improvements in general public health, and the development of vaccines and antibiotics, access to treatments for leukaemia and heart conditions, the life expectancy of people with Down syndrome has increased to 60 years. Today most people with Down syndrome enjoy good health and an active life.

What is 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. It causes a progressive change in brain function from normal functioning to mild changes in thinking and behaviour to dementia over 1-2 decades. Alzheimer's disease causes changes to the brain including the build-up of plaques and tangles in the brain, which results in loss of connections between brain cells as well as the loss of brain cells. Memory, other types of thinking and activities of daily living decline as the disease progresses. The brain changes of Alzheimer's disease can be present for many years before someone develops dementia.

How Many People with Down Syndrome Develop Dementia?

People with Down syndrome are more likely to develop dementia than other people in the population. Different 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.[1] It is uncommon for someone with Down syndrome to have dementia before the age of 45 years.

Why is Dementia so Common in People with Down Syndrome?

People with Down syndrome have 3 copies of chromosome 21, rather than the usual 2 copies*. Trisomy 21 changes the expression of genes on chromosome 21, as well as some genes on other chromosomes, which affects how the body develops and works. The amyloid protein

* A small percentage of people have partial forms of trisomy 21 (e.g. mosaic Down syndrome).

precursor (APP) gene which is involved in the development of Alzheimer's disease is located on chromosome 21. As a result, the APP protein is overproduced in people with Down syndrome which increases their likelihood of getting Alzheimer's disease.

Are Changes to Memory and Thinking Always a Sign of Dementia?

There are several other health and medical conditions that can have an impact on a memory, thinking and independence with activities of daily living. If you are concerned about changes in a person's thinking and abilities then it is important for them to be assessed for a range of other conditions including:

- infections
- sleep disturbances
- untreated thyroid disease
- a vitamin or mineral deficiency
- a mental health concern such as depression or anxiety
- problems with sight or hearing
- other physical and medical conditions
- effects of medications.

It is important to get advice from a health care professional as soon as possible to rule out any of these potentially reversible health issues that can cause memory changes.

Risk Reduction of Alzheimer's Disease and Healthy Ageing

There is good evidence from the general population that the risk of developing Alzheimer's disease can be reduced through adopting healthy lifestyles and treating medical risk factors. There has been very little research specifically on Down syndrome and dementia risk reduction. However, much of what is known about the general population could likely apply to people with Down syndrome as well.

This section provides an overview of how healthy living and addressing health issues might promote healthy ageing and brain health throughout the life span. In each section there are a series of actions which are suggested to help support risk reduction.

Healthy and Active Living

This section provides an overview of the links between lifestyle factors in maintaining brain health.

Healthy Eating

Diets low in saturated fat and high in antioxidant rich fruits and vegetables, and fish have been associated with better brain function and reduced risk of dementia. There is evidence that Omega-3 fatty acids promote neurological and vascular health.[2] Fish and fish oils are a rich source of omega-3 fatty acids. While the benefits of specific nutrients are not yet clear, what is good for the heart is thought to be also good for the brain. A healthy diet is likely to contribute to brain health and may reduce the risk of developing dementia.

- With regards to dietary supplements always seek medical advice. Supplements can be expensive and few have proven benefits. Adopting a nutritious and healthy diet is preferable to the use of supplements.
- People with Down syndrome may need some extra support in making good decisions about their diet. This might include education about preparing and planning for healthy eating choices and shopping for healthy foods. Advice from dietitians can be useful.

Exercise

Exercise is good for general health, improves bone health, increases strength and balance, and reduces the risk of falls and injuries. Exercise is also good for the brain. The research is still not clear what role exercise plays in brain health for people with Down syndrome.

Nonetheless, exercise also has general health benefits. Exercise can be helpful in reducing the impact of osteoarthritis for people with Down syndrome. Osteoarthritis of the hips and knees is common in people with Down syndrome, and can also affect the spine, neck and arms. Osteoarthritis causes pain and reduced mobility, leading to a loss of muscle mass and strength. A person with Down syndrome who has osteoarthritis may be distressed or irritable, become less independent and be less interested in activities that they had been involved with previously.[3]

People with Down syndrome tend to have low blood pressure, low heart rates and the heart rate doesn't increase as much with exercise. This might make exercise a lot harder and less fun.

- Encourage incidental exercise in other activities such as walking the dog, or a regular walk to local shops to get supplies or to post letters. Even housework can be beneficial e.g. sweeping, vacuuming, raking up leaves.
- Think of things that the person with Down syndrome will enjoy. Consider team sports, dance, or group or personal training.
- NDIS funding may be able to be used to support a person with Down syndrome to attend a gym or take part in sporting groups. It will only cover the additional costs of supports not the costs that others would need to pay. For example, a gym membership would not be covered but a support worker to assist the person in attending the gym may be covered.

Maintaining a Healthy Weight

Obesity is a risk factor for Alzheimer's disease (and vascular dementia) in the general population, especially obesity in middle age. Obesity is also associated with a range of other risk factors for dementia including sedentary life style, diabetes, high cholesterol and high blood pressure.

People with Down syndrome have higher rates of obesity but low rates of heart attacks and strokes – except for strokes due to congenital heart disease.[4] [5]

It is not known whether obesity is a risk factor for dementia in people with Down syndrome or not. Further research is needed.

Learning and Social Engagement

The brain is an intricate system of interconnected brain cells. Each brain cell has an axon with dendrites – like a tree trunk with branches – which form a web of connections. Physical and mental exercise has been found to strengthen the connections in the brain. The density of the connections increases with years of formal education. The number of connections declines in people with mild cognitive impairment and Alzheimer's disease.

At this time, there are no studies about how the connections between brain cells change in people with Down syndrome who are developing dementia, but it is most likely that the connections thin out.

It is likely that education and social engagement also help protect the brains of people with Down syndrome. Over time the average age for diagnosis of dementia in people with Down syndrome has been increasing from the younger 50s to the mid 50s. It may be the case that this is because people with Down syndrome have better opportunities including early intervention, pre-school, primary and secondary education and for some post school education and training.

People with Down syndrome should be supported to be life-long active learners and provided with active learning opportunities including:

- post-school education to further develop or apply literacy, numeracy and computing skills
- occupational training
- activities that provide both social, physical and mental engagement such as dance, drama, team sports, music, art, cooking

Activities should be designed to be challenging but achievable.

Health Care and Health Conditions

Managing your physical health and any chronic health conditions is a key factor in maintaining brain health and reducing your risk of dementia. This section provides a brief overview of some of the key health issues that relate to the development of dementia. It should be noted that there are other health conditions that may have an impact on risk of dementia which have not been included in this overview paper. As always, you should consult with your health professional to get advice that is relevant to your situation.

Access to Health Care

Many people with Down syndrome have complex health needs – trisomy 21 impacts upon the function of all body systems and increases the risk for some health conditions. With good health care and monitoring, many of the health concerns can be addressed or managed well.

Most people with Down syndrome require some support to access health care. Obtaining a history and reviewing the past health history are essential components of all health assessments. While the person with Down syndrome should participate in this discussion, clinicians will usually need to obtain additional information from someone who knows the person well and from written records.

- People with Down syndrome should have annual health assessments, relevant to their age and known health history.
- If someone with Down syndrome has sudden or significant changes over time in their abilities, emotional well-being and/or behaviour they should be assessed by their general practitioner, who might make a referral for allied health or specialist assessment. It is important to describe and document the best, or baseline, abilities of people with Down syndrome to help clinicians assess the nature and significance of these changes.
- Accurate and up to date health records should be maintained to inform assessment, diagnosis and treatment. One way of doing this is through the new My Health Record which will be available to all Australians from 2018. This e-health record can be used to document health information, baseline functioning, and families can provide tips to clinicians on how to best support the person with Down syndrome.

Stress

Chronic stress causes increases in a chemical in our body called cortisol. High levels of cortisol have been found to speed up progression to dementia in people who have a high risk for Alzheimer's disease[6]. Therefore, identifying and managing stress

is an important strategy for maintaining brain health. Some people with Down syndrome may find it difficult to cope with unpredictability or change or to adapt to new circumstances. Stressful events – such as the loss of loved ones or familiar people leaving, changes in where they live, their job and other things in their lives – can trigger depression and anxiety.

- **It is important to identify and address causes of stress and to minimise chronic stress by providing person-centred support, communication, emotional support, and training in relaxation.**

Depression

Depression is the most common psychiatric disorder in young people and adults with Down syndrome and can have a serious impact upon well-being and functioning. Depression is also a risk factor for dementia.

People with Down syndrome have low levels of certain chemicals in the brain which might explain why they have relatively high rates of depression, anxiety and obsessive compulsive behaviours. Treatment of depression with an antidepressant is evidence based and improves well-being, motivation, concentration and general functioning - and might also protect the brain.

Most people with Down syndrome who have depression respond to treatment with antidepressant medications. Psychological approaches are also helpful for depressive symptoms as well as anxiety, obsessive compulsive behaviours or loss of interest in past activities.

Treating depression in people with Down syndrome who have mild cognitive impairment or dementia can improve well-being and functioning. People with a history of depression who are treated with an antidepressant medication have lower risk for developing dementia than those who do not have treatment for depression.

- **If you have concerns about depression you should discuss this with the person's general practitioner. You could help with the assessment by completing the Depression in Adults with Intellectual Disability Checklist. This checklist gathers information about depressive symptoms and provides the doctor with some guidance about the diagnosis and treatment of depression. You will find a link to this Checklist at the back of this resource.**

- Sometimes serious depression, with decline in everyday functioning, is misdiagnosed as dementia, and the depression is not treated. If you are unsure about a diagnosis it is OK to question this – or to seek another opinion. Serious depression may require a referral to a psychiatrist or the local mental health service. People with Down syndrome have the same right as anyone else to access mental health services for serious mental illness. Mental health should be considered in the assessment process for dementia.

Obstructive Sleep Apnoea and Down Syndrome

People with Down syndrome have very high rates of obstructive sleep apnoea (OSA) due to differences in head and neck anatomy and poor muscle tone. In adults, but not children, obesity increases the severity of OSA. Some sleep apnoea is "central"– that is the brain "forgets" to breathe.[7]

OSA can have short-term and long-term health consequences. OSA can be well managed with the appropriate treatment which might improve daytime alertness, mood and cognitive functioning.[8]

Research shows that OSA increases the risk of developing dementia of Alzheimer's disease. This may be due to the sleep disruption causing an accumulation of a substance known as beta-amyloid which is known to be involved in Alzheimer's disease. There is also evidence that treatment of OSA with CPAP (continuous positive airways pressure) improves memory and thinking in people with dementia of Alzheimer's disease.[8]

- Proactive assessment for OSA is recommended. Screening for OSA should begin in childhood.
- Treatment with CPAP is safe, and effective if used correctly. Ongoing treatment with CPAP for people with OSA could potentially delay the onset of dementia.
- Psychological interventions are also available and this might help those who are reluctant to use CPAP for the treatment of OSA.

Diabetes

Diabetes is a major risk factor for Alzheimer's disease.[9, 10] Type I diabetes is an autoimmune disease and affects mostly children and young people. It is more common in people with Down syndrome. This type of diabetes is not preventable and requires lifelong insulin treatment. Type II diabetes is due to acquired resistance to insulin which is related to obesity. The prevalence of diabetes is high in older adults with Down syndrome and this might be related to higher rates of obesity in older adults.

- **Screening for diabetes should be routine in annual health assessments. If a person has diabetes it is important that the diabetes is managed with medications or insulin. Correct diet, maintaining a healthy weight and exercise are also important.**

Vitamin D

Vitamin D is produced by the skin with sunlight exposure and is also contained in certain foods including eggs, fish oils and dairy products. Vitamin D deficiency is common in the community and levels vary with the seasons.[11] [12]

Vitamin D deficiency (<50nmol/L) increases the risk for Alzheimer's disease. This risk increases with severe vitamin D deficiency (<25nmol/L) and decreases for vitamin D levels above 50nmol/L.[13]

- **Vitamin D levels should be checked in annual health assessments and deficiency corrected through the use of supplements under medical supervision. To ensure Vitamin D sufficiency levels should be >75nmol/L.[11]**

Cholesterol and Statins

In general, people have a lower risk of age related cognitive decline and dementia if they:

- have low cholesterol
- eat diets low in fat and cholesterol, or
- are treated with statins (medications used to treat high cholesterol) – especially statins that cross into the brain.[14] [15]

Older adults with Down syndrome (~50 years) who have high cholesterol (>5.2 mol/L) are twice as likely to develop dementia over 5 years. This risk is halved if they are treated with a statin.[16]

People with Down syndrome have low rates of ischaemic heart disease and strokes. Treatment of high cholesterol with statins (medications that reduce cholesterol) might not be considered a priority and there might be concerns about side effects. Statins can affect muscle and sometimes impact on cognition.

A recent randomised placebo controlled trial (the gold standard in research) of simvastatin, a statin that crosses into the brain, in older adults with Down syndrome found some improvements in thinking in those who received simvastatin vs those who received the placebo. However not enough people participated in the research to prove the effect of the simvastatin. There were no side effects from the simvastatin.[17]

- Cholesterol levels should be checked in annual health assessments. If cholesterol levels are found to be high, changes in diet should be considered to reduce cholesterol levels.
- If changes in diet are not possible or cholesterol levels remain high then treatment with a statin which crosses into the brain should be discussed with the treating doctor. As is the case with all medications, if a statin is prescribed it is important to monitor for adverse effects.
- Statins have not been proven to prevent or delay dementia of Alzheimer's disease and should not be prescribed for this reason. However, taking statins to reduce high cholesterol levels might reduce the risk of dementia.

Early Menopause and Hormone Replacement Therapy

Women with Down syndrome experience early menopause, on average by the age of 45 years. People with Down syndrome are at risk of osteoporosis and early menopause increases this risk. Women with Down syndrome who reach menopause younger than 45 years have a greater risk for developing dementia.[18] [19]

- It is not known if hormone replacement therapy (HRT) can reduce this risk of dementia in women with early menopause (<45 years).
- There are no guidelines regarding hormone replacement therapy in women with Down syndrome and few women with Down syndrome are offered treatment.
- The risks and benefits of HRT should be discussed the treating doctor or specialist.

Other Common Health Conditions in People with Down Syndrome Associated with an Increased Risk of Dementia

Many health conditions are much more common in people with Down syndrome than in the general population. In particular, people with Down syndrome are at an increased risk of infections and autoimmune disorders. Some of these disorders can increase the risk of dementia, for example a chronic bacterial stomach infection which causes ulcers (and pain)[20], thyroid disorders[21] and coeliac disease[22]. These disorders have effective treatments and can be detected with blood tests - although other tests may need to be done to confirm the diagnosis.

It is also important to look after teeth and gums. Dental infections are very common in people with Down syndrome, and can result in general poor health, pain, loss of teeth, and heart infections if the person has congenital heart disease.[23] Chronic dental infections can also increase the risk of dementia.[24]

Active healthy living and proactive health care which targets the specific health needs of people with Down syndrome will improve their health and well-being and has the potential to delay the onset of dementia.

Assessment and Support of People with Down Syndrome and Dementia

If a person with Down syndrome develops changes in their thinking and independence it is important for them to get an assessment and to be provided with appropriate support. Getting a diagnosis can be difficult at times as there is no simple single test for dementia and it relies on a comprehensive assessment. Once a diagnosis is made, there are a number of supports which can support people to live a high quality of life. This section outlines the assessment process as well as some suggestions for supports that could be provided to people with Down syndrome who have dementia. For specific advice on your circumstances it is important to get in touch with your GP or other health care professional.

Assessment of Alzheimer's Disease

Referral Pathways

Getting a diagnosis of dementia requires multiple assessments and ruling out other potential health conditions which could cause changes in thinking. Unfortunately, there is no simple blood test that can be done to get a diagnosis. Families and support workers often report difficulties in getting an assessment completed and often the person has seen many different doctors before they receive a diagnosis. It can be helpful to know in advance what the pathway is to get a diagnosis.

If you are noticing gradual changes in independence, abilities and thinking of the person you support ask their general practitioner for a referral to:

- A specialist intellectual disability health clinic - if available
- Memory clinic
- Medical specialist (geriatrician, psychiatrist of old age or neurologist) with expertise in dementia assessments if there is no regional memory clinic
- Or your local Down syndrome association or Alzheimer's association may be able to help with referral pathways.

If you are already attending a specialist intellectual disability health clinic, this is the best place to start. These clinics can provide a general assessment and refer on to a memory clinic or specialist. The advantage of having an initial assessment in a specialised health clinic is that other health conditions that might be contributing to thinking or memory problems can be identified. Specialist clinics may not be available in all areas.

Some areas have multidisciplinary memory clinics which have specialist doctors such as geriatricians, old age psychiatrists or neurologists who are experienced in dementia assessments. A memory clinic might also have neuropsychologists who can conduct detailed assessments of thinking and memory. Other clinicians may also be involved in assessment, support and linkage to other services.

If these clinics are not available in your area it is likely that your GP will refer you to a medical specialist such as a geriatrician, psychiatrist of old age, or a neurologist. These specialists are experienced in diagnosing and treating dementia but may have less training or experience in assessing people with Down syndrome. Although the basic principles of assessment are the same for people with Down syndrome, assessment can be clinically challenging in practice.

Assessment and Diagnosis of Dementia

A diagnosis of dementia of Alzheimer's disease in a person with Down syndrome is based on a history of gradual and significant decline from baseline in thinking and independence in everyday abilities over at least 6 months but usually 1-2 years, and where these changes are not due to any other condition.

Assessment should be methodical and comprehensive, including:

- A detailed history to establish a person's baseline abilities, and if there has been is a gradual decline in abilities over a year or longer.
- Assessment of thinking or cognition. This is not straightforward and results are difficult to interpret if there is no baseline assessment.
- Assessment for other physical and mental health conditions.
- Brain scan if possible. MRI is preferred over CT scan. Most people with Down syndrome cope well with having a scan – if they are well prepared and supported. Keeping still is the biggest challenge.

A documented baseline of a person's best level of thinking and abilities is most helpful in the assessment for Alzheimer's disease. It is recommended that all adults with Down syndrome have baseline assessments of thinking and abilities before the age of 35 years. Such assessments are also helpful identifying individual strengths as well as identifying what types of support might be helpful for each person with Down syndrome.

If this is not possible, previous medical, psychological/neuropsychological, speech and language assessments or assessments for supports are invaluable sources of information about past functioning. In addition, you can date and document a person's abilities e.g. describe step by step everyday activities such as dressing or making a cup of tea or coffee. Or you can keep videos. It is also helpful to date and keep or photograph examples of writing, art work, videos, to help in establishing the nature and degree of changes.

As previously outlined, other health conditions can cause changes in thinking and abilities. Therefore, an assessment for dementia requires a thorough medical assessment and management of other conditions.

If the diagnosis is uncertain, the person can have another assessment in 6 or 12 months, depending upon the situation. In the meantime, support should be tailored to the needs of the individual.

Supporting a Person with Dementia

Dementia affects everyone differently and the support a person will need will depend on their circumstances and what changes they experience. Whilst it is important to consider future needs and to plan ahead, the person should be supported to stay where they are currently living and participate in the things that they enjoy. Understanding how dementia has changed their thinking and memory helps with supporting the person and ensuring that their existing strengths are utilized. If there has been a significant change to every day functioning, a review of their NDIS plan should be requested so that they can get the supports they need.

Psychological/Well-being Support

People with Down syndrome who are developing dementia may experience distress, anxiety or depression as the disease progresses. It is important that they receive reassurance and support, and, if that is not effective, then they should see their doctor.

Changes in behaviour, low mood, anxiety and irritability are common in dementia and can sometimes be caused by changes to the brain because of dementia. Changes that happen rapidly (over the course of a few days) should be assessed by the person's doctor as they may be due to an infection or some other untreated medical condition. When these changes are due to dementia they are called behavioural and psychological symptoms of dementia (BPSD). Reassurance, support and adaptation of the environment are the preferred approach. However careful short-term use of some medications might be helpful, especially in alleviating distress and anxiety. Specialist care from geriatric medical services or aged psychiatry services may be required to provide the best support.

Family members may also want to seek support including 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 webchat service (go to www.dementia.org.au for more information).

Assistance with Every Day Activities

Attention, working memory and executive functioning are the first areas of thinking to decline. Attention is how our brains focus on tasks and take in new information. Working memory is holding in mind and using pieces of information. For example, if asked to put a cup in the sink, put the milk in the fridge and to turn out the light, working memory keeps each task in mind for a short time. Executive functioning is the

management of our thinking, working out what we need to need to do and how we go about it.

Changes in attention and working memory are common in mild cognitive impairment and early stage dementia. The person with dementia has difficulty processing new information, especially "auditory processing" – taking in and understanding what someone has said. Noisy, busy environments are distracting and potentially distressing. When talking with someone, make sure you have their attention, and keep your sentences short and simple. In the past, someone might have been able to follow a 3 step request but may now be only able to follow a 2 step or 1 step request or may need the request repeated. Show the person what you are saying and give them prompts e.g. hand them the cup and point to the sink.

We use executive functioning to work out what we should be doing given the day, time, context, and then how we get things done. This means initiating a task, doing the steps in the right sequence, monitoring that all is going according to plan, course correction and problem solving, sticking with task until it is complete and switching to the next task when it is completed. When executive functioning begins to decline you may notice that someone in the earlier stages of cognitive decline requires prompts to do a usual task. Once prompted all is well. Then you might notice that they have difficulty completing the steps of the activity. The person is still quite capable of doing each step, but they can't join up the dots.

> The best way to help is with structure and visual prompts.

For example, someone who once turned up to breakfast, appropriately dressed for the day may start wearing the same clothes every day, or layering clothes, or putting on jumpers in mid-summer. You could help the person with clothing selection the night before, and laying clothes out in the order in which they are put on. In time the person may not turn up to breakfast and might be found sitting on their bed partially dressed. You can provide verbal prompts or hand them the next item of clothing.

Medications

Currently there are no medications available that can slow the progression of dementia. There are, however, some medications which can improve the symptoms of dementia. For example, doctors may prescribe a cholinesterase inhibitor (e.g. Galantamine, Rivastigmine, Donepezil). These medications improve brain functioning by increasing the amount of acetylcholine – a chemical in the brain– but do not slow progression of dementia. These medications can be helpful, including improving thinking in mild cognitive impairment and early to mid-stage dementia.

While these medications are well tolerated in the general population, people with Down syndrome are more prone to side effects. If these medications are prescribed, you should discuss with the doctor the possibility of side effects and how these can be managed.

Managing other Health Conditions

Older adults with Down syndrome and dementia may have complex health issues. It is important to ensure that other medical conditions are being treated appropriately in order to ensure the best outcomes for the person with Down syndrome. Regardless of any medical conditions, a review of medications for a person with Down syndrome and dementia is important. Many common medications can impair thinking. The person's general practitioner can ask for a pharmacist to review medications and give advice.

Dementia Friendly Environments

Research shows that a well-designed environment can reduce confusion and disorientation and enable people living with dementia to live more independently with dignity. While this has not been studied specifically in people with Down syndrome, it is likely that the same strategies would provide assistance.

Dementia Australia has a Dementia-Friendly Home app which recommends practical changes that prompt families and support people to think about how the home can be changed in a way that may assist the person living with dementia. Many of the app suggestions are small, inexpensive ideas, such as placing labels with pictures on cupboard doors. More significant changes include installing motion sensors that turn lights on and off when people walk through the house and changing busily patterned wall or floor coverings.

Dementia Australia also has a website on Dementia Enabling Environments which provides specific tips for how to improve different rooms in the house to make it more appropriate for people with dementia - www.enablingenvironments.com.au/living.html

Often simple solutions can be found by thinking about what the person with Down syndrome and dementia is having difficulty with. For example, after his sister was getting confused about how to get from his home to the garden, a man painted the ramp from the verandah to the garden bright red. This provided a clear path to the garden.

Conclusion

People with Down syndrome are living longer and healthier lives than ever before. But with increasing life expectancies comes an increased risk of dementia. It is important to realise that there are ways to reduce the risk of developing dementia through adopting healthy lifestyles and managing health conditions. When dementia does develop, appropriate diagnosis and supports can assist a person to continue to enjoy an active life. Getting access to the right support and information early on is key.

The Down syndrome organisations (www.downsyndrome.org.au) and Dementia Australia (www.dementia.org.au) can provide access to local information and supports.

Resources

Depression in Adults with Intellectual Disability Checklist

People with intellectual disabilities may be unable to describe their feelings or experiences. This contributes to their doctors often finding it difficult to diagnose depression or other disorders of mental health. The Depression Checklist is a tool to assist in this process.

The Checklist is designed to be filled out by someone who know the person very well. It guides and records information the doctor can then use to screen for depression or related disorders in adults who are unable to self-report. The checklist is not a substitute for a clinical assessment.

The Depression in Adults with Intellectual Disability Checklist is available free of charge from the Centre for Developmental Health Victoria website.

www.cddh.monashhealth.org/index.php/depression-in-adults-with-intellectual-disability-checklist

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