

Down syndrome

A practical guide to ageing well



About this guide

This guide is for people with Down syndrome and the people who support them in their daily lives. This might be parents, other family members, or support staff. The aim of the guide is to provide information that will help people with Down syndrome to age well. This guide is a companion resource to Down Syndrome Australia's Guide to Ageing.

Ageing well includes being as healthy as possible as you age, staying safe, being as independent as you can, feeling financially secure, and having a positive outlook on life. All of this doesn't just happen; we need to prepare for getting older. This guide contains general information about ageing with Down syndrome as well as more information to help you plan for ageing well.

The guide contains information about mainstream community facilities and programs for seniors to help with being healthy, happy and ageing well. These are useful and relevant for everyone as they age but we have also included a lot of information specifically relating to older people with Down syndrome, so you can find specialist information.

Included in the guide is information on where to get advice and help when you need it. There are links to other resources where you can get more detailed information and some tips from people with Down syndrome and their families. We've also included some ideas about supports that could be in an NDIS plan for older people with Down syndrome.

You can start at the beginning and read through or you can use the contents page to go straight to the topic you want.



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Introduction

Getting older is a natural part of life. There are some positive things about getting older such as having more time to do the things you enjoy, but people can also find there are some not-so-positive things about being older. This can include having health conditions that can make you feel unwell or uncomfortable and make it harder to do things.

These days, people know more about some of the health conditions that can happen with ageing, and the importance of looking after ourselves better so that we can be healthier in old age. People with Down syndrome are now living on average into their sixties. Some people are living into their seventies and beyond. However, people with Down syndrome are more likely to have more health issues and feel the effects of ageing at a younger age than people without Down syndrome, so advice on how to age well is especially important.

People with Down syndrome are also likely to face other major life changes as they age, and need some support to deal with those changes. So, it's important to be aware of these, to plan ahead, and to know where to get information and help when you need it.

This guide provides the basic information to help with planning for ageing well and for managing the issues of ageing as they arise. The links to other resources will help you find more detailed information as you need it.

Planning for life's changes

Planning ahead for when we are older is important for all of us. It's especially important for people with Down syndrome, who may experience extra difficulties and need more support as they age. And it's important for families and carers to be aware of both opportunities and challenges, so they can plan to help the person age well.

There are many important issues for families to consider including how to plan for the future financial security of their loved one, and making arrangements for their care and support needs.

There's a lot to think about, so it's a good idea to start talking about future plans as early as you can. This means you can gather information and think about possibilities and choices without the pressure of having to make decisions quickly. It helps everyone – the person and their family – to be prepared and feel more confident about the future.

People with Down syndrome need to be included in these conversations, along with their families and other important people in their lives. You can use this booklet to help start these conversations and make notes as you go. You don't have to do it all at once; keep the booklet in a spot where you can read bits of it, or makes notes when something relevant pops into your head.

There are many people and organisations who can help you with this planning and we've included some of them in this booklet. You can also contact your local Down syndrome organisation and peer support networks for advice and recommendations on who can help you plan for the future. You will find some of these links in the next section of this guide, 'Planning for the future'.

Looking after yourself – a note for family carers

It can be hard to think and talk about the long term wellbeing of your family member with Down syndrome. As you do the planning, you may experience feelings that are confronting. You might feel sad or anxious or you might have feelings of regret and even guilt. These are very common feelings, but if you are feeling overwhelmed by these thoughts and emotions, think about getting extra support for yourself. Have a break if you can, talk to other family and friends, and talk with people in your Down syndrome peer support network. If you feel you need professional support, you can also ask your GP for a Mental Health Treatment Plan, so you can access psychologists and other relevant practitioners. These plans have a Medicare rebate.



Resources

Resources for family carers:

<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/family/looking-after-yourself/>

<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/siblings/support-siblings/>

<https://www.ndscenter.org/programs-resources/adult-siblings/>

NDIS and family carers:

<https://www.ndis.gov.au/families-carers/support-carers.html>

Planning for the future

A major concern for anyone who supports a person with a disability is how the person they care for will be supported in future. People wonder where their family member will live, who will provide the support they need, who will care about them, and how future support will be paid for. Planning ahead helps to remove some of these worries and provide some peace of mind.

Wills, trusts and guardianship

The Australian Government has produced a booklet called *Planning for the future: People with disability* as part of an information package developed to assist families planning for the future of their family member with disability.

The booklet includes guidance on topics such as wills, trusts, obtaining financial and legal advice and other things that families are often unsure about, such as guardianship and power of attorney. Parents often believe that they need to arrange guardianship when their children turn 18 years old, but this is not the case. Many people with Down syndrome will need support to make choices, but guardianship is not necessary or the best option, especially when the person has family or a committed group of people to help them make decisions. Parents cannot appoint a guardian for their adult son or daughter, and guardianship tribunals will only appoint a guardian if the person has a current need for one. You can look up the Office of the Public Advocate website in your state to find information about guardianship and administration, power of attorney, medical consent and other helpful information.



Resources

Planning for the future: People with disability booklet. This comes in several languages and contains a simple planning checklist.

<https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/general/planning-for-the-future-people-with-disability-booklet>

Here is some information about Special Disability Trusts:

<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/having-voice/special-disability-trusts/>

This is useful reading about supported decision making, including information about guardianship:

<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/having-voice/supported-decision-making/>

Circles of Support

Some people with Down syndrome and their families have set up a Circle of Support. These are groups of people who have been invited to form a community of friends and supporters around the person. They provide friendship and informal support to help the person make ongoing choices about their life now and into the future.

Circles of Support:

- bring more people and perspectives into the person's life
- can help families coordinate support
- increase the person's community connections and social life
- help with employment.

Importantly, Circles of Support give families more confidence for the future when they are less able to provide the support.

Some people set up more formal circles of support, such as microboards. A microboard is a small group of people, usually committed family and friends who form an *incorporated association* for the benefit of the person. While microboards are similar to Circles of Support, they differ by being a legal entity, which brings other benefits and roles including being able to apply for and manage funding for the person.



Resources

Resources about informal supports, including families and Circles of Support, and about microboards:

<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/informal-supports/importance-informal-supports/>

<https://www.ric.org.au/learn-about/building-support-networks/circles-of-support/>

<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/family/microboards/>

<http://microboard.org.au/what-is-a-microboard/>

Housing

Many adults with Down syndrome still live in the family home for all kinds of reasons. These include a lack of suitable housing options, not being able to afford support, concerns about safety, cultural reasons, and just wanting to stay together as a family. Other people may live in their own unit or home with support and some people live in group homes. No matter where the person lives it is important to talk about how this might work in the future as they age. This should include looking at the different possibilities and knowing about the supports that are available, so that the person and their family can make decisions.



Resources

Resources about housing and living arrangements:

Down Syndrome Australia has a resource called *Living independently*. It is designed to help people with Down syndrome and their families think about living arrangements. It has practical information including checklists to work towards living more independently. There is an Easy Read version that you can also use as a workbook.

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



NDIS ideas and tips

You can include goals in your NDIS plan to help you live more independently, whether you live in the family home or in your own place.

Supports can include:

- people to help you learn skills to look after yourself and your home
- home modifications
- home safety and security
- help with personal care if you need it
- help around the home such as cleaning, doing your laundry and gardening.

People can get some of these supports even if they are living in the family home.

If a person needs specialised housing, the NDIS may be able to help with these costs.

Here is some information on how the NDIS helps people with their living arrangements:

<https://www.ndis.gov.au/housing>

The NDIS can also fund what it calls 'assistive technology' (AT). Assistive technology can be things such as home and car modifications, wheelchairs, talking kitchen appliances or an app to remind you when to do daily tasks.

Bereavement

As we get older, we are all more likely to experience the loss of family, friends and other people close to us. We all experience feelings of loss and grief when a loved one dies, but people react in different ways and appreciate different kinds of support. Talking about death can be hard for anyone, and a person with Down syndrome may find loss even harder to understand and may struggle with expressing their feelings. A death in the family can also impact harder on a person with Down syndrome if that person was also their carer, as this may also include a change in living arrangements.

Access to skilled, empathetic and caring support is critical for a person with Down syndrome to work through their feelings of grief and loss as well as to support them in a new environment.



Resources

A practical guide from Down's Syndrome UK: <https://ds-int.org/resource/bereavement>

Down's Syndrome Scotland has a booklet called *Let's talk about death*, to support people with intellectual disability after someone close to them has died. The booklet is designed to be used by the person with Down syndrome with support from family or other support people. It is in easy-to-read language with pictures to help people to understand the information.

<https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-Talk-about-Death-2012.pdf>

Grief – an article from the Adult Down Syndrome Center in Illinois, US about helping people with Down syndrome understand and deal with grief and loss.

https://www.advocatehealth.com/assets/documents/subsites/luth/downsyndrome/grief_-_10_things_i_know.pdf

This website called Talking End of Life includes a free online toolkit to support family carers and staff in talking with adults with intellectual disability about end-of-life information.

It is an easy-to-use, practical website with lots of short videos and other resources.

<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>



NDIS ideas and tips

Support workers can be an invaluable source of help when a person and family is grieving. They can help the person to understand what is happening by using some of these resources and supporting the family or other carer/supporter. They can also help the person maintain their daily routines and adjust to new situations, such as changed living arrangements, if that is what is needed.

Health and wellbeing

“ I want to live a healthy life. I will need to look after myself more when ageing.”

Person with Down syndrome

The average age of the general population in Australia and other developed countries has increased greatly in recent years. As a result, there's been a lot of research on ageing.

Researchers say that there are some simple actions we should all take to be healthier and happier as we age. These include eating a healthy diet, keeping active, staying connected to people and community, and looking after our physical and mental health.

People with Down syndrome generally experience more health conditions and the effects of ageing at a younger age than people without Down syndrome, so these actions are even more important.

Included here is general information as well as extra information relevant to people with Down syndrome, some useful links, and some ideas on how you can use the NDIS to help with healthy ageing.



Resources

There are many relevant resources online. We've included some general ones here and others on specific topics throughout this guide.

Down Syndrome Australia's booklet, *Ageing and Down syndrome*, contains detailed health and planning information for people with Down syndrome, their families, medical professionals and other people involved in the health and wellbeing of older people with Down syndrome.

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

Down's Syndrome Scotland produced a booklet called *Let's talk about getting older*. The booklet is designed to be used by the person with Down syndrome with support from family or other support people. The language is easy to read with pictures to help people to understand the information. It explains the things to expect as you get older and how to keep healthy.

<https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-talk-about-getting-old-final-version-05.08.15.pdf>

Down's Syndrome UK's guide for parents and carers *Ageing and its consequences*:

<https://www.downs-syndrome.org.uk/download-package/getting-older/>

The National Down Syndrome Society in the US has produced *Ageing and Down syndrome: A health and wellbeing guidebook*.

<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>



Resources cont.

The Adult Down Syndrome Centre of Lutheran General Hospital has lots of resources (including videos and Easy Read) that many families recommend. The resources are divided into those for people with Down syndrome, for families and carers, and for professionals.

<https://www.advocatehealth.com/health-services/adult-down-syndrome-center/resources/>

Video – *Providing good support to people with intellectual disabilities as they grow older: what do we know and why is it so hard to achieve?* from Christine Bigby of the Living with Disability Research Centre, Australia. <https://www.youtube.com/watch?v=8-eAl8qlbm0>

Eating a healthy diet

As we get older, it's important to be at a healthy weight. Being very overweight or obese is associated with many medical conditions including diabetes, heart disease, joint pain, breathing problems such as obstructive sleep apnoea, and even depression. But we are often less active later in life, so we need to eat fewer kilojoules to be at a healthy weight. People with Down syndrome have a lower basal metabolic rate (BMR) than most people, which means they burn fewer kilojoules whether at rest or being active. But people with Down syndrome still need as many nutrients as everyone else for good health.

Eat for Health Australia says it's important for us all to choose food that has lots of nutrients most of the time, and have less healthy foods less often. Because of the lower BMR and increased likelihood of health conditions, food choices are especially important for people with Down syndrome as simply cutting kilojoules can put people with Down syndrome at risk of a nutrient deficiency.

Making good food choices means eating a wide variety of healthy foods. We should also limit food and drinks that contain saturated fats, added sugars, alcohol and low fibre foods.

A healthy diet such as a Mediterranean style diet – which includes foods like fruit, vegetables, nuts and grains – also appears to lower the risk of dementia. This is especially important for people with Down syndrome who have an increased risk of dementia. Osteoporosis is also more common, so it's important to eat enough calcium rich foods.

Making healthy food choices can be hard, especially in social situations. It helps to know what is healthy, what isn't, and why it's important to make good choices most of the time.

Drinks

Sometimes, it's what we drink that makes us less healthy. For example, fruit juice and cordial can be full of sugar and colas can also take calcium from your bones. These kinds of drinks make it harder to keep a healthy weight and keep your teeth and bones healthy.

Alcohol also adds to your weight and makes falls and injuries more likely.

When it comes to drinking alcohol, the Australian drinking guidelines recommend:

- drinking **no more than two standard drinks on any day** to reduce your risk of harm from alcohol-related disease or injury over a lifetime
- drinking **no more than four standard drinks on a single occasion** to reduce the risk of alcohol-related injury arising from that occasion.



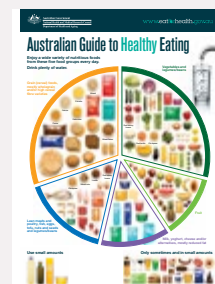
Resources

Here is a poster showing the five food groups:

<https://www.eatforhealth.gov.au>

Healthy eating visual support:

https://www.advocatehealth.com/assets/documents/subsites/luth/downsyndrome/healthy_eating_-_visual_support.pdf



Food choices in group and community settings:

<https://www.advocatehealth.com/assets/documents/subsites/luth/downsyndrome/new-format-documents/4-food-choices-in-group-settings-workshops-and-at-community-events.pdf>

Here are the guidelines which includes information to help understand how much is in a standard drink of different kinds of alcoholic drinks:

<http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/guide-adult>



NDIS ideas and tips

You can include health-related goals in your NDIS plan. While the NDIS won't cover medical and hospital services or medications, you can have supports in your plan to help you be healthy.

Goals such as learning to eat a healthy diet, or losing weight can be included in a broader goal about becoming or staying healthy and fit.

NDIS can fund 'individual advice to a participant on managing diet for health and wellbeing due to the impact of their disability'. This includes consultations with a dietitian and developing a diet plan. NDIS can also fund group sessions with a dietitian.

Support workers can help with:

- learning about healthy food choices
- putting together a healthy food plan
- going shopping and helping to cook healthy meals
- attending a cooking course – but the cost of classes won't be covered.

Staying active and fit

Regular exercise is a very important part of staying healthy as we get older. Physical exercise not only helps to keep our bodies healthy and our weight down but also helps our mental health and keeps our brains healthy. Physical activity is even more important for people with Down syndrome who can be overweight and be more likely to have health issues including musculo-skeletal conditions and dementia.

But as we all know, it's important to choose the kinds of exercise that you can not only do regularly, but that you enjoy. Some people will enjoy going to a gym, while other people may love swimming. Some will enjoy playing sport, such as a round of golf, while others love to dance or do yoga. Sometimes the cost of exercise advice and programs can be a problem, but there are reduced cost programs in the community – and remember that walking is a great free exercise.



Resources

Local Government Directory – You can usually find information about local exercise classes and fitness programs for older people in your local government community directory, either online or in printed booklets. Classes are often cheaper for older people or those who have concession cards. Just search for your local council online or call them to find out what's available.

Choose health: Be active is an Australian government resource. It has lots of practical advice on how much exercise older people should aim for each day, as well as the different kinds of exercises we need to stay healthy. It includes pictures of a range of different exercises designed for older people.

<http://www.health.gov.au/internet/main/publishing.nsf/content/phd-physical-choose-health>

Exercises you can do at home is a fact sheet with pictures, written for people with Down syndrome. (This page also has a lot of other health related information, including visual fact sheets and videos presented by adults with Down syndrome).

<https://www.advocatehealth.com/health-services/adult-down-syndrome-center/resources/people-with-down-syndrome>

“It's important to get good professional advice about exercise rather than just going to any gym. And a trainer to make sure the exercises are done properly and safely, and who give great encouragement for effort and PBs.”

Person with Down syndrome



NDIS ideas and tips

You can include fitness in your NDIS plan. It can be part of a broader goal to become or stay fit and healthy (which might also cover healthy eating), or it can be a more specific goal such as increasing skills in sporting activities. A broader goal gives you more flexibility to try different sports and activities and change them when you want to.

Expert advice: If a person needs expert advice about exercise due to the impact of their disability, they may be able to get it from an exercise physiologist or other therapist, who can help develop an individualised exercise plan. This could be for people starting to experience or trying to prevent musculo-skeletal problems such as painful knees or hips, or people working to improve their balance to prevent falls. They may also be able to get personal training or have a therapy assistant, other support worker or carer to help them with their exercise program.

Support workers can help with fitness goals such as getting to the gym or sports, doing other exercise classes, or going walking or swimming. Classes will usually accept the Companion Card too, so that support workers can go along for support at no cost. Most gyms are happy for support workers to help people do their gym program.

Looking after your health

Staying as healthy as possible as we age is important for a longer happy life. As well as following general advice to eat well and exercise regularly, it's important to have regular check-ups with your doctor, even if you aren't feeling sick.

People with Down syndrome experience the same stages of getting older as other people, but these stages can happen earlier. For example, women with Down syndrome will go through menopause, on average, about five years earlier than other women.

There are some health conditions that are more likely to happen in adults with Down syndrome than in the general population. Not all of these will occur in each individual but it is good to know what *may* occur. There are also some conditions that develop with age, and they may develop earlier in ageing adults with Down syndrome than in other people.

Yearly health checks

People with Down syndrome can have a full health check-up with their GP every year, with a Medicare rebate. Medicare call this an annual 'health assessment for people with an intellectual disability'. You may have to explain this when you make the appointment, and say that you will need a longer appointment to allow enough time. If a person with Down syndrome doesn't speak to communicate or takes longer to speak and be understood, then they can give you an even longer appointment time. Some GPs may ask their nurse to do some of the assessment such as measuring height, weight and blood pressure, before the doctor does the rest of the assessment.

The doctor has online access to information about what checks and tests should be carried out each year and at certain ages, as part of the annual health assessment.

GP managed health plans

People with Down syndrome are usually eligible for GP managed health plans. The GP can set up a team-care approach and make referrals to other health and allied health practitioners. Depending on your health issues these could include professionals such as diabetes educators, dietitians, exercise physiologists, OTs, physiotherapists, podiatrists, psychologists, speech pathologists. The team could also include nurses, social workers, optometrists and pharmacies, Meals on Wheels, and Aboriginal and Torres Strait Islander health workers.

These plans help to coordinate your health care. You can have a copy of your plan. There are Medicare rebates for the services you get as part of these plans, but it is still a good idea to check if there is any extra cost.



Keeping a personal health record

It's a good idea to keep a record of doctor's appointments, hospital visits, test results and scans. You should also include visits to the dentist and allied health appointments, such as OT, physio, podiatry (foot care) visits and any other therapies. It's also important to keep records of all medications the person takes. People with Down syndrome sometimes need to start medications on a lower dose than other people, so you should make notes about dosages and any side effects.



Resources

Ageing and Down syndrome – a booklet from Down Syndrome Australia that contains detailed information about the health conditions you should be aware of in older people with Down syndrome. It includes signs and symptoms to look out for and helpful strategies to prevent or manage these conditions, as well as links to research on the conditions. The booklet also has information on the medical tests and screening that people with Down syndrome should have in their health check-ups. https://www.downsyndrome.org.au/documents/resources/health/DSA_Ageing_Resource.pdf

Community Inclusion Toolkit – Down Syndrome Australia has produced a range of health-related resources for people with Down syndrome of all ages, their families and for health professionals as part of its Community Inclusion Toolkit. These include videos and fact sheets on hospital stays, finding the right GP, communication tips for health professionals, assessing children with Down syndrome, personal health records and much more. There are also links to other health resources:

https://www.downsyndrome.org.au/community_inclusion.html#health

Here is the link to information about the Medicare covered annual health assessment:

http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_mbsitem_intellectual_disability

Information for health practitioners and patients about GP managed health plans (Chronic Disease Management program): <http://www.health.gov.au/internet/main/publishing.nsf/content/mbsprimarycare-chronicdiseasemanagement>

Down Syndrome Australia's *About Me* personal health record:

https://www.downsyndrome.org.au/community_inclusion.html#health

NSW Council for Intellectual Disability's *My Health Matters* – an Easy Read folder created to improve communication between people with an intellectual disability and their healthcare providers. It is in a ring binder with pockets so you can easily add your own medical letters, reports and information. You can order it online or call 1800 424 065

<http://www.nswcid.org.au/my-health-matters.html>



Falls

Falls can happen to anyone but, unfortunately as you grow older, falls can become more common and you are more likely to injure yourself. Looking after your health and exercising will help to prevent falls but most falls happen at home, so you should look at reducing hazards and whether you need some home modifications or equipment.

<https://www.myagedcare.gov.au/getting-started/healthy-and-active-ageing/preventing-falls-in-elderly>



NDIS ideas and tips

The NDIS won't cover medical and hospital services or medications, but you can have supports in your plan to help you look after your health. For example, your health-related goals could be part of a broader goal about staying fit and healthy. You could also have a goal to learn to look after your own health more.

Think about some home modifications you might need, such as handrails, to reduce the risk of falls, and ask for these in your plan. You may also decide you need other equipment to help to do things and get around safely, such as using a walker.

Support workers can help people to understand and manage their everyday health. This could be helping people to use reminders to take medication, supporting them to go to medical appointments and keep their health records up to date.

Support workers can also help while the person is in hospital. This is not to do the work that hospital staff should be doing but, because they know the person well, they can help the person understand what is happening so they are less anxious, and help them with communication. They might also continue to do some of their regular household support tasks while the person is in hospital.

Dental health

It's important to continue to look after your teeth as you get older. People with Down syndrome are more likely to have gum disease and mouth infections so regular check-ups and cleaning in the dental surgery should be part of a person's health care. Private dental care can be expensive, so you may want to go to a government dental clinic for check-ups.



Resources

This page has links to dental health schemes in the different states: <http://health.gov.au/dental>

This fact sheet from Down Syndrome Australia's Community Inclusion Toolkit gives information about dental health for people with Down syndrome:

https://www.downsyndrome.org.au/documents/community_inclusion_toolkit/general/DSA-dental-health-C03.pdf

Looking after your mental health

Mental health problems, especially depression can be common in older people. Older adults with Down syndrome can be especially vulnerable to generalised anxiety and depression, but can also experience other psychiatric conditions.

Staying active and connected, and being as physically healthy as possible will help with mental health as we get older, but sometimes people need professional help to deal with their mental health.

It isn't always easy to tell when a person is developing mental health conditions, and when the person has Down syndrome, it can be even harder to know that things aren't ok. Carers and support workers need to look out for changes in behaviour, mood and communication, and whether the person is eating and sleeping as they usually do. Changes could be related to a health condition or to a mental health condition or dementia. It's important for the person to see their GP to find out what the problem is and organise the relevant treatment or management plan, including a specialist referral.



Resources

Monash University's Centre for Developmental Disability Health has produced a checklist to help assess whether a person with an intellectual disability may have depression.

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

GPs can write a Mental Health Treatment Plan, to access psychologists and other relevant practitioners, with the cost rebated by Medicare.

<http://www.health.gov.au/internet/main/publishing.nsf/content/pacd-gp-mental-health-care-pdf-qa>

An article from Down's Syndrome UK on how we can support people with Down syndrome to have good mental health.

<https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/mental-well-being/>

Feeling Down: Looking after my mental health – an Easy Read guide for people with Down syndrome.

<https://www.mentalhealth.org.uk/sites/default/files/feeling-down-guide.pdf>

Down Syndrome Australia have developed a resource about what people with Down syndrome and their families can do to support good mental health, as well as help identify when professional support might be required. The resource is available at:

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



NDIS ideas and tips

As with physical health, it is the health sector that is responsible for the health and medical care when someone has a mental illness. However, if a person's ongoing mental health condition affects the level of support they need – such as support workers to complete their daily living activities, get to appointments and remain connected to their community – then their NDIS plan should provide the overall level of support needed to ensure they regain their interest in being active in their own lives.

Down syndrome and dementia

People with Down syndrome are living longer, but they are more likely to get dementia and see symptoms at a younger age than other people in the population. This may be confronting to know but it is also helpful to understand the links between health and lifestyle so that you can take action. Down Syndrome Australia, Dementia Australia and Dr. Jennifer Torr have produced a booklet for families that includes information on how to reduce the risk of dementia, recognise the signs of dementia, and what you can do to support a person with Down syndrome if they do develop dementia. There are also many other resources as well as international research under way to address the high rate of dementia in people with Down syndrome.



Resources

Down syndrome and dementia: A guide for families – a booklet by Down Syndrome Australia
<https://www.downsyndrome.org.au/documents/resources/health/DSA-DA-guide-for-families.pdf?>

Down's Syndrome Scotland has produced a guide that has practical advice and tips, including photos, on how to best support a person with Down syndrome who has dementia:
<https://www.downsyndrome.org.au/documents/resources/health/Living-with-Dementia-final-05.08.15.pdf?ot=desc&o=date>

Dementia in people with Down syndrome: what does the research tell us? by Dr. Liz Evans and Tanya Duckworth. This article was published in *Voice*, journal of Down Syndrome Australia, December 2017. It looks at the research on why dementia is more common in people with Down syndrome than the general population, and gives recommendations for how families can support a loved one with dementia.

<https://www.downsyndromevoice.org.au/2017/2018/12/30/dementia-in-people-with-down-syndrome>

Jenny's Diary – this is a booklet and set of picture postcards, produced by the University of Stirling in Scotland. It is aimed at supporting conversations about dementia with people who have a learning (intellectual) disability.

<http://www.learningdisabilityanddementia.org/jennys-diary.html>

Online learning modules on dementia:

The Centre for Developmental Disability Health in Victoria has produced learning modules for disability staff supporting people who are at risk of developing, or who have already have, dementia. All the modules are freely available to anyone interested in improving the health and wellbeing of people with developmental disabilities (support staff and family carers can view these modules).

There are four modules in the series addressing key questions you may have when supporting someone with dementia.

Each module takes about 15 minutes to complete. You can pause or rewind at any time to make notes or review content and you can view them at their website: <https://cddh-online.monash.org/login/index.php> You will need to create your own user account to log in to the site which is at no cost.



NDIS ideas and tips

When a person has dementia, their support needs increase and their NDIS plan should be reviewed and changed to make sure they get the level of help they need. If the person doesn't have a plan review meeting scheduled for some time, you can ask for a review as soon as possible.

Dementia Australia has produced a booklet that explains how the NDIS can help people with younger onset dementia. While dementia in people with Down syndrome can progress differently from the general population, this booklet contains some very relevant and practical information. As well as information and checklists to help the person and their carers prepare for NDIS planning, it includes examples of weekly support schedules and the kinds of goals, supports and equipment that could be included in an NDIS plan. You can download the booklet here: <https://www.dementia.org.au/files/NATIONAL/documents/NDIS-toolkit-younger-onset-dementia.pdf>

Staying connected

One of the most important things you can do for your physical and mental health and general wellbeing as you get older is to have good social connections. We know that people who have good connections and strong relationships say they:

- have a better quality of life
- are more independent
- don't need as much help with daily living
- are less lonely
- have less depression
- have slower progression of dementia.

“ I want to be fit and healthy, living independently near my family, shops and buses. ”

Person with Down syndrome



Being connected keeps our bodies and minds healthier and actually helps us to live longer.

Connections can include:

- doing things with or keeping in touch with family and friends
- getting involved in clubs and classes
- being part of a walking group
- having hobbies, doing craftwork or playing games with other people to keep our minds active
- helping other people.

But as we get older, changes in our lives can reduce our social connections. These changes include retirement, changed living arrangements, not having as much contact with our families, health problems and not enough money to go out. For older people with Down syndrome, these can be even greater barriers so we need to make sure people get the support they need to stay connected.



Resources

Your community newspaper – local papers are full of events and activities. Grab a Texta and circle the ones that look interesting then look them up or give them a call.

Local government – a good way to find out what is available in your community is to look at your local council's community directory or call them to see what is available. You can also go to your local library or seniors centre to find out what is available.

Beyond Blue has a very good booklet called *Connections matter*. It is full of ideas and links to help older people stay socially active. It is a great resource for family carers and support workers to help a person think about and plan their social connection activities.

<http://resources.beyondblue.org.au/prism/file?token=BL/I366>



NDIS ideas and tips

Staying connected is an important NDIS goal for older people with Down syndrome.

This broad goal could cover support to:

- go out to social activities
- be part of a craft or hobby group
- join a club, women's group or Men's Shed
- go to church or the local senior citizens' centre
- attend fitness activities or local events
- be a volunteer or help other people.

Support workers can also help people to visit family and friends, and keep in touch with them including on social media, phone calls or FaceTime chats.

In addition to supporting a person to attend an event, support workers can help the person think about the things they would like to do, help make a plan and help to make the connections. They could use the list of resources above to make a start.

Costs, concessions and entitlements

One of the biggest problems that many seniors experience is the cost of living and the cost of keeping active and connected. Most people with Down syndrome have also never had the chance to put money aside for their retirement, so costs can be an even greater problem.

Often, benefits and concessions for seniors to mainstream activities are generally aimed at an older age group, but some organisations and services for seniors will welcome seniors with disabilities who haven't yet reached the 'official' senior age if they are on the Disability Support Pension. It's always worth asking!



Resources

Local government services – contact your local government to see if you can get a cheaper rate at leisure centres, swimming pools and community courses.

Seniors Cards – these cards are different in each state with different benefits, such as free local travel, discounts on bills and in shops. You apply in your home state. They are generally only for people aged 60 and over. <https://www.australia.gov.au/content/seniors-card>



Resources cont.

Companion Cards – most people with Down syndrome will already have a Companion Card, as you can get one at any age. You can use your Companion Card to attend participating venues and activities without having to pay for a second ticket for your companion (can be family, a friend or support worker). You can use your card all around Australia but you need to apply for your card in your home state. <http://www.companioncard.gov.au>

Concession rates – lots of organisations offer cheaper tickets and reduced price offers to people with any kind of pension card. Some, such as cinemas, also have days when they offer cheaper tickets.

Pensioner Concession Card – you get this automatically with the Disability Support Pension.

With this card, you can get cheaper medicine, bulk-billed doctor visits (this is up to your doctor), a bigger refund for medical costs when you reach the Medicare Safety Net, and help with hearing services. <https://www.humanservices.gov.au/individuals/enablers/benefits-pensioner-concession-card/39031>

Your state or territory government and local council may offer more discounts. They may lower your electricity and gas bills, property and water rates, public transport fares, and car registration. These can be different in each state or territory. This link may lead you to relevant concessions, but if not, search online for ‘pension concessions’ in your state. <https://www.australia.gov.au/information-and-services/benefits-and-payments/government-concessions-states-and-territories>

Travel concessions – these are worth checking out in your state. Depending on where you live, you can get free local travel on public transport and some very big discounts on regional travel. There are often discounts for carers too, older people with state Seniors Cards and you can use the Companion Card. This can cut everyday travel and holiday costs down a lot.

Airline concessions – the cost of airfares in Australia can make it difficult to have holidays and to visit family and friends. However, both Qantas and Virgin have schemes to cut costs for people who travel with a support person.

- Qantas domestic travel within Australia – customers who require a support person to travel are eligible for a reduced fare for both themselves (10%) and their support person (50%). Go to this link to apply for a Qantas Concession Card: <http://pwd.org.au/services/qantas-card/>
- Virgin domestic travel within Australia – the Disability Assistant Concession fare offers a 50% discount (applied to the base fare) to the support person’s fare. You need to contact the Virgin Australia Guest Contact Centre to make a booking and ask for the Disability Assistant Concession fare discount. <https://www.virginaustralia.com/au/en/help/contact-us/reservation-enquiries/>



“It’s always worth asking what concessions there are for people with disabilities, carers (such as ageing parents) and support workers. Many places don’t advertise or have signs up but will give you a discount. This can save a lot of money, especially when you’re on holiday.”

Family member of a person with Down syndrome



NDIS ideas and tips

The NDIS won’t pay for things like food, rent, tickets to go to events or memberships. But you can ask for money in your plan to help with your housing and transport costs, and for support to do things at home, get to places, and take part in daily life activities and regular or occasional events. Using your Pensioner Concession Card and Companion Card as well will help keep your costs down.



Down Syndrome
Australia

This resource is published by Down Syndrome Australia. We work with Australia's state and territory Down syndrome associations to provide support, information and resources to people with Down syndrome and their families across the country.

For more resources and information about Down syndrome, visit

 www.downsyndrome.org.au