




Down Syndrome
Australia

Adolescence





This document has been produced by
Down Syndrome Australia.

Down Syndrome Australia is the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome.

We work collaboratively with the state and territory Down syndrome associations to achieve our mission.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

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The content of this booklet has been put together from the resources that the state and territory associations have developed over many years.

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Overview

Adolescence is a time of change for any young person. Often, this is the time when young people may want more independence and to be responsible for making decisions for themselves. There are also physical and psychological changes which happen during this time. Adolescence is also a transition point for many young people to start high school and to start thinking about what they want to do after they finish school.

Each of these areas bring opportunities and challenges for a young person with Down syndrome. Parents naturally worry about normal things like social pressures, vulnerability, sexuality and physical safety. Just like other teens, adolescents with Down syndrome also need to learn about their bodies, relationships and sexuality.

This guide has been developed for parents and families to provide information about adolescence and Down syndrome. The document covers information about transition to high school, puberty, sexuality, post-school transitions and health and well-being. It is not necessarily meant to be read in one sitting, and families may find one or more of the topics to be of interest at a particular point in time. We have also provided information about where to go to get more information on each of the topics.



Transitioning to high school

Moving from primary school to secondary school can be a big adjustment for young people and their families. There are a range of issues to consider including:

- understanding your rights regarding education and disabilities
- selecting a school
- preparing a young person for the transition
- providing support in the new environment.

Legal rights

Some families find that transition to secondary school is a time when accessing inclusive education can become more difficult.

The UN Convention on the Rights of Persons with Disabilities, Article 24, protects the rights of students with a disability to have access to inclusive education. As part of the *Disability Discrimination Act 1992* in Australia, all education and training providers, in every state and territory, are legally required to ensure that all students are able to access and participate in education and training on the same basis. The Disability Standards for Education say that education providers must consult and make reasonable adjustments.

If you feel that your child has been discriminated against on the basis of their disability, you should talk with the school.

If you are not satisfied with their response you can take it to the Department of Education in your state/territory. If the issue is still not resolved, you can make a complaint through the Disability Discrimination Commissioner or the Australian Human Rights Commission www.humanrights.gov.au/complaint-information.

Selecting a school

Selecting a high school can be a difficult decision. It can be helpful to think about what the person with Down syndrome wants from schooling and what type of school environment would best suit their needs and personality. This decision should be made in conjunction with the person with Down syndrome by listening to their views and perspectives. Remember that no decision is set in stone, re-evaluate as needed — you can always change schools if circumstances change.

It is a good idea to visit the schools you are considering for the person with Down syndrome. When you are visiting the schools you should:

- Collect as much information as you can to get a good idea of whether this school will be able to provide a great education for your child.
- Take a list of prepared questions with you.
- Try to get a feel about whether this school is a positive and welcoming place.
- Find out what experience they have with including people with a disability in their school.

It is important that you talk to any key teachers, like the Year Level Co-ordinator or pastoral care team, as well as the Principal and the office staff. The attitude of the school towards students with additional needs is an important factor for consideration.

All children are eligible to attend a mainstream school, however, the decision on the best option for the child is up to the individual family. As a result some families may choose to send their child to a special school setting. For some families, it can be difficult to access an inclusive education for their child with Down syndrome, due to a school's negative approach to enrolment, a school not being inclusive, or other concerns like bullying. Some families



may choose a mainstream school because they find one that is a good fit for their child.

The research over the last 40 years shows that students with disabilities who are educated in general education settings, outperform their peers who have been educated in segregated settings, in both social and academic outcomes. You can get more information about inclusive education in the education section of the Down Syndrome Australia Community Inclusion Toolkit, available at www.downsyndrome.org.au/resources/toolkits/. It is important that parents understand the research about different school settings and different outcomes. But in the end, deciding on a school is an individual decision and each family needs to make that decision based on what is best for their child and their family.

Tips for transition to school

Prior to the school year

- Take part in the school's planned transition program attending all the events including those that have been planned for all incoming students, as well as those specifically planned for your child.
- As a family, attend school events such as Open Days, productions, tours, and so on. Have your child give you a tour of the school.
- Speak openly and frequently to your child about the impending move to secondary school, using it as a prompt for increasing independence.
- Speak about 'school rules'. If personal safety is of concern, highlight a specific rule such as, 'Students must be in the classroom when the bell goes'.
- Use a countdown calendar which the child marks off. Use photos on the calendar featuring the school, new classrooms and teachers.
- Make up a pictorial or colour coded timetable of their week: refer to it and review it regularly. This will assist them in reading a timetable at their new school.
- Establish a good routine at home focusing on preparing for school each day and reading and homework sessions.
- Build independence skills. Practise getting dressed/undressed, showering, packing bags, opening containers, using folders and books.

During the school year

- Establish an approach to communication with the school that will work for you and the teachers. Daily contact may have been possible in the primary setting, however, in secondary school, this is not always possible and it is not conducive to building autonomy and independence in your child. Corresponding by email, a communication book or a student diary may be possibilities.
- Check the school diary for notices and communications every night.
- Try not to schedule too many after school commitments, particularly during the first term of high school.
- Allow time for winding down, processing and relaxing each day.
- Ensure that meetings are scheduled with members of the support team and that minutes are taken, signed and distributed.
- Keep a folder of all relevant documents including Individual Education Plan (IEP), semester reports and educational, speech, psychological and occupational therapy assessments.
- Trust teachers to do their job, but be open and willing to share information, research and ideas that will support your child.

Additional resources

www.downsyndrome.org.au/blog/resource/transition-to-secondary-school/

www.raisingchildren.net.au



Puberty

Children with Down syndrome experience the same progression of physical and hormonal changes associated with puberty as other young people. However, they may experience a delay in the development of social maturity and emotional self-control. Learning about their bodies and puberty is essential to helping young people to be educated, aware and to stay safe.

Below we have addressed some common questions that are relevant to puberty.

Do children with Down syndrome experience the same change in emotions as other young people during adolescence?

The emotional changes that often occur during adolescence are the same for pre-teens and teens with Down syndrome as with other people the same age. Any adolescent who lives in the community, attends school and is exposed to media inevitably develops an awareness of sexuality. Teenagers and young adults with Down syndrome often express interest in dating, marriage and parenthood, just like teenagers and young adults without Down syndrome. They can be expected to experience typical adolescent changes in mood and outlook. Every person is different and if you have any concerns about emotional changes you should speak with your child and seek additional support if needed.

How can I prepare my child for puberty?

Providing information about puberty in a timely way can help your child be ready for the changes that puberty brings. It is important to talk to girls about menstruation before they experience it, as it can be scary for her if she is unaware and unprepared. Providing clear information using visuals and images to describe the changes that will occur can help with understanding.

How do you support a girl who is getting her period?

Girls with Down syndrome will get their period at the same age as other girls. Females generally begin menstruating as early as age 10 or as late as age 14. Most girls and women with Down syndrome have regular cycles with the same minor irregularities typical of their age peer group. Managing a period is not usually a problem for most girls with Down syndrome, however it can be more difficult for some girls.

All girls and women should be given the opportunity to manage their own periods. They might need:

- Teaching – girls should be taught to manage their periods as independently as possible. Some women learn quickly, while others need formal teaching programs and regular refreshers of their knowledge.
- Support – some girls need assistance to change their pads and underwear. Other girls need reminders to change pads, or someone in the background prompting them through the process.

Period underwear is another option for managing menstruation. The use of period underwear to manage menstruation may be NDIS-funded for NDIS participants.

If you are helping a girl with her periods, be respectful of her dignity and privacy and let her choose who supports her with this personal task. Religious and cultural beliefs can affect how girls manage their periods and these beliefs need to be considered and respected. When supporting any person with personal care, remember the basics of good hygiene.

For more information about managing menstruation, visit the Planet Puberty website. www.planetpuberty.org.au/the-body/periods/period-product-options/

You can find Easy Read menstruation resources on the Women with Disabilities Australia Website. <https://oursite-easyread.wwda.org.au/sex-and-your-body/your-body/what-is-menstruation/>

Sexuality and relationships

Like other adults in our community, people with Down syndrome have sexual feelings and intimacy needs. It is important that the expression of these feelings – in socially acceptable and age appropriate ways – is supported by families and caregivers to promote safety and wellbeing. Below we have addressed some common questions that are relevant to sexuality and relationships.

What about dating?

Developing an interest in having a boyfriend or girlfriend is common as people go through adolescence. There is no reason why a young person with Down syndrome cannot have a consensual relationship. Information about common dating expectations, personal safety and appropriate behaviour should be provided.

What type of sex education is appropriate for people with Down syndrome?

Sex education should be understandable, age appropriate and provided in a way that the person with Down syndrome understands. It should include information on the physical and emotional aspects as well as decision-making, cultural norms, peer pressures, relationships, consent, social skills and opportunities. It is also important to talk about your family's beliefs, expectations and any rules you have for your children.



The information you provide about sex for young adults with Down syndrome should be focused on understanding their bodies, emotions, behaviours and relationships within their social and cultural environment. Information should be factual, realistic and focus on the importance of personal responsibility, safety and community expectations for adult behaviour.

Can women with Down syndrome use birth control?

Approximately 50% of women with Down syndrome are fertile. Women with Down syndrome may use any method of contraception without added medical risk. The person with Down syndrome needs to be involved in any decision making about contraception. The method chosen will depend on personal preference, ability to use the contraceptive effectively and possible side effects. General practitioners are able to provide advice on the range of contraceptive options available and make a recommendation.

Are there any special considerations for people with Down syndrome in regard to sexually transmitted diseases?

Men and women with Down syndrome have the same susceptibility to sexually transmitted infections (STIs) as the rest of the population. Use of condoms during sexual intercourse is the best known form of protection against sexually transmitted infections. Sexual education should include information on sexually transmitted diseases and how to reduce the risk of transmitting them.

What about higher rates of sexual abuse? What can be done to reduce the chance of abuse?

Evidence shows that people with an intellectual disability are at a higher risk of sexual abuse. It is important for all people with Down syndrome to have an awareness of personal safety, be able to protect themselves and report any concerns they have about how other people are treating them. Sexual education and learning about protective behaviours early in a person's life – and having this reinforced as they mature – can help support and develop an understanding of personal safety.



People with Down syndrome should be educated on the boundaries of appropriate physical interactions in social settings, so they understand the difference between safe and appropriate behaviours and abuse. People with Down syndrome should be taught how to use assertive behaviours as well as to be able to ask for help if they are feeling unsafe. Having a trusted network of friends and family to discuss any issues is important.

If a woman with Down syndrome becomes pregnant, will the baby have Down syndrome?

At least half of all women with Down syndrome are able to have a baby. Between 35 and 50% of children born to mothers with Down syndrome are likely to have trisomy 21 or other developmental disabilities.

Are males with Down syndrome fertile?

Research into the fertility of men with Down syndrome is limited. However, in general, men with Down syndrome have a lower overall fertility rate than that of other men of comparable ages. Regardless of this, contraception should always be used for protection against sexually transmitted infections and pregnancy, unless a couple has decided upon parenthood.

What is the best approach to talking about sexuality and relationships?

There isn't a standard way to approach sex education that works for all people with Down syndrome, therefore information needs to be appropriately tailored to the person's level of understanding. For example, some young people may need basic information utilising pictures whilst others may understand more detailed information. Young people with Down syndrome may need extra education and support to express their sexuality in positive ways.

The points below might help you think about how to discuss puberty and sex education with the person with Down syndrome:

- Do some research and make sure you have all the information you need.
- Think about the best time and way to approach the conversation, aiming to respond when the person shows an interest.
- Discuss with the school what type of sex education they provide and in what format. They may have experience and resources to help young people with Down syndrome.
- Think about the type of language you want to use, that will be understood by the person with Down syndrome.
- Be open and prepared to answer any questions.
- Try to keep the information simple.
- Stories, anatomically correct dolls, role playing conversations about relationships, rather than straight text or discussion, might be useful tools to help the young person understand.
- Sex education with your young person will likely be an evolving learning process, rather than a one-off conversation about sex. You may need to discuss it many times to support understanding about sexuality.

Additional resources

Healthy Relationships and Sexuality Guide www.downsyndrome.org.au/blog/resource/healthy-relationships-and-sexuality-guide-pdf/

Healthy Relationships and Sexuality (Easy Read) www.downsyndrome.org.au/blog/resource/healthyrelationshipseasyread/

Planet Puberty – www.planetpuberty.org.au

Women with Disabilities Australia – <https://oursite-easyread.wwda.org.au/sex-and-your-body/>

NDSS – www.ndss.org/resources/sexuality/

<https://shvic.org.au/for-you/people-with-a-disability/talking-to-children-with-cognitive-disabilities?p=for-you/people-with-a-disability/talking-to-children-with-cognitive-disabilities>

www.raisingchildren.net.au/

Post school transitions

It is important to start thinking about what types of things the person with Down syndrome might like to do after they finish school, whether this be employment or further study.

It is important to support the young person with this and help them to make decisions about where, and what type of work or study they might like.

Some considerations might be:

- What does the person with Down syndrome enjoy doing?
- What are their strengths and what do they need more support with?
- Are they interested in doing more studies?
- What kind of employment would they be interested in?
- What assistance can you provide?
Where can they get other help?

Down Syndrome Australia has developed resources for employment. These can be accessed on our Right To Work website
www.downsyndrome.org.au/right-to-work/

We also have information on education and some case studies about post-school education available in the education section of the Down Syndrome Australia Community Inclusion Toolkit available at: **www.downsyndrome.org.au/resources/toolkits/**

Additional resources

Right To Work – **www.downsyndrome.org.au/right-to-work/**

Job Access – **www.jobaccess.gov.au**

NDIS – **www.ndis.gov.au/understanding/ndis-and-other-government-services/employment**



Physical and mental wellbeing

Being healthy and active is important at any age, but is perhaps more so during adolescence as the young person is experiencing many changes both physically and emotionally. Physical health and mental health are linked, and looking after both promotes wellbeing.

To encourage good physical health, the person with Down syndrome should be encouraged to:

- eat a healthy, well balanced diet
- exercise and keep active
- get enough sleep
- not take any drugs or alcohol before the legal age.

To support and promote good mental health:

- have open and clear communication with the person with Down syndrome, especially if problems arise
- normalise talking about feelings, emotions and mental health
- spend time together
- encourage the safe use of technology and social media
- encourage the person with Down syndrome to build friendships and social connections with others
- highlight the person's successes and achievements
- focus on building confidence, rather than being negative
- encourage and support the person with Down syndrome to seek further help if required.

Adolescence can be a challenging time for teenagers and their families, but it is a transition point in life and supporting the person with Down syndrome through this time can help build a strong, happy, healthy future for that person.

Additional resources

www.healthymind.org.au/

Beyond Blue – www.beyondblue.org.au

Black Dog Institute – www.blackdoginstitute.org.au

Headspace – www.headspace.com



Associations

National: 1300 881 935

New South Wales

Down Syndrome NSW

T: 1300 881 935

E: admin@dsansw.org.au

W: www.downsyndrome.org.au/nsw

Victoria

Down Syndrome Victoria

T: (03) 9486 9600

Toll Free 1300 658 873

E: info@dsav.asn.au

W: www.downsyndrome.org.au/vic

Queensland

Down Syndrome Queensland

T: (07) 3356 6655

E: office@downsyndromeqld.org.au

W: www.downsyndrome.org.au/qld

South Australia

Information Service South Australia (Down Syndrome Australia)

T: 1300 344 954

E: infoSA@downsyndrome.org.au

W: www.downsyndrome.org.au/sa

Western Australia

Down Syndrome WA

T: (08) 6253 4752

E: admin@downsyndromewa.org.au

W: www.downsyndrome.org.au/wa

Tasmania

Down Syndrome Tasmania Inc.

T: 1300 592 050

E: info@downsyndrometasmania.org.au

W: www.downsyndrome.org.au/tas

Northern Territory

Down Syndrome Association NT

T: (08) 8985 6222

W: www.downsyndroment.com.au

Australian Capital Territory

ACT Down Syndrome Association Inc.

T: (02) 6290 0656

E: admin@actdsa.org.au

W: www.downsyndrome.org.au/act



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