



Down Syndrome
Australia

Communicating with people with Down syndrome

This fact sheet has been developed to provide information and strategies for health professionals when communicating with people with Down syndrome and their families. It has been developed in consultation with people with Down syndrome and their families.

What people with Down syndrome would like health professionals to know

- With the right supports people with Down syndrome live normal, happy lives. Research has found that 99% of people with Down syndrome surveyed indicated that they were happy with their lives.
- People with Down syndrome who were surveyed wanted health professionals to know that they have the similar hopes and dreams as their peers¹.
- In Australia there is a wonderful community made up of people with Down syndrome and their families. Connection to community is important to everyone.

¹ Am J Med Genet A. 2011 Oct; 0(10): 2360–2369. Published online 2011 Sep 9. doi: 10.1002/ajmg.a.34235



- Everyone with Down syndrome is different and may have different health concerns. Look at the person first and don't just focus on the Down syndrome.
- Current information about Down syndrome can be found at: www.downsyndrome.org.au.

How to have a good conversation

“Be kind and friendly. Most families will pick a doctor for life for kids with Down syndrome. If we chose you, it's for a reason. We are looking to build a relationship with your practice so our child is comfortable with your team.”

The way people communicate is different for everyone with or without Down syndrome. The easiest way to find out how they need you to communicate is to ask them and their family directly. Some other helpful points are below:

- Use easy to understand language during the consultation.
- If an acronym is unavoidable, explain it at the beginning of your conversation or at the beginning of the written correspondence.
- Talk directly to the person with Down syndrome. Build rapport and trust with the person. Listen to them as they explain their needs. Speak directly to the person with

Down syndrome and talk to the family on how best to communicate or explain things to the person.

- Explain things clearly using balanced language. Try to avoid complex medical terminology. Break the information down and talk about one topic at a time. Allow the individual time to process the information.
- Ask questions one at a time and encourage the person to ask questions back.
- Give the person enough time to respond themselves, even if this means waiting a little longer.
- Check back with the person to ensure they have understood what has been said.
- If any type of examination is required then check in with them to see how they are feeling. Explain what you are going to do before going ahead.
- Consider any background noise and whether this is impacting the person's understanding of the consultation.
- Consider having some visual prompts to help the person understand what you are talking about.
- Have patience and don't rush the person with Down syndrome.
- Provide the person with easy read information to take away.

Useful resources

Adults - 3dn.unsw.edu.au/sites/default/files/ddn/resources/12644_UNSWMed_3DNPromo_Algorithm_Adult_Jul16_LR_FA.pdf

Adolescents - 3dn.unsw.edu.au/sites/default/files/ddn/resources/12500_UNSWMed_3DNPromo_Algorithm_Adolescent_May16_LR_FA.pdf

Contact details for Down syndrome organisations

There is a Down syndrome association in each state and territory. You can contact these associations for support and advice. We are here to help you. Our associations are made up of a wide range of parents, professionals and people with Down syndrome who work or volunteer with us. Please visit our website at www.downsyndrome.org.au or call 1300 881 935 to be automatically connected to your closest association.



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🌐 www.downsyndrome.org.au