



Tips for GPs on prenatal screening and talking to parents about Down syndrome

Deciding whether or not to do prenatal screening

Parents have the right to make an informed decision about prenatal screening. Not all parents will want to screen.

People who do want to screen will do so for different reasons:

- Some families may want to screen without wanting further diagnostic testing.
- Some may want a confirmed diagnosis to help them prepare for their child's birth.
- Others will want to use screening as the first step in making a decision about whether to continue their pregnancy.

You can support parents to make an informed choice about prenatal screening by providing them with information about:

- What information can be expected from prenatal screening including that further testing would be required to confirm a diagnosis.
- What conditions the screening test may identify together with balanced information about each of these conditions, including Down syndrome.
- What will happen after they get the results including the decisions they will need to make if they receive a high chance result. Explain the difference between a screening test and a diagnostic test. **Don't presume that undertaking screening implies any particular decision or action after a high chance result.**

Prenatal screening should only be undertaken if the family gives their consent after receiving up to date information. Parents may need additional time to decide how to proceed. They will need to consider how the information provided fits with their personal circumstances and the values that are important to them.

Providing screening results

Receiving news during pregnancy about a high chance result from screening or a prenatal diagnosis of Down syndrome can be overwhelming. Parents often process a range of emotions during this time. Many parents say that the way they felt immediately after being delivered the diagnosis was not how they felt after a few days to process the news.

Some tips on how to communicate the results to prospective parents:

- Use balanced language (e.g. 'chance' not 'risk') as you communicate up-to-date, evidence-based information about life with Down syndrome (see further information below). Avoid the use of directive or emotive language (e.g. I have some bad news).
- Share the information in the most supportive environment possible – preferably in person. If appropriate, suggest their partner or support person also attend.

“We were given the results, then the first question was; ‘would you like to terminate?’. There was no information provided on what it would mean to raise a child with Down syndrome. No one offered to put us in touch with another family. There was a presumption we would terminate. Doctors need more updated information and better skills to handle these matters.”

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- Explain what the results mean and the difference between a screening test and a diagnostic test.
- Explain the options that the family has in terms of further testing including delaying diagnostic testing until later in the pregnancy when the risk of miscarriage is reduced, or waiting until birth to confirm the diagnosis.
- Connect the family with appropriate supports including their local Down syndrome organisation (if relevant) and the option to meet with a genetic and/or general counsellor before they make a decision on how to proceed.
- An information sheet from Down Syndrome Australia [What is Down Syndrome?](#) can be shared with parents.
- Offer to meet with the family again in the next few days after they have absorbed the initial information. Do not place the family under undue time pressures to make decisions about further testing or continuation of the pregnancy.

Evidence-based information about Down syndrome is critical

Evidence-based information is critical to enable informed choice. Key facts that you may want to share with parents include:

- People with Down syndrome have an extra copy of the 21st chromosome.
- About 15,000 Australians have Down syndrome. Babies with Down syndrome are born to parents of all cultural and socio-economic backgrounds.
- There is no known cause. Some people appreciate confirmation that Down syndrome is a natural condition, not caused by anything they did or did not do during pregnancy.

- All children, including those with Down syndrome, have strengths and weaknesses that cannot be predicted before birth. In general, people with Down syndrome have mild to moderate intellectual disabilities, low muscle tone, and higher chances for some health issues, particularly heart conditions. Most of these health conditions are treatable.
- While people with Down syndrome do experience challenges, recent advances in healthcare, inclusive education and public attitudes have greatly improved their quality of life. Research has found that people with Down syndrome have reported a high level of satisfaction with life. This progress has provided greater opportunities and more people with Down syndrome are finishing school, finding jobs and forming meaningful relationships.
- Most families report their lives are enhanced by having a family member with Down syndrome.
- In Australia today, most people with Down syndrome will enjoy a long, happy and healthy life.

Children with Down syndrome are eligible for funding for Early Childhood Early Intervention (ECEI) and support from the National Disability Insurance Scheme (NDIS).

Connecting parents

The Down syndrome community is strong, vibrant and proud. Many members are keen to share their experiences so there is a better understanding of what life is really like for people with Down syndrome and their families.

The national network of Down syndrome associations can link people with other parents with similar experiences. To get connected or to find out more, contact Down Syndrome Australia on:

P: 1300 881 935

W: www.downsyndrome.org.au

E: info@downsyndrome.org.au

This resource has been developed based on the lived experiences of people with Down syndrome and their families as well as the available evidence.