Supporting the prevention and diagnosis of Fetal Alcohol Spectrum Disorder (FASD).

A guide for healthcare workers

Published: December 2025

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Alcohol and Drug Foundation

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition caused by alcohol exposure during pregnancy. It affects how the baby's brain develops, which can lead to long-term challenges with learning, memory, behaviour, emotions, and physical development.[1]

FASD is the most common preventable non-genetic cause of developmental and intellectual disability in Australia. Yet, it's often underdiagnosed.

Many people affected by FASD don't receive a formal diagnosis and the support they need early on. This delay or absence of diagnosis can lead to long-term impacts on education, employment, mental health, substance use, and involvement with the justice system.[2-6]

As a healthcare professional, you can play a vital role in both preventing FASD and supporting people and families affected by FASD.

This guide provides information, tools, and practical tips to better equip you to recognise and respond to FASD in your work.

Understanding FASD

FASD is the diagnostic term for severe neurodevelopmental impairments that result from brain damage caused by prenatal alcohol exposure.

These impairments can impact an individual's ability to learn, concentrate, remember information, and navigate emotional and social situations throughout their life.[1]

Although the term *'fetal'* might suggest that FASD only affects babies, it's a lifelong condition and can be diagnosed in children, adolescents, and adults.

HOW DOES ALCOHOL CAUSE FASD?

When alcohol is consumed during pregnancy, it easily passes through the placenta to the baby.

The baby's liver is not fully developed, so it takes longer to break down alcohol. This means alcohol can stay in the baby's body longer and at a higher concentration than in the mother.[1]

Because alcohol is toxic, it can permanently damage the baby's developing brain, leading to:

- **thinking and learning difficulties**: memory problems, poor attention, difficulty with cause-and-effect reasoning and problem-solving
- **emotional and behavioural challenges**: trouble managing emotions, coping with stress, impulsivity, and poor judgment
- **social difficulties**: challenges understanding social rules, sticking to routines, and learning from experience
- **motor skill issues:** difficulties with movement and coordination, such as trouble with balance, walking, running or using hands and fingers for tasks like writing, buttoning clothes, or using utensils.[1]

Alcohol also affects the development of other organs, which is why people with FASD often experience co-occurring physical health problems.

More than 400 medical conditions have been found to co-occur with FASD, affecting almost every system in the body including:

- central nervous system (brain)
- vision
- hearing
- cardiac
- circulation
- digestion
- musculoskeletal
- respiratory.[7]

SIGNS OF FASD

FASD is a spectrum disorder, meaning it affects people in different ways and to varying degrees.

The severity of FASD can depend on:

- the amount of alcohol consumed
- the timing of exposure during pregnancy
- the parent's overall health, genetics, and use of other substances.[1]

Some people with FASD may have distinct facial features, known as sentinel facial features, including:

- short palprebal fissures (eye openings)
- thin upper lip
- flat or indistinct philtrum (the area between the nose and upper lip).[1]

While these features may suggest prenatal alcohol exposure, they're not required for diagnosis of FASD.[8]

A person can also be diagnosed with FASD if there is confirmed prenatal alcohol exposure and ongoing challenges in three or more areas of brain function – such as attention, memory, or decision-making.[8]

How common is FASD in Australia?

There's currently no national data on the prevalence of FASD in Australia.[9]

This is due to several factors, including:

- the absence of routine assessments and screenings
- inconsistent data collection and reporting across states and territories
- limited awareness of the full spectrum of disorders within FASD.[10]

A recent study from the University of Sydney estimates that around 3.6% of Australians may have FASD – or around one child in every classroom.[11]

Because FASD is often missed or misdiagnosed, especially in vulnerable communities, the actual number may be even higher.[2]

Based on these estimates, the lifetime economic and social costs of FASD in Australia are estimated to range between $2.4 billion and $6.1 billion annually.[12]

These figures account for both diagnosed and undiagnosed cases, underscoring the urgent need for improved assessment, diagnosis, early intervention, and ongoing support for people living with FASD.

Australian attitudes and behaviours towards alcohol use in pregnancy

The good news is that more Australian women are choosing not to drink during pregnancy. In 2022–23, 72% reported avoiding alcohol while pregnant, an increase from 65% in 2019.[13]

But we know drinking before a parent realises they're pregnant remains common.

Since about half of all pregnancies in Australia are unplanned, alcohol exposure often occurs before pregnancy is known.[1] Around two in three women who were unaware they were pregnant in the early stages reported drinking alcohol during that stage.[13]

While most women reduce or stop drinking once they know they're pregnant, 15% continue to consume alcohol.[13]

The Foundation for Alcohol Research and Education's (FARE) 2020 Annual Alcohol Poll explored Australians' views on alcohol use during pregnancy and found that:

- nearly 1 in 3 Australians believed it was safe to drink alcohol at some stage during pregnancy
- 1 in 4 thought certain types of alcohol were safe to drink while pregnant.[14]

There is no known safe time, amount, or type of alcohol to consume during pregnancy. Alcohol can affect a baby's brain and body at any stage of pregnancy.

The safest choice is to stop drinking when trying to conceive.

The poll also found that 30% of Australians were unaware of the link between alcohol use during pregnancy and FASD, highlighting the need for greater awareness and education.[14]

The role of health professionals in preventing FASD

As a healthcare professional, you are a trusted source of information.

Yet, nearly half of women (53%) who had been pregnant in the past year reported not receiving any advice about alcohol use during pregnancy.[13]

Stigma and shame can make it hard for people to talk about alcohol use during pregnancy. You can help prevent FASD by creating a safe, non-judgmental space that encourages open conversations and supports early intervention.

What this looks like in practice:

- **Display inclusive materials**: use posters or infographics about alcohol use during pregnancy to signal that your clinic is a safe space. FASD Hub and NOFASD offer helpful visual resources.
- **Make alcohol conversations routine**: use simple, trusted tools like the AUDIT-C to ask about alcohol use. When screening is part of regular care, it helps reduce shame and encourages open and honest conversations.
- **Offer tailored interventions** based on screening results:
  - Low risk: Provide brief education about how alcohol can affect fetal development.
  - High risk: Refer the individual to appropriate support or treatment services to manage their alcohol use.

- **Provide accurate and timely information** on the risks of alcohol use during pregnancy:
  - Clearly communicate that no amount, time or type of alcohol is safe to consume at any stage of pregnancy.
  - Explain that alcohol is a toxic substance. Drinking during pregnancy can harm the developing baby. It may lead to birth defects in the brain and organs, which may affect overall development.
  - Share information from the Every Moment Matters campaign. It offers up-to-date, evidence-based guidance on drinking alcohol during pregnancy and breastfeeding.
- **Discuss contraception options**: Talk with patients/clients at risk of unplanned pregnancy about the contraception options they can access, and provide advice for what they can do to reduce harm if/when they suspect they are pregnant.

FASD diagnosis

BARRIERS TO FASD DIAGNOSIS

There are several barriers that contribute to FASD often being underdiagnosed or misdiagnosed.

Barriers include:

- **Stigma**: Fear of judgment can prevent parents from disclosing their drinking during pregnancy. Health professionals may also hesitate to ask, concerned about damaging trust or causing distress.[15-17]
- **Limited awareness and unclear referral pathways**: Many health professionals are unfamiliar with FASD, including how to recognise symptoms in adults or where to refer patients for assessment. This can lead to missed or delayed diagnoses.[18, 19]
- **Complex process**: Diagnosing FASD requires a multidisciplinary team, typically including paediatricians, neuropsychologists, speech pathologists, and occupational therapists, to assess multiple areas of development.[1]
- **Symptom overlap with other conditions**: FASD is sometimes described as a hidden disability. Its symptoms often resemble those of other neurodevelopmental disorders such as ADHD or autism. And without thorough assessment, behaviours may be misinterpreted or dismissed as typical for a child's age. According to NOFASD, 4 in 5 people diagnosed with FASD were initially misdiagnosed.[7, 17, 20, 21]
- **Limited services**: Specialised clinics are scarce, especially in rural and remote areas. Families often face long wait times and few options for assessment. On average, it takes four years from the onset of symptoms to receive a FASD diagnosis.[17, 21, 22]

Due to these challenges, many Australians living with FASD never receive a formal diagnosis or get the support they need.

CHALLENGES WITH ADULT FASD DIAGNOSIS

FASD doesn't go away with age. Many adults live with FASD, but it often goes unrecognised.

Health professionals are typically trained to identify FASD in children, not adults. In adulthood, the signs can be harder to spot. People may have developed coping strategies, or their symptoms may be mistaken for other conditions, such as ADHD, autism, or mental health issues.[7]

Adults with FASD may experience difficulties with:

- living independently
- managing finances
- maintaining employment
- forming and sustaining social connections.[23]

These challenges can lead to feelings of exclusion, low self-esteem, and increased risk of mental health issues such as depression and anxiety.

IMPACT OF UNDIAGNOSED FASD

Without a diagnosis, people with FASD are often left feeling confused and overwhelmed by the challenges they face – whether it's learning, managing emotions, or navigating social situations.

> *"The most difficult challenges I think that I faced growing up were definitely going through the school system. I really struggled with every aspect of that – keeping up with schoolwork, understanding my lessons, staying focused, making friends and being able to socialise with my peers."* – *Jess*[24]

These difficulties can be misunderstood or mislabelled, which means people don't receive the support they need. Over time, this can lead to ongoing challenges in areas like education, employment, mental health, substance use, and involvement with the justice system.

Undiagnosed FASD can have significant long-term consequences, including:

- **Lower life expectancy**: A UK study found that people with FASD had an average life expectancy of just 34 years – 42% lower than the general population. Leading causes of death included suicide, accidental injuries, and overdoses related to alcohol and other drugs.[3]
- **Disproportionate justice system involvement**:
  - At Banksia Hill Youth Detention Centre in Western Australia, 36% of detained young people were diagnosed with FASD.
  - In Canada, youth with FASD are 19 times more likely to be incarcerated than their peers without the condition.[4, 5]
- **High rates of substance use**: Nearly half of adults with FASD engage in risky alcohol or drug use. Over their lifetime, they're up to 20 times more likely to develop substance use disorders.[6]

It's important to recognise that the impacts of undiagnosed FASD are most acutely felt by affected individuals and families.

But we also know that undiagnosed FASD has broader impacts by placing pressure on health, education, justice, and social systems.

THE IMPORTANCE OF DIAGNOSIS

Getting a diagnosis of FASD can be life-changing, for both individuals and their families.

A diagnosis:

- **Brings clarity:** It helps explain behaviours that may have previously seemed confusing or difficult.[17]
- **Reframes behaviour**: Instead of seeing someone as lazy or defiant, a diagnosis recognises that these challenges are linked to brain injury. This understanding can lead to more compassionate and appropriate support from families, educators, and professionals.[17]
- **Guides tailored support**: Because FASD affects people in different ways, diagnosis helps identify the type and level of support that best suits the individual's needs.[17]
- **Highlights strengths and needs**: A diagnostic assessment not only identifies areas where support is needed, but it also highlights a person's strengths. This helps families, teachers, and health professionals set realistic expectations and develop strategies that empower individuals to build on their strengths.[17]
- **Improves access to services**: Diagnosis can enable access to supports such as the National Disability Insurance Scheme (NDIS) and other services that help individuals with FASD thrive at home, in school, and in the community.[17]
- **Leads to better outcomes**: With the right support, individuals with FASD are better equipped to live safer, healthier, and more fulfilling lives. Families can also feel more confident in supporting their loved ones.[17]

> *"Same with the teachers – they said, 'Well, why can't you do this? It's easy, why can't you just do it?' I didn't know – I just couldn't do it. And now that I'm here [with a FASD diagnosis], there's an answer to why I can't, and that's just... a relief."* – *Lola*[25]

Diagnosis is a gateway to understanding, support, and improved outcomes – helping individuals with FASD reach their full potential.

Updated Australian guidelines for diagnosing FASD

In April 2025, Australia released updated national guidelines to support the assessment and diagnosis of FASD.

These updates build on the original 2016 guide and reflect the latest research, clinical experience, and lived experience of individuals and families affected by FASD.[8]

The revised guidelines take a lifespan approach, recognising that FASD is not just a childhood condition. Diagnosis is supported at any age, from infancy through to adulthood, with a focus on making the process more accurate, inclusive, and accessible.[8]

Key updates include:

- **Refined diagnostic criteria**: based on current evidence, the criteria aim to improve assessment accuracy. For example, facial feature assessment is no longer mandatory, acknowledging the limitations in assessing facial features across culturally diverse populations.
- **Flexible terminology**: individuals and families can choose language that best reflects their experience, such as FASD or 'neurodevelopmental disorder associated with prenatal alcohol exposure'.
- **Greater emphasis on clinical judgement**: health professionals are encouraged to take a person-centred approach. Instead of listing specific tests, the guidelines offer detailed advice on assessing different areas of brain function, allowing practitioners to select tools suited to the individual's age, background, and needs.
- **Culturally safe practices**: an Indigenous framework supports respectful and inclusive assessments, helping ensure cultural safety throughout the diagnostic process.
- **Plain language summaries**: these help families understand the diagnostic process and what to expect, empowering them to be actively involved.
- **Practical tools for clinicians**: the guidelines include templates, visual summaries, and decision-making aids to support consistent and confident diagnosis.[8]

These updates aim to reduce stigma, improve early identification, and ensure people with FASD receive the support they need to thrive.[8]

Health professionals are encouraged to familiarise themselves with the new guidelines and access the available training modules to ensure assessments are safe, accurate, and person-centred.

CULTURALLY SAFE PRACTICES

Culturally safe care is essential when supporting Aboriginal and Torres Strait Islander people affected by FASD.

The updated national guidelines include an Indigenous framework to guide respectful, inclusive, and culturally informed assessments. This framework helps health professionals:

- recognise the importance of culture, community, and connection
- engage in collaborative, person-centred decision-making
- create safe spaces for yarning and open conversation
- use strengths-based approaches that honour lived experience.

It encourages practitioners to move beyond clinical checklists and take a holistic view of the individual, their family, and their cultural context. This can help ensure assessments are not only accurate, but also meaningful and empowering.

To support these principles in practice, the Strong Born campaign was launched in 2023, offering a community-led approach to culturally safe conversations around FASD, alcohol use during pregnancy, and breastfeeding.

The campaign provides educational resources for families and health workers, aiming to reduce stigma and shame by fostering safe, supportive environments. It encourages yarning, listening, and connection - helping families feel seen, heard, and supported.

As the name suggests, Strong Born is about helping babies be strong born by giving them the best start to life through awareness, support, and community-led care.

Tips for healthcare workers supporting people with FASD

Healthcare workers are often a key connection point for individuals with FASD and their families. Effective support means providing your clinical expertise in a compassionate, flexible, and person-centred way.

Here are practical ways to build trust, improve communication, and provide support that leads to better outcomes.

1. CHECK AND BUILD YOUR KNOWLEDGE AND CONFIDENCE

Start by assessing your own knowledge of FASD and strengthening your understanding of the condition and recent evidence-based approaches.

Accessing reliable information and training can help you identify risks early, and feel more prepared for sensitive conversations:

- **Stay up to date**: engage with current guidelines, webinars, and training opportunities.
- **Use trusted resources**: platforms like FASD Hub and NOFASD offer evidence-based information.
- **Learn from lived experience**: explore resources like What I wish people knew about me – living with FASD and What I wish health professionals knew about FASD to deepen empathy and understanding.

2. BUILD TRUST AND CREATE A SAFE SPACE

Stigma, shame, and past negative experiences can make it difficult for people with FASD to engage with services. A respectful, non-judgmental approach helps build rapport and encourages openness:

- **Listen actively**: give your full attention, acknowledge their feelings, and avoid interrupting. This shows respect and builds connection.
- **Use inclusive, strengths-based language**: when discussing alcohol use or FASD-related concerns, choose words that are respectful and supportive. Focus on the person's strengths and potential solutions.
- **Respect cultural identity and lived experience**: ask about cultural preferences, involve family or community supports where appropriate, and make all decisions collaboratively.

3. COMMUNICATE CLEARLY AND SUPPORT UNDERSTANDING

People with FASD may be verbally fluent, but they can struggle with comprehension, memory, and following instructions – especially under stress.

- **Use plain, everyday language**: avoid medical jargon or abstract concepts.
  - For example, instead of saying *"It's important to manage your emotions"*, try *"Let's talk about what helps you feel calm when things get tough."*
- **Break down complex ideas**: present one idea at a time, using short sentences and simple steps. This helps reduce cognitive overload and supports better understanding.
- **Check for comprehension regularly**: ask open-ended questions like *"Can you tell me what you understood from that?"* rather than *"Do you understand?"*.
- **Use visual aids**: use diagrams, pictorial guides, or written checklists to reinforce key messages and aid memory.

4. BE FLEXIBLE AND PATIENT

People with FASD may need more time to process information, complete tasks, or regulate emotions.

- **Allow extra consultation time**: schedule longer appointments or follow-ups to reduce pressure and allow for repetition or clarification.
- **Use real-life examples to support understanding**: explain things using relatable examples or analogies.
- **Adapt your approach**: observe how the person communicates and responds emotionally. Slow down, offer breaks, or simplify conversations if needed.

5. TAILOR SUPPORT BASED ON DIAGNOSTIC STATUS

People may be at different stages of awareness and diagnosis when it comes to FASD. Some may be unaware they are affected, others might suspect they have FASD but haven't been diagnosed, and some may already have a formal diagnosis.

Tailoring your support to each stage can help improve engagement and lead to better outcomes.

If you suspect someone may have FASD:

- **Explore concerns gently**: ask about memory, learning, emotional regulation, or prenatal history without making assumptions. Use tools like the NOFASD screener to guide conversations.
- **Initiate referrals**: connect them with GPs or multidisciplinary teams experienced with FASD assessment.

If someone presents with a suspected FASD diagnosis:

- **Validate their concerns**: acknowledge the challenges they're facing and the importance of seeking clarity.
- **Explain the assessment and diagnosis process**: outline what's involved and reassure them that support is available regardless of the outcome.
- **Support navigation**: help them prepare for assessment by gathering relevant documentation, such as:
  - birth records (date, weight, length)
  - medical history (birth defects, illnesses, surgeries)
  - school reports and teacher concerns
  - details of any facial features
  - history of alcohol exposure during pregnancy.
- **Initiate referrals**: connect them with GPs or multidisciplinary teams experienced with FASD assessment.
- **Share funding information**: let them know FASD is recognised under the Medicare Benefits Schedule, which, if eligible, can help reduce financial barriers to assessment and support services.
- **Provide reassurance**: emphasise that diagnosis is a step toward tailored support and improved quality of life.

If someone has a confirmed FASD diagnosis:

- **Focus on their strengths and goals**: ask what's working well and what they'd like to achieve. Use this to guide care planning.
- **Support transitions**: help plan for changes like starting school, entering the workforce, or moving to adult health services with clear steps and consistent support.
- **Coordinate support**: with consent, work across systems like education, justice, disability, and social services to ensure continuity of care.

6. CONNECT PEOPLE WITH SERVICES AND RESOURCES

You don't have to do it all alone. Linking individuals and families with appropriate services can strengthen their support network and improve outcomes.

Resources and services for people with FASD:

- NOFASD National FASD Hotline (**1800 860 613**): A service that provides free and confidential advice about FASD, including FASD assessment, diagnosis and referral options.
- FASD Hub Service Directory: Find health professionals and services with FASD experience and expertise.
- NOFASD offers comprehensive information on FASD for parents, carers and families, as well as tailored resources specifically for adults living with FASD.
- FASD Hub provides tailored information relevant for individuals with FASD, families and carers, as well as curated Aboriginal and Torres Strait Islander resources and research.
- Australian Indigenous FASD framework: A resource targeted at building the capacity of Aboriginal communities to access FASD knowledge, resources, assessments, diagnosis and support services.
- Strong Born campaign: A campaign that provides tools and resources for families and communities to support culturally safe conversations about alcohol use during pregnancy and breastfeeding.

Resources for health professionals:

- Australian guidelines for assessment and diagnosis of FASD: Updated guidelines that aim to improve assessment and diagnostic services for FASD in Australia.
- Australian Indigenous FASD framework: A resource targeted at building the capacity of non-Indigenous practitioners to deliver FASD knowledge, resources, assessments, diagnosis and support services.
- Supporting alcohol-free pregnancy and safe breastfeeding: A free online course that aims to give healthcare professionals the tools, information and confidence to discuss alcohol use in a non-judgemental way with patients who are planning a pregnancy, are already pregnant or breastfeeding.
- FASD-Informed Practice for the Australian AOD Workforce: A free, evidence-based course aimed at supporting professionals to better understand and respond to individuals diagnosed with FASD, or possibly living with undiagnosed FASD.
- The FASD Hub provides current information about diagnosis, training and education, and supports for health professionals.
- Strong Born campaign: A campaign that provides tools and resources for health workers to support culturally safe conversations about alcohol use during pregnancy and breastfeeding.

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