

Information and resources for clinicians after a diagnostic assessment

The following are some approaches to providing support and intervention for an individual and/or their parents or caregivers after a diagnosis of FASD has been made. They are relevant for children, adolescents and adults. These approaches are also important to address patient needs even when the diagnostic assessment is inconclusive or FASD has been excluded.

1. Explain the diagnosis:

Using a *non-judgemental approach* that recognises the range of emotions that might be experienced by individuals, parents or caregivers when a diagnosis of FASD is given, explain that making a diagnosis can:

- Improve understanding of FASD.
- Improve understanding of the individual's difficulties while also identifying their strengths and help parents and carers adjust their expectations and provide support accordingly.
- Provide opportunities for individuals, parents and caregivers to express and/or process a possible range of emotions.
- Facilitate early intervention to improve a child's development.
- Identify individuals and/or their family members who are in need of assistance e.g. referral to alcohol and other drug services.

2. Provide individuals, parents and caregivers with:

- The reports of assessments from health professionals.
- The outcomes of the assessments, e.g. diagnoses; provisional diagnoses; need for further assessment.
- The details and implications of a FASD diagnosis (or non-diagnosis).
- Some 'plain English' information about FASD, support after diagnosis and contact details for NOFASD Australia (Printable information on pages 4 and 5)
- A contact number for a clinician who can respond to any questions that arise following diagnosis about the assessment and/or management plan.

3. Develop a management plan with individuals and/or their parents and caregivers so they:

- Can identify their priorities and goals for inclusion in the management plan.
- Are aware of therapy options and family support mechanisms available as appropriate interventions put in place.
- Are empowered during future assessments, management and support.
- Are aware of accessible parent, caregiver, family and personal networks in their community.
- Are aware of support organisations.

- Are aware of the need for referrals and further medical review and of potential waiting times for services.
- Receive a copy of the management plan.

4. Consider support and interventions:

Build therapeutic interventions around the individual's:

- Strengths, interests and positive attitudes.
- Willingness to participate in family, school or institutional activities and routines.
- Engagement with their family, peers and/or caregivers.

Key approaches include:

- Educating individuals, parents and caregivers about FASD and related impairments.
- Improving parent, caregiver and teacher understanding of interactions with the child, adolescent or adult living with FASD.
- Ensuring appropriate educational support and accommodations are implemented.
- Targeting therapy programs towards supporting the individual's key functional difficulties.
- Medication (when indicated and appropriate).
- Advocating for the individual e.g. in education, child protection or justice systems.

Challenges to address may include:

- Challenges of daily life – e.g. caregiver fatigue, the need for routine and repetition for many individuals living with FASD, emotional or behavioural problems including aggression.
- Family's need to access multiple health services, potentially with limited communication between different service providers.
- Service providers with limited knowledge about FASD
- Need for individuals, parents and caregivers living with FASD to educate teachers, health and other professionals about FASD.
- Lack of recognition of a FASD diagnosis as a disability, providing a hurdle to obtaining funding for educational and other assistance
- Lack of recognition of co-existing mental, developmental or physical health conditions

Breen C & Burns L. Improving services to families affected by FASD. National Drug and Alcohol Research Centre University of New South Wales. November 2012.

<https://ndarc.med.unsw.edu.au/project/improving-services-families-affected-fetal-alcohol-spectrum-disorders-fasd>

Eight Magic Keys

- These eight strategies underpin successful strategic interventions for students with FASD and are one example of an approach that can be taken.
- They are simple, functional strategies to use with young people with FASD and can be used by caregivers, teachers and health professionals.

- They were developed for use by the FASD Centre for Excellence, Substance Abuse and Mental Health Services Administration
<http://www.faslink.org/EightMagicKeys.pdf>



Printable information on Fetal Alcohol Spectrum Disorder and post diagnosis support for parents and caregivers

This information was provided by NOFASD Australia



Fetal Alcohol Spectrum Disorder (FASD) is a condition that may be diagnosed in a person who, before they were born, was exposed to alcohol. The alcohol in any alcoholic drink (beer, wine or spirits) is rapidly absorbed into the mother's blood stream and crosses the placenta to the unborn child to change otherwise healthy development. FASD is characterised by damage to the developing brain, leading to abnormalities in how the brain works. This can show up in several different ways, such as problems with learning, memory, language, judgement, decision-making and planning, movement or sensation. Some, but not all individuals can also have facial features that are characteristic of FASD.

Alcohol can cause harm to the unborn child at any time during pregnancy (including before pregnancy is confirmed) and the level of harm depends on the pattern of the mother's alcohol use - the percentage of alcohol in drinks, the number of drinks, and over what time the alcohol drinks were consumed. Binge drinking for example, means a high level of alcohol is consumed in a shorter period of time.

In addition to the alcohol exposure, the vulnerability of a pregnancy and an unborn child may also be affected by other factors like genetics, family alcohol use across generations, the father's alcohol use prior to conception, the mother's age and general health (for example, nutrition, tobacco use) and other environmental factors like stress (exposure to violence, living with poverty, factors at work).

FASD is not always obvious at birth and might not be noticed until the child doesn't reach developmental milestones or behaviour and learning difficulties become a worry once the child starts school. FASD can also be first diagnosed in adolescence or adulthood. Different professionals might need to be involved to assess the areas of the child's life where help is most needed.

A person who was exposed to alcohol before they were born might now be any age. A proper diagnosis, appropriate services and support can help any person living with FASD to prevent behaviour from worsening, encourage attendance and participation at school, and help sustain work and build understanding, social relationships and friendships. Parents, families and communities need to be involved in this individual's life and work together.

FASD lasts a lifetime but with the right help and caring, a good quality of life is possible. Care at home is incredibly important but can be challenging. Parents and carers need to care for themselves and be offered support too. NOFASD Australia can help. Please contact us on 1300 306 238.

With grateful acknowledgement to NOFASD Australia, a non-government national organisation registered as an incorporated association in South Australia under the Associations Incorporation Act 1985.

Post Diagnosis – Support

<p>NOFASD Australia is a strong and effective voice for people living with FASD and offers information, resources and ongoing support to individuals and families via telephone, email, online or by post.</p> <p>NOFASD Australia has a wide network of parents and carers in most locations across Australia and we can connect you with other experiences parents, and people who understand what you are going through.</p> <p>FASD lasts a lifetime but a better quality of life is always possible. Our knowledge and experience in supporting individuals, parents and families before and after diagnosis can help you.</p> <p>We work with people to share information, resources and offer professional support to service providers who might already be supporting your family or we can help connect you with these people in your community.</p>	<p>CONTACT DETAILS</p> <p>Telephone: 1300 306 238</p> <p>Email: enquiries@nofasd.org.au</p> <p>Website: http://www.nofasd.org.au</p> <p>Online contact: http://www.nofasd.org.au/contact-us</p> <p>Face book: https://www.facebook.com/NOFASD.Australia/</p> <p>Postal address: GPO Box 448, WYNYARD TAS Australia 7325</p>
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NOFASD Australia raises public awareness of FASD through community education for individuals, parents/carers or groups and we deliver training to service providers who support families.

Parents, carers and their supporters can join the NOFASD Network and receive our monthly e-newsletter. If you do not have email, we can post out copies of the newsletter each month. NOFASD Australia has a Facebook page on which we post daily news and items of interest for individuals, parents and families from Australia and around the world.

The information you provide is private and confidential, we will always seek your written consent to share any personal information for any purpose and we respect your right to choose anonymity.

NOFASD Australia is non-government national organisation registered as an incorporated association in South Australia under the Associations Incorporation Act 1985 and has held Health Promotion Charity status since 2007.

Australian FASD websites and resources

Australian FASD support organisations



<http://www.nofasd.org.au/> 1300 306 238

NOFASD Australia is the national organisation representing the interests of individuals and families living with Fetal Alcohol Spectrum Disorders.

NOFASD Australia provides:

- Support for individual/ parents/caregivers/families before, during and after a diagnostic assessment.
- An online and free telephone support and advocacy service.
- A website with resources for individuals, parents/caregivers and families
- Up- to- date information on Australian FASD Support Groups
- *FASD in Australia* – a series of YouTube videos
- *Education and training workshops in your child's school*
- *Fact Sheets about common behaviours and ways of managing these behaviours*



<http://www.rffada.org/>

The Russell Family Fetal Alcohol Disorders Association is a national organisation dedicated to prevention and ensuring the individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning.

rffada provides:

- A website with resources for families and individuals
- Support groups and Facebook groups
- Facebook groups for parents and carers, people living with FASD and birth parents
- Training for organisations

Australian FASD websites and resources

- Alcohol, pregnancy and FASD – Telethon Kids Institute, Perth, Western Australia
<http://alcoholpregnancy.telethonkids.org.au/>
- Understanding FASD – A Guide for justice professionals
 - A series of videos produced by the Alcohol, Pregnancy and FASD group at the
 - Telethon Kids Institute
<http://alcoholpregnancy.telethonkids.org.au/fasd-justice/professional-development/>
- Understanding and addressing the needs of children and young people living with Fetal Alcohol Spectrum Disorders (FASD) – a resource for teachers
<http://www.kimberleyfasdresource.com.au/>

International FASD websites

University of Washington FAS Diagnostic and Prevention Network

<https://depts.washington.edu/fasdpn>

Centers for Disease Control and Prevention

<http://www.cdc.gov/ncbddd/fasd/diagnosis.html>

American Academy of Pediatrics – FASD toolkit

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

Substance Abuse and Mental Health Services Administration

<http://www.samhsa.gov/>

The Asante Centre

<http://www.asantecentre.org/>

Canada FASD Research Network

<http://www.canfasd.ca/>

National Organisation for Foetal Alcohol Syndrome – UK

<http://www.nofas-uk.org/>

Fetal Alcohol Network New Zealand

<http://www.fan.org.nz/>

Other Australian websites and resources

NHMRC Guidelines to Reduce Health Risk from Drinking Alcohol.

<https://www.nhmrc.gov.au/health-topics/alcohol-guidelines>

Australian Indigenous Alcohol and Other Drugs Knowledge Centre

<http://www.aodknowledgecentre.net.au>

- **AODconnect:** a national directory of alcohol and other drug treatment services for Aboriginal and Torres Strait Islander people. An app for health professionals working in the alcohol and other drugs sector looking for a culturally appropriate service in different states of Australia
- **Stay strong and healthy pregnancy videos:** includes a guide for health professionals in discussing alcohol with Aboriginal pregnant women, assessing risk to mother and baby and providing appropriate advice in a culturally sensitive environment.
- Resources and training material to support prevention and management of FASD in FASD Indigenous communities

Women Want to Know Project and Resources

<http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/wwtk>

- Resources - online e-learning courses, videos - for health professionals to routinely discuss alcohol and pregnancy with women and to provide advice that is consistent with the [National Health and Medical Research Council's Australian Guidelines to Reduce Health Risks from Drinking Alcohol](#).

Foundation for Alcohol Research and Education

<http://www.fare.org.au/>

Australian Parenting Information and Programs

- The Australian Parenting website <http://raisingchildren.net.au/>
- Parent helplines and hotlines <http://raisingchildren.net.au/articles/hotlines.html>
- Triple P – Positive Parenting Program <http://www.triplep.net/glo-en/find-out-about-triple-p/>

Australian Foster Carer Associations

- Foster Carer Association of WA (Inc) <http://www.fcawa.com.au>
- Fostering NSW <http://www.fosteringnsw.com.au>
- Foster Carer Queensland <http://fcq.com.au>
- Foster Carers Association NT <http://fostercarersnt.org.au>
- Foster Carers Association of Tasmania <http://www.fcatas.org.au>
- Connecting Foster Carers – South Australia <http://cfc-sa.org.au>
- Foster Carers ACT www.fcaact.org.au