

Appendix A7: Information for individuals and caregivers after a diagnostic assessment

What happens after all the assessments?

- The doctor will share and discuss with you the results of the medical and other assessments.
 - The doctor will also discuss the diagnosis, which may be Fetal Alcohol Spectrum Disorder or another diagnosis.
 - In some cases, the doctor may need to obtain extra information before making a diagnosis.
- You should ask any questions you have and ask for a copy of the assessment findings. These may be in the form of a letter or a report and the doctor may be able to provide this to you at the appointment or if not, post it to you after the appointment. Ask how long it might be before you can expect a letter or a copy of the report.
- You can discuss with the doctor or another member of the team **any specific goals** you have for your family member and for the family as a whole. This is part of developing a management plan for the person with FASD.
- Depending on the person's specific needs, the doctor or another team member may make a referral to other health professionals for therapy, for example to an occupational therapist, speech therapist or a psychologist.
- Ask about where to go for any therapy or other services and if there are any costs and waiting times to access these services. You may also want to ask about any private therapy services that are available locally and how much these are likely to cost.
- In the case of a child who is going to school, part of the child's ongoing therapy goals may involve the school. The doctor or another team member may be able to approach the school about this and provide the school with the report or a copy of the child's management plan.
- Also ask if you can phone the doctor or another member of the team with any questions once you have had time to read the information the doctor has given you and you have had an opportunity to discuss the diagnosis with members of your family.

Support organisations for individuals and families

National Organisation for Fetal Alcohol Spectrum Disorder Australia (NOFASD)

An incorporated association and health promotion charity. The mission is to be an effective voice for individuals and families living with FASD, while supporting initiatives across Australia to promote prevention, diagnosis, intervention and management.

- Ensuring the voice and concerns of the parents and carers of children and adults living with FASD is represented and included where it needs to be
- A helpline, advisory and referral service for those who have FASD or are supporting someone who has FAS
- A regular newsletter providing the latest information on all aspects of FASD for all relevant stakeholder
- Community and digital education and training service
- An up-to-date comprehensive website of curated resources and links to assist in all aspects of FAS
- Service provider training to increase sector knowledge and further FASD awareness

How to contact NOFASD Australia

Website: <https://www.nofasd.org.au/contact-us/>

Email: enquiries@nofasd.org.au

Phone: 1800 860 613

Russell Family Fetal Alcohol Disorders Association (rffada)

A not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a “no blame no shame” ethos.

The mission is to support families, to provide information, training and education to increase the capacity of communities, organisations and individuals to support those people living with FASD to live to their full potential.

How to contact rffada

Website: <https://rffada.org/>

Email: elizabeth@rffada.org

Phone: 0412 550 540

Foster Carer Associations

- Foster Carer Association of WA (Inc) <https://www.fcawa.com.au/>
- Fostering NSW <http://www.myforeverfamily.org.au/splash-page/1>
- Foster Carer Queensland <http://www.qfkc.com.au/>
- Foster Carers Association NT <http://fostercarersnt.org.au>
- Foster Carers Association of Tasmania
http://www.fostercare.tas.gov.au/foster_care_association_of_tasmania
- Connecting Foster Carers – South Australia <http://cfc-sa.org.au>
- Foster Carers ACT <https://www.acttogether.org.au/our-services/foster-care/>

Other Australian resources

FASD Hub Australia

Information on FASD for Australian health, justice and education professionals, service providers, researchers, policy makers and parents and carers.

- Understanding FASD - What is FASD and Living with FASD
- Alcohol and pregnancy
- FASD assessment and diagnosis
- Managing FASD
- Preventing FASD
- Resources
- Research Publications
- Training opportunities
- List of clinics and services across Australia
- FASD Research Australia Centre of Research Excellence

Website: <https://www.fasdhub.org.au/>

Email: fasdhub@telethonkids.org.au

Some FASD websites and resources from overseas

Please note that these websites and resources may refer to services and programs that are not available in Australia.

Terms used to describe FASD may also be different to terms used in Australia.

Country	Support Group	Research/Other
New Zealand	FASD Care Action Network (FASD-CAN) https://www.fasd-can.org.nz/	Fetal Alcohol Network New Zealand (FANNZ) http://www.ahw.org.nz/Issues-Resources/Fetal-Alcohol-Spectrum-Disorder
Canada	Support for FASD – lists Canadian support groups by province https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/support.html	CanFASD – Canada FASD Research Network https://canfasd.ca/
USA	National Organisation on Fetal Alcohol Syndrome (NOFAS) https://www.nofas.org/	Centers for Disease Control and Prevention https://www.cdc.gov/ncbddd/fasd/research.html
UK	National Organisation for Foetal Alcohol Syndrome – UK http://www.nofas-uk.org/	