

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

These Australian organisations are independent and not-for-profit. You can contact them at any stage of the diagnostic process - before, during or after a diagnostic assessment.

National Organisation for Fetal Alcohol Spectrum Disorder Australia (NOFASD)



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

What does NOFASD provide?

- Support for parents/caregivers before, during and after a diagnostic assessment.
- An online and free telephone support and advocacy service.
- A website with many resources for individuals, parents/caregivers and families
- Strategies to care for your child
- A National Parent Advisory Group
- Up-to-date information on FASD Support Groups around Australia
- *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
 - Impulse control, behaviour and consequences
 - Information processing
 - Memory
 - Patterns and connections
 - Sensory issues and attention
 - Sleeping and eating

How to contact NOFASD Australia

Website: <http://www.nofasd.org.au/> (**Contact Us** section on website)

Phone: 1300 306 238

Email: enquiries@nofasd.org.au

Russell Family Fetal Alcohol Disorders Association (rffada)



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.

What does rffada provide?

- A website with lots of resources for families and individuals;
- Face to face support groups for parents of children with FASD in some parts of Australia;
- Facebook groups for parents and carers, people living with FASD and birth parents;
- Training for organisations

How to contact rffada?

Website: <http://www.rffada.org/> (**Contact Us** section on website)

Postal address: PO Box 6795 Cairns Queensland 4870

Other Australian resources

Living with Fetal Alcohol Spectrum Disorder – A guide for Parents and Caregivers

This guide includes:

- Understanding FASD
- Primary disabilities and secondary conditions
- FASD from infancy to adulthood
- Care strategies – understanding behaviours, the importance of structure

Produced by the Drug Education Network in Tasmania, Australia.

<http://www.den.org.au/wp-content/uploads/2014/11/Living-with-FASD-A-Guide-for-Parents-and-Caregivers.pdf>

Alcohol- effects on unborn children

This website includes:

- What is FASD:
- How alcohol can affect developing babies;
- What are some of the problems caused by FASD;
- Contact numbers and links

Produced by the Government of South Australia, Women's and Children's Health Network
<http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=122&id=1950>

Telethon Kids Institute – Alcohol, Pregnancy & FASD

This website includes:

- What is FASD?
- Diagnosing FASD
- Our research
- Resources



<http://alcoholpregnancy.telethonkids.org.au>

The Australian Parenting website

This website does not specifically refer to FASD, but may provide you with some useful general information

<http://raisingchildren.net.au>



This website provides

- Information, discussion forums other resources for parents, including pregnancy, newborns, toddlers, pre-school, school, pre-teens and teens
- One section of the website provides information on Disabilities
- Includes a free downloadable app on *Children with Autism Spectrum Disorder*
- Parent helplines and hotlines <http://raisingchildren.net.au/articles/hotlines.html>

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

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.

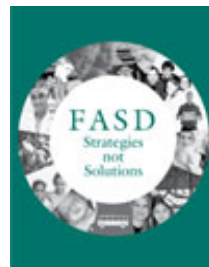
FASD Strategies not Solutions_(Canadian)

<http://edmontonfetalalcoholnetwork.org/resources/strategies-not-solutions/>

This manual is designed for caregivers who, in their everyday lives, encounter children and youth affected by Fetal Alcohol Spectrum Disorder.

It includes information about:

- How to guide your child's behaviour
- Choice making
- Impulse control
- Communication
- Calming Techniques
- Feelings and emotions
- Age-specific strategies: eating, play time, sleep and wake time, self-care, recreation, relationships and sexuality and self-harming



Parenting children affected by Fetal Alcohol Syndrome – A guide for daily living (Canadian)

http://fasd.typepad.com/fasd_support_in_alberta/2006/11/parenting-child.html

This guide includes:

- *Parenting suggestions:* effective communication, consequences and positive feedback, transitions, structure and routines, supervision.
- *Guidelines for daily living:* routines, dressing, the bathroom, mealtime, bedtime, sleep, managing hyperactivity, managing impulsivity, sensory considerations, social skills, handling money
- *Special considerations for infants:* sensitivity, illness, crying, feeding, sleep, take care of you.
- *Special considerations for adolescents:* structure and supervision, life skills, adolescents in the justice system

Strategies parents find helpful in raising their children living with FASD (Canadian)

<http://come-over.to/FAS/PDF/TorontoStrategiesParents.pdf>

This booklet highlights strategies families have found helpful raising their children with FASD, in a variety of ages and topics.

- Infants and toddlers (0 – 2 years)
- Preschoolers (3- 5 years)

- School age (6 – 12 years)
- Adolescents (13-17 years)
- Young adults and adults (18+ years)

FASD: Finding Hope – Knowledge Network (Canadian)

<http://findinghope.knowledge.ca/home.html>

Online videos about:

- About FASD; Prevention; Assessment and diagnosis
- Resources for parents (please note some of these are applicable to Canada only)

Let’s Talk FASD: Parent Driven Strategies in Caring for Children with FASD (Canadian)

http://www.faslink.org/fasdtool_fullproof2.pdf

National Organisation for Fetal Alcohol Syndrome (NOFAS-USA)

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

Not-for-profit organisation committed to FASD primary prevention, advocacy and support

National Organisation on Foetal Alcohol Syndrome (NOFAS-UK)

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

- Dedicated to supporting people affected by Fetal Alcohol Spectrum Disorder (FASD) and their families and communities;
- Provides information on FASD for the general public and medical professionals

