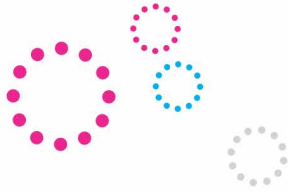


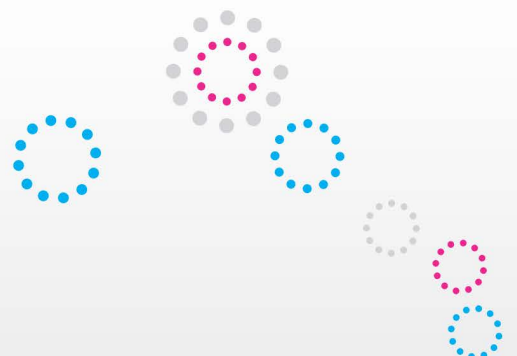


National
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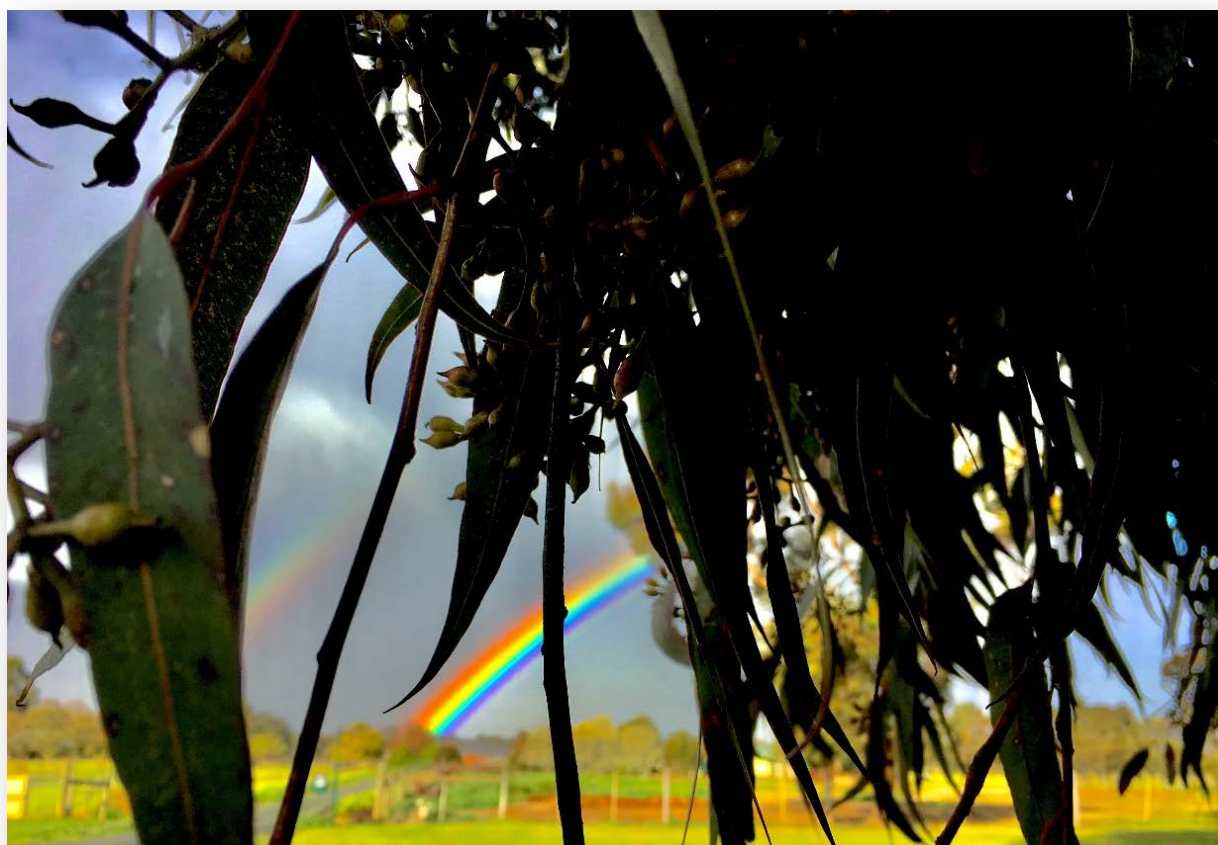
TOOLKIT

For parents, caregivers and families



‘Hope from the Darkness’

FASD Support for Parents and Carers in Australia



*After the storm, look for the glimmer of hope.
(Artwork concept and image from Jacob, aged 12, who has FASD)*

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About this toolkit

This toolkit for parents and carers has been designed to provide information about Fetal Alcohol Spectrum Disorder (FASD) that will enable you to better understand your child and advocate for them - to ensure their physical, emotional, and educational needs are met so they have the best life possible.

This toolkit provides information on what FASD is, the effects of alcohol exposure on the child's growth and development and information that will help you meet your child's needs at home, school and onwards through their lifespan. It also includes a small section especially for adults living with FASD.

We hope the information in this toolkit will provide you with the knowledge you need to increase your ability to make better decisions about your child and that this in turn will not only improve their life but also your life and the lives of those around you.

The importance of language

[Language Guide](#) The language we use when talking about FASD is important. The following guide has been produced in an effort to promote the dignity of those with FASD and their families.

What about dignity and respect?

As a parent or carer of a child or young person with FASD it is also important to remember to always talk about your child living with FASD with dignity and respect. You might like to read this interesting perspective written by another parent: [What About Dignity and Respect?](#)

What is FASD?

FASD is a term used for the conditions caused when a developing fetus is exposed to alcohol.

Alcohol can cause damage to the unborn child at any time during pregnancy and the level of harm is dependent on the amount, frequency and timing of alcohol use. Other factors also influence the outcome such as individual genetic factors in both the mother and the child, age, the physical and mental health of the mother, other substance use and external factors such as exposure to stress, violence or other negative experiences.

Leading health authorities and researchers across the world advise that there is no safe time and no safe amount of alcohol that can be consumed if you are pregnant, planning a pregnancy or you could become pregnant. Alcohol can cause damage to any system of the developing fetus and in recent medical literature there were found to be over 400 different diagnoses and problems associated with FASD.

What is a safe amount to drink?

The Australian Guidelines to Reduce Health Risks from Drinking Alcohol state very clearly that maternal alcohol consumption can harm the developing fetus or breastfeeding baby and for women who are pregnant or planning a pregnancy, not drinking is the safest option. They also state that for women who are breastfeeding, not drinking is also the safest option.

Resources

[Australian Guidelines to Reduce Health Risks from Drinking Alcohol](#)

[What is a safe amount to drink](#) – Australian alcohol use in pregnancy prevention campaigns and advertisements

[Alcohol Think Again](#) video

[Women Want to Know](#)

[It's not just Mums who need to avoid alcohol when trying for a baby](#)

Why is diagnosis important?

Diagnosis is based on the presentation of characteristic features that are unique to the individual and may be physical, intellectual, developmental and/or neurobehavioural. FASD is complicated and no two people are alike.

Research has found that early diagnosis of FASD is a “*protective factor.*” A protective factor is anything that stops one problem from causing another to develop. A written medical diagnosis of FASD will help anyone who is working with your child to better understand that their learning and behavioural issues are a symptom of FASD and this helps when making plans to help your child with the challenges they face.

When children or adults have no visible signs of alcohol exposure their problems may be wrongly blamed on poor parenting or on other disorders. FASD is a complex disability that is quite unlike all others and interventions that work are often specific to the disability. The quality and type of interventions truly matters. International studies tell us that early diagnosis and interventions for FASD are linked with better long term outcomes for the child and the family who support them.

If FASD is suspected, an accurate diagnosis can:

- Help you to better understand your child and their behaviour
- Help the older child/adolescent or adult better understand themselves
- Be a guide to the best support and services
- Aid communication among clinicians, caregivers, educators, and families.

Signs that your child may need to be evaluated for FASD

Children with FASD are very different from each other. One child might have only a few characteristics and another might have many. In very young children, it can be hard to detect the early signs unless the child has very obvious facial features and developmental delay. FASD is often not evident until they start pre-school or school. It's best to get advice and support early if you're worried that your child may have FASD.

It is important to consider having your child evaluated for FASD if:

- There is a maternal history of regularly drinking prior to pregnancy being confirmed.
- There is maternal history of regular drinking during pregnancy or drinking heavily on an occasion during pregnancy.
- The child is not growing and developing as expected. For example, they may have developmental delays, such as using fewer than expected words for his or her age, not learning from their mistakes or they may be smaller than other children of the same age.
- They are having problems learning, behavioural problems and problems getting along with others.
- The child has distinctive facial features of FASD. Some of the features include a small face, narrow eye openings, a short, upturned nose, and a flattened groove between the nose and the upper lip. These features are often not noticed until a child is 2 to 3 years old. These can be hard to see and *only a very small percentage of children affected by prenatal alcohol have these distinctive facial features.*

The observations you make can be useful to the assessment, diagnosis and planning process. This simple tool - [FASD – A Checklist](#), will help get you started. We suggest you complete it and take to the assessment with you.

The Diagnostic Process

FASD is often referred to as the 'invisible disability' as it often goes undetected, whether it be overlooked, ignored, attributed to another cause or even simply blamed on 'poor' parenting or the environment the child is living in. There is still a lack of understanding of FASD in the service provider community but we are hopeful that the publication of [An Australian Guide to the Diagnosis of FASD](#) will change this.

[E-learning modules for Health Professionals](#) involved in FASD diagnosis have also been designed to provide clinicians with an understanding of the referral and screening criteria for FASD.

This presentation from Professor Elizabeth Elliott from Australia provides a great overview of the diagnostic process - [The Story of Alcohol Use in Pregnancy](#)

Australian Clinics and Health Professionals that can help with diagnosis

The Australian FASD Hub is a new website where you can find a list of health professionals in Australia who can assist with diagnosis – [Australian FASD Hub](#)

Should you experience any difficulties accessing diagnosis please call NOFASD Australia.

Phone 1300 306 238 (free call) or enquiries@nofasd.org.au

FASD Characteristics across the lifespan

The individual characteristics of FASD will vary from child to child however, [FASD Characteristics Across the Lifespan](#) is a guide which demonstrates how individuals living with FASD will typically experience some or all of a variety of characteristics.

Understanding FASD – How FASD affects learning, thinking and behaviour

Caring for an individual with FASD can be challenging. It is important to realise that their world is different from ours. The brain is complex and FASD is permanent brain damage.

Many people with FASD will have normal or sometimes even high intelligence but they still struggle with learning and relating to the world around them and the majority will need a circle of external support for their lifetime.

Common behaviours and features of a child with FASD

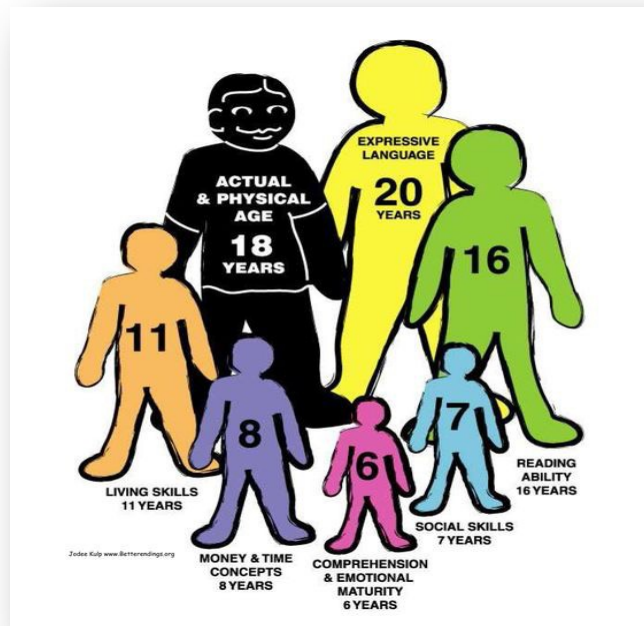
Challenges can be decreased if you are able to recognise the common behaviours and features of a child with FASD. These may include the following, but can vary from child to child:

- learning difficulties (don't seem to be learning as well as other children)
- impulsiveness (acting without thinking)
- difficulty relating actions to consequences (don't learn from mistakes)
- social relationships (have trouble making and keeping friends)
- attention/hyperactivity (may have been diagnosed with ADHD)
- memory (know something one day but seem to forget it the next); and
- developmental delays (may not reach developmental milestones on time).

The maturity and development of children with FASD can be uneven and confusing. Strong abilities in certain areas, such as expressive language (the way they talk), can hide impairment in other areas. For example, a young person of 18 may speak as well as a 20-year-old but only have the understanding and emotional maturity of a six-year-old.

Caregivers are encouraged to always “think younger” when assessing their child’s abilities and to accept their immaturity in certain areas as a symptom of FASD.

This graphic overleaf from Jodie Kulp from [Better Endings New Beginnings](#) illustrates this well.



When we don't have an understanding of the brain difference between neurotypical children and those with FASD we often expect our children to behave in a certain way. These expectations can set them up for failure over and over again.

This leads to an increased risk of later life problems such as:

- incomplete education
- involvement in the criminal justice system
- family and economic dependence
- poverty and homelessness
- alcohol and other substance abuse
- sexual victimisation
- unplanned and early parenthood; and
- difficulty parenting their own children and subsequent risk for them.

Strengths of children with FASD

Children with FASD do best when their individual strengths are recognised. Every child with FASD has their own set of unique strengths, yet unfortunately they are often only defined by their problem behaviours or their disability. While it is important to understand and accept the disability and focus on solving problems related to behaviour, this approach can mean forgetting to appreciate your child as a whole person.

When we only focus on their problems we limit their possibilities but when we also focus on their amazing strengths we can help them be more successful in school and in the community.

Appreciating them as a whole person, not just a person with a disability, and maintaining a focus on what they do well can also help to decrease other secondary challenges. Common

strengths include:

- Highly verbal
- Bright in some areas
- Artistic, musical, mechanical
- Athletic
- Friendly, outgoing, affectionate
- Willing
- Helpful
- Generous
- Good with younger children
- Every day is a new day!

This little booklet provides more information about how you can focus on strengths to help your child: [*A Focus on Strengths: Useful and Practical Tips*](#)

FASD Interventions and Strategies

Evidence based interventions for FASD

Evidence based interventions are therapies that have been shown through scientific studies, to consistently improve outcomes. A list of those therapies can be found here:

[*Evidenced based interventions*](#)

The overseas experience tells us that children with FASD benefit from early intervention, the earlier the better, but unfortunately there are very few therapists currently using any of these interventions in Australia. There are however many strategies that service providers and parents have found work well with children/adults living with FASD.

Services for supporting children or adults who have FASD

There are many types of practical services that might help your child living with FASD. These can include occupational therapy, speech therapy and physiotherapy. Every child with FASD is different so if your child has a diagnosis, the health professional you consulted will help you work out which of these services may be necessary to best meet the needs of your child.

- **Occupational therapists** support children and young people to develop their fine and gross motor skills, cognitive skills, social skills and independent living skills in order to increase success in their daily lives. They can also provide strategies that can help with sensory processing issues.
- **Speech therapists** can support children with their speech development, receptive and expressive language development and visual resources and communication programs for children who are non-verbal or developing language.
- **Physiotherapists** can provide treatment designed to enable children to achieve their own level of functional motor skills like sitting or standing. Toys, games and specialised equipment are used to encourage the development of the child's motor

skills, in conjunction with specific handling skills. The physiotherapy program becomes part of the child's activities during the day, as parents are shown the best way to assist their child during day to day care and play

[FASD Hub Australia](#) has a service directory with a listing of health professionals who have FASD experience and expertise.

FASD Management Strategies for Parents and Caregivers

These strategies are based on the knowledge accumulated over many years from the collective wisdom of parents, carers and service providers.

[Who has to change?](#) Trying their hardest, doing their best! - What it is like to live with Fetal Alcohol Spectrum Disorder

[NOFASD Australia fact sheets](#) for free download

[Baby Steps: Caring for babies with prenatal substance exposure](#)

[Strategies Not Solutions](#): A resource developed to educate caregivers and the community in managing the behaviours associated with FASD throughout the lifespan. The project relied heavily upon caregivers and professionals who provided information, advice, and feedback.

[Tips for Parents and Caregivers](#): These tips and examples prepared by the FASD Network of Saskatchewan were compiled from years of experience as caregivers to individuals living with Fetal Alcohol Spectrum Disorder. The tips were meticulously researched and tested by the 12-member board that leads the Network.

[I am a Caregiver of a person with FASD](#): This is a great handout to give to others

['Fred's Story'](#) – In this video international expert Diane Malbin, explains why we need to think differently and try to prevent unwanted behaviour before it happens. This video complements Diane's book "Trying Differently Rather than Harder" (available on Amazon \$AUD45.00 including postage).

[Eight magic keys of success](#) – nine short videos.

[Advice for Families About FASD](#) – a video from NOFAS-UK.

[Behavioural Symptoms & Accommodations for FASD](#)

[Handling escalation: from Anger to Out-of-Control](#) – a video from Oregon Behaviour Consultants

Sex Education and FASD

Because of the discrepancy between developmental age and social/emotional age puberty can be a difficult time for children with FASD and their family. Children with FASD of all ages may exhibit inappropriate sexual behaviours. A common question that is asked by parents and professionals is, "How do we talk about puberty and sexual health to individuals with FASD?" Fortunately there are some resources that parents of children with FASD have found useful. We also suggest you check to see what is available at your local library.

[Inappropriate Sexual Behaviour in FASD](#)

[The Healthy Bodies Toolkit](#) – available on line

The ["Sexuality & Safety with Tom & Ellie"](#) series

Talking to children about FASD

Children and young people with FASD also need to know about and feel that it's okay to talk about their disability. The earlier you start, the easier it is. Some parents wait too long, and then they don't have the courage to discuss it with the teen, who may eventually get into serious trouble.

Explaining FASD to your child

Some ideas about how to talk to your child about FASD can be found on this tip sheet:

[Explaining FASD to your child](#)

Talking to children about their sibling who has FASD

As in any family, positive and negative feelings may develop between siblings or because of siblings. It's important to talk to other children in the family about their brother or sister who is living with FASD as this will help them to develop an attitude of inclusion and acceptance.

This is a great little book that provides lots of information and ideas and is available for free download: [Helping your kids understand their sibling's FASD](#)

This free download is aimed at children who have a sibling with a Fetal Alcohol Spectrum Disorder (FASD). It provides a definition of FASD and answers questions a child might have, focusing on the feelings of the sibling. It also contains a resource guide, games, and activities: [My Sibling Has a Fetal Alcohol Spectrum Disorder \(FASD\). Can I Catch It?](#)

Diagnosis and Support for adults who have FASD

Although the need exists, there are currently very few Australian health professionals who offer assessment/diagnosis of adults who may have FASD. Check out the [FASD Hub Australia](#) website to see if there is a clinician in your state who can help with Adult FASD diagnosis. If there is no clinician available in your state, please call us on 1300 306 238 (free call) or email enquiries@nofasd.org.au as we may be able to provide further suggestions.

Adults who have a known history of prenatal alcohol exposure (PAE) and where FASD is suspected may benefit from a neuropsychological assessment. The results of this assessment can be used to inform service providers and ultimately affirm and support adults who have FASD. Such an assessment may also lead to eligibility for NDIS support.

Specific information about adult FASD assessments that you can give to your neuropsychologist can be found here: [The value of the neuropsychological assessment for adults with Fetal Alcohol Spectrum Disorder: A case study](#)

Resources

Here are some links to articles that have more information specifically for supporting adolescents and adults who have FASD:

[Working with Adolescents or Adults with FASD](#): This presentation comes from Dr Vanessa Spiller from Jump Start Psychology in Queensland. Dr Spiller has a particular interest in working with children and families affected by FASD.

[Supporting Success for Adults with FASD](#) – This Canadian booklet has been developed with the support and advice of individuals with FASD and family members and professionals involved in the lives of adults with FASD.

[Adults and Adolescents with Fetal Alcohol Spectrum Disorder 2016](#) – video recordings from the International Conference on FASD

Many adults with FASD may be very emotionally fragile and reactive people and this can often have a greater impact on their ability to function than their cognitive impairments. Knowing how to respond in a manner that doesn't escalate their reactive behaviour is very important: [Safety planning for persons who are emotionally fragile and explosive](#)

How to support an adult with FASD who becomes a parent

There are very few published resources available on this topic, but information and support are available from the NOFASD Parent & Family Support Team. Phone 1300 306 238 (free call) or email enquiries@nofasd.org.au

[Parenting with FASD – Challenges, Strategies & Supports](#): This booklet focuses on some of the parenting-related experiences and challenges faced by people with FASD. Highlighted as well are strategies, suggestions and resources found to promote positive parenting. (\$US15)

[Parenting with Fetal Alcohol Spectrum disorder – research article](#) This paper focuses on issues associated with parenting and living with FASD.

FASD and Employment

Unless employers have a good understanding of FASD most young people and adults with FASD experience failed job placements over and over again. Because they can often speak very well they may be able to secure a job placement themselves, but they can rarely maintain it. To achieve success, they will need someone who can advocate for them and provide support in the workplace. Disability Employment Services (DES) can help people find employment and keep a job. Go here for more information

<https://www.jobaccess.gov.au/>

There is a range of resources specific to FASD and employment. [FASD in the workplace](#) - This is a great little publication written for employers by Claire Gyde from [FASD-Can in NZ](#) and is certainly suitable for downloading and sharing with employers in Australia.

[The Six Factors of Employment Sustainability for adults with FASD](#)

[Employment and FASD: Strategies for Success](#)

[Kick Starting Your Child's Career Journey – A guide for families of young people with Disability](#)

FASD and the Law

Unfortunately, young people and adults with FASD may find themselves in the justice system: as offenders, victims, witnesses or other parties in criminal, civil and child protection and family law matters. Valuable justice system resources can be found on the Telethon Kids website: [FASD & Justice resources](#)

Respite services

If you are providing support for a young person over 18 who has been diagnosed with FASD, you may be eligible for respite support services through the national network of Commonwealth Respite and Carelink Centres (CRCC). These centres assist carers with options to take a break through short-term and emergency respite. Where appropriate, a CRCC can help with putting in place regular respite for a carer to reduce the need for unplanned and emergency respite. CRCCs also provide information about carer support services in their local area. The nearest CRCC can be contacted by phoning **1800 052 222** during business hours or **1800 059 059** for emergency respite support outside standard business hours. (Freecall except from mobile phones).

Are you an adult living with FASD?

If you need some help to work out where you can go for support, please give us a call on 1300 306 238 (free call) or email enquiries@nofasd.org.au

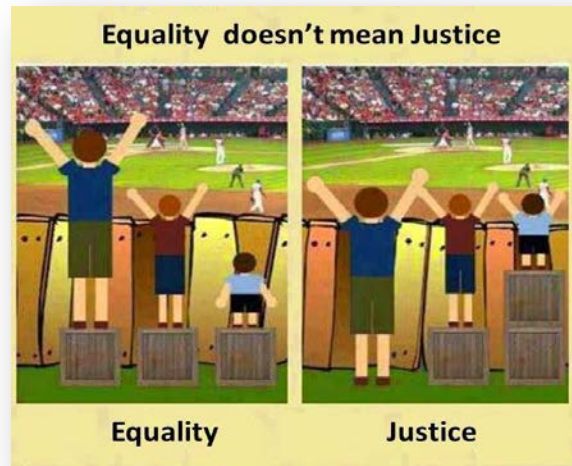
Your rights

If you have Fetal Alcohol Spectrum Disorder, it's important to understand that you have the same rights as everyone else. Because those rights are often not respected in the same way that they are for those without disabilities (particularly in the case of 'invisible' disabilities such as aspects of FASD), there are special protections for certain rights, such as the right to being supported in ways that meet your needs.

Human rights are rights that everyone has. Every person should be treated equally. Your rights and freedoms should be protected by our government.

You can find more information about your rights in [The Human Rights Handbook for people with developmental disabilities](#)

People with Disability Australia also have a [Directory of Australian organisations who provide support and advocacy for people living with disability](#)



Resources for adults who have FASD

[Things to know if you have FASD](#)

[So you have been diagnosed with FASD – now what!](#) – A handbook of helpful strategies for youth and adults.

[My Adult FASD Diagnosis: Clarity for a Man and his Mom](#)

[New Beginning: Better Than This](#) by Liz Kulp, who has FASD. In her book she shares information and gives readers a private look into the mind and heart of an adult living with FASD.

Being an effective advocate for a person with FASD

You cannot outgrow FASD. It is permanent and a life-long condition. There is no cure. It can be a struggle to find diagnosis, supports and help as there is no disability category where they fit in. Advocating for early diagnosis and appropriate management and interventions can help reduce problems as the child grows into an adult.

Communicating your child's requirements to educators, medical professionals, lawyers, and other professionals can be a daunting task, as they may have heard of FASD before but do not truly understand what having FASD means.

Remember to believe in yourself for you are the most important advocate your child can have, after all, who knows your child better than you do and who holds your child's problems closest to their heart? Being an advocate means representing your child and speaking up when your child can't. It's a demanding role but also a fulfilling one.

Although FASD awareness is slowly becoming more prominent and resources more readily available, knowing about FASD is not the same as understanding FASD. Talk with your child's teachers and other professionals and find out if they are FASD-aware. It is important to try your best to develop a relationship with the professionals in your child's life, however if you think the professionals are not helping your child, do not be afraid to get a second

opinion.

General Advocacy tips

When communicating with other people who will have care of your child it's important to:

- **Be prepared:** Provide or bring any documents you need, such as letters you have received, notations from phone calls, or information you want to convey. In the case of a face-to-face or telephone conversation, take something with which you can make notes.
- **Request to bring someone you trust with you for support.**
- **Know what you are going to say:** What is the main point you want to get across? What are the points you want to make along the way?
- **Communicate clearly:** In a face-to-face or telephone conversation, speak clearly and confidently (even if you don't feel that way). Turn towards people when they are talking and most importantly, try to remain calm – deep breaths will help.
- **Bring it back to the topic:** If conversation strays, it's okay to say, "If we could get back to what we were talking about..." or "Can we focus on the topic please?" If someone is talking over the top of you, it's okay to say, "If I can finish what I was saying..." or "Please let me have my say."

[Disability Advocate video](#) This Australian video from the Raising Children Network is all about being an advocate for children with disability. Parents talk about finding information, and planning and coordinating treatments for their child.

Advocating in the School system

If your child is attending pre-school or school, it is important to make an appointment to meet with their teacher. Depending on the age of your child and previous school experiences, you have valuable information that educators require to formulate appropriate programming and behavioural strategies that will ensure your child's progress both academically and socially. [After a diagnosis of FASD What do I tell my child's teacher](#)

Your child may be eligible for school support. Government, independent and Catholic schools all have support and funding for children with disability. The type of education or school support your child can get depends on the school and the state or territory you live in. [You can find more information here](#)

Unfortunately, many teachers do not have a good understanding of FASD and often misinterpret the symptoms of FASD as poor behaviour. This means that at some stage you will most likely have to advocate for your child in the school system. [10 Ways to Be an Effective Advocate for Your Child at School](#)

This is a guide that comes from the Education Department in WA that has some tips about talking with your school [Talking with my school](#)

At the beginning of each school year you can help by letting teachers know a little more information about your child. For example, by writing an introduction letter:

Dear [teacher]

My name is [your name] and I am the parent/carer of [child's name], who will be in your class this year. [Child's name] is very good at [list all or as many of their positive qualities and strengths as you can] but struggles with learning, attention, memory, following directions, and maintaining friendships with peers. With your understanding and support, [child's name] can know success. Structure and routine are very important as [child's name] is overwhelmed by unexpected change. [Child's name] follows single and clear instructions quite well and even though s/he can repeat the instruction, this does not necessarily mean s/he understands.

Please contact me should you have any questions about [child's name]

Yours sincerely
[your name]

You might then follow up with an appointment to talk about your child's needs in greater detail and perhaps share the following links with school staff to provide them with further information.

[Hey Teacher!](#) (from FASD-Can in NZ)

[Understanding and addressing the needs of children and young people living with Fetal Alcohol Spectrum Disorders \(FASD\)](#) – Australian resource for teachers

[You never know who has a disability you can't see](#) – this is a great 5-minute video for teachers

[Behavioural Symptoms and Accommodations for FASD](#) – a great printout for handing to teachers.

School Disability Policies

If you feel the school does not understand your child, it is important to know your rights. You will need to communicate with staff at your child's school to find out what policies are in place for children with extra support needs. To get a head start, you can research some of this information through the School and the Department of Education websites in your state (see the list on the next page).

It will be useful, to have a few basic features of communication up your sleeve (refer back to the tips on page 8). This will help you develop good relationships with the school, so you can collaborate to get services for your child. 13.

The following websites provide information about the Disability policies for each state.

- NSW Department of Education [Disability, Learning and Support](#)
- Victoria State Government: [Program for Students with Disabilities](#)
- Tas Department of Education: [Students with Disability](#)
- WA Department of Education: [Children with Special Learning Needs](#)
- SA Department for Education & Child Development SA: [Children with Disability and](#)

[Special needs](#)

- NT Government: [About Special Education and Disability](#)
- ACT Government Education Directorate: [Disability Education](#)
- Queensland Government Education: [Disability Policy](#)

Education advocacy resources

[A Parent's Toolkit – School issues for students with disabilities](#) is a Disability Advocacy of NSW publication that can be adapted for other states.

This guide comes from the University of Canberra (also includes links to videos) [Disability Standards for education: A Practical Guide for Individuals, Families and Communities](#)

The Australian Raising Children Parenting website also has helpful information: [Education Rights for Children with Disability](#)

Home schooling as an option for children with FASD

Educating a child with FASD has many obstacles, many which often cannot be accommodated in the mainstream school environment. Before beginning their educational journey, children with FASD are already struggling with processing information, interpreting body language of others, following instructions and many other skills that are not developing like those of their peers.

Homeschooling, or home education, can be a viable option for these children. While it does require commitment and has challenges, for those caring for a child with FASD and dealing with the impacts as described above from the mainstream school environment, it's an opportunity to provide the best learning opportunities for their child that they possibly can, not only from a tailor-made education plan, but from the reduction in anxiety for the child not dealing with the day to day stress of mainstream school.

Each state and territory has its own rules regarding the requirements both to register and ongoing commitments for homeschooling. These can be found here:

[Queensland](#)

[New South Wales Victoria Tasmania](#)

[South Australia](#)

[Western Australia](#)

[Northern Territory](#)

[ACT](#)

For support to register and ongoing support, click on this link which will provide you with access to your state or territory's information <http://www.hea.edu.au/>

Parent/Carer and Family Support

The staff and family support team at NOFASD Australia understand the feelings of isolation sometimes experienced by families living with FASD. While we are unable to provide direct assistance such as treatment or legal services we do provide confidential telephone and email support to individuals living with FASD and their parents, carers, family members and service providers.

If you are seeking referral information to diagnostic and related supports throughout the country or would like the opportunity to share your experience or concerns with our staff or family support person. Phone 1300 306 238 (free call) or email enquiries@nofasd.org.au.

Support Groups

Having your own circle of support is very important. NOFASD Australia offer parent and family support via 1300 306 238 (free call) or email enquiries@nofasd.org.au.

You may find it helpful to talk and share your experiences with other parents/carers in similar circumstances to yourself. There are some active FASD Facebook support groups and a small number of face to face groups in Australia. You can find contact details for these [support groups here](#).

[MyTime groups](#) are also active in every state and provide support for mothers, fathers, grandparents and anyone caring for a child with a disability or chronic medical condition. It's a place for you to unwind and talk about your experiences. It's a world away from appointments and therapy. It's support for you.

If you live in Queensland this publication also contains important information: [My Child has Foetal Alcohol Spectrum Disorder](#).

Carers Allowances and Respite

If you are providing unpaid care for a child/adult with FASD there are options for support/respite. [Disability and Carers](#)

The Companion Card Scheme

The National Companion Card Scheme enables eligible people with lifelong disability to participate at venues and activities without incurring the cost of a second ticket for their companion. [More information can be found here](#)

The National Disability Insurance Scheme (NDIS)

The goal of the NDIS is to shift support funding from being based on labels and diagnoses to being about a person's individual needs in gaining independence and integrating into the community.

Both children and adults with FASD should be eligible for support through the NDIS as they most likely will have significant and permanent disability that reduces their functional capacity, or psychosocial capacity in undertaking one or more of the following activities:

- communication
- social interaction
- learning
- mobility
- self care or
- self management

The NDIS supports your child, as well as you and your family and eligibility for services will be determined by the National Disability Insurance Agency (NDIA).

Although a diagnosis of FASD may not be necessary to qualify for support, supporting documents will be required. This means you will need to have assessments from allied health professionals, for example, psychologists, neuropsychologists, speech therapists or occupational therapists that demonstrate your child's needs.

In order for a support to be deemed reasonable and necessary by the NDIA it must:

- Be related to the participant's disability
- Not include day-to-day living costs unrelated to disability support needs
- Represent value for money
- Be likely to be effective and beneficial to the participant; and
- Take into account informal supports given to participants by families, carers, networks, and the community.

These are the support categories the NDIS will fund:

- Assistance with daily life at home, in the community, education and at work
- Transport to access daily activities
- Certain independent living supports
- Daily living skills training/therapy to assist independence
- Social skills and behaviour support
- Improved living arrangements
- Improved health and well-being through dieticians, personal trainers, or exercise physiologists
- Psychology services for anger management for those with cognitive impairment or autism
- Learning improvement support

- Finding and keeping a job
- Increased social and community participation
- Improved life choices
- Assistive technology
- Vehicle modifications; and
- Home modifications.

The NDIS will not cover the following:

- Supports unrelated to their disability.
- Rent, groceries, utilities etc.
- Something funded elsewhere – for example school support or mental health services covered by MHCP.
- Pediatricians' consultations and medication management; or
- Psychology services for anxiety.

Online Guides

There are a number of guides that have been published to help families of people living with disability understand the NDIS:

- [Association for Children with a Disability](#): Getting ready for the NDIS - NDIS Planning Workbook. The aim of this workbook is to help you prepare for your child's planning meeting with the NDIS
- The Raising Children Network provides information that may be helpful [National Disability Insurance Scheme: FAQs](#)
- [Discover guide](#) is a practical, comprehensive and up-to-date guide to the NDIS, prepared by La Trobe University in conjunction with Endeavour Foundation, aims to help people understand the various components of the NDIS and how to access them. It also includes additional legal information on whole-of-life planning for people with a disability.
- [Reimagine](#) - one of the primary categories under the NDIS where people with FASD should be eligible to qualify for services is Psychosocial Disability. Although this website has been designed for people with a mental health condition it has excellent information about psychosocial disability and how to apply for services under the NDIS.

NOFASD Australia is here to support you so please contact us if you need any help with completing forms for the NDIS. We may also be able to help if you have been denied NDIS funding. Please phone 1300 306 238 (free call) or email enquiries@nofasd.org.au

Should your child for some reason be ineligible for NDIS funding please don't despair! There are a range of supports available to carers that are not part of the NDIS, including respite support, counselling, education, training, peer support and advocacy. For information about what supports and services are available in your area, call the **National Carer Advisory Line** on **1800 242 636**.

Taking care of yourself

Caregiving can be incredibly rewarding, but it also can cause emotional and physical stress. As a caregiver, you might be so focused on the person you're caring for that you don't even realize that your own health and well-being are suffering. It is important to know and watch for signs of caregiver stress.

Caring for someone living with FASD is very challenging. Understanding your own feelings and caring for yourself will help you to be able to take care of your child, particularly if your child requires considerable attention or supervision that leaves you drained and frustrated.

This website has some great tips about caring for yourself: [Caring for me](#)

You can also call the **Carer Gateway** for support and advice **1800 422 737** (free call).

If you feel overwhelmed, please don't feel you are alone – we're here to help you with practical support and advice. Just call us on 1300 306 238 (free call) or email enquiries@nofasd.org.au

Reading List

The following Resources have been strongly recommended by other parents/carers raising children with FASD:

- *“Trying Differently Rather Than Harder”* – second edition (author: Diane V Malbin, MSW)
- *“Foetal Alcohol Spectrum Disorders – Parenting a child with an invisible disability”* (author: Dr Mary Mather) – available for purchasing online from various bookstores.
- *“The Perfect Love Story”* This book written by Claire Gyde, Chairperson of FASD-Can New Zealand, is witty, wise and truly FASD-informed. It is not available to download but a printed copy is free for parents and carers by emailing enquiries@nofasd.org.au

Websites that have FASD specific information

[NOFASD Australia](#)

1300 306 238 (free call from any landline in Australia)

NOFASD Australia is working towards ensuring FASD is recognised as a disability in Australia, promoting social inclusion by advancing the rights and interests of people living with FASD, and providing the necessary supports to individuals and families at a grassroots level. [Register here](#) to subscribe to the NOFASD monthly e-newsletter. You can also follow NOFASD Australia on Facebook and Twitter to keep up to date with the very latest information and resources on FASD.

[FASD Hub Australia](#)

FASD Hub Australia is a website developed by an alliance of organisations working to

provide a 'one stop shop' for information, tools and resources that are current and evidenced based. It provides information on FASD for Australian health professionals, teachers, justice professionals, service providers, researchers and parents and carers.

[Aboriginal Drug & Alcohol Council \(SA\) Inc.](#)

ADAC provides responses to a range of state and national committees and strategies, helps communities deal with the problems associated with substance misuse, develops health promotional materials, undertakes research on its own and in collaboration with various universities and key national research organisations. The ADAC website has a fantastic array of FASD Educational Resources.

[Australian Indigenous Alcohol & Other Drugs Knowledge Centre](#)

The AOD Knowledge Centre Fetal Alcohol Spectrum Disorder (FASD) portal – is for people working, studying or interested in addressing the harms of alcohol use in pregnancy. It aims to provide a central collection of policies and strategies, publications, resources and training materials supporting prevention and management of FASD in Aboriginal and Torres Strait Islander communities.

[Drug Education Network \(DEN\)](#)

A non-government organisation in Tasmania funded to deliver a range of health promotion, prevention, and early intervention programs to reduce the harm associated with alcohol, tobacco and other drug (ATOD) use.

[FASD C.A.R.E WA](#)

The Fetal Alcohol Spectrum Disorder Collaboration for Assessment and Care, Research and Education are a team of health care professionals who aim to provide high standards of clinical care for children and youth living with FASD.

[Synapse](#)

Synapse is dedicated to reconnecting the lives of those affected by brain injury. Their vision is for a world where anyone affected by a brain injury is able to lead a life of quality, based on their own decisions and choices.

[Telethon Kids Institute \(WA\) – Alcohol Pregnancy & FASD](#)

The Telethon Kids Institute is one of the largest, and most successful independent not-for-profit medical research institutes in Australia, comprising a dedicated and diverse team of more than 500 staff and students.

[The CICADA Centre NSW](#)

This specialist centre provides diagnosis and clinical care for children and young people affected by alcohol and drug use and support leading research and education in key areas of need in Fetal Alcohol Spectrum Disorder (FASD), parental drug and alcohol use and adolescent drug and alcohol use.

FASD tool kit NOTES

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