

Appendix A6: Information for clinicians: Issues that individuals and their caregivers may experience during the FASD assessment process

The effects of alcohol on the fetus are not widely known. While there are many reasons why people use alcohol, overwhelmingly the majority of birth mothers do not intentionally seek to harm their children. It is important that any language used by clinicians explains that any harm is caused by alcohol rather than the mother's behaviour and avoids *blaming the mother*. The more appropriate language to explain Fetal Alcohol Spectrum Disorder (FASD) is "when alcohol was consumed during pregnancy" or "when the fetus is exposed to alcohol during pregnancy". It is important to offer non-judgemental support and advice. An early diagnosis and well-structured management and treatment plans can greatly improve the health outcomes and life of a person with FASD and their families.

Respect is paramount to successful treatment. It is a vital tool in the elimination of discrimination and stigma and is pivotal to creating an environment where the issue of prenatal alcohol exposure can be discussed.

Adopt a consulting style that enables the person and their caregivers to participate as partners in all decisions about their healthcare and take fully into account their race, culture, and any specific needs. People with FASD should have a comprehensive care plan that is agreed between them and their caregivers, and their care providers.

The strategy for treatment should be individualised according to the degree of severity within the syndrome; other medications and comorbidity; the lifestyle and preferences of the family and/or carers.

Speaking to the person and their caregivers

The diagnostic assessment process is a particularly sensitive and emotive time for the individual and their caregivers, especially for birth parents. They may like to ask a support person, friend or relative to accompany them to the appointment.

Before the diagnostic assessment process

- Use clear language.
- Explain the assessment process and any medical terminology.
- Explain that the assessment process may or will involve taking a photo of the person's face, being aware that some individuals and their caregivers may find this confronting or experience some discomfort.
- Discuss the Information on FASD diagnostic assessment for individuals and caregivers and provide a copy (Appendix A4).
- Discuss the Australian FASD Diagnostic Assessment Consent Form (Appendix A5) and gain informed consent for the assessment and provide a copy.
- Some parents or caregivers may themselves be affected by fetal alcohol exposure – be aware of the possibility of intergenerational alcohol harm.

Speaking to a person undergoing diagnostic assessment for FASD

During the diagnostic assessment process

- Make eye contact with the person and use their name.
- Keep instructions brief and use language that is not ambiguous.
- Ask simple and single questions needing one answer - that is, closed questions.
- Don't speak too quickly, use repetition and ensure the person has understood the instructions and what is required of them.
- The use of visual cues can be useful.
- Don't assume that because the person is able to speak well that he or she can also understand what you are saying and follow through with suggestions or advice.

After the diagnostic assessment process

- Discuss the content of the reports from the occupational therapist, speech pathologist, psychologist or other health professionals with the person and their parents/caregivers and provide a copy of each report.
- Provide a definite referral and 'next steps' plan and ensure they are appropriate for the diagnosis whether FASD or any other diagnosis.
- Provide some written information on the diagnosis and management plan so the person and their parents or caregivers can take it away and read it at a later time and discuss it with other people.
- For a child of school age, discuss how this information will be important to share with their school. Parents or caregivers will need to provide consent for any reports to be sent directly to the school; however, the parent or caregiver may take their copy of the reports to the school to develop an appropriate plan and access services through the education system.
- Allow the person, caregivers or their support person to ask questions during the appointment and provide contact details for follow up communication if required.

Listen to the concerns raised by the parents or caregivers

Many people will have tried numerous avenues to obtain a diagnosis. For the person and their parents or caregivers this may result in them feeling frustrated, disempowered and not being believed. They may have also experienced health professionals as unwilling or not confident to raise the issue of fetal alcohol exposure as a possible cause. The person and their parents/caregivers may experience grief, loss, anger and guilt and require validation that these are normal feelings.

Encourage the person and their parents or caregivers to talk to a counsellor or contact a support group that provides information, advocacy and support for people living with FASD and families caring for people living with FASD.

- National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia)
<http://www.nofasd.org.au/> or phone 1800 860 613
- Russell Family Fetal Alcohol Disorders Association (rffada)
<http://raffada.org> or phone 0412 550 540