Fetal Alcohol Advisory Support & Training Team

THE UNIVERSITY of EDINBURGH

Understanding Fetal Alcohol Spectrum Disorder (FASD)

Summary Guide

Understanding alcohol and pregnancy

Whether you are pregnant, or trying for a baby, it's important to remember that drinking alcohol while pregnant can put your baby at risk.

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition that results from a baby being exposed to alcohol before birth.

This exposure to alcohol can affect how the baby's brain and body can develop.

If you are a pregnant woman who needs support to stop drinking, contact your midwife or doctor.

Alcohol and pregnancy
No alcohol, no risk.

The Chief Medical Officers' guideline states that

- If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.
- Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink, the greater the risk.

The Chief Medical Officers' guideline for both me and women (who are not planning a pregnancy) is that:

- You are safest not to drink regularly more than 14 units per week, to keep health risks from drinking alcohol to a low level.
- If you do drink as much as 14 units per week, it is best to spread this evenly over 3 days or more.

What is FASD?

The term Fetal Alcohol Spectrum Disorder (FASD) describes the range of physical, emotional and developmental delays that may affect a person when they were exposed to alcohol during pregnancy.

Diagnosis of FASD involves assessments by a Paediatrician, Clinical Psychologist, Occupational Therapy and Speech & Language Therapist.

Fetal Alcohol Syndrome

also referred to as FASD *with* facial features*

- Result of exposure to alcohol during pregnancy
- Affects how the central nervous system works
- Distinctive Facial Features:
  - Small head
  - Small eyes
  - Smooth philtrum (area between nose and mouth)
  - Thin upper lip

** Cook et al (2016)*

Fetal Alcohol Spectrum Disorder

also referred to as FASD *without* facial features*

- Result of exposure to alcohol during pregnancy
- Affects how the central nervous system works
- Absence of Distinctive Facial Features
  - FASD is often referred to as a 'hidden disability'

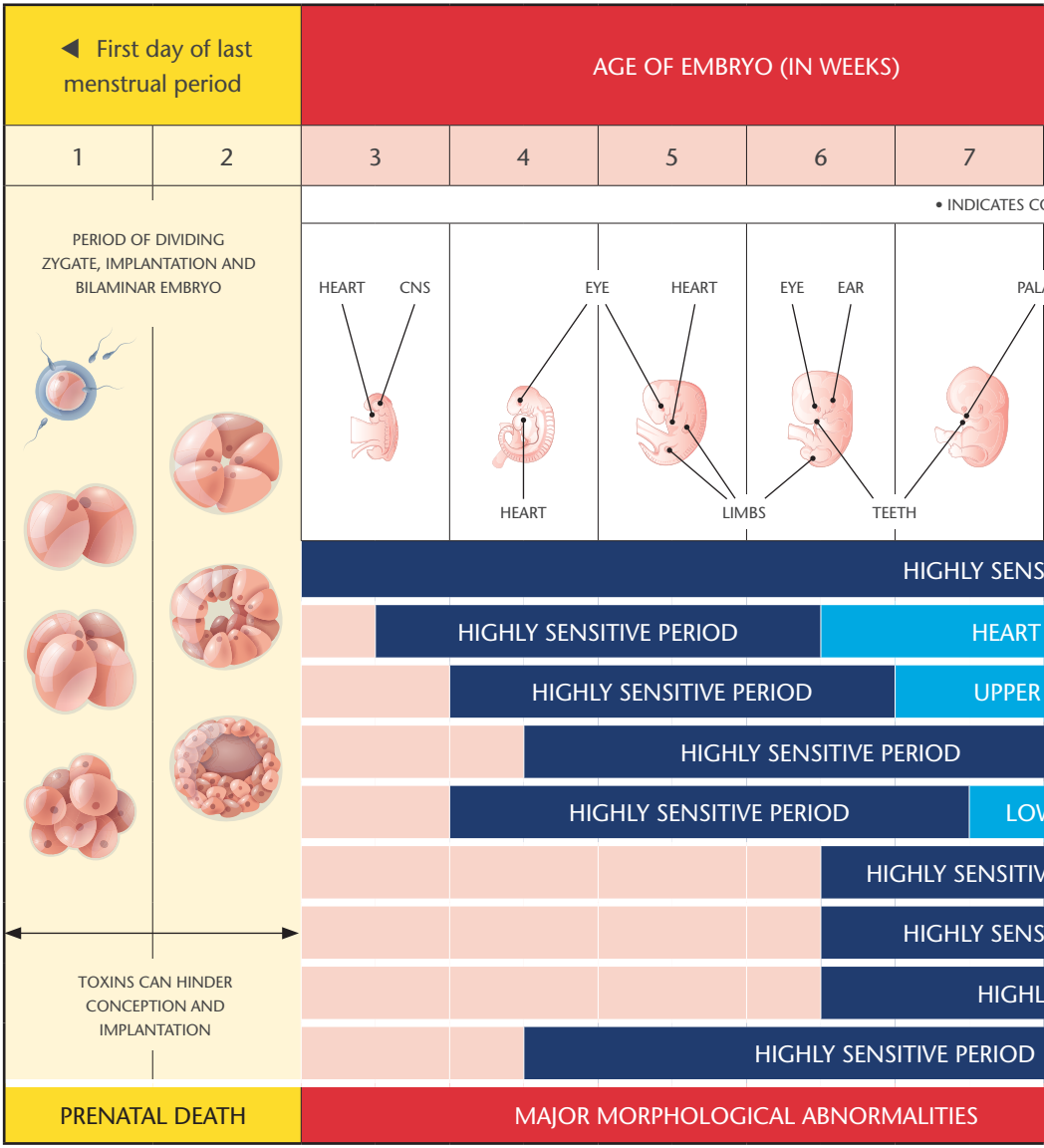
** Cook et al (2016)*

"Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition that results from a baby being exposed to alcohol before birth. This exposure to alcohol affects how the baby's brain and body can develop.

People with FASD may require additional support at home, school and work."

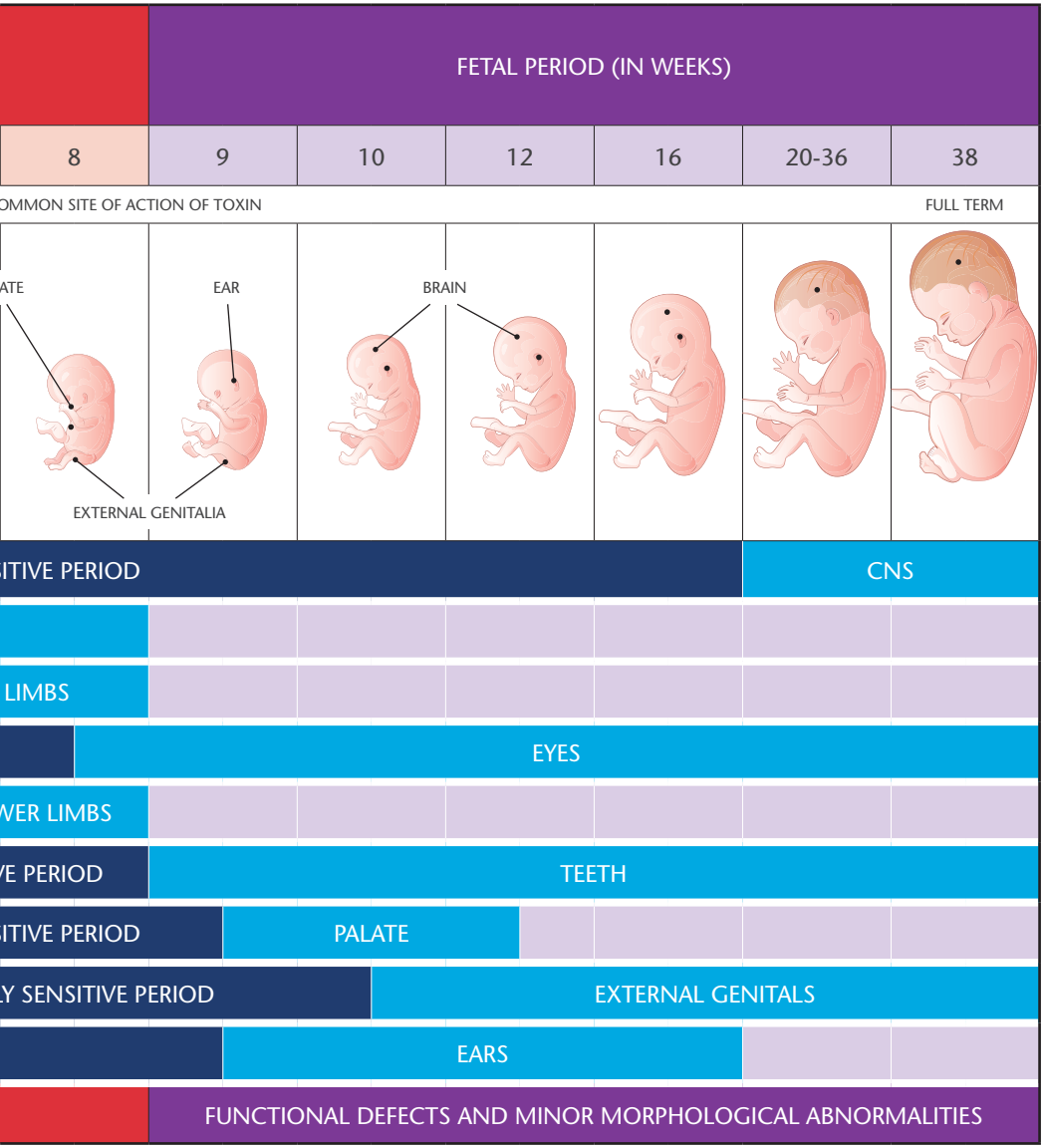
(Dr. Sally Longstaffe MD, FRCPC Medical Director, Developmental Pediatrician, Manitoba FASD Centre)

When can alcohol damage the d



Indicates highly sensitive periods when toxins may induce abnormalities

leveloping baby?



Brain domains and FASD

'The degree of damage to the unborn baby will depend on its stage of development at the time of exposure to alcohol because different parts of the brain develop at different times during pregnancy'

(FASD: Parenting a child with an invisible disability. Brown & Mather, 2014)

There are 9 brain functions that can potentially be affected by alcohol during pregnancy.

Executive Functioning

- May have trouble with planning, sequencing, problem solving and organisation.
- May be impulsive.
- Have difficulty controlling emotions
- Are challenged by transitions and change.
- Often repeats mistakes and has difficulty understanding consequences
- Difficulty with abstract ideas/concepts
- Difficulty managing time

Sensory and Motor

- May be unable to make sense of what is going on around them.
- May under or over react to sensory input, for example, light, noise, touch, smell and/or taste and movement.

Academic Skills

- May have difficulty in school particularly with maths, reading, time and mone .
- May have difficulty with comprehension, organisation and planning
- May have difficulty with age appropriate tasks
- May have normal IQ.
- Can learn better with visual or 'hands on' approach.

Brain Structure

- Brain and head circumference may be small.

Living & Social Skills

- May not understand personal boundaries and have difficulty reading social cues.
- May be socially vulnerable and easily taken advantage of.
- May have difficulty seeing things from another s point of view
- Socially and emotionally immature… may behave younger than actual age.

Focus & Attention

- Can be easily distracted, over-stimulated or impulsive.
- May have difficulty paying attention and be over active
- May appear to struggle sitting still.

Cognition *(Reasoning & Thinking)*

- Difficulty with attention, learning, memo y, planning and organisation.
- Difficulty with understanding complex ideas
- Wide range of IQ - only a small proportion have intelligible disability

Communication

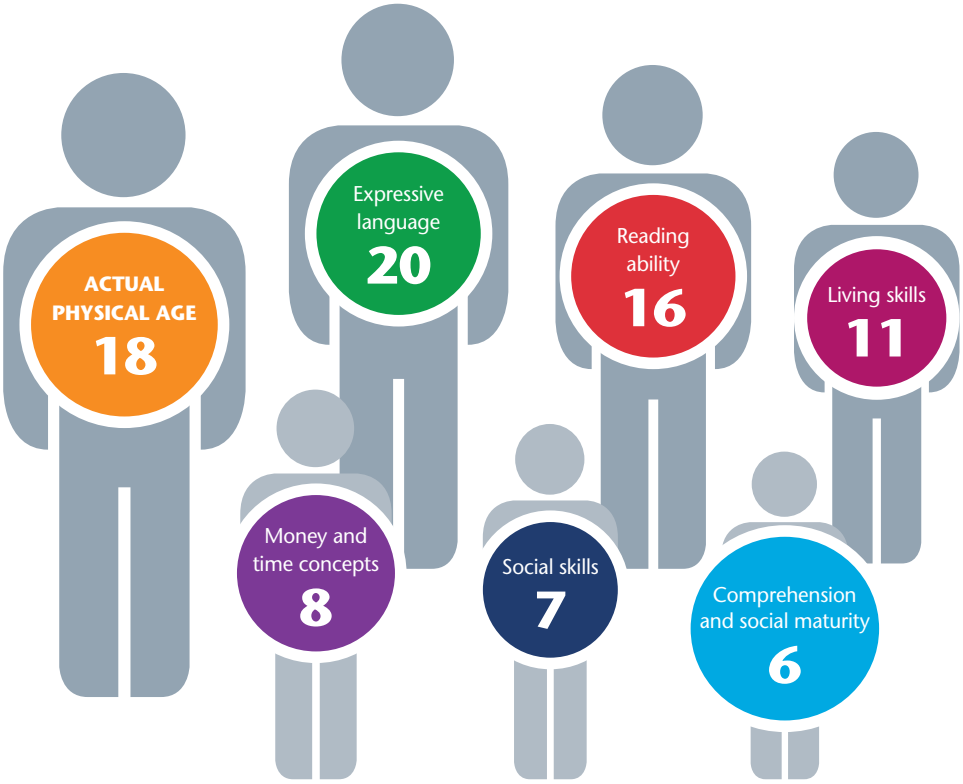
- May speak well but not always understand the full meaning.
- Delayed language milestones for age.
- Difficulty with lengthy conversations
- Difficulty following instructions
- May be able to repeat instructions but not able to follow them through.

Memory

- Difficulty with long and short term memo y – may seem forgetful.
- Difficulty recalling sequences or complex instructions
- Relatively better visual memory.
- Easily forget steps in normal daily routine.
- Appear to lie but are really 'filling in the blanks'

Developmental age and FASD

The diagram below shows relative stages of development for a teenager with FASD.



Example of developmental stages of 18 year old with FASD

In some ways the young person may be developmentally average or indeed, ahead of their peers, yet, in other areas they may be well behind.

Imagine how problems could be avoided. It may me useful to adjust expectations to match a child's ability. The FASD brain has to work harder than other brains, so it may take your child or teenager longer to complete assigned tasks.

6 guiding principles to helping children with FASD reach their potential

Adapt the environment - Children with FASD have an invisible brain-based condition. This means the best strategies are ones that change the child's environment rather than focusing on changing the child. Creating a calming physical space, having clear and consistent schedules and routines, and communicating appropriately can be helpful. Being supported and supervised by people who understand and have adapted their expectations of the child will create the best environment for children to reach their potential.

Think younger - Children with FASD develop differently than their peers. It can be helpful to think about our expectations and adapt these to 'think younger.' Children with FASD may be socially immature and need more support and supervision than what is expected of their chronological age. Using simple language and concepts will help.

Build on strengths- Every child with FASD is unique and will have their own strengths and difficulties. Identifying thei strengths and using these when planning daily-living, learning and leisure activities will enable children to grow in self-esteem and be successful in their learning. Praise children when they make even small achievements - they have often worked hard to get there.

Keep it simple - Children with FASD can become overwhelmed easily. Therefore, it is important to keeps things simple. Break down more complex tasks into simple steps so that children don't need to "fill in th blanks." Allow time for breaks and be aware of spending too long on a task. It can help to do only one task at a time, give one instruction at a time and say exactly what you mean. Keep the environment uncluttered and focused on the task at hand.

Be patient - It can take many tries for a child with FASD to learn and sometimes they can forget even once you think they've got it! You will often have to repeat instructions again and again. It's important to be patient and calm. Finding someone to talk to, ways you can be supported and what helps you cope will help you to achieve this.

Work as a team - Children with FASD may have many family, friends and professionals helping them to achieve their potential. These people are often important for providing the extra supervision and structure that children with FASD need. Children will learn best if there is consistency in language, routine, rules and expectations from all these people. This means communication between everyone, including the child, should be open and clear.

FASD and sleep

Sleep issues are common amongst children with FASD. Sleep can be affected by a number of different factors. These include brain differences (structural and chemical), physical and emotional health and sensory issues. It may also be the case that children do not have an awareness of time and routine.

Common issues may be trouble falling asleep, staying asleep and waking early, or having restless sleep. The first step t helping with poor sleep is to promote good sleep habits. This is called ***sleep hygiene.***

It may be useful to consider:

Sleep Environment - It is important to create a calming environment for sleep

- If possible, make the bedroom for sleep only. Avoid TV, electronic games, computers and phones in the bedroom because these devices create blue wave length light they keeps you awake. Make sure the space is uncluttered and comfortable.
- Reduce noise and light (to total darkness, if possible). Black-out blinds can be really useful.
- Be aware of sensitivities to touch and ensure that pyjamas and bedding are comfortable. Find out what your child's preferences are for different materials, temperature, tight or loose fitting, and the weight of blanket and duvets. Please note "weighted blankets" are no longer recommended.

Sleep Routine - It is important to create a clear and consistent routine before bedtime

- Establish bedtime routines. A visual schedule may help reinforce expectations and sequences.
- Include a scheduled wind-down time for about 30-60 minutes before bedtime. Calming activities include eating a low sugar snack and/or drink, a warm bath, stories, massage or quiet time together, or listening to calming music.
- Avoid screen time (e.g. TV, computer or video games) at least an hour before bedtime.
- Limit activates that increase stress or excitement including homework or stimulating story books. Be aware that a busy household can be over stimulating for some children.
- Avoid exercise such as running or trampolining which stimulates the hormones that keep us awake.
- Avoid food and drinks containing caffeine or high sugar.

Some children and young people with FASD may continue to struggle with sleep despite good sleep promoting environments and routines. In such cases, talk to your doctor or other health care professional to see what further supports or options are available in your area. It may also be helpful to complete a sleep diary for your child, which may support you and your doctor to consider your child's needs.

Understanding alcohol units

Information and guidance

			
Single Gin & tonic ABV 40% **1 UNIT** *120 calories*	**Sambuca shot** ABV 42% **1 UNIT** *123 calories*	**Pimms** ABV 25% **1.3 UNITS** *156 calories*	**Alcopop** ABV 5% **1.4 UNITS** *160 calories*
			
Red wine (125ml) ABV 12.5% **1.6 UNITS** *85 calories*	**Bottle of lager** ABV 5.2% **1.7 UNITS** *145 calories*	**Double whisky** ABV 40% **2 UNITS** *128 calories*	**Double whisky + coke** ABV 40% **2 UNITS** *129 calories*
			
Mojito ABV 40% **2 UNITS** *150 calories*	**Champagne** ABV 11.5% **2 UNITS** *133 calories*	**Cosmopolitan** ABV 12.5% **2 UNITS** *151 calories*	**White wine (175ml)** ABV 12.5% **2.3 UNITS** *244 calories*
			
Pint of bitter ABV 5% **2.8 UNITS** *288 calories*	**Pint of lager** ABV 5.2% **3 UNITS** *244 calories*	**Pint of cider** ABV 5.3% **3 UNITS** *194 calories*	**Bottle of wine** ABV 13.5% **10 UNITS** *510 calories*

Information and support:

For general enquiries please contact:

Fetal Alcohol Advisory Support and Training Team (FAASTT)
www.faast.ed.ac.uk
Email: FAAST@ed.ac.uk

Notes

Fetal Alcohol Advisory
Support & Training Team

THE UNIVERSITY of EDINBURGH