Preventing Fetal Alcohol Spectrum Disorder

Dr Doug Shelton
Clinical Director
Community Child Health
Gold Coast
Synopsis

- Overview
- Diagnosis & common presentations
- Aetiology
- Prevalence
- Prognosis
- Intervention Options
- Services
FASD OVERVIEW
FASD

- Leading preventable cause of developmental disability in the western world
- More children born each year with FASD than with autism, spina bifida, cerebral palsy, Down syndrome and SIDS combined.
FASD – why bother?

- FASD is already in all our caseloads
- We just don’t recognise it
- CDS 2000 – 2013
  - Approx 10,000 clients = nil FASD
- 2014 Feb to present
  - 32 FASD
FASD – why bother?

- Undiagnosed FASD
  - School dropout
  - Mental health
  - Relationship issues
  - Sexual health
  - Risk taking
    - Drug & alcohol misuse
Alcohol Consumption in Australia
Figure 2. Total alcohol per capita consumption (15+ years; in litres of pure alcohol), 2010
Figure 6. Prevalence of past 12-month abstention (%; 15+ years), 2010

Legend:
- <20.0
- 20.0–39.9
- 40.0–59.9
- 60.0–79.9
- 80.0–100.0
- Data not available
- Not applicable
# Secondary Students in 2011

<table>
<thead>
<tr>
<th>%</th>
<th>Year</th>
<th>Month</th>
<th>Week</th>
<th>Binge (week)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>51</td>
<td>30</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Females</td>
<td>50</td>
<td>29</td>
<td>16</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>50.7</td>
<td>29.1</td>
<td>17.4</td>
<td>6.4</td>
</tr>
</tbody>
</table>

FASD DIAGNOSIS
Accurate diagnosis

- Guides intervention
- Informs prognosis
- Prevention
  - Secondary & tertiary disabilities
  - Recurrence
- Accurate prevalence
- Access to services (?)
- Allocation of resources (?)
What is FASD

- **Diffuse** brain injury caused by prenatal alcohol exposure.
- **Fetal Alcohol Spectrum Disorders** (FASD)
  - a continuum or spectrum
Key Features

- Growth
- Face
- Brain (CNS)
Key Features

- Growth
  - Who knows about growth?
- Face
  - Who can pick dysmorphic features?
- Brain (CNS)
  - Who understands child development & behaviour?
Key People

- Growth
  - General Practice understands growth charts?
- Face
  - General Practice can pick dysmorphic features?
- Brain (CNS)
  - General Practice understand brain development & behaviour?
Diagnosis

- Use recognised guidelines
- DSM5 - Conditions for further study
  - Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure

1. [http://www.cmaj.ca/content/172/5_suppl/S1.full.pdf+html](http://www.cmaj.ca/content/172/5_suppl/S1.full.pdf+html)
2. [http://depts.washington.edu/fasd/pn/htmls/4-digit-code.htm](http://depts.washington.edu/fasd/pn/htmls/4-digit-code.htm)
### Abbreviated Case-Definitions of 4-Digit Code

<table>
<thead>
<tr>
<th>Rank</th>
<th>Growth</th>
<th>Face</th>
<th>CNS</th>
<th>Alcohol</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>h &amp; w &gt; 10 %</td>
<td>No features</td>
<td>No Dysfunction</td>
<td>Confirmed Absent</td>
</tr>
<tr>
<td>2</td>
<td>h &amp;/or W 4 - 10 %, not ≤ 3 %</td>
<td>1-2 features</td>
<td>Moderate Dysfunction</td>
<td>Unknown</td>
</tr>
<tr>
<td>3</td>
<td>h or W ≤ 3 %</td>
<td>2.5 features</td>
<td>Severe Dysfunction</td>
<td>Confirmed</td>
</tr>
<tr>
<td>4</td>
<td>h &amp; w ≤ 3 %</td>
<td>All 3 features</td>
<td>Structural / Neurological Abnormalities</td>
<td>Confirmed High</td>
</tr>
</tbody>
</table>

3434 is one of twelve 4-Digit Codes for FAS
4-Digit Code FAS Face (Rank 4)\textsuperscript{11-13}

1) Short PFL \leq -2 SD
2) Smooth Philtrum Rank 4 or 5
3) Thin Upper Lip Rank 4 or 5

Palpebral fissure length (PFL) = endocanthison to exocanthison
FASD PRESENTATIONS
FASD

- An invisible brain based disability that manifests itself behaviourally
- Most children look “normal”
## Comparison

<table>
<thead>
<tr>
<th></th>
<th>Alcohol exposed</th>
<th>Unexposed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Abnormal facial features</strong></td>
<td>17 percent</td>
<td>1 percent</td>
</tr>
<tr>
<td><strong>Delayed growth</strong></td>
<td>27 percent</td>
<td>13 percent</td>
</tr>
<tr>
<td><strong>Cognitive delays (including intellectual)</strong></td>
<td>35 percent</td>
<td>6 percent</td>
</tr>
<tr>
<td><strong>Language delays</strong></td>
<td>42 percent</td>
<td>24 percent</td>
</tr>
<tr>
<td><strong>Hyperactivity</strong></td>
<td>27 percent</td>
<td>2 percent</td>
</tr>
</tbody>
</table>

Aros S et al. (2006). Prospective identification of pregnant women drinking four or more standard drinks (> or = 48 g) of alcohol per day. *Subst Use Misuse, 41*(2):183-197
Adolescent language problems in FASD

- Often verbal and therefore appear intact
- Expressive language
  - Scripts
  - “Cloak of competence”
- Very literal in their thinking and interpretation
- Receptive language delay
  - Looks like purposeful oppositional behavior
Clinical situations and language

- Treatment
  - Motivational interviewing
  - CBT
  - Group programs
- Health promotion
- School
- Judicial system
- Child welfare
- Parenting techniques
Other affected brain domains

- Social & emotional
- Memory
- Cognition
- Executive function
- Attention control
- Academics
- Adaptive skills
- Soft & hard neurological signs
SPECIAL GROUPS
Parents with FASD

- Do the parents have FASD too?
- Multiple complex instructions
  - Negotiating the system
    - Health
    - Education
- What about siblings?
- How do we check their understanding?
Justice System

- 60% will confront the justice system
  - Complex legal language
- Impulsivity leads to minor offences
- Highly suggestible
  - High level pressure to plead guilty
- May appear disengaged, untruthful and lacking remorse

Heather Douglas
FASD Symposium, 2011
Links

- Alcohol & domestic violence
  - If there is one always ask about the other
- Alcohol as self-medication for
  - Mental health
  - Trauma
AETIOLOGY
Alcohol

- The strongest teratogen in general use
- It is used more frequently than any other
- Crosses placenta

Stats
- 60% Aust pregnancies unplanned
- 61% consume some alcohol in pregnancy
- 60% confront justice system
Do all children with PAE get FASD?

- Depends on individual factors
  - Genetics
    - Metabolism of alcohol
  - Size of person
  - Timing
  - Type of drinking
    - Binging is worse
Mouse D7 EtOH exposure

- A = normal. B – E graded exposure
- Where facial dysmorphology is more pronounced, brains are more affected

PREVALENCE
## Gold Coast Population

**2011 Census QuickStats**

All people - usual residents

Australia | Queensland | Statistical Area Level 4

**Gold Coast**

Code 309 (SA4)

<table>
<thead>
<tr>
<th>People</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>507,642</td>
</tr>
<tr>
<td>Male</td>
<td>246,043</td>
</tr>
<tr>
<td>Female</td>
<td>259,599</td>
</tr>
<tr>
<td>Median age</td>
<td>38</td>
</tr>
</tbody>
</table>

| Families                | 135,874|
| Average children per family | 1.8  |
Epidemiology

- US & western European
- All levels of FASD
- Pre-school populations
- 2-5%

People on GC with FASD

- Prevalence 2% = 10,152
- Prevalence 5% = 25,383
- Comparison
  - Type 2 Diabetes 4% = 20,305
  - Autism spectrum disorders 1% = 5076
  - Childhood cancer 618/year Aust wide
  - Child abduction & murder by stranger <1:1,000,000

Aust Paediatric Cancer Registry
1983-2006
On the Goldie?

- Potentially 25,000 individuals with
- Functional impairments in
  - Behaviour & mental health
  - Learning & cognition
  - Language & understanding language
  - Memory & executive function
Population of Australia

- 23.13 M (ABS 2013)
- 5% = 1.16M
- 2% = 462,600
PROGNOSIS

FASD  n=415 (Streissguth 2003)
Life history interview 450 questions
Mental Health

- Mental health 94%
- Children depression 60%
- Adults > 90% depression
  - Suicide attempt 23%
  - Suicide threatened 43 %
Disrupted School

- Suspension, expulsion or drop-out
  - School age 43%
  - By adulthood 70%

- Problems
  - Attention control
  - Disruptive in class
  - Back chatting
  - Fighting & peer relations
Trouble with the law

- Police, charged or convicted of crime
  - > 12 yrs = 60%
- First behaviour shoplifting
- ~ 50% crimes against people
  - Theft, assault, DV, murder
- Property damage
- Possession/selling
- Sexual assault
Inappropriate sexual behaviour

- > 12 yrs 45%
- Prob much higher
Confinement

- Inpatient Rx for mental health or drugs
  - > 12 yrs 60%

- Adults
  - > 40% incarceration
  - 30% mental institution
  - 20% confined for substance abuse Rx
Alcohol or Drugs

- > 12 yrs 30%
- Adults
  - Males 53%
  - Females 70%
  - NB: 5 X background rate
Independent living

- Dependent living - 80%
- Probs with employment – 80%
Protective factors

- Early diagnosis
  - Universal protective factor for all secondary disabilities
- Eligibility for services
- Living in stable home
- Protection from violence
ASKING ABOUT ALCOHOL
Asking about alcohol

- Always ask
  - If you don’t ask you won’t know
- Use screening questionnaires
  - AUDIT-C
- 97% of women want advice (ICHR)
1. How often do you have a drink containing alcohol?
   □ a. Never
   □ b. Monthly or less
   □ c. 2-4 times a month
   □ d. 2-3 times a week
   □ e. 4 or more times a week

2. How many standard drinks containing alcohol do you have on a typical day?
   □ a. 1 or 2
   □ b. 3 or 4
   □ c. 5 or 6
   □ d. 7 to 9
   □ e. 10 or more
3. How often do you have six or more drinks on one occasion?
   □ a. Never
   □ b. Less than monthly
   □ c. Monthly
   □ d. Weekly
   □ e. Daily or almost daily

Questions

- Was your pregnancy planned or unplanned?
- When did you discover you were pregnant?
- What lifestyle changes did you make then?
  - Cigarettes
  - Alcohol
  - Folate & antenatal care
  - Other mind bending substances
  - Family, home & living circumstances
Answers

- **Low risk**
  - Planned, 4 weeks or less, nil EtoH.

- **High risk**
  - Unplanned, > 4 weeks, ceased alcohol when pregnancy noted.
  - Drank throughout pregnancy
  - Binge drinking
    - > 4 std drinks on one occasion
Current recommendation

- Best to consume NO alcohol during pregnancy

- NO =
  - None
  - Zero
  - Zip
  - Zilch
Paternal Alcohol
Alcohol & Men

- Direct effect on spermatogenesis
- Indirect effect by facilitating partner drinking
  - 75% of those who drank in pregnancy did so with partner
  - 40% partner initiated session
    - McBride et al., 2012
- Boys/Men can make a difference
Mouse model

- Epigenetic changes transmitted to subsequent non-alcohol exposed generations
- 2-3 generations to wash out
- Transmitted via paternal line

Feng Zhou, PhD, Professor of Anatomy, Cell Biology, Medical Neuroscience, and Psychology, Indiana University School of Medicine, Indianapolis, IN
Figure 6. 
Number of genes containing two consecutive probes showing increased- and decreased-methylation in each chromosome. (A) Neural tube close group. (B) Neural tube open group. There are decreased- and increased methylation changes of genes in each chromosome. Highly significant changes were seen in Chromosome 7, 10 and X. These chromosomes are also known to be enriched for imprinted or silenced genes.
Prevention

- Contraception & Sexual health
  - Unprotected sex + alcohol
    - STI
    - Pregnancy
    - Baby with FASD?
- Include boys/men
Suspected FASD

- Multiple Learning, language or
- Social or mental health problems
- PAE?
- Ask the question “could this be FASD?”
- Siblings ?
- Parents ?
Confirmed FASD

- Advocate
- Interpreter
- Collaborator
- Enabler
- “External brain”
- Siblings?
FASD SERVICES & TRAINING
Services

- Since Jan 2014
- FASD Diagnostic Team
- Courses in FASD Diagnosis
  - Twice yearly
  - Next November 2015
FASD Service - Gold Coast

- Criteria
  - 0-10 years
  - Definite prenatal alcohol exposure
  - Developmental concerns

- Older kids
  - Register
  - Beg, borrow & steal

- Contact
  - 07 5687 9183
  - Judith.warner@health.qld.gov.au
Summary – FASD

- 100% preventable (in theory)
- Is common
- An invisible brain based disorder with a behavioural phenotype
- General Practice is in a unique position to
  - Prevent FASD
  - Identify FASD
  - Optimise outcomes for children with FASD
THANK YOU