



Fetal Alcohol Spectrum Disorder

- Culture, Context and the Need for Collaboration

Dr Chris Steer – Scottish Government Advisor for FASD
Dr Sarah Brown – Consultant Paediatrician



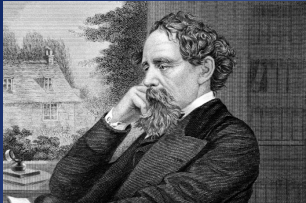


Scottish Government funded

Fetal Alcohol Advisory & Support Team

@FASDAdvisoryAAA

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The Pickwick Papers/Chapter 33

Charles Dickens. C. 1832

'Report Of The Committee of the Brick Lane Branch of the United Grand Junction Ebenezer Temperance Association

'Your committee have pursued their grateful labours during the past month , and have the unspeakable pleasure of reporting the following additional cases of converts to Temperance'

'Betsy Martin, widow, one child, and one eye. Goes out charing and washing, by the day; never had more than one eye, but knows her mother drank bottled stout, and shouldn't wonder if that caused it (immense cheering). Thinks it not impossible that if she had always abstained from spirits she might have had two eyes by this time (tremendous applause). Used, at every place she went to, to have eighteen-pence a day, a pint of porter, and a glass of spirits; but since she became a member of the Brick Lane Branch, has always demanded three-and-sixpence (the announcement of this most interesting fact was received with deafening enthusiasm).'

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HM Prison Liverpool 1899.

Sullivan WC. A note on the influence of maternal inebriety on the offspring. J Ment. Sci. 1899; 45: 489-503.

“The intoxicants consumed were in the form of beer, whisky, and rum; as a rule the patients drank any sort of liquor they could get.”

Mortality of Infants of Female Inebriates. – Amongst the 100 women of our series, twenty were able to give details of female relatives also of drunken habits, who had had children. Of these 120 female inebriates were born 600 children, of whom 265 (44.2 per cent.) lived over two years; 335 (55.8 per cent.) died under two years, or were dead-born.

“..... of the children comprised in our series, 219 lived beyond infancy, and of these nine, or 4.1 per cent., became epileptic.”

“.....this primary influence of alcohol is due in part to the permanent effects of the poison on the maternal organism, inducing a transmissible degenerate condition; in part to a direct toxic action on the embryo, owing to continued excesses during pregnancy and lactation.”

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Fetal Alcohol Syndrome & Fetal Alcohol Spectrum Disorders - The Modern Era.

•Lemoine P et al. 1968.


“Les enfants des parents alcooliques : anomalies observees a propos de 127 cas” (Quest Medical. 25.476-482)

-Described abnormal physical and behavioural patterns in the offspring of women who drank heavily in pregnancy.



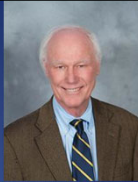
Paul Lemoine (1917-2006) later reflected – “the 127 cases of a modest paediatrician from Brittany did not create any interest, whereas 8 American cases became immediately convincing !” (also notes Jacqueline Rouquette’s earlier unpublished thesis from Paris in 1957)

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Jones K.L and Smith D.W. 1973

"Recognition of the Fetal Alcohol Syndrome in Early Infancy"
(Lancet 2. 999-1001)



The first of three papers describing a typical pattern of facial dysmorphism, growth restriction and developmental delay in 8 children. The first clinicians to utilise **"Fetal Alcohol Syndrome / FAS"**



Dave*:- "So Ken, what do you think of this?"

Ken:- "Not much Dave"

Dave*:- "This is the most important thing I have ever seen!"
😊

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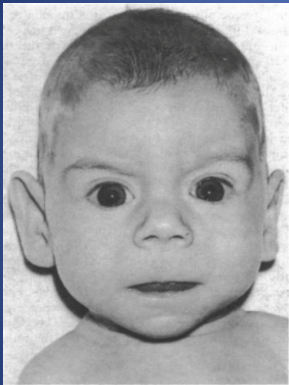


FIG 1—Infant with facial features of fetal alcohol syndrome. Note short upturned nose, absent philtrum, and thin upper lip.

"Alcohol and the fetus in the West of Scotland"

Beattie J, Day R, Cockburn F and Garg R A "
BMJ. 1983. 2nd July. 287.17-20

- 40 cases of FAS between 1971-1981

"Further prospective research is urgently needed to define the origins and extent of the problem the problem of the fetal alcohol syndrome in the UK so that appropriate resources can be allocated for education, intervention and prevention"

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Subsequently...

Streissguth A.P and O'Malley K 2000 (*Seminars in Clinical Neuropsychiatry* 5(3):177-90) introduce the umbrella term **"Fetal Alcohol Spectrum Disorder (FASD)"**

"FASD" acknowledges that around one in ten children and young people damaged by pregnancy alcohol exposure has typical facial features of FAS, but the rest don't, whilst still demonstrating evidence of brain and organ damage ; they are all within a **"SPECTRUM"**.

This population on assessment show a range of physical, mental, behavioural and/or learning difficulties with life long implications and very variable prognosis and frequent "secondary disabilities" .


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FASD DIAGNOSTIC SYSTEMS * (!):


- Centres for Disease Control (CDC) ; Bertrand et al. 2005
- Institute of Medicine - *Revised* (IOM) ; Hoyme et al. 2016 (previously 1996/2005)
- Four Digit Code; Astley 2006 (original 2000)
- DSM 5 ("Neurodevelopmental disorder associated with prenatal alcohol exposure.") APA 2013
- Canadian (Revised) ; Cook et al. 2016 (original 2005)

(* See BMA Board of Science "Alcohol and Pregnancy. Preventing and managing Fetal Alcohol Spectrum Disorders. "February 2016 ; **Now SIGN Guideline 2019 supports - Canadian Guideline**)

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Healthcare
Improvement
Scotland



SIGN
Evidence-based
clinical guidelines

SIGN 156

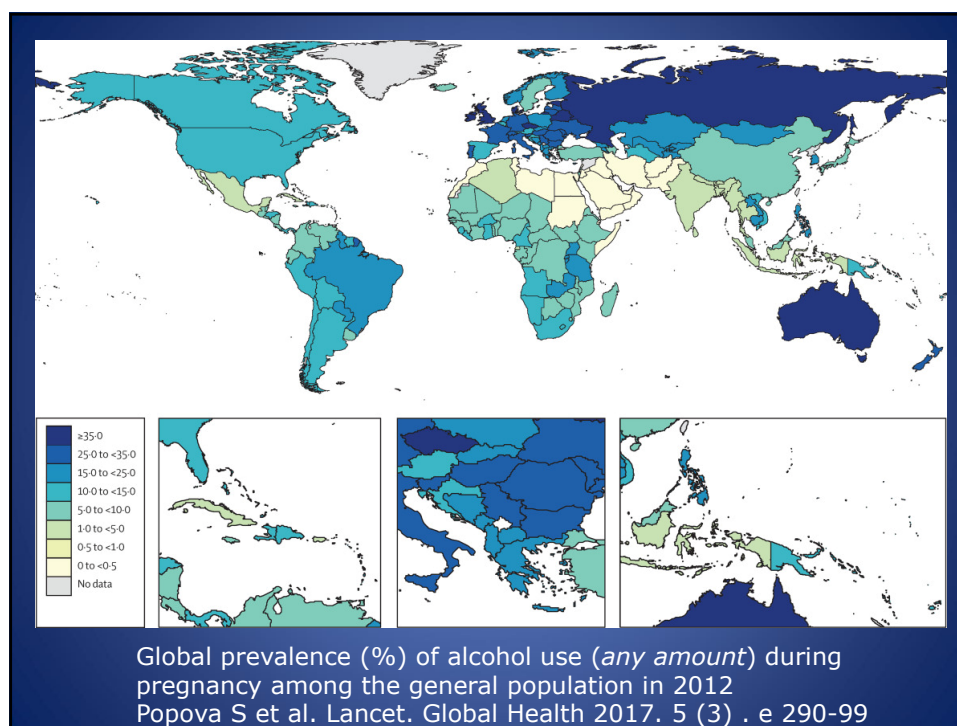
Children and young people exposed prenatally to alcohol

A national clinical guideline
January 2019

Descriptor Categories:- (n.b. growth criteria no longer applied)

- FASD 'with sentinel facial features'
- FASD 'without sentinel facial features'
- 'At Risk for FASD'

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Global prevalence of alcohol consumption in pregnancy Popova et al 2017

► Top 5 countries % consumption

- Ireland 60.4
- Belarus 46.6
- Denmark 45.8
- UK 41.3
- Russia 36.5

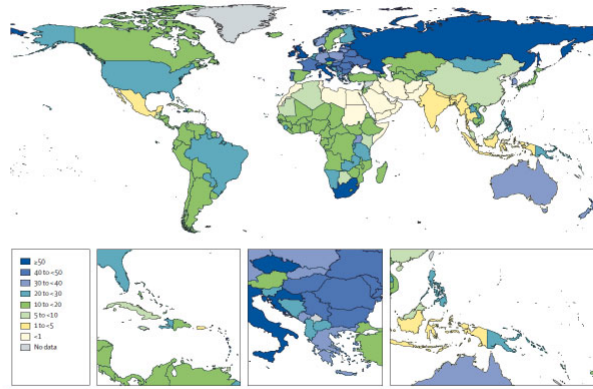
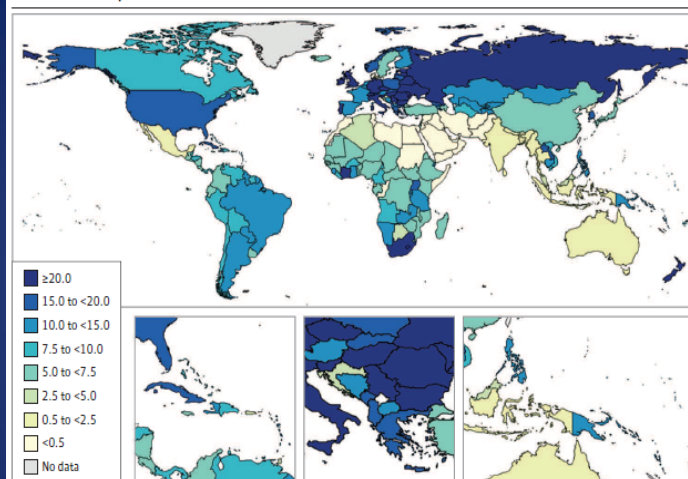


Figure 2: Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population in 2012

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Figure 1. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth in the General Population in 2012



Data are expressed as number per 1000 population.

Lange S. et al. JAMA Pediatrics 2017. 171 (10) 948-956

UK PREVALENCE of FASD 20-50/1000 POPULATION (2-5%)
SIGN GUIDELINE 156 (2019) - 32.4 per 1,000 (95% CI 20.0 to 49.0) (- 3.2%)
THE ACTUAL FIGURE may be higher – see biomarker studies

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Scottish Government supported Strategies targeting Pregnancy alcohol exposure and harm

Awareness Raising and Training:-

- ☐ On Line FASD e-Learning modules (NES 2013/2019) – upgrade due
- ☐ Outreach Clinician Training from Winnipeg Manitoba (2013/16/19)
- ☐ National FASD Clinician's Forum (2015, et seq.- biannual)
- ☐ National FASD Care Pathway (2016, Dr. Patricia. Jackson et al.)
- ☐ SIGN Guideline 156 (2019 Drs. Patricia Jackson, Helen Mactier, Jennifer Shields, Sarah Brown et al.)

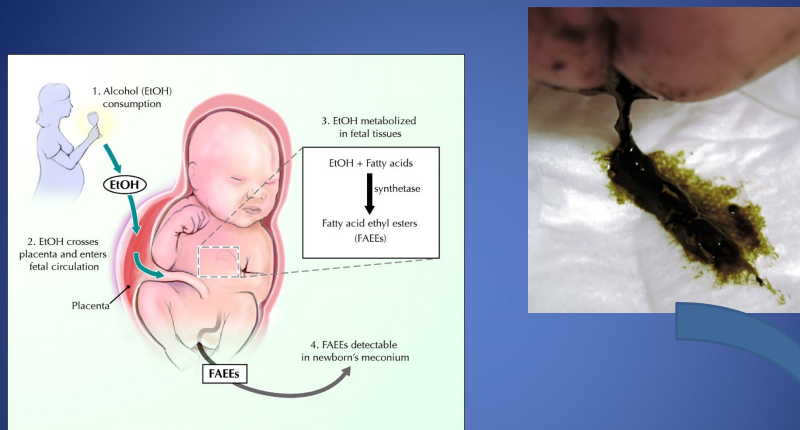
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Other Measures:-

- ❑ **Awareness Raising / Liaison** – education, social work, third sector, preconceptional health care (“Ready Steady Baby” initiative), justice
- ❑ **Research:-**
 - i. Scottish Paediatric Surveillance Unit Enhanced Passive FAS Surveillance Study of FAS in under sixes (2010-2014) 41 cases in 60 months (Neil McIntosh, Forrester Cockburn, John McClure, Maggie Watts)
 - ii. Alcohol Biomarker Study (Meconium Alcohol Ester) (Abernethy et al. 2017/18)
 - iii. Fetal Alcohol Assessment and Support Team: NHS Ayrshire & Arran. Prospective Study of Multidisciplinary FASD Assessment 2016-2018 (McGruer & Shields 2018) Clinical Lead: Dr Sarah Brown & team now undertaking awareness road shows UK wide.

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Pregnancy alcohol exposure and Meconium Alcohol “Biomarkers”



Fatty Acid Ethyl Esters, - “FAEE’s” (and Ethyl Glucuronide levels)
Reflect Fetal Alcohol Alcohol Exposure from around 20 weeks
to term

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16/09/2019 16:08 on 4 July 2017. Downloaded from <http://fbs.bmj.com/> copyright.

Determining the pattern and prevalence of alcohol consumption in pregnancy by measuring biomarkers in meconium

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 Published Online First 4 July 2017

ABSTRACT
Objective To investigate the feasibility of determining the pattern and prevalence of alcohol consumption in pregnancy by measuring ethanol biomarkers in meconium.
Design Population-based observational study.
Setting Inner-city maternity unit in Scotland, UK.
Population Random sample of singleton infants delivered after 36 completed weeks' gestation.
Methods Fatty acid ethyl esters (FAEEs) and ethyl glucuronide (EtG) in meconium were measured by liquid chromatography-mass spectrometry. Samples were frozen at -20°C before analysis. Results were compared anonymously with demographic data including maternal age, parity, smoking, ethnicity and postcode and with infant gestation, birth weight and head circumference. Written informed consent was obtained from all subjects.
Results 235 samples of meconium were analysed (70% of eligible babies). Only four (1%) of mothers declined to participate. FAEEs were detected in all, including four samples below the limit of quantification (10 ng/g). 98 (42%) samples had FAEE concentrations >600 ng/g. EtG was detectable in 93 (40%) samples; in 35 (15%) EtG concentration was >30 ng/g. No mother reported heavy alcohol consumption in pregnancy. FAEE concentration correlated with EtG (Pearson's coefficient; $p < 0.001$). There was no association between either biomarker and maternal age, parity, smoking, ethnicity or postcode, or infant gestation, birth weight or head circumference.
Conclusion Measurement of ethanol biomarkers in meconium is a feasible tool for determining the pattern and prevalence of alcohol consumption in pregnancy. Data suggest that at least 15% of pregnant women in the west of Scotland are consuming significant quantities of alcohol during latter pregnancy.

What is already known on this topic?

- Alcohol use in pregnancy is commonly under-reported and direct measurement of alcohol metabolites in mothers is difficult due to its rapid metabolism.
- Biomarkers of alcohol can be measured in meconium to assess continuing alcohol use in pregnancy.

What this study adds?

- Confirms under-reporting of alcohol use in pregnancy.
- Measurement of ethanol biomarkers in meconium is a feasible tool for determining the pattern and prevalence of alcohol consumption in pregnancy.

households (22% vs 13%).²⁻⁵ Ethanol is teratogenic and the current UK government recommendations are for complete abstinence from alcohol consumption during pregnancy.⁶ Despite this advice, some women drink heavily before they realise they are pregnant, and others continue to drink through their pregnancy.⁷ Prenatal alcohol exposure (PAE) may lead to miscarriage, premature birth and increased perinatal morbidity and mortality.^{8,9} Fetal alcohol spectrum disorder (FASD) describes a continuum of difficulties with learning, development, attention, social relationships and impulsive behaviour. At the severe end of the spectrum, fetal alcohol syndrome (FAS) is characterised by intra-

Recent Scottish Meconium Biomarker Study. Published 2018.

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Abernethy C. et al. 2018 Princess Royal Maternity Hospital. Glasgow. (Inner City, Northern and Eastern Suburbs of Glasgow)

- N = 235 mother and babies
- Analysis of Fetal Meconium Fatty Acid Ethyl Esters and Ethyl Glucuronide**

Results

- Data suggests 40% of pregnancies in this study population were exposed to alcohol.
- Significant & potentially harmful* quantities in 15%
- No association between biomarkers and age, ethnicity, parity, postcode, smoking status, birth weight or head circumference

= 1 in 7 pregnancies

(* >2 drinks (3.5 units) per day or binge drinking of >5 (8.75 units) drinks per occasion)



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Alcohol Framework 2018: Preventing Harm
next steps on changing our relationship with alcohol

ACTION 18: we will continue to prevent and reduce the harm caused by alcohol consumption in pregnancy through increased awareness of the risks, increased awareness of, and improved diagnosis and support for, Fetal Alcohol Spectrum Disorder.

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Scottish Government P.S. September 2018



Delivering for Today, Investing for Tomorrow
The Government's Programme for Scotland 2018-19

"IMPROVING OUR POPULATION HEALTH" :



"We will also increase our support for children and families affected by Fetal Alcohol Spectrum Disorder (FASD). Over the next year, we will work to set up a third sector hub that will focus on both preventing instances of FASD arising in the first place and supporting families following diagnosis."

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Alcohol facts and figures

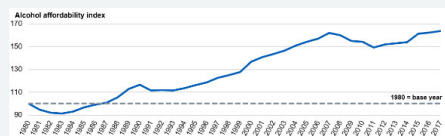
 

- Patterns of alcohol use in woman have changed significantly over the past 30 years
- Alcohol has become more affordable and more available
- 73% of alcohol sold through supermarkets and other off licenses

Affordability of alcohol

Long term trend

In the UK since 1980 alcohol has become 64% more affordable¹.

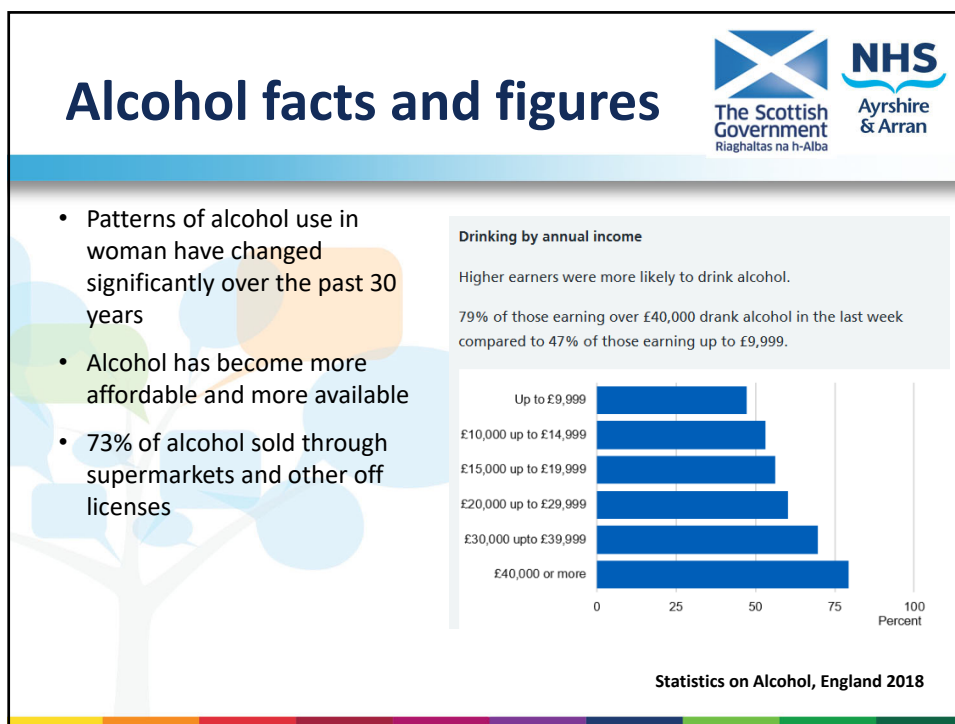


Alcohol affordability index

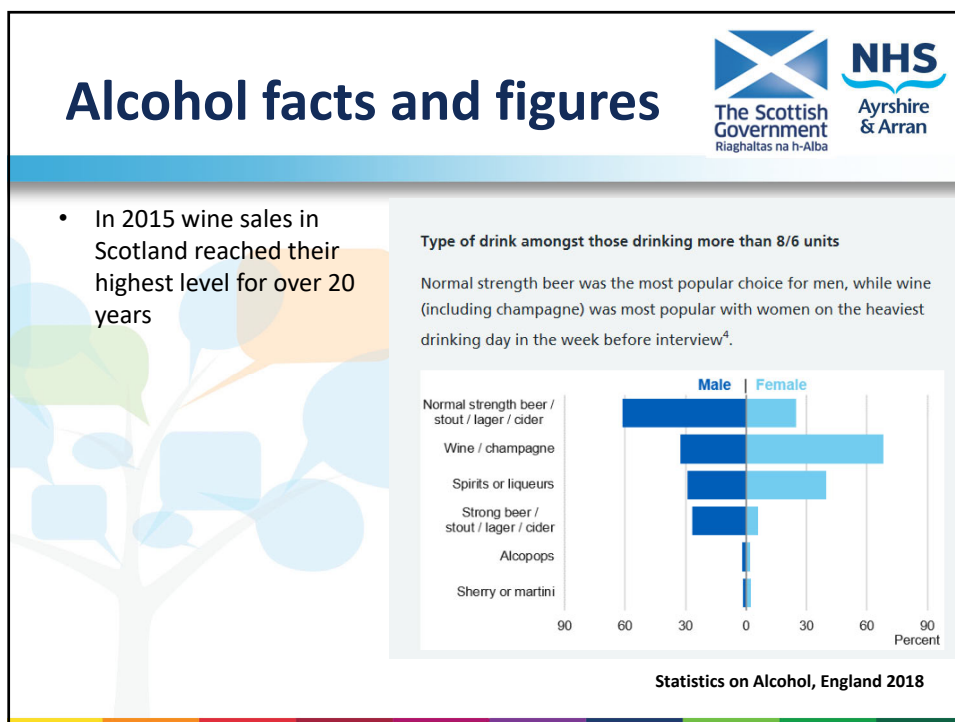
1980 = base year

Statistics on Alcohol, England 2018

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Drinking Culture

The Scottish Government
Riaghaltas na h-Alba

NHS
Ayrshire & Arran

- Women 'binge' drink to levels which would be teratogenic to a fetus - a binge is classified as 6 units of alcohol in one sitting
- 46% of pregnancies in the UK are unplanned/ambivalent (Wellings et al 2013)
- **The UK has the 4th highest rate of drinking in pregnancy in the world (41.3%, 32.9–49.%)**

The Lancet Global Health 2017



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Alcohol guidelines - pregnancy

The Scottish Government
Riaghaltas na h-Alba

NHS
Ayrshire & Arran

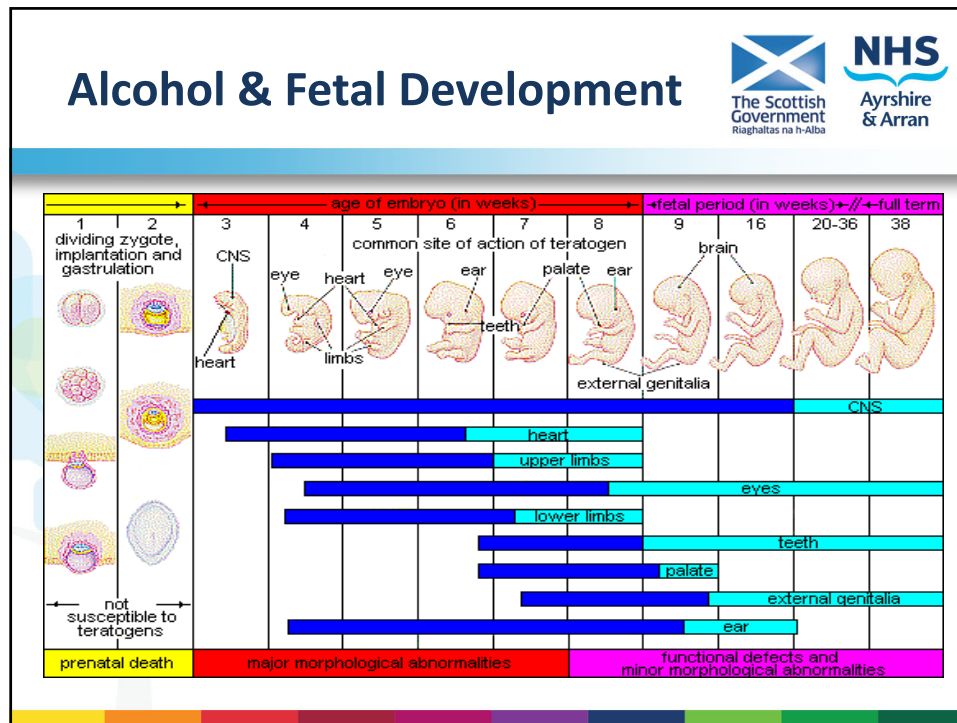
The new guidelines bring the rest of the UK in line with Scotland:

The CMO 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.**
- Despite this many pregnancies are alcohol-exposed





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Alcohol & Fetal Development

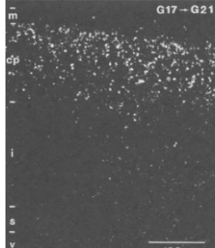



- Alcohol can destroy brain cells and damage the nervous system and other organs
- Prenatal alcohol exposure inhibits both neuronal production and neuronal migration, processes which are crucial for development.
- Drinking in pregnancy can lead to long-term harm to the baby, with **the more you drink the greater the risk.**

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

American Institute of Medicine Report to Congress, 1996

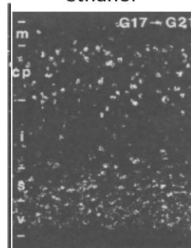
control



Neurons are 'born' here

And then migrate to here

ethanol





Neurons are 'born' here

And then migrate to here

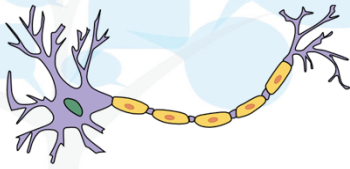

Images from Miller (1996).

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Connectivity



- Alcohol affects
 - Neuronal migration
 - White matter myelination
- “10-second children in a 1-second world”

- Takes longer to ‘lay down information’
 - Patience required
 - Different techniques
 - Expectations
- Expressive language often better than receptive

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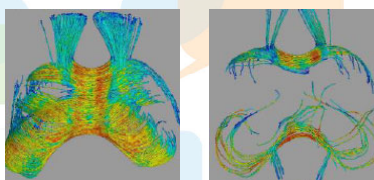
Functional Imaging

Less connections

Control

FAS



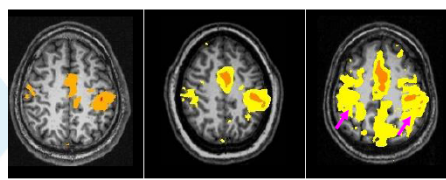
Diffuser Tensor Imaging studies
(CIFASD)

Work Harder

Control

ARND

FAS



Functional MRI

Images used with permission of Dr Edward Riley & the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD).

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What is FASD?



A spectrum of lifelong acquired brain injuries :

- Congenital abnormalities in the structure, size, growth and/or function of the brain and central nervous system.
- Difficulties with development, learning and/or behaviour.
- *May not be detected at birth but can become apparent later in life and carries lifelong implications*
- Vast majority:
 - ‘Patchy profile’
 - Academic difficulties
 - Social difficulties
 - Behavioural problems
 - No growth deficits/no facial features
 - Not microcephalic



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What is FASD?

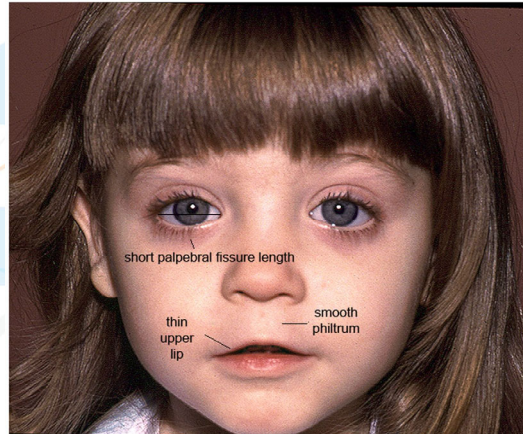


- Alcohol is most common cause of developmental disability in the western world *Clarke & Gibbard, 2003.*
- FASD 2-5% + of population (3 %.....)
 - Autism 1%
- **England**– population 66.5 million
- 13.9m children and young people (<18 years)
 - 400,000 children and young people affected (3%)
- **Greater London** – population 8.8 million
- 2.1m children and young people (<18 years)
 - 63,000 young people affected
 - Conservative estimate
- 1 child in every class of 30.....



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Fetal Alcohol Syndrome



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Fetal Alcohol Syndrome



NOT ALL CHILDREN WILL HAVE
FACIAL FEATURES

THIS DOES NOT MEAN THAT THEY
HAVE NOT BEEN AFFECTED BY
ALCOHOL

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High prenatal alcohol exposure



- What amount confers risk?
 - No known safe amount
 - Maternal factors (weight, health, liver function)
- Canadian Guidelines
 - ≥7 standard drinks/week (*1 standard drink= 1.7 units UK*)
 - ≥4 or more drinks on 2 occasions
- DSM IV
 - ' more than minimal exposure to alcohol during gestation, including prior to pregnancy recognition'
 - ' minimal drinking is 13 drinks a month, with no more than 2 drinks on the same occasions'
 - Binge – 6 units

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Factors which can mitigate effects

- Nutrition and metabolism
- Health and concurrent drug use
- Mother's Age
- Stage of pregnancy
- Pattern of Drinking
 - "Binge culture"
- Paternal Factors



Pre-natal alcohol exposure does not always = FASD

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Lifestyle conversation

- Thinking back, can you remember how many weeks you were when you knew you were pregnant?
- What was your life like before you were pregnant?
 - Were you working? At college?
 - Were you happy?
 - Were you generally healthy? Were you on any medications?
 - Were you out much?
 - When you were out, can you remember how much you would have to drink?
 - Would you have anything to drink before you went out?
 - How many drinks would you usually have in a day/week/month?
- Was it a planned pregnancy? Were you taking folic acid?
- How was your pregnancy- Did you keep well? Did you have any concerns?
- Do you remember if you drank any alcohol during your pregnancy? Either at the beginning or the end of your pregnancy?
- What about any drugs and/or smoking?

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Nine brain domains affected by FASD

- ➔ 'Patchy' cognitive profile with a disorganised brain
- ➔ 3 or more affected domains indicates CNS impairment
- ➔ Highly variable from individual to individual
- ➔ FASD is a whole body diagnosis



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What you see is NOT always what you get: *(an example profile)*

Neuropsychological profiles differ significantly from individual to individual

- Age may not correlate with functional ability in key areas of their life
- Individuals may function well in some domains, yet need significant support in others.
- Building up a strengths profile of every individual is key

The infographic shows a person's profile with various skills and ages. The person's actual physical age is 18. Their skills are: Expressive language (20), Reading ability (16), Living skills (11), Money and time concepts (8), Social skills (7), and Comprehension and social maturity (6).

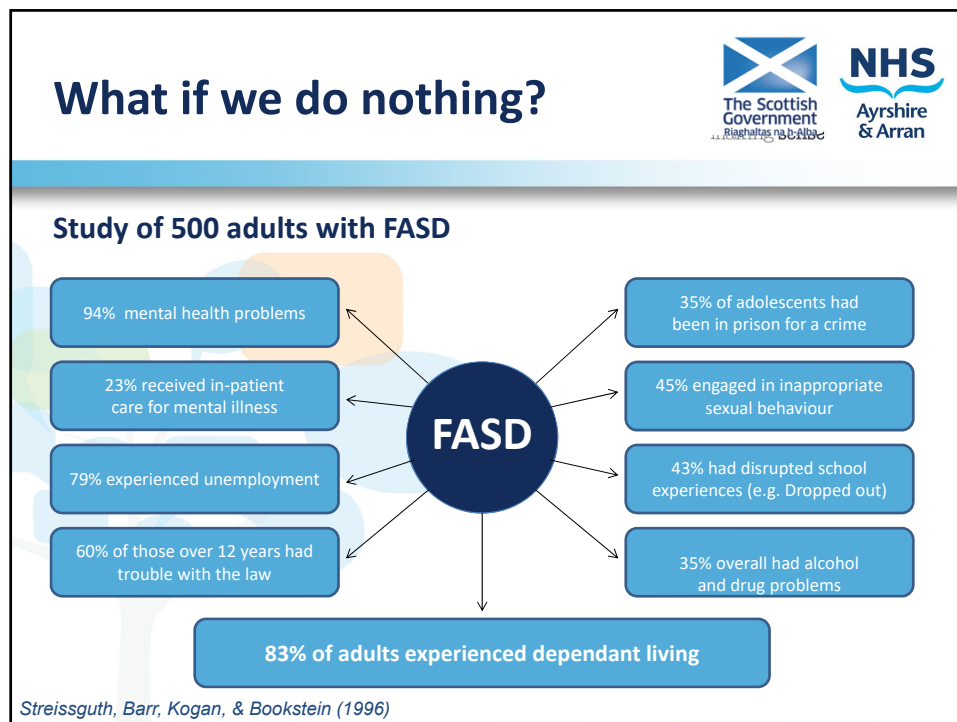
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Prognosis if not accurately understood.....

As they grow older they can experience:

- Social difficulties in relating to their peer group
- Difficulties with educational attainment
- Mental health issues
- Unemployment
- Dependent living
- Addiction issues
- Homelessness
- Involvement with criminal Justice
- Become vulnerable adults
 - likely to experience future trauma

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Successful Outcomes




- Early identification and diagnosis provides a crucial window of opportunity:
 - To educate
 - To provide early intervention
 - To link with resources
 - To facilitate successful transition to adulthood



Diagnosis and early intervention is known to improve outcomes

(Streissguth 2004, Burd et al 2003)

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Factors contributing to better outcome are known



- Providing diagnosis at young age
- Guarding from violence and abuse
- Stable and supportive home environment



References

Burd et al *Recognition and management of fetal alcohol syndrome*
Neurotoxicology and Teratology 25 (2003) 681-688

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What is the point of the diagnosis?



- Misclassification
 - Inappropriate care and assessments
 - Increased risk of mental health issues
 - Risk in future pregnancies
 - Costly

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What is the point of the diagnosis?



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Post-Diagnosis



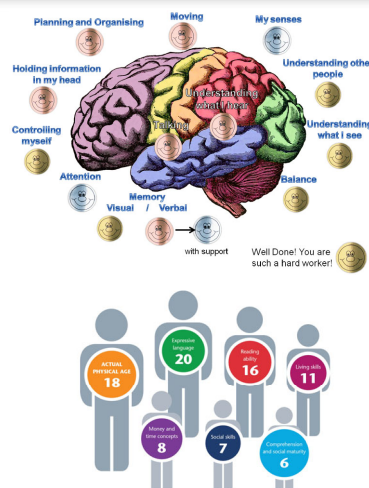
- Diagnosis alone does not improve outcome
- Appropriate interventions
- Education
- Support
- Goals
- Improve outcome
- Requires collaboration

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The importance of collaboration: parent and caregiver views



- Having to, “*fight to be heard*,” prior to MDT assessment, and finally feeling “*heard*” by the team
- Facing “*stigmatisation*” & having their parenting doubted.
- Assessment process helped them, and others, to understand their child
- Hope that the understanding will enable their child to achieve their potential and prevent emotional distress

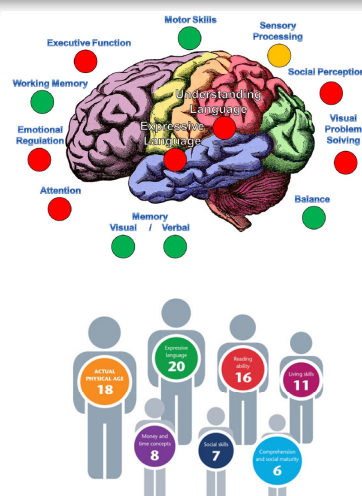


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The importance of collaboration: professionals' views





- Professionals clearly felt that MDT assessment helped them make sense of the unique profiles of each child
- Feeling, “*informed but not yet empowered*,” to work with affected individuals.
- **Strategies** were highlighted as an area where **education wanted to collaborate with clinicians**




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What does collaboration look like?

Collaboration can take many forms and it relies on forging new relationships

- Training professionals from diverse disciplines to improve expertise and confidence
- Mainstreaming FASD assessment and diagnosis rather than creating specialist services
- Creating new pathways – e.g. Edinburgh's MDT incorporating educational psychology
- Third sector relationships – e.g. Adoption UK's FASD Hub (now including support for birth parents)
- Creating resources to empower parents, caregivers, educational professionals and more



HOW WE CAN HELP


SUPPORT SERVICE FOR PARENTS & CARERS
of children and young people who were (or are suspected of having been) exposed to alcohol during pregnancy, a condition known as Fetal Alcohol Spectrum Disorder (FASD). The service intends to offer information, support and training to relevant professionals and carers.

FASD Diagnosis and Management Training
Venue: Golden Jubilee Conference Hotel
Dardrean Road, Glasgow
G81 4SA

AGENDA

Tuesday 18th June 2013 Day 1: Overview and Cases
09:30 – 09:55 REGISTRATION
09:55 – 10:15 Welcome
10:15 – 10:45 John Fergusson, Deputy Director Improving Health and Wellbeing, Scottish Government
10:45 – 11:15 Introduction and contextualisation of the SIGN Guidelines
11:15 – 11:45 Dr Chris Steer, Scottish Government Advisor
11:45 – 12:15 Dr Jani Salonen and Dr Sarah Brown, Ayrshire and Arran FASD Alcohol Advisory and Support Team (FAAST)
12:15 – 12:45 Dr Maria Ryan, Senior Professor of Paediatric Studies, University of the West of England
12:45 – 13:15 General presentation on FASD and Diagnostic Guidelines
13:15 – 13:45 MR FASD Team
13:45 – 14:00 BREAK
14:00 – 14:30 Panel Presentation "In See or Not to See"
14:30 – 15:15 MR FASD Team
15:15 – 15:45 Case 1: Representative Case
15:45 – 16:00 CLINICAL
16:00 – 16:30 Breakout Sessions by Discipline
16:30 – 16:45 a. ST: Education Centres
16:45 – 17:00 b. ST: Clinics
17:00 – 17:15 c. Psychology (Auditorium)
17:15 – 17:30 d. Pharmacy (Auditorium)
17:30 – 18:00 Case 2 (Younger School Age 7-8 year old)
18:00 – 18:45 CLOSE

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Tesco wine tasting plans slammed

Plans by supermarket giant Tesco to recruit pregnant women as wine testers have been attacked by experts.

Tesco says the women will help it select the best wines because they have a better sense of taste and smell.

But a leading doctor has dismissed the claim saying there is no scientific evidence to support it.

Dr Doris Campbell of the Royal College of Obstetrics and Gynaecology said it could also encourage women to drink during pregnancy.

Wine tastings


Tesco said its operation - code-named Cot du Rhone - would involve mothers-to-be being asked to join regular wine tastings at stores across the country.

Tesco said the idea came from its expert wine taster Helen McGinn, who is currently pregnant along with three other members of the wine team.

"The four of us have all remarked how more

“ We'll be better equipped than ever to sniff out the best

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