

2019

Fetal Alcohol Spectrum Disorder (FASD) Prevention
Common Messages



Halton FASD
Preconception and
Pregnancy Action Group

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Fetal Alcohol Spectrum Disorder (FASD) Prevention Common Messages Document

Purpose

These common messages will provide consistent, clear messaging and information for the Halton FASD collaborative who are working to prevent Fetal Alcohol Spectrum Disorder (FASD) in the Halton community. The order in which the messages are presented are not prioritized. Each common message in the following document is framed in green, is stated as fact, and the evidence is included with the reference number beside the statement. These messages are not written in a language that will resonate with all audiences but can be tailored to communicate with specific target audiences on an as needed basis.

Background

For the purpose of this document, Fetal Alcohol Spectrum Disorder (FASD) is defined as a diagnostic term used to describe impacts on the brain and body of individuals exposed to alcohol during pregnancy.

Canada FASD Research Network (CanFASD) has created this common definition of FASD for use in a Canadian context for use by governments, service agencies, and researchers. The objective of using this definition is to:

- Reduce stigma, given that many existing definitions are quite harsh and use incorrect or outdated information
- Increase understanding of the disability
- Increase consistency in our messaging
- Reduce confusion

FASD is a lifelong disability and each individual with FASD is unique in strengths and challenges. Individuals with FASD may experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.

FASD is also considered an invisible disability as only 10% of individuals with FASD exhibit facial features (1). The presence or absence of facial features depends on whether alcohol was consumed in a very narrow window of time during pregnancy. Facial features only occur when alcohol is consumed during days 18-21 of the pregnancy and do not determine the severity of impact to the brain (2) (3).

The exact prevalence of FASD is unknown. Based on the most current research, the estimated prevalence of Fetal Alcohol Spectrum Disorder in the general Canadian population is 4% which means about 22,000 residents in Halton (4).

Prevalence of Alcohol Use in Halton

Compared to Ontario residents, Halton residents are more likely to be regular drinkers, and less likely to be non-drinkers (5). Although across Ontario men consume more than women, over the past years there are more women drinking and those that are drinking are drinking more (6).

Considering alcohol and pregnancy, about half of pregnancies are unplanned (7). In Halton, three out of four women of reproductive age (15-49) are regular or occasional drinkers (8). Also, 20% of Halton adults think that drinking alcohol was safe during pregnancy (9) and 10.5% of Canadian women report consuming alcohol during pregnancy (10).

Fetal Alcohol Spectrum Disorder (FASD) Prevention Common Messages

1. There is no safe amount or type of alcohol to drink when pregnant or planning to become pregnant.
2. Alcohol is a known teratogen that can affect the fetus at any stage of pregnancy.
3. Accessible and safe contraception is an excellent FASD prevention strategy.
4. It is safest not to drink if there is a potential for pregnancy.
5. Women do not intentionally seek to harm their unborn children.
6. It is important to support individuals with alcohol exposed pregnancies.
7. FASD can be prevented.
8. Screening, Brief Intervention and Referral (SBIR) is one part of a comprehensive and integrated strategy to prevent FASD and to help women stop or reduce use of alcohol when pregnant.
9. Current studies suggest that up to 4% of individuals in Canada have Fetal Alcohol Spectrum Disorder (FASD). This equates to about 22,000 Halton residents.
10. FASD is a diagnostic term. There are two diagnostic categories in Canada; FASD with sentinel facial features and FASD without sentinel facial features
11. FASD is a lifelong disability. The effects can be neurological, behavioural and physical.
12. In most cases, FASD is an invisible disability. Only a small percentage of individuals with FASD have physical features.
13. It is important to use language which is sensitive and does not assign blame when working in the area of FASD.
14. There are potential long-term risks, harms and outcomes for individuals with FASD who do not have an FASD informed community of support.
15. FASD can impact individuals, families and communities of all cultures, education and economic levels.

Alcohol Use and Pregnancy

1. There is no safe amount or type of alcohol to drink when pregnant or planning to become pregnant.

Extensive research demonstrates that there is no safe level of drinking during any stage of pregnancy. Even low levels of prenatal alcohol exposure have been shown to have negative long-term developmental effects. It does not matter what type of alcoholic drink is consumed as all types of alcohol can harm the baby's developing brain any time throughout the entire pregnancy (4).

When alcohol is in the mother's blood circulation, it passes to the developing baby's system and is broken down much more slowly than in the mother's. The fetal alcohol level is therefore higher, the effects last longer and this increases the risk of harm. The risk of miscarriage, preterm birth, low birth weight and small for gestational age babies, placental abruption and intrauterine growth restriction all increase (7) (11).

The Canadian Maternity Experiences Survey reports that 62.4% of the women surveyed drank alcohol during the 3 months prior to pregnancy or before realizing they were pregnant (10). Within the first weeks after conception, the development of the central nervous system, heart and other organs has begun and can be affected, before many know that they are pregnant.

It is recommended, both parents who plan to be pregnant avoid at-risk alcohol consumption in the preconception period (12).

2. Alcohol is a known teratogen that can affect the fetus at any stage of pregnancy.

Alcohol is a known teratogen (chemical or drug) that can cause birth defects by affecting the growth and formation of the fetus's body and brain. It is important to note that the central nervous system and brain develop throughout the entire pregnancy; therefore, it is never too late to reduce or stop alcohol use (13) (14).

Informing a health care provider of prenatal alcohol exposure allows practitioners to provide better, and more effective, follow-up or referrals if any concerns are identified later with a child (15) (16).

3. Accessible and safe contraception is an excellent FASD prevention strategy.

Reducing the risk of alcohol exposed pregnancies often focusses on preconception information about avoiding alcohol during pregnancy, but another effective approach is preventing pregnancy during alcohol use, or ideally a combination of both (17).

If there is the potential for becoming pregnant and an individual is consuming alcohol, they should be using effective contraception (16) (17).

4. It is safest not to drink if there is a potential for pregnancy.

Consuming alcohol can affect a woman's reproductive hormones causing imbalances affecting their menstrual cycle, making it irregular and changing the timing of menopause. This results in an increased risk for pregnancy (7) (11). Statistics indicate that approximately 50% of pregnancies are unplanned and that risky drinking is currently on the rise among women (17).

Alcohol can cause sperm abnormalities, lower sperm count and DNA changes. Paternal preconception alcohol consumption appears to have an impact on birth outcomes and may make the fetus more sensitive to maternal prenatal alcohol exposure (12).

5. Women do not intentionally seek to harm their unborn children.

Research tells us that women do not intentionally seek to harm their unborn children. There are many reasons why some women drink during pregnancy but drinking during pregnancy is most consistently predicted by:

- how much women drank before they were pregnant
- being in an abusive relationship (18).

Other reasons include;

- Unaware they are pregnant
- Unaware of the extent of damage alcohol can cause the fetus
- Underestimate the harms alcohol consumption can cause because they know others who drank during pregnancy and their children appear healthy
- Alcohol is the norm in their social group, so abstaining may be difficult
- Individuals may be using alcohol to cope with difficult life situations such as violence, depression, poverty or isolation
- Individuals may struggle with alcohol addiction (18)
- Conflicting or inaccurate messaging from healthcare providers (19) (20)

6. It is important to support individuals with alcohol exposed pregnancies.

From a harm-reduction perspective, the message to be shared is it's never too late to quit or cut down to reduce the harm of alcohol exposure in pregnancy. Depending on the level of alcohol dependence it is important to discuss with a health care provider /addictions counsellor how to do so safely (15).

Substance use is heavily influenced by others. Patterns of alcohol use mirror their partner's habits both negative or positively (21). Family and friends of a pregnant woman can support her by offering non-alcoholic beverages, attending alternative events with her, or helping her find support to reduce or stop her drinking (22).

Universal screening for alcohol consumption should be provided regularly for all pregnant women and women of childbearing age with follow up initiated for infants with any prenatal alcohol exposure (23).

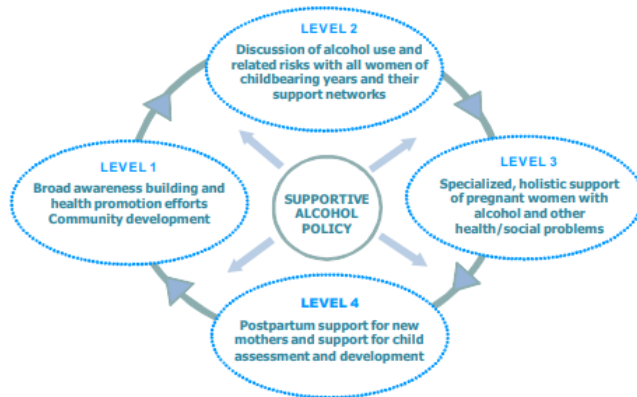
FASD Prevention

7. FASD can be prevented.

FASD is caused by prenatal alcohol exposure i.e. when a developing baby is exposed to alcohol. Women who do not drink before conception and while they are pregnant are not at risk for their baby having FASD. Unless otherwise reported, it is advised to assume alcohol is used by all women (24).

Many studies have been done on how to reduce the incidence of FASD. The answer is not as simple as just telling women not to drink in pregnancy. It has been found that many strategies are required to lower rates of FASD (25).

Four levels of FASD prevention strategies -



(26)

Level 1 – Raising Public Awareness; This involves interventions to promote awareness about the risks of alcohol use in pregnancy and/or where to get assistance. It is important for advancing social support and change for women, their partners and communities who lack information. This prevention level is more effective if it is used in combination with the other prevention levels as part of a comprehensive approach.

Level 2 – Brief Counselling with Girls and Women of Childbearing Age; All pregnant women and women of childbearing age should be engaged regularly in discussions about alcohol consumption. These efforts by support networks and healthcare providers provide an opportunity for a universal approach to screening and safe discussion with women about reproductive health, contraception, pregnancy, alcohol use, and related issues. A service provider who takes an empathetic, collaborative approach is one of the strongest predictors of whether a woman will be able to change her alcohol and drug use.
(See following section on “Screening and Brief Intervention (SBIR)” for more information.)

Level 3 – Providing Specialized Preconception and Prenatal Support; This support involves the provision of recovery and holistic support services that are specialized, culturally specific and accessible for women with alcohol problems, trauma and related mental health concerns. Non-judgemental supports for pregnant women can help them stop or reduce their use of alcohol in pregnancy. These services are needed not only for pregnant women, but also before pregnancy and throughout the childbearing years.

Level 4 – Providing Postpartum Support; This support assists new mothers to maintain/initiate positive changes in their health and social networks, and to support the health and development of their children or future pregnancies. It also involves support for mothers who were not able to make significant changes in their substance use during pregnancy. It may also involve early intervention services for their children (26) (27).

Supportive Alcohol Policy at the Core of the Four Levels of Prevention

Supportive alcohol policy is at the centre of the four levels of prevention. Evidence-based alcohol policies, when widely implemented, have considerable potential to reduce the health and social harms from alcohol, including influencing rates of FASD through each level. Alcohol policies are critical because they determine the availability of alcohol and other aspects of the environment in which decisions about drinking are made.

In consideration of alcohol promotion and marketing, there has been an exponential increase in targeting females over the last 20 years and this has affected the amount women are drinking, the frequency with which women are drinking and the number of women binge drinking. Policies which address and work to limit such targeted advertising also can help to prevent FASD (26) (27).

Screening Brief Intervention Referral (SBIR)

8. SBIR is one part of a comprehensive and integrated strategy to prevent FASD and to help women stop or reduce use of alcohol when pregnant.

Health care and social service providers are encouraged to discuss alcohol use and related concerns such as other substance use, mental wellness, contraception, and safer sex with all girls and women of childbearing age. Research shows that 5 to 10 minute counselling sessions can reduce alcohol consumption during pregnancy by up to 30%. Real or potential alcohol problems can be identified and through intervention, a woman can be motivated to address them (28).

There are many SBIR validated screening tools. Some use checklists, steps or stages, and flow charts to guide the discussion between women and service providers. Screening is generally viewed as an opportunity to prevent or diagnose FASD by determining if a woman is drinking alcohol at a risky level or in a harmful way. By screening for alcohol and birth control use before pregnancy the risk of FASD can be decreased by 50% (27). If a woman is “at risk,” screening is followed by an intervention which may include sharing information about substance use, setting a goal, co-developing a plan, or agreeing to revisit the topic at another visit. For a woman with more serious substance use or addiction concerns, service providers are encouraged to share information about available community resources, to make a referral, or assist her in accessing more comprehensive care (28).

If a woman indicates she does not consume alcohol at screening, then positive reinforcement is beneficial. Research shows it is helpful to provide brochures and other information about a healthy lifestyle during pregnancy, including details about alcohol abstinence and the effects of alcohol on the fetus (14).

Universal SBIR for alcohol use does not need to be the purpose of the visit to the Health Care Provider and can be seen as part of a reproductive life and/or a healthy living plan. Primary care clinics and centers, hospital emergency rooms, trauma centers, and other community settings provide opportunities for early intervention with at-risk substance users before more severe consequences occur (29) .

Healthcare professionals can access a clinical guide to SBIR at <http://www.sbir-diba.ca/> (30) .

Understanding Fetal Alcohol Spectrum Disorder

9. Current studies suggest that up to 4% of individuals in Canada have Fetal Alcohol Spectrum Disorder (FASD). This equates to about 22,000 Halton residents.

- The Chief Public Health Officer's Report on the State of Public Health in Canada 2015 ALCOHOL CONSUMPTION IN CANADA states a 2-5% prevalence rate (31).
- Based on the most current research, the estimated prevalence of Fetal Alcohol Spectrum Disorder (FASD) in the general Canadian population is 4% (32). However, rates of FASD are believed to be much higher in certain groups (33).
- The exact prevalence of FASD is unknown. There are significant limitations to prevalence research.
 - need confirmation of prenatal alcohol exposure, which can be hard to obtain from the birth mother
 - stigma
 - multidisciplinary team process for formal diagnosis (16)

10. FASD is a diagnostic term.

There are two diagnostic categories in Canada; FASD with sentinel facial features and FASD without sentinel facial features.

- As of 2015 the term FASD is understood to encompass any alcohol-related diagnosis from the past. All other acronyms will no longer be used for diagnostic purposes (34).
- The addition of an at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be diagnosed. Individuals who do not meet the diagnostic criteria but are still at risk of FASD receive the same services as those with a diagnosis of FASD, as required to address their current needs (16).

11. FASD is a lifelong disability. The effects can be neurological, behavioural and physical.

- No two people with FASD will have the same challenges. Some of the neurodevelopmental impairments include:
 - Slow processing pace- takes more time to respond, understand or complete tasks.
 - Learning and memory- unable to learn from experience, often requires re-teaching.
 - Language and Communication – can be highly verbal, but lack comprehension skills both written and verbal.
 - Abstract thinking- does not understand consequences and unable to generalize learning to new situations.
 - Theory of Mind- difficulty understanding another's understanding or perspective. Assume others have the same understanding/ knowledge that they do.
 - Attention issues and Hyperactivity- unfocused, distractible, restless.
 - Executive functioning – difficulty with judging, planning, delaying gratification, organization (time and money), impulsivity, rigid thinking, memory.
 - Social Skills-acting younger than their age, not aware of social cues or norms.
 - Motor skills – impaired balance and coordination (2).
 - Affect Regulation – mental health concerns
 - Circadian Rhythms- issues with sleep (difficulty falling and staying asleep) and eating (not aware of hunger cues, fussy, difficulty managing weight) (16).

- Individuals with FASD are at increased risk for mental health issues, difficulty at school, addictions, trouble with law, homelessness, inappropriate sexual behavior, and difficulties maintaining employment (2).
- These outcomes can be preventable with access to informed and proper supports and resources.

12. In most cases, FASD is an invisible disability. Only a small percentage of individuals with FASD have physical features.

- The sentinel facial features associated with FASD are small palpebral fissure length (opening between the eye lids), smooth philtrum (area between upper lip and nose), and thin upper lip (16).
- Facial features do not determine the severity of the impact to the brain (2).
- Only 10% of individuals with FASD exhibit the facial features (1).

13. It is important to use language which is sensitive and does not assign blame when working in the area of FASD.

- Refer to FASD as caused by prenatal alcohol exposure, moving emphasis away from the behaviour of the birth mother
- Canadian terminology uses cognitive or neurodevelopmental disability for describing people who may have cognitive challenges
- In line with the CanFASD language guide, avoid the terms primary and secondary disabilities (34).

Prevention of Further FASD Impacts

14. There are potential long-term risks, harms and outcomes for individuals with FASD who do not have an FASD informed community of support.

- FASD informed community of support can include family, caregivers, professionals and more
- There is sufficient evidence to conclude that individuals in the child welfare and correctional systems experience disproportionately high rates of FASD (33).
- High rates of mental health difficulties, substance use occur among individuals with FASD (2).
- Making a diagnosis of FASD requires a multidisciplinary team and involves a complex physical and neurodevelopmental assessment (16).

- When FASD goes undiagnosed, individuals often struggle with a disability that is neither acknowledged nor understood and they remain disconnected from crucial supports that can make a difference to quality of life (35).

15. FASD can impact individuals, families and communities of all cultures, education and economic levels.

- Affects all cultures and social/economical statuses (33).
- Is not limited to individuals with addictions/substance misuse issues
- The impacts are widespread affecting individuals, families and communities (35).
- populations with social determinants of health factors however may show disproportionately higher rates of FASD (33).

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