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Chapter 1

Our continuing love affair with alcohol

Here's to alcohol, the cause of and the solution to all life's problems.

(Homer Simpson, *The Simpsons*)

IN THE BEGINNING...

There is nothing new about the issue of alcohol; the pleasures and problems that it brings have been with us for a very long time. Alcoholic drinks have been produced and consumed by humans for thousands of years. Alcohol has medicinal, antiseptic and analgesic properties. Alcoholic drinks encourage relaxation and social cohesion and have played a significant role in religion. However, the role of alcoholic drinks in society has often been highly controversial and the subject of great debate. The contradiction between alcohol as essential for pleasure and drunkenness as a social evil is found throughout world history.

Archaeological evidence suggests that as long ago as 10,000 BC, our Neolithic ancestors fermented and drank beer. Tools to produce wine, dating back to 7,000 BC, have been discovered in China. By 4,000 BC, wine had started to appear in Egyptian pictographs. The ancient Greeks wrote at length about the positive and negative effects of alcohol and many of the great philosophers had strong opinions on the subject. Plato, for example, believed, 'He was a wise man who invented beer'. He and his contemporaries were, however, strongly critical of drunkenness.

During the time of the Romans, the trade in wine and other alcoholic beverages grew rapidly across the Empire. Every villa had its own vineyard. The Roman philosopher Seneca stated that, 'Drunkenness is nothing but voluntary madness'. Alcohol was distributed free, or at cost, for festivals and victory celebrations and frequently led to large-scale disorder and riots.

Modern European drinking habits still reflect the pattern established nearly 2,000 years ago by the Greeks and Romans. Wine drinking in moderation, usually with meals, still predominates in the south of Europe. In the north of Europe, where vines could not easily be

cultivated, beer drinking, without accompanying food, is more common. The beer drinking countries – Germany, Austria, Belgium, Denmark, the Czech Republic, Britain and Ireland – would, however, be regarded as semi-barbarian territory by the Romans. Thanks to the Romans, wine is still regarded as the most civilised and cultured of drinks. Wine not beer is still the drink served to impress at banquets, political summits and dinner parties because of its enduring association with class, status and wealth (Standage, 2005).

THROUGH THE AGES

By the end of the Middle Ages, most European nations had developed their own distinctive brewing and distilling styles. In Europe, religious orders have had a large part to play in the history of alcohol. It was monks who first perfected brewing and the large-scale production of beers and wines, which they would sell to the public. Religious orders of the time successfully managed the paradox of simultaneously regarding alcohol as a gift from God whilst at the same time condemning drunkenness as a sin.

The issue of excessive alcohol consumption in the UK has been an issue in debates about public health and social morals for over 300 years. The large-scale distillation of alcohol from grain into spirits, often flavoured with juniper, became immensely popular during this time. In 1690, the English Parliament even passed a law to encourage 'the Distillation of Brandy and Spirits from Corn'. This led to a massive surge in gin production and consumption, which was quickly blamed for widespread health problems and social unrest. Hogarth's print, *Gin Lane*, published in 1751, painted a graphic picture of the social disorder that followed the availability of cheap gin. Concern over the effects of gin on society led to the Gin Acts, of 1736 and 1751 respectively, which taxed and regulated the production and sale of gin. Distilled spirits, particularly rum, were also the currency that fuelled and closed the malevolent triangle of the slave trade, linking spirits, slaves and sugar.

The problems escalated as British cities grew rapidly during the industrial revolution. In the early 18th century, the mortality rate from gin was thought to be so high that it stabilised London's rapidly growing population. Temperance movements mushroomed around the 1860s in response to public concern, fuelled by the teachings of evangelistic religion and social reformers like Joseph Rowntree.

Distilled drinks, alongside firearms and infectious disease, helped to shape the modern world, as the inhabitants of the Old World sought to establish themselves as rulers of the New. Alcohol played a role in the enslavement and displacement of millions of people from indigenous cultures who were supplied by copious quantities of alcohol in exchange

for goods or land. Today, this association with slavery and exploitation has gone but the damage persists. The highest prevalence of foetal alcohol spectrum disorders in the world are found in the indigenous populations of Australia, New Zealand, Canada and the USA. Alcohol has always provided an escape from poverty and hardship, an association that endures.

History also suggests that banning the sale of alcohol does not decrease consumption but simply encourages the growth of a black market in illicit and more dangerous formulas. In the USA in the 19th century, spirits were produced and consumed in almost unbelievable quantities. By the 1820s, a surplus of corn had led to a massive growth in the production of whisky. It is thought that during this time, the equivalent of a pint of whisky for every man, woman and child was being drunk every day across America. This led to the beginning of the Prohibition movement, which sought to ban all forms of alcohol across the USA. Prohibition reached its climax with the National Prohibition Act in 1919, which led to the banning of the sale and manufacture of alcohol across the USA between 1920 and 1933. Owing to the massively lucrative trade in black market alcohol that followed, Prohibition is widely regarded as having done more to boost organised crime than any other Act in the history of the USA.

MORE RECENTLY...

In the UK, the late 20th and early 21st centuries have seen widespread increases in public drunkenness. UK society has a particularly close relationship with alcohol; it is central to most of our rituals, such as weddings, christenings, funerals, leaving parties, stag nights and hen nights, and even our everyday life. The ubiquitous teapot on the dining tables of post-war Britain has been steadily replaced by the wine bottle. For most people, drinking alcohol is associated with socialising and pleasurable experiences. Responsible drinking is all about understanding the harm alcohol can have on your health, both mentally and physically, if not consumed with care and moderation. Despite numerous public health campaigns, a substantial number of drinkers regularly consume more than the recommended weekly guidelines, because they lack sufficient understanding of the harm alcohol can have and frequently cannot make sense of the confusing unit system by which alcohol strength is measured.

In modern-day UK, there is still a conflict of views as to whether alcohol is an attractive elixir or a dangerous poison. It has been accepted for two hundred years that alcohol can have a negative impact on family life, leading to domestic violence and the neglect of children. During two World Wars, successive Governments were concerned about the

deleterious impact of alcohol on industrial production because of the country's need for a punctual, sober, reliable workforce. More recently, the debate has focused on the cost to individuals and society of premature illness and death and the impact on NHS, police and community resources.

There is, however, one important group in society for whom alcohol will always be a poison and that is the unborn child. The unborn child has not been a part of 2,000 years of debate. The damage that prenatal alcohol causes to the developing foetal brain will be the focus of this guide.

KEY LEARNING POINT

- Whatever the benefits and disadvantages of alcohol to society, for the unborn child it is always a dangerous poison that must be avoided.

Chapter 8

How presentation varies with age

My child is in permanent conflict with a world she doesn't understand and cannot make sense of.

(Birth mother)

We cannot predict the degree of damage or the eventual outcome. We can only manage our expectations. That's one of the secrets to staying sane.

(Adoptive parents)

Superficially my daughter appears to be so capable but actually has no ability to cope with school at any level.

(Adoptive parent)

The main burden of caring for children affected by alcohol is caused by their long-term problems with learning, language and behaviour. The pattern of these difficulties changes as the child moves from infancy to adulthood and the impact of the damage presents in different ways at different ages. Individually, the affected children can show very different patterns of strengths and difficulties because of the unpredictable nature of the pre-birth damage to the frontal lobes of the brain.

INFANTS AND TODDLERS

At this age, the symptoms are vague, non-specific and not diagnostic. Infants are often tremulous and irritable or may spend prolonged periods of time sleeping. They have a weak sucking reflex and may have feeding difficulties. They are often uninterested in food and feeding can take hours. Eating difficulties are a major source of stress for parents. Some children overeat, some undereat, some eat very slowly, while others never seem to feel hungry. Despite adequate nutrition, an affected child may gain weight only very slowly. Children are frequently referred to hospital for investigation of their poor weight gain or failure to thrive.

Sleep, or the lack of it, is a big issue, particularly in very young children. Patterns vary – an affected child either needs more sleep than other children or does not sleep at all. Sleep problems have a number of different causes. Affected children often lack an internal body clock and have no concept of time. They struggle to differentiate between night and day and to understand that night time means sleep. They have erratic sleep patterns with no predictable sleep–wake cycle. For all carers, it is exhausting and challenging to care for a child who does not sleep, engaging in a nightly battle to establish a regular sleeping routine.

As toddlers, the lack of interest in food, slow weight gain and disrupted sleep pattern continues. Affected children have a low muscle tone and can be slow to achieve their developmental milestones. They struggle with fine motor skills, holding a pencil, learning to dress and undress, and using a spoon and fork. They can be hypersensitive to noise, bright lights, temperature and touch. Toilet training can be slow.

Speech often develops very early and the children can be excessively talkative. They are very sociable but over-friendly and indiscriminate with relationships. They have a short attention span and are easily distracted and hyperactive. They tend to move from one activity to another, showing little in the way of focused play. They are unable to comprehend danger and do not respond well to repeated verbal warnings. They are prone to temper tantrums and non-compliance. They respond badly to change and prefer routine.

The child's carers are left with a growing feeling that "something is not quite right" but cannot identify what is wrong. They are given a lot of well-meaning, often contradictory advice from family, friends and even child care professionals but nothing really seems to work. The gap between the behaviour of an alcohol-affected child and their peers steadily widens as the child gets older.

SCHOOL-AGED CHILDREN

During the early years in school, the typical child begins to develop better concentration, more social interaction and an increasing capacity to learn new skills, particularly literacy and numeracy. For the child with FASD, it is often in school that their problems first become more noticeable as the child begins to show difficulties across multiple areas.

Children affected by prenatal alcohol have deficits in the executive function of the brain. This is essential for:

- organisation and planning;
- focusing and maintaining attention;
- storing and retrieving memories;

- inhibiting inappropriate actions;
- stopping emotions from getting out of control;
- understanding social situations and social behaviour;
- abstract thinking.

The affected child will therefore show some, or even all, of the following difficulties.

- Attention deficits and poor impulse control become more apparent as the demands for classroom attention increase. An affected child will find it difficult to wait for their turn, to follow rules or to co-operate. They often interrupt the work or play of others and are inappropriately intrusive. Consequently, FASD is often incorrectly diagnosed as attention deficit hyperactivity disorder (ADHD) and treated inappropriately with medication that is ineffective or that may even make the child worse.
- The child's memory, especially memory for language, is weak. The child needs constant repetition and reminders for even basic activities at home and school. Information is learned, retained for a while and then lost. The child may tell you that they understand your instructions, but then is unable to carry them out. Children rapidly learn to act as though they understand, but cannot follow a series of actions through by themselves. They often watch and follow another child who knows what to do. Language-based behavioural strategies or talking therapies are usually ineffective.
- The child exists in the "here and now". They are unable to monitor their own work or behaviour, cannot transfer learning from one situation to another or learn from experience. Their behaviour patterns can be inflexible. Their logic is faulty and they lack critical thinking and judgement skills. They have difficulty in abandoning strategies that have proved to be ineffective in the past and are unable to apply previously learnt rules to a new situation.
- Affected children often have good verbal skills, a superficially friendly social manner and obvious good intentions that mask the seriousness of their problems. They talk too much and too quickly but have little real information to communicate. They like to be the centre of attention and their outgoing and friendly manner, which is often seen as positive in early childhood, becomes more problematic as the child grows older. They are increasingly seen as immature and naïve. They have poor peer relations and can become progressively socially isolated, preferring to play with younger children or adults rather than with their peer group. Consequently, FASD is often incorrectly diagnosed as an autistic spectrum disorder.
- As they progress through school, the affected child's reading and spelling skills usually peak. They have increasing difficulty in completing

assignments and mastering new academic subjects. As they are usually very concrete thinkers, they have trouble working with ideas. They have increasing problems with abstract thinking and are unable to link cause and effect. They struggle to understand concepts, especially mathematical ideas, money and time. They find it difficult to identify and label emotions or feelings. They tend to fall further behind their peers as schoolwork becomes increasingly abstract and concept-based.

- Affected children are frequently misjudged as being lazy, stubborn and unwilling to learn. Their skills in school can often fluctuate from day to day, giving the mistaken impression that their poor performance is deliberate.
- During the first two years in primary school, most affected children will achieve some basic reading and writing skills and the extent of any learning delay may not be initially apparent. In a good primary school where there is a lot of structure and routine, some children will not present until this structure is taken away, normally in a secondary school setting. Sadly, very many affected children will fail in school because in addition to a low normal IQ, they lack the core abilities needed to learn and succeed: sitting still, listening, concentrating, understanding cause and effect, following complex verbal instructions, planning, and organising their time.

ADOLESCENCE AND ADULTHOOD

As an affected child matures into adolescence and adulthood, any facial deformities become less noticeable but the short stature and microcephaly (small head) remain. Unfortunately, by this stage, the child will have often been affected by other factors that complicate the presentation. Trauma, bullying, abuse, educational failure and placement moves can become routine. For the looked after child, the documentation of these events may be missing or unavailable. Puberty complicates the presentation even further. A combination of poor understanding, communication problems, an inability to always recall what was said plus their struggles to cope with everyday life can lead to secondary problems with depression, anxiety and low self-esteem that further affect the young person's functioning.

Where children are diagnosed early and followed up, many of these issues can be minimised. Without diagnosis, adults affected by prenatal alcohol experience major psychosocial and adjustment problems for the rest of their lives. They have difficulty holding down jobs, problems managing money, poor social skills, low motivation and may become increasingly withdrawn and isolated. Antisocial behaviour and inability to live independently are common. Affected adults are more likely to have problems with alcoholism or drug abuse themselves. They have

difficulty showing remorse or taking responsibility for their actions, and frequently behave in ways that place themselves or others at risk. A high degree of impulsivity and a total lack of inhibition mean that affected individuals are easily influenced and subject to peer manipulation and exploitation. They are at high risk for sexual abuse, problems with the police and involvement in the criminal justice system.

STRENGTHS OF THE FASD CHILD

Although the difficulties that alcohol-affected children experience are lifelong and the underlying brain damage is untreatable, FASD is not a hopeless diagnosis. As individuals, these children have a complex profile with a mixed pattern of major weaknesses and real strengths. It is essential to recognise and reinforce these strengths, which will increase the child's confidence and self-esteem. They can also be used as strategies for education and behaviour management.

Parents usually describe their affected children with great affection as loving, caring, kind, sensitive, loyal and compassionate. They are often friendly, cheerful and outgoing individuals who can flourish in an accepting or modified environment. They can be energetic, determined and very hardworking if they have the right skills to complete a task. They have a very strong sense of fair play and are co-operative and loyal. They are curious and like to be involved in family and social activities. They are empathetic to very young children, the elderly and animals, with whom they are nurturing, sensitive and gentle. They often have exceptionally good, long-term visual memories and can be wonderful storytellers with a rich fantasy life. They can be curious and questioning with a profound sense of wonder. Many have artistic, musical or creative skills and enjoy tasks such as cooking or gardening.

KEY LEARNING POINT

- FASD is not a hopeless diagnosis. Consistent, patient, loving, “industrial-strength” parenting with structure and appropriate expectations plus support in school can help affected children to reach their full potential. That potential will be limited by alcohol-related brain damage but setting the bar at the right height, and identifying what a child can do versus what they cannot do, will help them achieve some success in their life. Above all, early diagnosis will hopefully prevent some of the “secondary disabilities” that blight the lives of these children and their families.