Responsibility from the Start!

Fetal Alcohol Syndrome

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Foreword by the German Federal Drug Commissioner

Every year in Germany, some 4,000 children are born with a wide range of problems due to maternal consumption of alcohol in pregnancy. Known as fetal alcohol syndrome, these severe disabilities have no cure. While some deficits can be eased by targeted therapy, most of those affected cannot lead an independent life and need ongoing care and supervision.

> **Education and information is needed for parents, guardians, teachers and public servants.**

Children affected by FAS and their families need early diagnosis so that they can get necessary help in good time and experience understanding for their special cognitive, emotional and social difficulties. Comprehensive education about fetal alcohol syndrome is the only way to avoid secondary disabilities.

Children with prenatal alcohol damage suffer from physical malformation, mental/intellectual disabilities and severe behavioural problems. They have trouble learning and retaining new material, recognising contextual relationships, and adhering to rules. They are restless and easily distracted, intrusive and aggressive, easily led and poor at recognising and avoiding danger. The cause – alcohol-related organic brain changes – is often not understood, and affected children face correspondingly frequent criticism and correction in disregard of their hardship and their needs.

This leaflet aims to promote a better understanding of children, adolescents and adults with prenatal alcohol damage. It offers practical everyday tips for successfully helping those affected and gives pointers to potential therapy, school and statutory assistance for them and their families.

While the consequences of prenatal alcohol exposure cannot be reversed, understanding and appropriate assistance can help affected children, adolescents and adults embark on a life in which they can develop their abilities despite their disabilities.

As the Federal Drug Commissioner, I wish the leaflet every success and a broad readership.

Mechthild Dyckmans, MdB
Federal Drug Commissioner

Introduction

Children, adolescents and adults with fetal alcohol syndrome (FAS) are confronted in life with demands that pose great problems for them because of alcohol-related prenatal organic brain damage. Due to unawareness, people around them meet their behavioural disorders and social and emotional problems with incomprehension or helplessness and ultimately even rejection. Many affected children and adolescents have to put up with being told they are merely ‘cheeky’ or ‘lazy’. Parents are accused of not properly rearing their children.

FAS is not rare. One in every 300 newborns exhibits the full syndrome, and alcohol-related damage is thought to arise in every hundredth child. Such children and adolescents are frequently given another diagnosis (ADHD, autism, attachment disorder, conduct disorders). Many parents who find no help for their child among these other diagnoses – and in subsequent attempts at therapy – and then continue to seek an explanation undergo a veritable Odyssey before FAS is finally identified and confirmed. Many of these parents in search of an answer encounter much criticism for making the effort at all – including, regrettably, from professionals.

This leaflet aims to help promote understanding for the difficulties associated with FAS and offers practical hints and tips for everyday life.

Terms and definitions

Maternal consumption of alcohol during pregnancy can have lifelong consequences for children. As symptoms can be more or less strongly pronounced, the term ‘fetal alcohol spectrum disorder’ (FASD) has come to be used. This brings together all alcohol-related influences on the development of the embryo and the fetus. FASD encompasses the full fetal alcohol syndrome (FAS) and partial FAS (pFAS). In pFAS, the physical changes are less pronounced or absent, but as with FAS there are a wide range of embryo-fetal brain function and behaviour difficulties as a result of the neurotoxic effects of alcohol. pFAS is not to be regarded as a weak form of FAS, as affected children display equally great social and emotional restrictions and a similar degree of suffering to children with full FAS.

A straightforward classification of FAS has proved useful in everyday diagnostic practice:

- **FAS with confirmed maternal alcohol exposure**
- **FAS with unconfirmed maternal alcohol exposure**
- **Partial FAS with confirmed maternal alcohol exposure**

Effects of alcohol on the unborn child

Alcohol easily crosses the placenta. The unborn child is therefore exposed to the same blood alcohol level as the mother. The developing fetal liver has little or no ability to break down alcohol. Alcohol interferes with cell division and stunts growth. It also causes organ damage. It primarily disrupts the development of the brain.

Physical features of FAS

Despite adequate nutrition and good support, many children with FAS stay smaller and lighter than healthy peers, and have a smaller head circumference. This growth deficiency is sometimes made good later on, but in many cases the children only attain below-average height. The typical features of FAS include facial malformations. The upper lip is thin. The philtrum – the groove between nose and upper lip – is extended and flattened. The nasal bridge is shortened and widened, and the nostrils tend to be prominent. The eyes appear smaller and further apart; the ears are low-set and turned to the back of the head. The facial changes mostly normalise in the course of childhood. In adulthood, only the thin upper lip and small eyelid openings tend to remain. Alongside the typical facial changes, there may also be skeletal changes, heart defects, and genital and kidney malformations. Many affected children, however, can look perfectly healthy. Their intrusive behaviour, which results from alcohol-related brain damage, may thus frequently seem inexplicable and wilful.

FAS – from child to adult

Children with FAS

In the first few years, children with FAS display speech development defects. While speaking ceases to present any difficulty in time, and FAS children can cause astonishment with a wide vocabulary and a highly talkative nature, their ability to understand often stays within narrow limits.

Sight and hearing may be affected, as may the sense of touch. Many children are thus oversensitive to touch (and hence to seams in clothing or water on the skin). On the other hand, many FAS children have a remarkably high pain threshold. Temperature sensitivity is also impaired. There is often an inability to sense appetite and satiety.

Motor development may be delayed. In some cases, children are marginalised because of their poor fine motor skills. Not infrequently, however, they develop exceptionally good gross motor skills, although they easily overestimate their abilities in this regard.

The intellectual deficits are most evident in logical thinking. Abstract reasoning and the capacity to learn rules and logical relationships are impaired. There is low ability to retain learned solutions and apply them to other situations. Most alcohol-damaged children show severe attention deficits. They only have a short attention and interest span, and are easily distracted. Accordingly, they are unable to keep arrangements and poor at carrying out assigned tasks.

Children with FAS are unable to sit still and quickly switch from one type of play to another without seeing games through to the end. The children have difficulty controlling their own emotions and find frustrations hard to tolerate. They are unable to assess the risks of their own conduct, for example in play. Natural fear of danger is generally lacking. The children are consequently reckless and high-spirited. They get into dangerous situations in road traffic or when climbing things. In contrast to other children, FAS children fail to learn even from bad experiences. Aside from this, affected children are mostly exceptionally willing to help, but naïve, gullible and easily led; they are often unable to judge the social consequences of their actions. They are all-too trusting towards other children and even strangers. As a result, they repeatedly find themselves in unpleasant situations to their own disadvantage. This also applies to children with FAS who score normally in an intelligence test.

Adolescents with FAS

Adolescents with FAS, too, are naïve towards strangers and unable to see through others' intentions. Given a friendly word, they are happy to do others' bidding without being able to realise what is happening or that their trust is being misused. Girls with FAS who respond gullibly to attention from others and in some cases seek contact in a sexualised form themselves are at special risk. Boys wanting to get in with others of their own age are similarly easily misled. Approaches such as "If you want to be my friend, then ..." are often enough. Adolescents with FAS are hangers-on rather than leading the action. Held to account by adults, they can neither understand nor explain their own conduct. As a result, they soon get into similar difficulties again. A vicious circle mostly develops, with increasingly outraged sanctions from authority going hand in hand with growing helplessness and desperation on the part of the affected adolescents and young adults.

Adults with FAS

Adults with FAS are underdeveloped for their age. They are not sufficiently independent or accountable to live autonomously. They need ongoing instruction and control (for example with bodily care, planning the day and attending work). Problems likewise persist with regard to social contacts, understanding of time and money, adhering to rules, and placing themselves and others at risk through heedlessness. Statutory support is generally needed in respect of finances and healthcare.

Even where affected adolescents attain a school leaving qualification, difficulties arise at the latest during vocational training, where the scope for assistance by parents and teachers is no longer available, placing a heavy burden both on the young adults with FAS and their initially well-meaning instructors. Failure and broken-off training may result.

An institutional living and working environment provides adults with FAS with a predictable and thus fear-reducing setting in which they can show their capabilities and skills.

Everyday assistance

General

Children and adolescents react very emotionally to assigned tasks – not because they are unwilling or lazy, but because they themselves feel they are unable to do what is asked of them. Once an over-demanding situation is brought to an end and tasks are assigned to fit their ability level, the children liven up and become calmer and easier to deal with. Children and adolescents with FAS need very clear structures and simple instructions on how to behave. A prescribed structure to the day with ritualised activities of daily living, a steady pattern and regular control should be ensured on a lasting basis without spontaneous change. Children and adolescents with FAS find this very helpful and it leads to improvements in social behaviour. In such an environment, they feel themselves secure and protected from demands they cannot cope with. In most cases, prescribed structures and instruction remain necessary through adolescence and young adulthood.

Provocations

Those around children with FAS often perceive the behaviours they show as a form of provocation. They 'provoke' with noises and tics, they are unable to sit still and succumb to the smallest of distractions, or else they cease to perform tasks they have previously carried out without difficulty. Parents of children with FAS are likely to be able to name a host of 'provocations' they face from day to day. Here again it is important to understand that children with FAS do not deliberately aim to provoke people around them. Such behaviours are attributable to the alcohol damage, not to wanton misconduct. Undesirable behaviour should lead to clear consequences to give the child guidance. The child is not able to judge for itself whether its conduct is right or wrong, and therefore needs outside feedback on its behaviour.

Lying and stealing

Due to cognitive impairments, children and adolescents with FAS do not understand things that have happened or they have experienced, and forget chains of events. On asking, memory gaps are readily filled with invented tales. The children often believe such tales themselves. Simply enquiring whether it is true or thought up can halt the child mid-tale and prompt it to think.

Children and adolescents with FAS find it hard to tell between ‘yours’ and ‘mine’. They are often unthinking when it comes to their own property and tend to do things like giving away or forgetting their toys. They also take items from others without thinking it wrong. Here, support and oversight by caregivers is key. At the same time, it is important for the child or adolescent not just to be pulled up for taking an item, but to be clearly told that it belongs to someone else. Likewise, it should be explained how it feels to have something taken away. It is helpful to have simple, fixed rules when it comes to dealing with others’ property. The child’s own things can all be marked in the same way, for example. Items of value around the home should always be kept where the child or adolescent cannot get at them.

Anger and aggressive behaviour

FAS sufferers do not deal well with frustrations and situations where they are over-challenged. They often have aggressive outbursts. Such outbursts can be stemmed by avoiding over-challenging situations day to day, explaining time and again how things are done, and setting rules. In acute situations, it can be helpful to have a calm room – not for use as a punishment, but as somewhere to come down by cutting out overpowering outside stimuli.

Promoting strengths

People with FAS often feel ‘inadequate’. They see for themselves that they are unable to do what is asked of them, that they forget assigned tasks, and that those around them react to their behaviour with irritation. In some areas, on the other hand, children and adolescents with FAS are gifted. They may be talented in music or in sports, for example. Many children with FAS are responsible and caring with animals. Parents and teachers should work patiently to uncover and promote such abilities.

At school

Placed in ordinary schooling, affected children often find themselves constantly over-challenged. They develop anxieties because every day brings changing circumstances and new demands. They have problems at school despite normal or only slightly reduced intelligence. Individual instances or phases of good performance fail to reflect what FAS children ‘could achieve if they only exerted themselves’. Phases of good performance are just as much part of FAS as ‘bad’ phases. An FAS child who completed an exercise one day can be clueless faced with the same exercise the next. Aggression after being asked to do something or avoidance of homework are almost never proof of 'laziness' in a child with FAS, or of parental failure, but are sure signs of the child being over-challenged.

FAS children who do keep up in class tend not to come up to the social standards of their peers. They are taunted, taken advantage of and given the blame for pranks – at times without them noticing that they are being played with and without being able to dissociate themselves.

The choice of school should therefore not only be based on the child's 'school performance'. Many behavioural and social anomalies in the FAS child soon go away after switching from an over-demanding to an appropriate type of school. Special schools are reluctant to accept FAS children who do well in intelligence tests. As the children's problems relate to coping with everyday life and social dealings, a special school is nonetheless often the more appropriate choice. The change of school should be made before a child ceases to enjoy learning and 'switches off'.

In many cases, the desire to provide an FAS child with a calm learning environment can only really be satisfied at home. In the classroom, an FAS child should not sit at the back. FAS children cope better in small classes. The teacher should make a point of asking if the child has understood a set task or noted what has to be done for homework. It is not always possible to provide conditions of this kind. Specific assistance can be discussed, however, in direct consultation with the teacher.

ADHD therapies are not helpful with FAS. Even good training cannot prevent the performance ups and downs seen with FAS children. Many training elements are still useful, however: Children with FAS need to revisit the same subject matter more times than other children. Long explanations are less helpful than demonstrating the desired conduct and practising it with the child. Instructions should be clear and simple, and should always relate to one thing at a time. Likewise, tasks should be assigned one at a time – a second task only when the first is properly finished. Eye contact should be made while giving instructions. Explanations are sometimes better given in pictures rather than words. Support is sometimes necessary in starting a new or indeed a known task, as it is to remind the child of the task in hand.

In the workplace

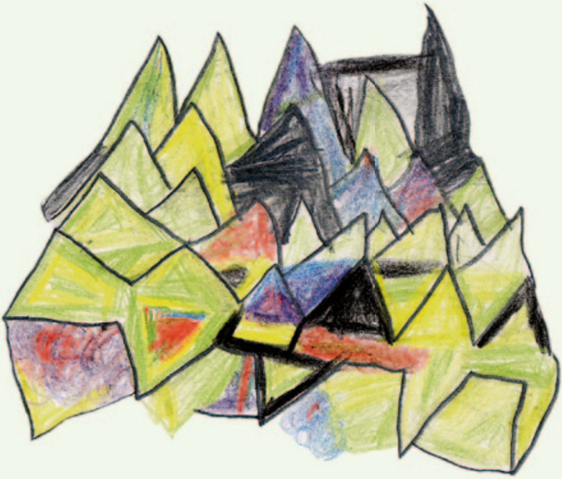
Adults with FAS very quickly come up against their limits in the workplace. Vocational training in the primary labour market in particular poses challenges that people with FAS perceive as highly stressful and over-demanding. This is because they are expected to work independently and master steps in a process; instructions are given only once and then taken as understood. These are all things that a person with FAS cannot do. The result is high drop-out and dismissal rates. Trainers, superiors and colleagues of people with FAS should be aware that they need wide-ranging assistance even in adulthood.

Adults with FAS are neither lazy nor lethargic. In many cases they are motivated and like to show what they can do. This can work if tasks are clearly and simply worded and instructions are explained and repeated several times. Support is needed with starting both new and known tasks.

Given clear structures and routines that give guidance, people with FAS are quite capable of being eager and willing. It may be necessary to provide for frequent breaks or to restrict the length of the working day. A suitable working environment is often found at sheltered workshops for people with mental disabilities and other forms of sheltered employment.

FAS and addiction

The prenatal alcohol exposure does not in itself heighten addiction risk for people with FAS. The fact that about 12 percent develop addiction problems has to do with adolescents and adults with FAS being open to stimulus and easily led. This calls for a watchful eye and early intervention from carers.



Therapy forms

Medication

Many parents are concerned that medication such as methylphenidate may alter the child's personality. In fact, medication generally allows FAS children to live out the personality they actually have, without the attention deficits and behavioural anomalies caused by FAS. Aggression and impulsive outbreaks can be significantly reduced with risperidone. Medication is often the only way to open the door to learning and to enable children to have friendship-based contact with peers.

Other forms of therapeutic assistances

The developmental impairments in children with FAS call for early support and in some cases therapeutic measures (such as early intervention, occupational therapy, and speech therapy). Children with FAS generally learn slowly and forget what has already been learned. Parents and professionals need to take that into account in their expectations regarding therapy outcomes. Psychotherapeutic and psychiatric measures should be behaviourally oriented with the main focus on the children's behaviour in everyday conflict situations. Children and adolescents with FAS are willing and cooperative in psychotherapy. They are mostly unable to keep promises, however, because they soon forget them or do not understand what is expected. Children or adolescents with FAS are consequently sometimes assumed to be therapy-resistant or to intentionally disappoint the therapist. Therapy is then broken off by the professional, adding yet another experience of personal failure and rejection for the child.

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Useful tips

Parents of children with FAS often face severe stress and strain. They need to think of their own welfare, keep space for themselves, and seek timely help to relieve the burden. Parents find initial understanding and support with others in the same situation, for example in FAS self-help groups.

Useful tips

Integration assistance (Eingliederungshilfe) for children and adolescents with or at risk of psychological disability

Children and adolescents in Germany are entitled to integration assistance from public youth welfare services on account of psychological disability if (1) there is a strong probability of their psychological health being at variance from what is typical for their age for longer than six months and (2) in consequence their ability to participate in society is or can be expected to be impaired (German Social Code Book VIII (SGB VIII), section 35a).

Integration assistance for children and adolescents with a physical or mental disability; integration assistance for adults

Anyone who as a result of a physical, psychological or mental disability is, or is at risk of being, significantly restricted in their ability to participate in society is entitled to integration assistance under the SGB (Book XII, section 53). This means that child and youth welfare services only have special responsibility for young people with a psychological disability. This can result in jurisdictional problems when it comes to FAS, because it is not always clear from the symptoms of FAS whether a disability is psychological or mental.

It is not up to applicants to clarify this, however. The problem is resolved by the jurisdiction rule in SGB XI, section 14. This states that if an agency receives an application for integration assistance, the agency must decide if it is responsible. If it considers itself not responsible, it must forward the application to the responsible agency within two weeks. The second agency must then provide the assistance, regardless of which agency is actually responsible.

Disabled person's pass

Children, adolescents and adults with FAS are entitled to a disabled person's pass if their disability goes beyond a certain level. The pass can be applied for by parents or legal guardians. The level of disability and the applicable categories are decided by the pensions office (Versorgungsamt). The categories that can be assigned in connection with FAS are B, G and H (relating to accompanied travel on public transport, parking exceptions, and tax concessions) (SGB IX, section 146).

Care categories

Many children, adolescents and adults with FAS are unable to carry out basic care activities without instruction and control. Basic care includes support with bodily care, eating and drinking, and mobility.

The assignment of a care category (Pflegestufe) makes it possible to provide assistance such as short-term care in institutional accommodation. Even if their level of care is below Category 1, children, adolescents and adolescents with FAS may still be given assistance for people with substantial general attendance needs (SGB XI, section 45a).

Appointment of legal guardianship for adults

Young adults with FAS are unable in many ways to take on responsibility for themselves and their lives. Many cannot handle money or live independently. Everyday activities are forgotten, or they neglect bodily care and their health. It can therefore be useful to apply for the appointment of a legal guardian beyond the age of 18. As the appointment of such a guardian should take place where possible in mutual agreement with the young adult, it helps to initiate such an arrangement early on with the adolescent FAS sufferer.

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Links

- **www.fetales-alkoholsyndrom.de**
  www.fasd-deutschland.de
  (including self-help groups)
- **www.bvkm.de**
  (with good leaflets on disability topics)
- **www.bbpflegekinder.de**
  (magazine on disabled foster children)
- **www.pfad-bv.de**
  (Bundesverband der Pflege und Adoptivfamilien e. V./Federal Association of Foster and Adoptive Families)

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