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Fetal Valproate Spectrum Disorder (FVSD)

A guide to understanding and helping people with FVSD.

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Who is this booklet for?

FVSD patients often require involvement from healthcare and other professionals. This booklet is designed for people with FVSD and their families. It may also be helpful for liaising with professionals about FVSD.

What is FVSD?

Fetal Valproate Spectrum Disorder (FVSD) describes a range of physical, sensory, learning, and social differences that can affect people who were exposed to the medication sodium valproate before birth. The type and level of differences vary from person to person and can be influenced by factors such as the amount of medication taken during pregnancy, the stage of pregnancy when exposure occurred, genetic background, and other health conditions. There is no single test for FVSD, so diagnosis involves detailed assessments by specialist healthcare professionals and may include checks to rule out other conditions with similar features. People with FVSD have individual strengths and support needs, which are identified through assessment, and care and support should always be tailored to the person.

How is FVSD diagnosed?

A diagnosis of FVSD is often made by a team of specialist health care professionals working together. One example of this is the Fetal Exposure to Medicines Service (FEMS). This team includes clinical geneticists, neuropsychologists, physiotherapists, occupational therapists, and speech and language therapists.

Overview of FVSD

Below is a list of the most common features of FVSD. Not everyone with FVSD will have all these features, and the level of impact can vary from person to person. Some people may also experience fewer common features.

Physical health

- May be born with physical differences which may or may not be obvious.
- Differently shaped fingers or toes, weak hand muscles.
- Visual problems (e.g. squint).
- Hearing differences.
- Reduced strength and speed.
- Challenges with coordination and balance.

Mental health

- Social and general anxiety.
- Low mood and energy.
- Differences in regulating emotions.

Sensory processing

Some individuals may have a heightened sensitivity to noise, movement or touch. Some may be slower to notice signals from their environment and from their body such as:

- hunger,
- pain,
- emotions,
- the need to use the toilet.

Some may have a heightened sensitivity e.g. to noise, movement or touch and become easily overwhelmed.

Language

- Early speech, language and communication needs.
- Differences in understanding and using spoken language.
- Often diagnosed with a language disorder.

Social skills

May be diagnosed with autism and may need support with:

- making and managing friendships,
- recognising and expressing feelings,
- being in busy or crowded places,

May present with differences in social communication without having an autism diagnosis.

Thinking (cognitive) skills

May need support with:

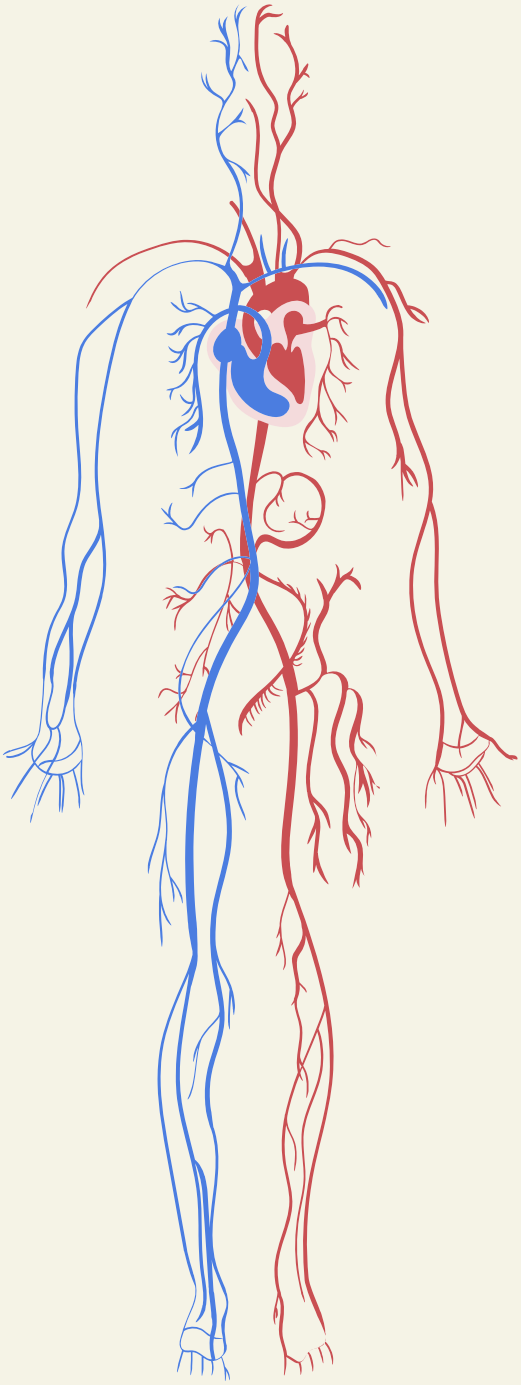
- paying attention, understanding and retaining new information.
- executive functions such as getting started and finishing tasks, being organised, and planning.

Health and skills

Physical health - more information

Common physical features of FVSD

- Physical differences which may be noticed at birth (birth defect) or later in life.
- Facial features that are different to the family.
- Differences in the shape, size and strength of hands and fingers. This can impact on activities of daily living.
- Frequent ear infections which can affect hearing.
- Need glasses or have a squint.
- Experience teeth abnormalities and problems such as poor enamel quality, missing teeth and teeth in the wrong place.



Differences with muscle strength and coordination can vary but often include:

- Reduced postural tone (tone is the natural resting tension in muscles) and reduced strength in hips, shoulders and trunk. This can make it difficult maintaining an upright sitting or standing position and completing movements more tiring.
- Altered range of movement including loose (lax) joints in the fingers, elbows and knees.
- Ankle tightness.
- Curved upper spine (kyphosis).

The combination of looseness and tightness in different joints along with postural changes can lead to:

- Pain, muscle aches and discomfort
- Challenges with activites or movements such as walking, running, climbing and balance.
- Poor ‘proprioception’ (the body’s sense of where it is positioned). This can lead to clumsiness and balance issues.
- Issues with coordinating both sides of the body together (bilateral coordination).
- Reduced balance, strength and speed.
- Feeling physically tired (fatigued) when completing normal amounts of activities.

Physical health - continued

Things that may help:

These physical challenges can impact on everyday activities. Some of the things which may help can include:

- Maintaining physical health through activity and exercise is encouraged within a person's abilities and interests.
- Small aids e.g. pencil grips, laptop/tablet, jar opener, non-slip matting.
- Allowing extra time for tasks.
- New tasks may take longer to learn. Support and practice may be needed to break tasks down into small parts.
- Support with planning the day, prioritising the most important activities and balancing this with time to rest, calm and reset.
- Care should be taken to match the physical requirement of a task/job to the abilities of the person. Support may be required for physical activities which require bilateral co-ordination and high-level balance activities.

It can be helpful to pace activity throughout the day, for example:

- Regular short breaks particularly when completing tasks that require long periods of sitting, standing or being physically active.
- Adaptations for a task to be completed in an alternative position.
- Limiting the distance that needs to be walked and use of stairs.
- Making others aware of difficulties.

Mental health – more information

Common mental health features of FVSD

- Increased risk of feeling anxious. This can frequently be related to social situations, or more general in nature.
- Low mood.
- Differences in regulating emotional responses, for example becoming frustrated and angry very easily or quickly.

Things that may help:

- A referral to a mental health team should be considered when emotional health symptoms are impacting on daily life. Referrals to occupational health programmes may also be helpful. It is important that the persons cognitive and language abilities have been formally assessed and are considered when selecting the appropriate mental health approach.

Sensory processing – more information

Common sensory processing features of FVSD

- Being slower to notice internal signals such as hunger, pain, temperature, emotions or needing the toilet.
- Being slower to notice the sensory signals from the environment, meaning that people with FVSD may struggle to respond in the best way.
- Being hyper-sensitive to specific sensations such as noise, movement or touch. This can mean that people with FVSD may over-respond or may avoid specific situations, activities or environments.

Things that may help:

- Pre-planned toilet and meal breaks, prompts to drink water, and using timers or alerts on a phone. Extra time and prompts to notice what their body is telling them may also be helpful.
- Use of calming and alerting sensory strategies and incorporating them within daily routines (e.g. fidget toys and access to quiet rooms).
- Using noise cancelling headphones when out and about or where trigger/background noise is likely.

Language skills – more information

Common language skill features of FVSD

- May have speech, language and communication needs and a referral to speech and language therapy may be needed.
- Language skills can continue to develop as children with FVSD grow older but differences with understanding and using spoken language may always be present to some degree.
- A diagnosis of language disorder is more common for people with FVSD.

Things that may help:

- A preschool referral to speech and language therapy if support is required for speech, language and communication needs.
- To break down spoken instructions into shorter chunks.
- Repeat instructions and explanations.
- Provide visual support for spoken language e.g. demonstration, pictures, gestures, written key words.
- Allow additional time for responses.

Social skills - more information

Common social skill features of FVSD

People with FVSD are more likely to be diagnosed with an autism spectrum condition or having autistic features. They may show differences in the way they interact with other people. For example, they may need help with the following:

- Making and managing friendships.
- Recognising and expressing their feelings.
- Find it difficult to be in busy or crowded places.
- Literal understanding of what other people say.

Things that may help:

- If social difference is suspected, a referral to local autism pathway can be discussed with the GP.
- Support to develop and maintain friendships. For example, provide opportunities to build relationships with peers by taking part in shared interest activities e.g. sports, clubs etc.
- Education for others to understand and accept differences in social interaction e.g. eye contact may be uncomfortable and should not be requested.
- Building a relationship with a specific trusted person in education/ work setting. Accessing support from that person when social interaction and/or sensory demands feel overwhelming.

Thinking (cognitive) skills - more information

Cognitive development can be delayed and whilst children with FVSD continue to develop and learn new skills, they often function below age-expected levels. In some cases, they may require support to live as independent adults. It is important that formal assessments are carried out and that difficulties are not assumed to be due to autism or another co-exiting diagnosis.

Common features with thinking skills

- Attention span can be lower.
- Processing of information can be slower.
- The amount of information which can be held in mind (i.e. verbal instructions) is lower.
- Understanding and remembering new information can be more challenging.
- Differences with executive functions such as:
  - getting started on and finishing tasks,
  - being organised,
  - acting impulsively,
  - multi-tasking and planning.

Things that may help:

- Support with planning and undertaking everyday tasks.
- Allow more time for thinking tasks to allow for slower processing and tiredness.

Things that may help in an education and workplace setting:

A neuropsychological assessment is recommended for children before starting school, and again at the end of primary school. This is done by a neuropsychologist or educational psychologist and can be organised via school or GP.

- Extra support from teaching staff or colleagues to map out strengths and to identify what extra help is required.
- For new learning, it can be helpful to repeat information and/or instructions. It may also help to repeat information and revisiting previously learnt topics.
- Reduction is the number of subjects, to provide more time to focus on fewer subjects.
- Instructions should be written down in clear steps e.g. flowcharts, and visual demonstrations given where possible.
- More time to complete tasks.
- Movement breaks.

continued...

Things that may help in an education and workplace setting:

- Support to maintain attention and reduce sensory challenges e.g. a quiet working environment and regular breaks.
- In an education or work environment, teachers and employers should be aware that people with FVSD can feel overwhelmed quickly and that this can show as anxiety or distress. Having a plan of how to deal with feelings of overwhelm should be in place. For example, a nominated person to talk to or a calm space to visit.
- A review may be required for an education and health care plan. For the workplace a referral to occupational health may be helpful to review what adaptations are available.
- Flexibility with work schedules or timetables is important to allow time for hospital appointments. Because FVSD can be complex, people living with FVSD may need to attend regular appointments throughout the year to manage their care.
- Ensure reasonable adjustments are provided in line with the Equality Act 2010 to support the individual in the workplace.

Further support and information

The leaflet has been produced as part of the Fetal Exposure to Medicines Service pilot which was funded by NHS England to develop clinical pathways for those affected by their in-utero exposure to valproate in the North of England. More information about the service can be found:

Manchester University NHS Foundation Trust & Newcastle Upon Tyne Hospitals NHS Foundation Trust

Epilepsy Action: Charity offering support, advice and training
https://www.epilepsy.org.uk/

Epilepsy Society: Charity offering advocacy, research and care
https://epilepsysociety.org.uk/

First Do No Harm Report: The Report of the Independent Medicines and Medical Devices Safety Review. Cumberlege J. London, England, Crown Copyright.
https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf

INFACT: Independent Fetal Anti Convulsant Trust
https://infactuk.com/home/

Kooth: A judgement-free forum to get advice, help others and share your story
https://www.kooth.com/

Mind: Mental Health Charity
https://www.mind.org.uk/

National Autistic Society
https://www.autism.org.uk/

OACS – Organisation for Anti-Convulsant Syndrome
https://www.oacscharity.org/

Speech and Language UK: Children's Communication Charity
https://speechandlanguage.org.uk

Stamma: The largest UK charity representing people who stammer
https://stamma.org

UK Teratology Information Service (UKTIS) Monograph https://uktis.org/monographs/use-of-sodium-valproate-in-pregnancy/

YoungMinds: a mental health charity for children, young people and their parents
https://www.youngminds.org.uk/

FVSD affects each person differently. We have included space on **page 16** for you to add information about how FVSD affects you. If you find this helpful you may want to consider using the 'My Health and Care Passport which is available at:
https://www.england.nhs.uk/wp-content/uploads/2024/06/PRN00983iv-health-and-care-passport-template.docx

If you have any queries about FVSD after reading this leaflet please contact your GP.

Common questions

What is Fetal Valproate Spectrum Disorder (FVSD)?

Some medicines when taken by pregnant women, can cause a recognisable features in the baby. These may be noticeable at birth, or only later, and may lead to difficulties through life. FVSD describes the range of physical, sensory, social and cognitive difficulties that someone may have if exposed to the medication sodium valproate in the womb.

How can FVSD affect a person?

We are still learning about the full range of difficulties associated with FVSD. The most common features are outlined in this leaflet. The effects and the combination of symptoms experienced can vary from person to person. How a person is affected will depend on the dose and timing of sodium valproate exposure during pregnancy, their genetic makeup, and other factors such as co-existing medical conditions.

Will it happen again if I have more children?

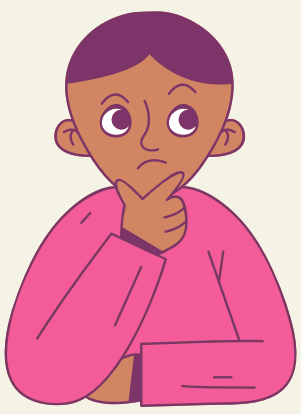
FVSD occurs when medicines containing sodium valproate are taken during pregnancy. If you are a woman taking sodium valproate, it is important to discuss switching to another anti-seizure medicine with your prescribing doctor. **It is important that you do not to stop taking valproate before you have spoken to your doctor.**

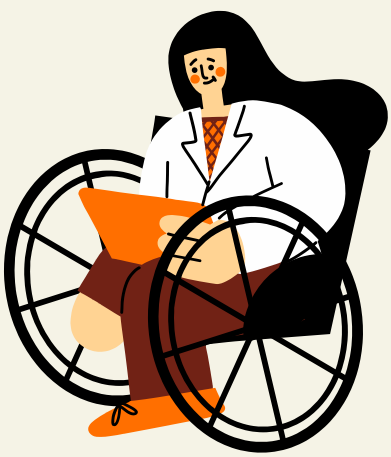
If I have FVSD, will I pass it on to my children?

It is not currently fully understood whether FVSD can be passed on by those who have the condition to their own children.

If I have a genetic condition does that mean I don't have FVSD?

It is possible to have a genetic or other diagnosis as well as FVSD.





My FVSD journey

This page has important, personalised information about me including how to communicate with me.

I like to be called ...

How FVSD affects me ...

Things that I am good at ...

Things that make me sad ...

Things that I find hard...

What I need from you ...

Date completed: _____