



Condition Insight Report (CIR)

Fetal Valproate Spectrum Disorder (FVSD)

Version 1.3

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Created in collaboration with INFACT

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Overview

What is the condition usually called / any abbreviations used?

Fetal Valproate Spectrum Disorder (FVSD) otherwise known as Fetal Anti-Convulsant Syndrome (FACS) and Fetal Valproate syndrome (FVS)

Brief overview of the condition

FVSD occurs when a developing foetus is exposed to valproic acid. This usually occurs when a mother uses anti-convulsant medication, also known as Anti-Epileptic Drugs, or AEDs (for example Epilim). However AEDs are not only used to treat epilepsy but are also used to treat pain, migraines, bipolar disorder and other mental health conditions.

On average, 40% of children exposed to this medicine are affected and it's possible that many more have been affected and not diagnosed. Many women were not told about the risks prior to conception until 2014. Women of childbearing age may no longer take the medicine without signing a risk acknowledgement form with their doctors.

What is the generally preferred term for someone with this condition?

A person living with fetal valproate/fetal anti-convulsant syndrome.

Presenting Symptoms

Symptoms will vary but may include:

- **Physical birth defects** such as overlapping fingers and toes, club foot, hip dislocation, cleft lip and/or cleft palate, characteristic facial features, malformation of vital organs, genital abnormalities, skeletal abnormalities such as scoliosis
- **Characteristic facial features** can include: high, broad forehead; skin of the upper eyelid covering the inner corner of the eye (epicanthal folds); thin, arched, wide-spaced eyebrows; a small, upturned nose with a wide bridge; a long, shallow midline groove between upper lip and nose (philtrum); and a thick lower lip
- **Myopia**- A condition in which one can see near objects but cannot see far objects clearly
- **Hearing restrictions**
- **Spina Bifida**
- **Congenital heart defects**
- **Breathing difficulties** which can include asthma.
- **Hypermobility**
- **Developmental conditions** such as Attention deficit disorder, learning disability/difficulty, behavioural problems, autism spectrum disorder, dyslexia and dyscalculia.
- **Speech and Language problems** such as mutism.
- Associated mental health conditions such as **anxiety and depression**
- Associated neurological conditions such as **epilepsy/seizures**.

Prognosis/Review Period

FVSD is a lifelong condition. People who have FVSD may have an intellectual disability (or learning disability). Some health conditions are more common in people who have FVSD resulting in health related and physical challenges. Many people with FVSD receive help and support to enable them to live as independently as possible. They will always need continual help and support over their lifetime.

An award review period should be given based on the claimant's prognosis and likelihood of change in function. Long term review periods (6-8 years) can be considered in some younger claimants with FVSD as their functional restriction may change due to maturity and educational opportunities. However, there will also be situations where a shorter- term review period is also appropriate. Once the person has reached the age of maturity their functional restrictions are less likely to change significantly and may increase with age. No review may be given in cases where there is no likely change to functional impairment.

Fluctuations

Due to the extensive range of presenting symptoms an individual living with FVSD might experience it is critical to explore any changes in symptoms with them. This will support your understanding of whether there is variance from one day to the next in their presentation, and if this will affect reliability and/or your understanding of what the majority of days looks like for them.

Think about exploring things like:

- **How has their presentation been over the past 12 months?**
What changes, if any, have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previously?
- **What is the extent of any hearing loss?**
Do they wear aids and if so how effective are they in all environments?
- **Changes in treatment** or discussed future treatment, if any, or if not why and brief historic input. For any upcoming treatment what is the expected outcome?
- **For any breathing restrictions**, what is the difference between symptoms at rest and what occurs during exertion? What level of exertion causes a change, recovery period and impact this has?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY 

Do they have any symptoms which could cause a safety consideration?

Depending on the reported impact of the FVSD, where it is appropriate, cover how risks are mitigated and if there is a history of incidents within activities 1, 2, 3, 4, 5, 9, 11 and 12 to ensure you have addressed the needs of the individual claimant.

Safety considerations can arise as a result of physical and psychological symptoms.

TIMELY 

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Pain, fatigue, spasms/ stiffness, distractions, confusion, oppositional behaviour can all affect time frames of how long it takes an individual to complete a task.

This will vary for each individual, but there are no specific time frames outlined for what is reasonable.

Ensure to ask:

- How long it takes to complete tasks such as 1,4,5,6 and 12.
- Why they feel it takes them this long?
- Where they report having any breaks in task, how long are these breaks and how frequent?

ACCCEPTABLE 
STANDARD

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

How they have adapted to any birth complications will be their 'normal'. This may mean they do not raise these during superficial questioning.

Exploring **HOW** they complete each task in depth to help draw out any compensation strategies which can then be explored further.

REPEATEDLY 

Are they able to repeat a task as often as required? Is this the same every day?

The birth abnormalities that can occur as a result of FVSD must also be properly explored, but be mindful to be sensitive how you explore it. People with FVSD may have good/bad days. How they are on any given day is not how they might be all the time. You need to try and establish what is the majority of days for them and how they feel before, during and after an activity where appropriate.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

- Individuals may struggle to identify their restrictions as a result of FVSD as this will rely on supportive medical input and correct diagnosis
- Individuals may not want to discuss their own disability openly for fear of being prejudiced against
- The type and regularity of assistance that is provided/relied upon coming from any family or friends. The extent to which this informal care is relied on is often not recognised
- The impact of any internal damage that is not apparent to the assessor
- Mothers of the individuals have a hidden neurological condition which led to consumption of the medication
- Many individuals with learning disabilities want to be like everyone else so may minimise their restrictions

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?



In general

- **Do not stare**
- **Avoid the term *victim*.** If you need to refer to the condition, ask them what they prefer
- Remember they have lived with their condition since birth instead of discussing restrictions consider avoiding this term and instead being general with what they need support with and how they complete tasks
- Be sympathetic to the restrictions of not only the individual but also the mother, especially if supporting them and appreciate it may be a very difficult topic to address
- Ensure any **companion is made to feel welcome** and allowed to contribute to the assessment. The parent can in some cases be the best advocate for their child, support them to contribute
- **The parent may want to speak to you away from their child's ears, you must have consent from the claimant for this, unless the parent is appointee**
- **Give the person time and wait for their response.** Some people with FVSD have processing difficulties – so try to put them at ease, and don't pressure them to answer immediately
- Make your **questions as clear as possible**, and be prepared to repeat a question if necessary. Also consider asking the question in a different way



Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Developmental delay, birth defects, breathing difficulties and associated mental health conditions could all impact the motivation and cognitive ability alongside the physical ability to stand, prepare fresh ingredients and sufficiently cook items.

Remember in PIP...

Can someone prepare a meal reliably?
Someone's physical ability to complete an activity is not the only area to be considered here. If there is evidence of cognitive deficit, are they safe cooking? Can they tell if food is cooked? Are they safe around knives and flames? Furthermore, if there is a lack of motivation, do they require prompting to cook? Are they cooking the majority of days? Do they require support or supervision? If there are issues with motor skills, can they safely cut food or hold pans? Do they require physical assistance?

Activity 2: Taking nutrition

Developmental delay can impair an individual's ability to cognitively understand or complete the activity, birth defects may impair swallowing and cause higher risk of aspiration and associated mental health conditions could all impact the motivation to complete the task.

Remember in PIP...

You need to have established the individual's ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources. Are they at risk of choking? Do they require soft or blended food? If there is weight loss secondary to their condition, do they require prompting to eat regularly? Is this prompting throughout the duration of the meal?

Activity 3: Managing therapy and monitoring a health condition

Many of those living with FVSD will have treatment which they may or may not need support with. This could include physiotherapy, occupational therapy, speech and language therapy, talking therapy and/or medications.

Remember in PIP...

If someone lacks insight, you must establish how they are managing their treatment. Do they require prompting or support to administer their medication? Do they have poor compliance?
Furthermore, if they receive therapy in the home environment, do they require assistance with this? How long does this assistance take?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

Developmental delay can impair an individual's ability to cognitively understand or complete the activity, birth defects may impair physical ability to complete the task and cause higher risk of falls and associated mental health conditions could all impact the motivation to complete the task.

Remember in PIP...

You must not only consider physical ability to complete the activity, but also recognition of the requirement to wash and motivation. Do they require prompting to wash regularly? In the absence of prompting, how often would they wash? If they have a physical restriction, how are they managing to wash their entire body? Can they physically get in and out of an unadapted bath? How long can they stand for? Do they require assistance to wash their body? If so, is this their entire body? How long would it take them to wash unassisted? Would this be acceptable when considering the extent of their symptoms?

Activity 5: Managing toileting needs and incontinence

Developmental delay can impair an individual's ability to cognitively understand or complete the activity, causing higher risk of infections, birth defects may impair physical ability to complete the task and cause higher risk of falls.

Remember in PIP...

You must explore not only someone's ability to get on and off the toilet, but also to reliably clean themselves. This will be a sensitive area to explore, so should be probed delicately. Can they reliably clean themselves after going to the toilet? If they have aids, can they reliably use them or do they require assistance? If they report incontinence, can they self manage? Is this of both bladder and bowel?

Activity 6: Dressing and undressing

Developmental delay can impair an individual's ability to cognitively understand or complete the activity, birth defects may impair physical ability to complete the task and associated mental health conditions could all impact the motivation to complete the task.

Remember in PIP...

How do they manage to dress themselves? Are they capable of selecting appropriate clothing? Do they require prompting to do this? If they can dress, how long does it take? Can they manage fastenings, buttons and laces? How do they feel after? Do they require assistance or use any aids to dress?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

Physical birth defects and other complications can cause restrictions with communication, either their ability to clearly express themselves or to understand others.

Remember in PIP...

The scope of the activity is to be able to both express **and** understand. It is not enough that someone can hear what another person is saying. Can they process it and respond appropriately and in a timely manner? How do they manage with communicating with others? Do they require support to do so?

Activity 8: Reading and understanding signs and symbols

Developmental delay can restrict the ability to read and understand signs and symbols.

Remember in PIP...

Simply being able to read information is not adequate to manage this activity. The information someone is reading must be **understood**. What level of information can they understand? Although retention of information is not considered, it is clinically reasonable that someone will have difficulties processing, and this should absolutely be explored during the assessment.

Activity 9: Engaging with others face to face

Associated mental health conditions such as anxiety or developmental conditions such as Autism will affect the ability to engage with others and form relationships.

Remember in PIP...

If there are cognitive changes reported, you must explore their ability to safely engage with others. Are they vulnerable? Are they at risk when engaging? Do they require support? If they have anxiety, who can they engage with regularly? How do they manage engaging with unfamiliar people? Do they require support from a specific individual to do so? **REMEMBER: Just because someone reports they can mix with others, this does not mean they are doing so safely.**

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

High levels of depression may mean that some make unwise decisions. Some may rely on support from family members, friends or others to manage their money, plan a budget and make financial decisions due to developmental delay or other factors.

Remember in PIP...

If someone has a cognitive deficit it may be that they are unable to prioritise finances. Could they reliably manage a household budget? Do they require support? How would they cope with an unexpected bill? Can they manage future financial planning? Also, could they understand change expected in a shop?

Lack of motivation and anxiety alongside impulsivity must also be considered here.

Activity 11: Planning and following a journey

Very high levels of anxiety can be present and as a result some may not go out alone. Developmental delay can cause restrictions with safety going out, difficulties planning and following journeys, dealing with change and safely using public transport.

Remember in PIP...

You must explore safety in this activity. If someone is completing journeys, are they safe? Do they have road safety? Are they impulsive around cars? Also could they maintain concentration when out of the home? Are they vulnerable? Could they manage a diversion or plan and follow a new route? How would they cope on public transport? What would they do if they got lost? Have there been any incidents when out of the home? If they report anxiety, does this meet the threshold of OPD? If so, how often can they go out with support? Do they need support on all journeys?

Activity 12: Moving around

Physical birth defects may affect balance and the individuals ability to move around safely.

Remember in PIP...

Firstly, establish when someone is walking, do they require an aid? If so, what aid? Was this prescribed or self purchased? How often are they having falls? How do they manage this?

What is their gait?

How far can they walk and how long does this take? How does walking make them feel?

Does breathlessness/fatigue increase each time they walk? When they walk a second time, does pace reduce or distance reduce? If they experience fatigue, how do they feel later in the day? How many times could they repeat the distance they walk? How long does it take to recover from mobilising?

Lived examples are also extremely beneficial. How do they manage up and down the stairs? How do they manage with chores? How do they manage their shopping? How many aisles can they walk and how long does it take? If they go to their GP surgery or hospital, how far is it from the car? How long does it take them to get to the required department and how far is this?

Additional reading or other resources

EXTERNAL

- <https://www.oacscharity.org/about-fetal-anti-convulsant-syndromes#!>
- <https://rarediseases.org/rare-diseases/fetal-valproate-syndrome/>
- www.infactuk.com
- <https://www.facebook.com/FetalValproateSyndrome>
- www.pharmaconsent.org

INTERNAL

- Desktop Aid – CSE, MSE, Activity 12, Activity 6, Learning Disability, Autism, Breathlessness

Version control

Version	Date	Signed off by	Comments
1.0	21.05.20	Dr Shah Faisal	New re-banded document
1.1	23.06.20	Rebecca Noble	Disclaimer inclusions Inclusion of infactuk web link
1.2	14.03.23	Rebecca Sparks	2 yearly review and changes to 12 PIP activities.
1.3	07.02.2024	Jade Mayfield, DWP and INFACT	Addition of review period section and changes to presenting symptoms.

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