

Condition Insight Report (CIR)

MESH

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Overview

What is the condition usually called / any abbreviations used?

The diagnosis given can depend on the Consultant/ Doctor investigations and knowledge, however many are labelled with “mesh injury” or “pelvic pain”.

Many GP’s are not fully informed about the complications, or do not realise a mesh implant is the cause of the presenting complaint so finding support and treatment can be difficult for those living with it. **This also means medical evidence is likely to be limited.**

Brief overview of the condition

Polypropylene Mesh implants are medical devices used by surgeons to treat herniated tissue where there is a gap in the abdominal wall that cannot be stitched together due to loss of tissues so Mesh is used. Predominantly used to treat inguinal abdominal hernias and, in women things such as pelvic organ prolapse and incontinence, that can commonly occur after childbirth.

After years of use it was found that this can have "life-changing side effects" to those who were implanted. Many have sought specialists to support removal of the mesh but studies have found, even after removal many continue to have the same symptoms.

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

A person living with Mesh Injury / Mesh Complications.

Presenting Symptoms

Each individual will experience symptoms differently and severity will depend on the site and extent of the Mesh implant. Common symptoms can include, but are not limited to:

- Severe **pain** (in areas like vagina and lower abdominal) which can radiate to other areas of the body
- **Reduced mobility** as a result of pain and the impact it has on neighbouring muscles, nerves and ligaments
- **Fatigue** is common due to the draining effects of living with the pain and limiting effects it can cause
- **Nausea**
- Memory problems can be a result of the disabling effects of the pain and fatigue or medication
- Sleep disorders
- **Anxiety**
- **Incontinence**
- Nerve damage
- **Oedema** which can occur in the legs and inflammation/swelling to affected muscle groups
- Peripheral Neuropathy
- Recurrent and chronic infections including of urinary tract
- **Depression** including thought of suicide

Mesh is not “inert”, it can harden, contract, attach to muscles, nerves or other parts of the body. It can cause bleeding where it can cut into neighbouring muscles. Over time it can also degrade and migrate to other parts of the body. As it is a plastic it can release toxins which have been linked to **autoimmune disorders** such as Sjogren's syndrome, Lupus, Reynaud's and others.

It frequently causes organ perforation, tissue erosion and fistulae which can require multiple surgeries to reduce neuromuscular problems. If nerves have been damaged during surgery and the effects have not gotten better after 6 months-one year then the likelihood is that the nerve damage will be permanent.

Medications can have an impact on:

- Reduced concentration can be affected due to medication or problems with mood. This may only become evident after a period of time or post an activity.
- Cognition and ability to communicate effectively

For many this will not be their sole condition and they will also be dealing with other comorbid symptoms.

Fluctuations

Whilst there can be many fluctuations day to day, many of those living with mesh injury report that pain is constant affecting their mobility and also toileting.

Due to the nature of the condition and variable symptoms, this is **KEY** to explore.

Think about exploring things like:

- **How has the condition been over the past 12 months?**

What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?

Where **pain/fatigue** are reported:

- What level?
Can they quantify this, do they use a scale and can they describe it? What level of severity? Can they discuss this in this way over what might be a 'typical' day for them?
- Triggers?
Whilst exertion is a main trigger, what amount of exertion is enough to cause further limitation? How are triggers managed?

Where **regular infections/oedema** are reported:

- How often? How long do they last? How are they managed? Any therapy interventions including district nurse input during this time?

Reliability

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

S  **AFETY**

T  **IMELY**

A  **CCEPTABLE STANDARD**

R  **REPEATEDLY**

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

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?

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

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

Remember that safety should always be considered where appropriate if there are any symptoms which could cause an issue within activities 1, 2, 3, 4, 5, 9, 11 and 12.

Also consider any comorbid conditions and their impact.

E.g. Shooting pain can cause falls. Are there any incidents of this occurring if they experience this?

Pain, fatigue and other symptoms can affect how long it takes them to complete an activity. 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?

Due to the symptoms those living with mesh injury can experience they have to adapt in many ways to complete everyday tasks. This will be their new 'normal'.

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

Remember some individuals will not find it easy to volunteer this information. Ask for specifics.

For a lot of mesh injured people a good day is one where you can get out of bed.

Being able to repeat tasks can be very variable. Whilst an individual may be able to give you an example of how they complete an activity you need to know how often they could complete it in this way. How do they feel before, during and after a task?

How do they manage this?

Sensitivities

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

Many mesh injured people suffer from incontinence and its effects can be devastating. Their lives can revolve around the toilet which can be difficult to talk about, especially with strangers.

Due to the disabling effect mesh injury can cause many are depressed and find it challenging to look and be their best. For many “putting on a brave face” becomes a way of life. Please be mindful that individuals are likely to make an effort for an assessment as being vulnerable in front of professionals is not easy for anyone. This effort made for any one-off appointment does not mean this is the norm for them, or that they are not suffering extreme pain etc.

Customer Care

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



In general

- Ask what they would like to be called during the session, it makes it feel more personal.
- Please be sensitive and show empathy, the effects of the condition are disabling enough without being made to feel they are trying to “con” anyone.
- Mesh injury has historically been poorly recognised by the medical professional so evidence can be difficult to come by and discussing the challenges of living with the condition and fighting for support can be difficult.
- Please allow them time to consider and answer questions as pain and fatigue can make it challenging to focus for prolonged periods of time.

During face to face interactions

- Do not judge someone by how they look on the outside. Even people with chronic disabilities/illnesses can make eye contact & be presentable; this doesn't mean they are well.
- Offer a break and/or opportunity to get up and move around if they need to.



Functional Impact

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

Activity 1: Preparing food

Depending on the type of Mesh implant there could be difficulties standing to prepare meals due to pins and needles, pain down the legs or into the back. Fatigue can make the task take much longer. Psychological mood changes can also reduce motivation to prepare and cook.

Remember in PIP...

The psychological and physical aspects of this activity need to be covered where both are affecting the individual. What type of activities they can do and how they mitigate any risks, whether they could repeat any tasks done more than once in a day and the extent of any support provided.

Activity 2: Taking nutrition

Motivation to eat due to nausea and depression can be affected for individuals with mesh injury.

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. Motivation should be covered where it is reported to impact this task. Consider what level of prompting is required, to complete the task or is being given food sufficient?

Activity 3: Managing therapy and monitoring a health condition

This will depend on the type of symptoms experienced as to whether there are any therapies or pain relief due to the medical support they have been able to get.

Remember in PIP...

Therapy input in a domestic setting, which covers majority of weeks and where they require supervision, assistance or prompting to complete should be explored and considered.

Ensure to explore how any medication is managed including compensation strategies like alarms to combat restrictions and any side effect management.

Functional Impact

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Activity 4: Washing and bathing

Many struggle to wash and bathe due to the pain and fatigue. It can take much longer to complete the task and many use aids in the bathroom or have support.

Remember in PIP...

Explore what management strategies are used to manage the effects of symptoms and consider whether aids would help or whether the action would still be unreliable due to one or more aspect of STAR. Remember to consider both physical and psychological affects here and provide advice for the most affecting aspect.

Activity 5: Managing toileting needs and incontinence

Some individuals suffer recurrent and/or chronic infections and need to wear incontinence pads to support their incontinence, others need to self catheterise.

Many make use of raised toilet seats, grab handles and easily accessible toilets.

Remember in PIP...

If the claimant is incontinent, how frequent is it and is this of one or both?
Can this be managed with pads independently or do they need assistance to maintain hygiene?
How do they transfer on/off?

Activity 6: Dressing and undressing

Many take a change of clothing when going out in case of incontinence and some require support to change due to extreme pain and fatigue. Movements can be harder to complete.

Remember in PIP...

Explore what management strategies are used to manage the effects of symptoms and consider whether aids would help or whether the action would still be unreliable due to one or more aspect of STAR. Remember sitting down is not considered an aid. When they are sat does this help or would they still need support and why is this. Ensure to probe for specific detail about how they complete the task.

Functional Impact

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Activity 7: Communicating verbally

Could be impaired on a cognitive level due to severe side effects of the medication or comorbid conditions.

Remember in PIP...

That there are specific boundaries for what is considered basic and complex. How their emotions impact on their ability to manage relationships and respond to individuals is likely to be managed in A9.

Activity 8: Reading and understanding signs and symbols

Can be impaired due to difficulties with cognition.

Remember in PIP...

There are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 9: Engaging with others face to face

Can be impaired if mood affected, i.e. depression, anxiety causing isolation.

Lack of intimacy which can be due to dyspareunia or complete loss of libido. Many relationships fail, even those of long term.

Remember in PIP...

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals.

Functional Impact

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

Activity 10: Budgeting

Can be affected due to cognitive or mood impairment.

Remember in PIP...

That there are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met, considering motivation to complete the task.

Activity 11: Planning and following a journey

Can be impacted due to cognitive effects of medication, anxiety around state of continence and other related anxiety.

Remember in PIP...

Where there is associated anxiety you must explore the 4 stages to a journey 1. Frequency and type of outings 2. before a journey 3. during a journey and 4. post a journey. Does it meet OPD threshold? Any social anxiety and/or anxiety related to change? If so to what extent, how and when does this manifest, how it is managed, is it present on all journeys or just unfamiliar ones? Are there any cognitive changes which could affect their ability to plan and follow a route? How would they plan a route to get to an appointment at a specific time?

Activity 12: Moving around

Many rely on Motability cars to get around due to reduced mobility. Due to pain, fatigue and side effects of medication. The implant itself or removal of can cause nerve, ligament and muscle restrictions which impair the ability to walk reliably.

Leg muscles become weak, which can cause loss of balance and falls, difficulty walking, spasms, tightness, hypersensitivity, numbness, stinging, burning, aching (on one or both sides).

Remember in PIP...

Individuals may struggle to provide specific information. Try to use examples to help or things in their area they might be able to refer to. You must explore whether any journey discussed is repeatable, where possible how long it takes them, how they feel whilst doing it, and any incidents of note such as falls in the past 12 months?

Additional reading or other resources

EXTERNAL

- <http://scottishmeshsurvivors.com/>
- <https://www.nice.org.uk/guidance/ipg599>
- <https://www.gov.uk/government/news/government-announces-strict-rules-for-the-use-of-vaginal-mesh>
- <https://www.immdsreview.org.uk/downloads/Evidence/FOR%20PUBLICATION%20Patient%20Groups%20-%20Pelvic%20Mesh.pdf>