Capita

Condition Insight Report (CIR)

MESH

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Overview

Mesh injury is a term used to describe the debilitating outcomes of the surgical implantation of surgical mesh (made of plastic based or organic materials, is net-like in appearance, ranging in size between 12-32cm in length and can include surface areas of 30cmx30cms) and subsequent interventions to remove the implant or parts of it.

Main underlying conditions associated with use of vaginal and surgical mesh:

- **Hernia** occurs when an internal part of the body pushes through a weakness in the muscle or surrounding tissue wall. Types of hernias are: incisional, ventral, umbilical, inguinal, femoral, hiatus, epigastric, spigelian, diaphragmatic and muscle. Not all forms of hernia may receive mesh surgery and therefore may not develop mesh injury. This will vary on the individual and treatment offered.
- **Stress urinary incontinence (SUI)** is the involuntary leakage of urine when the bladder is under pressure. SUI can be caused when the pelvic tissues, ligaments and muscles, which support the bladder and urethra, are weakened or damaged so that the sphincter that closes the urethra fails when under pressure, and urine leaks out. Its only symptom is leakage during activities accompanied by increased abdominal pressure, such as coughing, sneezing, lifting, laughing, or exercising.
- **Pelvic organ prolapse (POP)** describes a variety of conditions that occur when one or more pelvic organs drop out of their normal position, often pushing into the vagina, causing a bulge. The bladder can push into the front, or anterior, wall of the vagina causing a prolapse (a cystocele). The rectum can push into the back, or posterior, wall of the vagina causing a prolapse (a rectocele). The uterus, or if the woman has had a hysterectomy the vaginal vault, can prolapse downwards into the vagina. In more severe cases prolapses can protrude out of the vaginal opening. Recurrent prolapse can be common.

For women with POP or SUI during surgery, mesh can either be inserted through an incision in the vagina (transvaginal insertion) or through an incision in the abdomen (abdominal insertion), and in some cases may require multiple surgeries which incorporate both methods.

Related abbreviations or descriptors that may be used in relation to mesh injury discussions:

- Ventral mesh rectopexy (VMR)
- Retropubic/ transobturator sling or hammock
- Chronic Inflammatory Response (CIR)
- Chronic pelvic pain (CPP)
- Tension free Vaginal Tape (TVT)
- Sacrocolpopexy (SCP),
- Overactive bladder (OAB),
- Underactive bladder (UAB)
- Bladder repair
- Rectopexy,
- Sacrohysteropexy,
- Interstitial Cystitis (IC)
- UTI (urinary tract infection)

Onset of injury

The presentation of Mesh injury may result suddenly, gradually or years after the implanting surgery and can be associated with comorbidities.

Medical support

Many GP's are not fully informed about the complications, or may not realise a mesh implant is causing the presenting complaint so finding support and treatment, even at A&E can be difficult. This means medical evidence can be limited.

Testimony from individuals

- '*This device took everything from me my health my life my job my dignity my marriage my freedom. There are a lot of us suffering*.' – mesh affected female
- '*This is not a life. It is an existence. With potentially another 40 years ahead… this is a depressing prospect*.' – mesh affected female
- '*I live in daily chronic pain I get to the point that I have to either sit down or I am going to collapse. I've told my consultant that it feels like a knife or something sticking into the wound where he operated*.' – mesh affected male
- '*I've lost my right testy (testicle) due to mesh. I've had 5 surgeries. And it has caused more pain and scarring. Pain on ejaculation. I now suffer mirror pain upon my left testy (testicle) feel like weight is dangling off of that. Pain, no sex life, impotence. suicidal thoughts*.' – mesh affected male

Possible complications

Post mesh insertion there can be various possible complications, below represents a few but is not an exhaustive list:

- **Foreign body reaction** causes inflammation and slow healing. This can be acute (short term) or chronic (long term) and will vary in severity between individuals. For some their reactions can be very severe and cause them additional complications. Some individuals' bodies will reject the mesh.
- **Seroma formation**. A seroma is an area, post surgery, that can become filled with fluid, much like the fluid from a blister. This may or may not resolve itself naturally. This can lead to infection.
- **Increased risk of infection**. At times bacteria can grow at the site of the mesh, causing infection with its associated inflammation and pain. Transient bacteremia can lead to complications like sepsis, discitis and osteomyelitis. Many individuals may need long term antibiotics and pain medications.
- **Adhesions**. This happens when tissues stick to the mesh or other tissues. Adhesions are usually painless however when pain occurs there is a problem. Adhesions to mesh can require further surgery following severe pain and/or other complications.
- **Extrusion, migation or erosion of the mesh into surrounding organs**, including the vaginal wall, bladder or urethra, resulting in pain with movement and muscle weakness. It can also lead to damage to surrounding organs, nerves, ligaments, tissue and/or blood vessels
- **Chronic pain** which can be present in and around the mesh site or be referred pain. It can be a feeling of electric shocks, spasms and sciatica. The location of the pain will be specific to the individual and injury incurred.
- **Nerve damage**. Nerves may have been damaged during surgery, which can become permanent and in some cases can lead to complications like peripheral neuropathy.

Presenting Symptoms

Each individual will experience symptoms and the complications of surgery differently. Severity can depend on the site and extent of the Mesh implant.

As well as the possible complications listed to the left, there are additional symptoms/ complications which can be present despite removal surgery. The impact of the complications/symptoms can be life-altering and life-long from which there may be no recovery.
These will be specific to the individual and some symptoms may be more specific to specific types of causes for mesh insertion than others. Further symptoms include, but are not limited to:

- Inflammation at or near site of mesh
- Fatigue, which may result in loss of concentration
- Impaired movement/ mobility, which may include an inability to sit or stand or drive without pain
- Loss of appetite due to pain
- Dyspareunia (the medical term for pain during sexual intercourse) and/or apareunia (avoidance of sexual intercourse) resulting in mental health difficulties and loss of support mechanisms
- Difficulty with excreting (faecal and urinary)
  - Bowel issues can include fistula formation, offensive discharge, difficulty defaecating, constipation, in some cases colostomy and ileostomy surgery
  - Bladder issues which can include recurrent UTIs, stress and/or urge incontinence and can lead to requirement for catheterisation
- Offensive vaginal discharge
- Haemorrhage
- Bleeding at the site of the operation, such as vaginal bleeding and/or blood in urine
- Psychiatric impacts such as depression, suicidal thoughts, agoraphobia, PTSD, anxiety
- Oedema which can occur in the legs and inflammation/swelling to affected muscle group
- Reoccurrence of the hernia
- Men can experience erectile dysfunction
- Both sexes may experience a loss in libido and avoid intimacy

Medications can have an impact on cognition, ability to communicate effectively, and reduced concentration, or problems with mood, which may only become evident after a period of time or post an activity.

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?

SAFETY

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

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?

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 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?

ACCEPTABLE STANDARD

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

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.

REPEATEDLY

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

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?

People with mesh injury may be unable to fully articulate the cumulative impact of the many comorbidities due to lack of knowledge, modesty, shame, and/or depression.

Many will have not (fully) discussed their condition with their accompanying person.

Mesh injury relates to many taboo topics, such as toiletry habits, vaginal discharge, limiting food and liquid intake to leave the home, intermittent or constant pain related to the sexual organs and groin. People with mesh injury often report being socially isolated, and having lost relationships to people, their workplace, and their communities. Some may harbour a sense of hopelessness and suicidal thoughts.

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.

Some may have issues with fertility and experience resulting issues with intimacy. Talking about this and the full impact of their experience and effects of the surgery may be very difficult and emotional.

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
- Confirming that you have read this document with the individual will support them feeling more at ease
- 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

- Please make eye contact when asking questions
- Ensure that toilet facilities are nearby and accessible to claimants managing incontinence issues. Provide information about toilet facilities prior to commencing the interview
- Do not make judgments based on their appearance, or their socio-economic situation
- Please remember whilst they may have made effort for any one-off appointment, this does not mean this is the norm for them, or that they are not suffering pain and other symptoms
- Offer a break and/or opportunity to get up and move around if they need to, also the option to stand rather than sit
- Remember that asking them to complete the musculoskeletal tasks can exacerbate their condition

Functional Impact

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

Activity 1: Preparing food

Individuals may have difficulties to prepare and cook meals reliably, safely and without assistance due to chronic and/or erratic pain in pelvis/ leg/ back. There may also be some joint weakness. Chronic fatigue can make the task take much longer. Individuals may need prompting or assistance to prepare and cook meals due to associated mental health conditions.

Remember in PIP…

Can someone prepare and cook a simple meal for one? How long can they stand in the kitchen? Can they chop and peel vegetables? Can they lift pans? Does completing this activity increase pain or fatigue? How do they feel after the activity? How long does it take to recover? Do they lack motivation to cook? Do they require prompting or assistance?

Activity 2: Taking nutrition

Individuals may need prompting to eat due to nausea and depression.

Remember in PIP…

Can they chew, swallow and bring food to their mouth? Can they physically cut food? Do they have motivation to eat? Do they require prompting? If they do, is this throughout the duration of the meal?

Activity 3: Managing therapy and monitoring a health condition

Depending on the severity of the symptoms, individuals may need supervision, prompting or assistance to manage mesh injury treatments.

Some might have longer term dressing or wound management needs and have support to manage this.

Remember in PIP...

Therapy is only considered within the scope of the activity if received in the home environment. If they do have therapy at home, do they require assistance? If so, why and how long does this take? If they require assistance to change dressings, how often is this and how long does it take?

Regarding their medication, can they manage this themselves? Can they administer their own medication? Can they remember to take it and are they motivated?

Functional Impact

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

Activity 4: Washing and bathing

Individuals may use aids or appliances to be able to wash or bathe, some may need assistance to wash and get in or out of the shower/bath due to weakness in legs and pelvis and the risk of falling or slipping. Depression may require prompting to maintain regular washing and bathing.

Remember in PIP…

You must explore how someone is managing the activity. How do they get in and out of the bath? Do they have any aids? Can they wash their entire body? How long does it take and how do they feel after? Does this activity increase their symptoms? How long does it take to recover? Do they need assistance with upper or lower body? Are they motivated to wash regularly?

Activity 5: Managing toileting needs and incontinence

Individuals will usually have difficulties in managing toileting needs or incontinence. Many can have lack of bladder and/or bowel control. Individuals with bladder retention may need prompts to use the bathroom. Many individuals suffer recurrent and/or chronic infections, vaginal discharge and/or bleeding and need to wear incontinence pads to support this. Others need to self-catheterise, and/or use colonic irrigation. Some individuals are fitted with an Antegrade Continence Enema (ACE) which allows bowel washout at convenient times, or may live with stoma solutions (colostomy/urostomy/ileostomy). Many make use of raised toilet seats, grab handles and easily accessible toilets.

Remember in PIP…

You must explore how someone gets onto and off the toilet and how they clean themselves. Does doing this cause more pain? We do not consider ability to mobilise to the toilet. Also explore if someone has incontinence on majority of days and how they manage this. Do they require assistance? Can they manage with aids?

Activity 6: Dressing and undressing

Those with pelvic and/or lower limb pain and/or joint pain may require assistance to be able to dress or undress. Prompting may be required to encourage dressing for individuals suffering from depression and chronic fatigue who fail to select appropriate clothing and dress accordingly.

Remember in PIP…

You must explore someone's ability to dress and undress within the scope of STAR. How long does it take them? Can they dress upper and lower body? Does this increase symptoms of pain and/or fatigue? Do they require assistance or use any aids? Can they dress reliably whilst seated? Are they motivated to dress daily or change clothes?

Functional Impact

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

Activity 7: Communicating verbally

Those who are severely impacted by side effects of the medication, or have comorbid conditions may need communication support.

Remember in PIP...

Can someone express and understand both basic and complex verbal information? Who do they speak to? Can they use a mobile phone? Do they have any cognitive or sensory impairments that may impact their ability to complete this activity? Can they understand the information?

Activity 8: Reading and understanding signs and symbols

Can be impaired due to difficulties with cognition.

Remember in PIP…

Concentration is not considered within the scope of the activity. However, someone must be able to not only read complex written information, but also understand it. What can they read? What do they have difficulties with and why? How do they overcome this?

Activity 9: Engaging with others face to face

Individuals may have difficulty communicating with people due to low self-esteem, social isolation, unpredictability of managing continence and pain situations outside of the home. The ability to establish and/or maintain relationships in terms of physical intimacy is usually difficult, if not impossible.

Remember in PIP…

Who do they engage with on a regular basis? How do they feel meeting unfamiliar people? If they have anxiety with unfamiliar people, who can support them? Why is this?

Functional Impact

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

Activity 10: Budgeting

Individuals may be negatively impacted by depression and coming to terms with changes in personal financial situation and budgeting for existing financial commitments.

Remember in PIP…

Can someone manage their household finances? Do they do online banking or shopping? Could they plan for future purchases? Could they understand change in a shop? Are they motivated to manage finances?

Activity 11: Planning and following a journey

Some individuals will need support to be able to undertake any journey due to the risk of experiencing overwhelming psychological distress, such as high anxiety, panic and agoraphobia and disorientation. Many can need a companion due to safety risks and the need for assistance in managing needs. Some will be unable to undertake most journeys due to the inability to use public transport safely and reliably, 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

Mesh injury can cause instability from constant and intermittent pain symptoms in the pelvis, legs and groin, depending on which mesh is used. Standing and sitting may not bring relief from walking. Individuals may need to park close to their destination and have access to toilets. Whilst the 'presenting symptoms' may vary, walking, sitting and standing are sources of pain for many mesh injured. Physically mobilising may be possible, however it carries the risk of aggravating the injury and causing fatigue from the activity and resulting pain. Some individuals use walking aids and or mobility scooters. 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...

Establish when someone is walking, do they require an aid? If so, what aid? Was this prescribed or self purchased?
How far can they walk and how long does this take? How does walking make them feel? Does pain/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.nice.org.uk/guidance/ipg599
- https://www.nice.org.uk/guidance/NG123
- https://pathways.nice.org.uk/pathways/urinary-incontinence-and-pelvic-organ-prolapse-in-women
- https://www.gov.uk/government/news/government-announces-strict-rules-for-the-use-of-vaginal-mesh
- **First Do No Harm.** The report of the Independent Medicines and Medical Devices Safety Review 8 July 2020 https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf
- Annex G – Pelvic mesh supporting information https://www.immdsreview.org.uk/downloads/Annexes/Annex-G-Pelvic-mesh-supporting-information.pdf
- Annex J: Personal Testimonies https://www.immdsreview.org.uk/downloads/Annexes/Annex-J-Personal-testimonies.pdf
- https://www.fda.gov/medical-devices/implants-and-prosthetics/hernia-surgical-mesh-implants

INTERNAL

- Desktop Aids on Fatigue, Activity 12, Activity 6 and Activity 4
- Other appropriate CIR documents e.g. Depression, Anxiety, PTSD, Fibromyalgia

Version control

Version	Date	Signed off by	Comments
1.0	08.06.20	Dr Shah Faisal	New re-banded document
1.1	25.09.20	Dr Shah Faisal	Disclaimer inclusion across all slides. Inclusions of sepsis, osteomyelitis, discitis to symptoms, colostomy bag or use peristeen colonic irrigation to activity 5, use of mobility aids and scooters to activity 12. Inclusion of additional NICE guidance and rewording of slide 2 overview and presenting symptoms.
1.2	14.10.20	Gareth Colhoun	Removal of reference to mesh groups and contributions
1.3	30.03.21	Dr Shah Faisal	Additional amends to slides 2,3 and 5 to incorporate hernia, testimonials, additional symptoms, sensitivity points.
1.4	06.07.23	Rebecca Sparks	2 year document review. Amendments made to 12 PIP Activities regarding what should be explored to establish if someone can complete an activity reliably.