

Condition Insight Report (CIR)

Amputee

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Completed in collaboration with
Blesma

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Overview

What is the condition usually called / any abbreviations used?

Amputation: Can be sub-categorised into upper limb or lower limb and multiples thereof. For example, single below elbow amputee or double above knee amputee.

Limb deficiency: For congenital limb loss which can also be sub categorised as above.

Brief overview of the condition

Removal of limbs or parts of limbs may be necessary at any age as a result of various conditions such as:

- Peripheral vascular disease. Restriction of blood flow to the periphery may occur for various reasons, it may be a complication of systemic disease such as diabetes or due to complications from smoking, this may be complicated by secondary infection such as gangrene which is one of the commonest causes of amputation in the lower limbs.
- Malignant disease
- Injury (trauma)
- Chemical trauma (substance abuse), toxins and syndromes also can cause insensitivity in the limbs (which in severe cases may result in need for amputation).
- Infective causes may include leprosy, contagious bacterial disease that affects the skin, mucous membranes and nerves, causing disfigurement and may also be caused by a variety of organisms, such as fungi or actinomycetes.
- Meningitis

Presenting Symptoms

Congenital absence of limbs or parts of limbs may give similar impairment as amputation, although it is important to recognise different **psychological reactions** that may occur from sudden loss of limb, as opposed to dealing with impairment during development.

Can include, but not limited to:

- **Difficulty mobilising** (environmental factors such as stairs, walking from the nearest car park/public transport link, doors)
- Difficulty **transferring** from seated to standing, bed, toilet, shower and vice versa
- Difficulty **standing**
- Restrictions **driving**
- Difficulty completing daily living tasks
- **Muscular or skeletal problems** caused by wearing a prosthesis
- Physical or phantom **pain**
- **Blisters/sores** affecting residual limb
- Nervousness and **body image issues**
- **Anger** (emotionally charged)
- **Stoicism** (not wanting to admit difficulties, or underplaying these)
- Other health conditions which may be the cause of the amputation e.g. heart condition, diabetes

The effective use of an artificial limb depends on the level of amputation, the person's age, build, motivation, state of health and physical fitness. Modern developments, using the latest technology, aim to produce a more functional prosthesis, using remaining nerves and muscle groups in the residual limb or microprocessors to control movement; though this is, as yet, mainly used when there has been loss of part of the upper limbs. Cost plays a part in the availability of prosthetic solutions, with some technically advanced prosthetic limbs only being available in specialised centres and therefore not in common use.

There can be restrictions with wearing a prosthesis due to:

- Change in residual limb size caused by temperature and humidity, fluid retention, infection, exercise, weight gain/loss
- Poorly fitted socket fit which can lead to pain and discomfort
- Age and other comorbid conditions
- Nerve responses e.g. phantom limb pain

Fluctuations



It is unlikely there will be any changes to the amputation or limb deficiency due to its permanent nature, unless there are further revisions or corrective surgery.

Those living with the condition could experience fluctuations into their management of the limb loss and use of any prosthesis in place.

Think about exploring things like:

- **How often are you able to wear your prosthesis?**
If they report variation you need to explore why this is and whether it is a result of sores, blisters, poor fitting, residual limb size variation, component failure, phantom limb pain, and/or generalised limb pain from nerve responses.
- **How frequent are any impacting factors** including, how long they last, how the symptoms manifest, what functional changes they have during this time?

NOTE:

Phantom limb pain sufferers experience acute sensations of pain that appear to come from the limb that has been amputated. It is estimated that between 50 and 80 percent of amputees develop phantom limb pain after an amputation. The term 'phantom' does not mean that the pain is imaginary. Phantom limb pain is a very real phenomenon which has been confirmed using brain imaging scans to study how signals are transmitted to the brain.

Reliability

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

SAFETY



TIMELY



ACCCEPTABLE
STANDARD



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?

Some tasks, such as those that require the ability to transfer can pose safety risks depending on the limb loss/ deficiency.

Exactly how they manage this needs to be considered and whether they require the prosthesis to complete it, and whether they are actually able to wear/use the prosthesis majority of days.

Not every amputee with a prosthetic limb can get about like a Paralympic athlete. Those competing on running blades and high end prosthetic limbs are in the minority and usually otherwise healthy.

A high proportion of individuals living with a limb loss or deficiency can take longer to complete tasks due to the exertion required to compensate for the loss of the limb. It can take some people months or years to adapt.

A prosthetic limb will never and can never replace an existing limb. There is no 'Swiss army knife' equivalent in prosthetics – no single prosthesis will allow the wearer to complete every task reliably. E.g. Single below knee amputation with well fitting prosthesis, no phantom limb pain or stump site issues - may be able to walk in excess of 200 metres reliably so may not be recognised within PIP mobility component will be considered in daily living elements.

A lower limb prosthetic wearer can exert more energy when walking. As an example, an individual with a single above knee prosthetic limb can be expected to exert 65%-80% more effort and energy in walking than an able bodied person.

Most amputees find they cannot wear their prosthesis for extended periods without issues.

Sensitivities

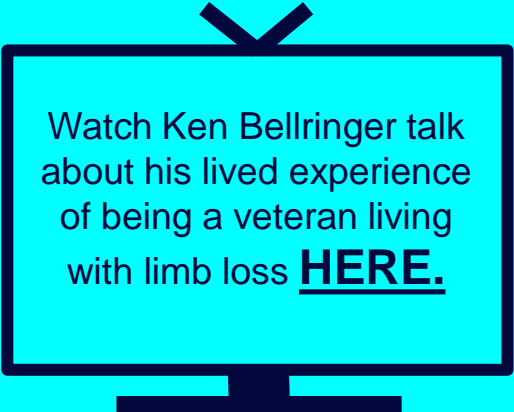
What areas might they find difficult to mention or perhaps understate the impact of?

Many claimants will learn to adapt to their amputation or limb deficiency. However they can overestimate their ability to manage a task reliably.

- Toileting and managing continence can be a very difficult topic to discuss

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

A person living with limb loss. An amputee or a limb deficient individual.



Watch Ken Bellringer talk about his lived experience of being a veteran living with limb loss **HERE**.

Customer Care

General

- **Be open and honest.** Recognise the amputation.
- Acknowledge the **claimant is the expert** in how it feels for them.
- Identify if a claimant is an armed services veteran. Evidence, which the DWP recognises, shows that veterans (whether an amputee as a result of service or not) have learnt the skills to cope in life and find it difficult to recognise and communicate when their ability to manage day to day life is compromised so please utilise companions.
- **Try to change the narrative** of the conversation from negative focus to neutral or positive strides where possible. For example instead of discussing their restrictions as 'how have you adapted', 'can you talk me through step by step of how you...'
- **Do not take answers at face value**, remember that those who have lived with a limb loss for an extensive period of time may find it difficult to remember or articulate that what they do is different. Ensure when a claimant says they can manage a task, you consider whether they manage it reliably and ask them further questions to clarify this.



Face to face

- Never assume either they need any assistance or they won't want any assistance. **Just ask.**
- **Avoid the use of the word 'stump'** unless the developed rapport has indicated.
- **Look first:** Particularly when considering a handshake at the start of the meeting. Do they have a hand to shake? It is ok to shake with left hands if necessary?



Functional Impact

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

Activity 1: Preparing food

Where the limb loss is and effects of any emotional changes need to be considered. Upper limb may affect ability to chop, lift and manipulate items. Lower limb may affect ability to stand and/or sit for any sustained period.

Fatigue due to limb loss can also have an impact.

Remember in PIP...

Think about their ability to prepare food at waist height. Can they reliably stand and if so, how long for? Can they transfer if they are using a wheelchair? Can they chop vegetables and lift pans? Do they require any aids in the kitchen or assistance to safely prepare food?

Activity 2: Taking nutrition

Where there is a limb loss or deficiency in the upper body it could impact on their ability to cut up food and/or take food to their mouth.

Remember in PIP...

Can they chew, swallow, cut food and bring it to their mouths? Do they utilise adapted cutlery? Do they require assistance to cut up food? If there are any secondary psychological conditions, do they require prompting to eat? Is this throughout the duration of the meal?

Activity 3: Managing therapy and monitoring a health condition

For those who experienced a limb loss due to poorly controlled diabetes it is important to cover their management of this and any support they might require. In the beginning post an amputation they might have therapy to support them building up strength and exercise tolerance to improve their independence post surgery.

Where loss of a limb has resulted in emotional changes some may have emotional therapy support to help them come to terms with changes to their sense of self.

Remember in PIP...

Any therapies completed within the domestic setting can be considered but must cover majority of weeks. Consider any supervision, prompting or assistance to complete any therapy and how long this is required. Such as dressing a new amputation site or extensive sores/blisters. Where there is an upper limb or associated mental health restriction consider how they have adapted to taking any medication or managing a condition like diabetes especially where injections may be required.

Functional Impact

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Activity 4: Washing and Bathing

The ability to transfer can be difficult as a prosthesis cannot be used in the shower mostly due to their metal components.

Care should be taken to explore how they are able to get in/and out and wash all areas of their body if they cannot use a prosthesis for this task.

Remember in PIP...

Where there are any restrictions with transferring, ensure to explore whether there is any history of falls or other incidents, and how they mitigate risks in this environment.

Where there is reported fatigue you must explore management strategies and consider whether aids would help or whether the action would still be unreliable. Can they wash their upper and lower body reliably?

Activity 5: Managing toileting needs and incontinence

For those who cannot transfer safely and cannot wear their prosthesis on the majority of days assistance can be required with toileting to manage their hygiene needs and to support them on and off.

Individuals may find this difficult to discuss.

Remember in PIP...

Ensure to explore specifics of how they transfer. Remember if they have a lower limb prosthesis it **MUST** be clear in the report if they can utilise this on the majority of days or not and how they manage generally. It may be a sensitive topic but you need to establish the specifics of how they complete this and what impact their symptoms have on their ability to carry this out.

Activity 6: Dressing and undressing

This will be different for each individual and depend on the site of amputation, quality of stump site, extent of amputation (e.g. above/below knee), phantom limb pain, and any musculoskeletal impact of the amputation e.g. a through hip amputation or bilateral above knee amputation may affect sitting balance.

Remember in PIP...

Remember you must consider ability to put on non-adapted clothing. 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. For example for those who may have bilateral above knee amputations you need to be exploring sitting balance and whether they need to lie down or not.

Functional Impact

Although an amputation itself may not impact these activities within the scope of the PIPAG, please ensure you explore any co-morbidities that might.

Activity 7: Communicating Verbally

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?

Activity 8: Reading and understanding signs and symbols

Remember in PIP...

Can someone read and understand basic and complex written information? What do they read? Can they read a text message or a book? Did they gain any qualifications in education?

Activity 10: Making budgeting decisions

Remember in PIP...

How do they manage their finances? Could they manage an unexpected bill? Do they do online banking or shopping?

Functional Impact

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

Activity 9: Engaging with others face to face

Individuals can struggle to adapt emotionally to their new sense of self which can impact the way they interact with others. They may have increased anger and aggression for example and feel emotionally 'charged'.

Remember in PIP...

It is likely for this to be impacted if there are associated mental health condition(s) or restrictions. 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.

Activity 11: Planning and following a journey

Accessing the community and getting out and about can be very difficult for someone with limb loss depending on where the site of loss is and how they have adapted including any use of a prosthesis. Additional comorbidities will also affect this.

Where individuals have an altered sense of self and have a mental health condition in addition they may find it very distressing attempting to go out and may need support. This will vary for each individual.

Remember in PIP...

Where there are associated conditions 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. For any associated conditions it is critical to explore the right points. Consider reviewing the Desktop Aid - Activity 11 for more pointers as needed.

Activity 12: Moving Around

Even after a person has adapted to the prosthesis, help or an aid or appliance may be needed. Even simple things like pavement camber, loose stones and sensory pavement at crossings are severe daily obstacles for amputees, often causing them to stumble and/or fall.

Remember in PIP...

This activity should be judged in relation to a type of surface normally expected out of doors, such as pavements on the flat and includes the consideration of kerbs. If the amputation is to the lower limbs, are they at risk of falls? Have they fallen, and what caused this? How frequently does this occur? Have they required a hospital attendance or admission due to injuries? Think carefully about doing an MSK – is this warranted by an underlying musculoskeletal condition?

Additional reading or other resources

EXTERNAL

- **Blesma**, the limbless veterans, is a charity which supports armed forces veterans who are amputees. However, there are general leaflets on amputation, which includes phantom limb pain, amputation explained and others at <https://blesma.org/news-media/publications/?category=welfare-leaflets>
- You can find more information about Blesma at <https://blesma.org/>
- For further information see NHS Conditions and Treatments: www.nhs.uk/conditions/amputation/Pages/Introduction.aspx

INTERNAL

Desktop aids on Fatigue, Activity 12, Activity 6, Washing and Bathing may support you with additional questions to explore during the assessment.

Version control