Condition Insight Report (CIR)

Stroke

VERSION 1.0

Last Updated 18/03/2022

Completed in collaboration with Stroke Association

Overview

What is the condition usually called/ any abbreviations used?

Stroke, TIA, CVA

Brief overview of the condition

A stroke is described as a serious life-threatening medical condition that happens when the blood supply to part of the brain is cut off. There are 2 main causes of strokes; an Ischaemic and haemorrhagic stroke. An Ischaemic stroke is caused by a blockage cutting off blood supply to the brain (blood clot) whilst an Haemorrhagic stroke is caused by bleeding around the brain which is caused by a weakened blood vessel which bursts"

A **transient ischaemic attack** or **TIA** is also known as a mini-stroke. It is the same as a stroke, except that the symptoms last for a short amount of time and no longer than 24 hours. This is because the blockage that stops the blood getting to the brain is temporary**.**
Whilst some strokes are associated with rapid recovery (within days), some are associated with permanent damage that persist unchanged from the initial event. Many strokes improve slowly over the course of up to a year – as below after 12 months, the likelihood of recovery of function becomes less. It is important to ensure that the history taken confirms whether there are fluctuations over time, or whether the claimant's condition is stable or improving.

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

Stroke Survivor or a person affected by stroke.

Presenting Symptoms

All strokes are different so for some people the effects may be relatively minor while others may be left with more serious long-term problems. A stroke can affect the way the body functions and affect activities of daily living.

Symptoms can include, but are not limited to:

- Problems with movement, balance and muscle weakness or paralysis which can affect mobility and balance. This usually happens on one side of body and can also cause a lot of pain and discomfort and excessive fatigue.
- Some have loss of sensation or their sensation is heightened.

There are also other effects that you can't see - Some of the 'hidden' effects of a stroke include:

- Problems with communication: many people have difficulty with speech and language after their stroke. A common communication problem, which affects around one third of stroke survivors, is aphasia. People with aphasia find it difficult to speak and understand what other people are saying to them, as well as reading and writing.
- Dysphasia is where someone may have no difficulties understanding, however, struggles to express themselves.
- Dysarthria happens when you're not able to control the muscles in your face, mouth and throat very well, so it's difficult to speak clearly. This can mean that your speech becomes slurred or slow or that your voice sounds quiet.
- Apraxia can occur to all muscle movements. Apraxia of speech is when you can't move the muscles in your face, mouth or throat in the order you need to when you're speaking. This can make it difficult for other people to understand you.
- Agnosia is difficulty identifying objects or what to do with the object.
- Problems with memory and thinking: it's very common to find that short term memory and concentration is affected by stroke, but it can also affect other thinking processes as well, such as problem-solving planning and finding your way around. May affect ability to take medication correctly, mix day and night up etc.
- Changes to emotions: a stroke has an emotional impact, which can lead to problems like depression and anxiety. It can also make it more difficult to control your emotions.
- Changes to behaviour. Some become disinhibited and emotionally labile.
- Changes to vision such as nystagmus, visual neglect or hemianopia

Fluctuations

The extent of the stroke will often determine whether there is likely to be any change in symptoms during a day. Certain effects of stroke can be hugely affected by their levels of fatigue.

Think about exploring things like:

- **Is their tone constant or changing?**
- **Where they have contractions or high tone,** do they suffer from any varying pain which changes during the day with their fatigue?

For general their pain and fatigue;

- **What level is this?**
  Can they quantify this? Do they use a scale and can they describe it?
  What impact will this have on them on a typical day?
- **Triggers?**
  Whilst exertion is a main trigger what amount of exertion is enough to cause further limitation?
  How are triggers managed?
- **For many memory restrictions**:
  Do they utilise a routine to manage their memory? If so, is this independently managed or are they prompted by a person/alarm/calendar etc?
- **How consistent is their presentation** e.g. with memory – can they always remember what day is it or who people are, how frequently does this change?
- **Are they orientated** to time, place, person, occasion?

Reliability

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

SAFETY	TIMELY	ACCEPTABLE 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?
It is important to explore safety for both physical and/or their cognitive changes. E.g. poor sitting or dynamic balance will affect how they safely complete tasks in the kitchen or when washing as will dense weakness on one side. Impulsivity, distraction or difficulties with sequencing could also reduce safety in the kitchen and on journeys.	Whilst an individual may be able to physically use aids to complete a task you need to determine if this continues to affect how timely a task is. Many will have trialled aids during rehabilitation so it may be useful to explore this. Cognitive changes can also impact how timely a task is. Some will have difficulties with initiation of a task and without support may become stiff with repetitive actions, unaware they have already completed this section. Full consideration of both physical and cognitive changes post stroke must be explored.	Strokes can affect individuals of all ages. Many may be determined to keep elements of their independence such as managing their personal care, but to do so have adapted to unusual ways of completing it such as holding items in their mouth, or using their low/high toned limb to keep an item in place. You need to explore the full extent of how tasks are completed to determine if they are reliable, timely and safe in PIP terms.	As fatigue is such a huge factor post stroke whilst they may be able to complete tasks this may not be the same every day. They may adapt by changing the timings of when they initiate tasks or need support to complete tasks at certain times. Establishing what covers the majority of days for them is important to supporting your advice.

Sensitivities

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

- Continence issues,
- Cognitive and behavioural changes,
- Vision restrictions such as hemianopia or neglect unless they have insight into this from others,
- Agnosia

For many post stroke their sense of self is altered as so much of who they are might have changed, even at a behavioural and likes/dislikes level. Many develop mental health conditions like depression as a result and families can also be hugely impacted.

Try to keep the conversation about their recovery and do not dwell on their limitations.

Watch **Lynn** talk about her experience of life post Stroke **HERE**.

Watch **this video about** vision problems post Stroke **HERE**.

Customer Care

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

In general

- A stroke survivor may have communication difficulties and difficulty in understanding questions - so may need support from a family member, a Speech and Language Therapist or a support worker when being asked questions, please utilise any support networks available
- If a person has communication issues:
  - Speak slowly and clearly using short sentences,
  - Wait for a response without interrupting
  - Check that their yes and no responses are reliable
- Be led by the stroke survivor and ask if they need any additional support
- Offer breaks when needed and as always, explain the process of the assessment and what is about to happen prior to starting

During face to face interactions

- Be careful about reaching for a hand to shake, look first to check this is not affected by tone and do not assume it is ok, ask the individual first
- Stroke survivors may be able to communicate with pen & paper, pictures etc. or need communication support. Even if they speak with support from another, please keep eye contact and include them into the discussion
- Use gestures to check responses or support understanding as you are able

Functional Impact

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

Activity 1: Preparing food

This may be affected by their behavioural, emotional, cognitive and/or physical limitations. They may be able to complete a task with support but would need support to initiate and safely sequence the task, even if they might be able to describe the action from memory. They might have apraxia or perseverate and need support to manage this.

Remember in PIP…

You would need to consider if they can safely complete this activity. If they have a cognitive deficit secondary to the stroke, can they identify risk in the kitchen or remember to turn the oven off? Regards to physical limitations, do they need assistance to cook? Do they have any left or right sided density? Do they have good core balance whilst seated?

Activity 2: Taking nutrition

Dysphagia and dysarthria can affect speech and swallowing due to the muscles in the throat and mouth being affected so can make stroke survivors at higher risk of aspiration unless taking a specialised diet. They may need to be reminded or supervised when they swallow as fatigue can increase the risk and they may be unable to identify the signs themselves.

Remember in PIP…

Can they reliably cut up their food and bring it to their mouth with left or right sided weakness?
Are they regularly spilling food?
Also, have they had any history of choking episodes? If so, how is this managed? Do they have food blended to prevent this risk?

Activity 3: Managing therapy and monitoring a health condition

Due to the range of cognitive and physical conditions that can occur post stroke, there are many reasons why a stroke survivor may need support to manage their medication or complete their treatment, such as physiotherapy exercises, speech and language exercises or occupational therapy exercises which can be completed to support their physical and psychological effects.

Remember in PIP...

Do they require assistance with their therapy in the home environment?
If so, how long does this assistance take, and will it be occurring majority of weeks?
Can they reliably get medication out of packets?
Do they always remember to take their medication?

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Activity 4: Washing and Bathing

Muscle weakness or high tone can hugely impact an individual's balance in standing and sitting. Even for those who have good sitting or standing balance may struggle to do dynamic tasks and reach out of their base of support, or even reach all areas they need to effectively.

Remember in PIP…

Consider the full scope of the activity. How are they managing to get in and out of the bath? If they have full left or right sided density, do they need assistance to wash their upper body? Could they independently lift their arm to remove dirt and sweat, or do they require the other hand to raise the arm? How long does it take them and how do they feel after? Do they need prompting due to cognitive deficit?

Activity 5: Managing toileting needs and incontinence

Getting on/off the toilet can be difficult especially where there is a weakness down one side. Ability to twist to wipe can also be challenging. Due to changes in sensation, some may be unaware the extent of their ability to effectively manage their hygiene needs and others are incontinent as a result of reduced sensory awareness.

Remember in PIP…

If the claimant is incontinent, how frequent is it and is this of bladder and bowel? Can this be managed with pads independently or do they need assistance to maintain hygiene? How do they transfer on/off? Do aids support them or not?

Activity 6: Dressing and undressing

Stroke often manifests as a unilateral paralysis, often of the upper limb which results in reduced ability to grip and may also result in reduced ability to undertake tasks involving fine movement. Dynamic movements may also be impacted as well as the cognitive ability to complete the task.

Remember in PIP…

To explore the full scope of the activity. How long does it take them to dress? Do they require assistance with their upper body due to left or right sided density? Could they independently lift their arm to dress their top half, or do they require the other hand to raise the arm? Can they manage fastenings? How long does it take them and how do they feel after? Can they dress whilst seated as this is not considered an aid.

Functional Impact

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Activity 7: Communicating Verbally

Dysphasia, Dysarthria and Aphasia can affect speech. Also consider potential difficulties with cognition post stroke.

Remember in PIP...

It is important to understand that the claimant needs to be able to both **express** and **understand** verbal information. This would mean that even if cognitively someone can understand what you are asking, if they have the inability to reply due to their condition, they are not completing the activity reliably. Can they provide appropriate responses to questions?

Activity 8: Reading and understanding signs and symbols

Visual changes can hugely impact the ability to read and the ability to process visual objects can be impaired. Also, a stroke may cause cognitive difficulties making it hard to understand what is being read.

Remember in PIP…

The distance of what the claimant is reading from their face is not considered.
Do they have any aids to read such as a magnifying glass? Can they read standard font?
Can they understand and process what they are reading?

Activity 9: Engaging with others face to face

Many can find engaging overwhelming post stroke due to the difficulties they experience processing information. Many experience anxiety. Some can become disinhibited post stroke and have a lack of understanding of their behaviour towards others so struggle to maintain relationships. This can include increased aggression.

Remember in PIP…

Who can they engage with? How do they feel around unfamiliar people? Are they vulnerable due to their stroke? If they do exhibit aggression, who can control/prevent this? If they experience anxiety, who can support them and why? Can it be anyone familiar?

Functional Impact

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

Activity 10: Budgeting

Cognitive restrictions can reduce someone's ability to budget and plan for future purchases or even recognise money and understand its value and purpose. Some can become impulsive and no longer have insight into their behaviour.

Remember in PIP…

Can they manage their own household bills? Do they require support? If so, how would they cope without this? Could they plan for future purchases? Would they understand change required in a shop?

Activity 11: Planning and following a journey

Changes to vision can cause restrictions with safely planning and following journeys as they are unable to recognise half of the world around them in some cases so may bump into things. Processing speeds can be slower so being able to take in large amounts of information whilst outside can be overwhelming. Many need support to manage this.

Remember in PIP…

Is there any impulsive behaviour or 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? How would they manage a diversion? Could they safely cross a road or see traffic? Have there been any incidents whilst on journeys historically? If so, when and what were they?

Activity 12: Moving Around

Problems with balance and muscle control and coordination can impact the ability to move around. Many require the use of aids however this will be affected by the extent of any tonal changes and their cognitive ability to use it. Many use wheelchairs when outdoors due to extent fatigue can impact their ability to move.

Remember in PIP...

Individuals may struggle to provide specific information. Start with where they walk day to day. Try to use examples to help or things in their area they might be able to refer to. You must explore whether any distance 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

- See Stroke Association Website: stroke.org.uk
- Stroke Association helpline:0303 3033 100
- For further information see NHS Conditions and Treatments: https://www.nhs.uk/conditions/stroke/

INTERNAL

- Desktop Aid – CSE, Activity 12, Activity 4

REFERENCES

- Lost without Words - Lynn's story - YouTube
- Vision Problems after Stroke - YouTube

Version control