

Condition Insight Report (CIR)

Down's Syndrome

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Completed in collaboration
with Down's Syndrome
Association.

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Overview

What is the condition usually called/ any abbreviations used?

- **Down's Syndrome**
- **Trisomy 21** – the most common form of Down's syndrome
- **Mosaic Down's Syndrome** – 2% of people with Down's syndrome may have this type.
- **Translocation Down syndrome**-3% of people with Down's Syndrome may have this type. This occurs when an extra part or a whole extra chromosome 21 is present, but it is attached or “trans-located” to a different chromosome rather than being a separate chromosome 21.

Brief overview of the condition.

Down's syndrome is a lifelong genetic condition. People who have Down's syndrome commonly have an intellectual disability (or learning disability). Some health conditions are more common in people who have Down's syndrome resulting in health related and physical challenges. Additional support may be needed to maintain good health and regular health checks. Many people with Down's syndrome live in a supported living environment and receive help and support to enable them to live as independently as possible. They will always need continual help and support over their lifetime and this increases with age due to early cognitive decline and early onset dementia for some at around the age of 45, or earlier.

Presenting Characteristics

People with Down's syndrome present varied levels of intellectual and physical disabilities. The affected children and adults have some distinct facial features as a result of them having an extra chromosome which affects how the baby's body forms and functions as it grows.

Not all affected individuals will have the same set of features. Some of the common features are as follows:

- Delayed development and behavioural problems
- Cognitive disability
- Slow development of motor skills
- Expressive language, grammar and speech difficulties
- Hearing loss and ear infections
- Problems with vision
- Obstructive Sleep Apnoea
- Heart defects
- Musculoskeletal problems
- Gastrointestinal issues
- Blood disorders
- Epilepsy
- Mental Health Disorders.

REMEMBER: It is also important to note that many people with Down's Syndrome go on to have jobs and live independently.

Fluctuations



People who have Down's syndrome generally need the same level of supervision daily. They may need prompting throughout the day. Needs generally increase with age as dementia can become a feature for around half of people around the age of 40 (sometimes earlier) and also an as yet not understood cognitive decline or regression that is not related to early onset of Alzheimer's disease. Needs are increased if the person has additional medical issues. People who have Down's syndrome age faster than people who do not have Down's syndrome, so a 45 year old may be considered as similar to a 60 year old who does not have Down's syndrome, in health and energy levels, or beginning to slow down.

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?

People who have Down's syndrome often see the best in people and situations and are therefore vulnerable and can be taken advantage of. It is therefore vital that they receive ongoing support and supervision in multiple aspects of their daily life to remain safe.

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?

People with Down's syndrome often need to stick to a rigid routine and may become distressed when they experience even minor change. Consequently, we need to consider if an activity would take them more than double a reasonable time, especially if any unexpected changes occur.

ACCCEPTABLE
STANDARD



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

Consider if someone reports they have adapted to completing an activity, are they doing this to an acceptable standard? It will be common that someone with Down's Syndrome will under report their restrictions and often they require constant supervision and support to look after themselves.

REPEATEDLY



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

People with Down's Syndrome often suffer from decreased muscle tone (hypotonia) and lax ligaments can cause extreme flexibility in joints, Pain, tiredness and weakness when walking are common in people who have Down's syndrome. You must explore when mobilising, if they can repeat distances and how this makes them feel.

Sensitivities

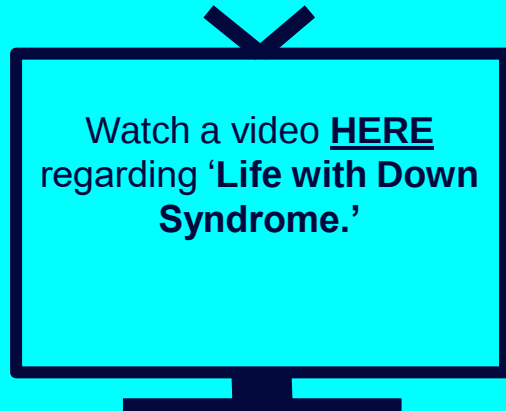
What areas might they find difficult to mention or perhaps understate the impact of?

Each person with Down's syndrome will have differing abilities. Many will overstate their ability and give the impression that they can lead an independent life. Most people will live a semi independent life with a varying level of intervention and support.

With regard to illness, many may understate because of their level of understanding, communication skill and anxiety around potential tests or hospitalisation.

DID YOU KNOW?

Health inequalities are common in people who have Down's syndrome, including diagnostic overshadowing that may prevent people from being properly assessed or treated. For further details see the DSA Health Alert report 2019.



Customer Care



You must consider if someone with Down's Syndrome has an appointee in place.

If this is the case, within Lot 2, the assessment can be completed in the absence of the claimant and all questions directed towards them. They are often a parent or carer.

Across Lot 4, although the customer must be in attendance with appointee in place, it remains appropriate to direct questions at the parent or carer, especially if there is evidence of a cognitive deficit.

When asking the person who has Down's syndrome about their care needs, the answers should be taken in conjunction with the parents answers because of potential over/understating ability . Visual and accessible resources should be used when communicating with the person about their needs.

Equally, you must ensure the claimant feels heard and their contributions to the assessment valued.

You must ensure that your assessment report accurately reflects who reported what during the assessment to ensure this is very clear to the Decision Maker at the Department.

REMEMBER: *If someone with a clear cognitive deficit does not have an appointee, and there is any doubt regarding their ability to provide informed consent to continue with the assessment, the assessment should not go ahead and advice should be sought from your Team Manager as to the next appropriate steps.*



Useful questions to ask.

Social & Occupational History.

Education

How did they manage in education? What support did/do they have? Are they attending a special needs school? Do they have a statement of educational needs? If they do have support, to what extent is this? What do they have support with? Have they obtained any qualifications? Do they have plans for further education?

Hobbies

What is their reading level? If they read any books, to what extent can they understand them? Do they have a scribe or reader? Do they have any aids or assistance to read?

If they go on the computer what do they do on there? Do they have any support or supervision? Can they navigate the internet? If so, what are they capable of doing?

Do they partake in any other hobbies? If they are part of any groups, what support do they have there? How do they get there and back? How do they overcome any barriers?

Going out of the home

How do they travel to education? Did they have funded transport? Have they had any driving lessons? Could they safely use a bus? Could they walk to the local shop alone? If so, how far is this?

Working

If they are in employment, you must probe how they are managing this. It is really important to not just allow surface level function to be represented in your report. You must always consider STAR and how they are managing activities reliably.

REMEMBER: If there are also physical restrictions reported secondary to their conditions, you must explore physical ability to get around the property, physically complete hobbies, mobilise around school/work/college.

Functional Impact

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

Activity 1: Preparing food

You must consider that people with Down's Syndrome often have a cognitive impairment that impacts their ability to safely complete activities. They often require high levels of supervision and guidance to complete tasks such as preparing a meal.

Remember in PIP...

Are they completing this activity safely? Do they require supervision? Have they had any accidents? Could they recognise if food is cooked? Do they have physical difficulties standing, lifting and chopping/peeling?

Activity 2: Taking nutrition

You must bear in mind that people with Down's Syndrome may have difficulties recognising hunger or if they are full. Equally, they may have physical difficulties secondary to their condition.

Remember in PIP...

Can they chew, swallow, cut food and bring it to their mouth? Are they eating regularly? Are they at risk of choking and if so, do they require supervision? Do they need prompting throughout the duration of a meal to either eat more or less?

Activity 3: Managing therapy and monitoring a health condition

It is common for people with Down's syndrome to state what they think people want to hear and over play their ability. In addition, those with medical problems such as diabetes or thyroid disorders may not be able to recognise a change in their behaviour requiring medical intervention. They may also lack insight into their conditions and such require support with medication and therapy.

Remember in PIP...

Can someone manage their medication or therapy independently? Do they have insight into their conditions? If they take medication, do they require supervision or prompting to safely manage this? If they require therapy, is this in the home environment and how long does the support received take?

Functional Impact

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

Activity 4: Washing and Bathing

Someone with Down's syndrome may lack the understanding of when they need to wash or how to wash to an acceptable standard.

Equally, you must consider any physical restrictions reported secondary to their conditions as this may impact their ability to wash to an acceptable standard.

Remember in PIP...

Do they require prompting to wash? Do they lack insight into personal care? Do they need assistance to wash or could they utilize aids to overcome physical restrictions? Are they safe?

Activity 5: Managing toileting needs and incontinence

A person with Down's syndrome may lack the understanding of when to empty their bladder or bowel, and how to clean themselves acceptably. They may also experience physical difficulties with toileting due to their condition..

Remember in PIP...

Do they have incontinence? Can they manage this themselves? Do they have any difficulties sitting on and standing from the toilet or difficulties cleaning?

Activity 6: Dressing and undressing

Someone with Down's syndrome may lack the understanding of when they need to change their clothes or how to select clothing.

Equally, you must consider any physical restrictions reported secondary to their conditions as this may impact their ability to dress to an acceptable standard.

Remember in PIP...

Do they require prompting to dress appropriately or change their clothing? Do they have any physical difficulties with dressing? Can they follow verbal prompts or do they need assistance? Do they need aids to overcome physical restrictions?

Functional Impact

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

Activity 7: Communicating Verbally

There are a range of factors that can significantly affect speech, language development and communication. People who have Down's syndrome typically have better receptive skills than expressive language ability, meaning that they can understand more than they can express. People who have Down's syndrome may simply agree to questions that they do not understand without communicating that they do not know the answer. People with Down's Syndrome may also experience selective mutism.

Remember in PIP...

The scope of the activity is someone's ability to both express **and** understand verbal information. Can they understand what they have been told? Does information need to be broken down and simplified? Are responses contextually appropriate?

Activity 8: Reading and understanding signs and symbols

People who have Down's syndrome commonly have an intellectual disability (or learning disability). This may impact their ability to understand what they are reading and they may have support in place to aid this.

Remember in PIP...

This is the ability not only to read written information, but also understand it. Are they reading comics/magazines with little understanding of the context? Could they read a text message? How did they manage reading in education? **Within the scope of PIP complex written information is more than one sentence.**

Activity 9: Engaging with others face to face

People with Down's Syndrome may be vulnerable to the actions of others. They may downplay their restrictions and provide responses/ complete actions, that they feel will please others.

They may also lack insight into the extent of their functional restriction.

Remember in PIP...

Is someone safe when engaging? They may like to be around others, but are they vulnerable? Who can they interact with independently? **Within the scope of PIP, if someone is vulnerable, prompting would not suffice.**

Functional Impact

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

Activity 10: Budgeting

Parents and carers are most commonly appointees where the person with Down's syndrome is unable to manage their financial affairs effectively, which is the case for most people.

Remember in PIP...

Can they manage both basic and complex budgeting? Would they understand what change to expect in a shop? Can they plan for future budgeting? Could they manage a household bill? Do they need support with any areas of budgeting?

Activity 11: Planning and following a journey

Many people who have Down's syndrome will only be able to cope with one familiar route that has been extensively planned and prepared, as long as no variables are introduced. This can lead to confusion and may result in people becoming lost and distressed. For the majority of people who are able to complete a familiar journey (and many are unable to), they rely on support by way of mobile phone communication with their parent or carer to step in and help.

Remember in PIP...

Can they do this activity safely? How do they manage familiar and unfamiliar journeys? How would they cope with a diversion? Can they use public transport? Have they had any travel training? Are they vulnerable? Do they have road safety awareness?

Activity 12: Moving Around

People with Down's Syndrome will often suffer from decreased muscle tone (hypotonia) and lax ligaments can cause extreme flexibility in joints, It is extremely common and can cause stumbling, falls and difficulty standing from a sitting or prone position. Pain, tiredness and weakness when walking are common in people who have Down's syndrome.

Remember in PIP...

Lived examples help to paint a clear picture of function to the Department. Where can they walk? How long does it take? Do they have falls? Can they repeat? Do they use aids? Have they had falls? Do they have pain?

Additional reading or other resources

EXTERNAL

[Life With Down Syndrome - YouTube](#)

[Down's syndrome - NHS \(www.nhs.uk\)](#)
<https://www.downs-syndrome.org.uk>

[Mencap-Supporting Learning Disability](#)

INTERNAL

- [Desktop Aid-Learning Disability or Difficulty.](#)
- [Information Gathering Toolbox](#)