

Condition Insight Report (CIR)

Retinitis Pigmentosa

Version 1.0

Completed 09.03.2023

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Overview

Brief overview of the condition.

Retinitis pigmentosa (RP) is a group of genetic eye diseases you inherit from one or both parents.

Some examples of RP and related diseases:

- Usher syndrome
- Leber's congenital amaurosis (LCA)
- Rod-cone disease
- Bardet-Biedl syndrome

CMV retinitis is a type of retinitis that develops from a viral infection of the retina.

CMV (cytomegalovirus) is a herpes virus. Most people have been exposed to the virus, but it usually causes no harm. When a herpes virus is reactivated in people with weaker immune systems, it can cause retinitis.

Retinitis pigmentosa, also known as RP, develops as a result of certain genetic disorders which cause the breakdown of cells in the retina.

The retina sits at the back of the eye and is responsible for converting light into signals to the brain, thereby giving us the ability to see.

Once these photoreceptor cells in the retina begin to degenerate, the person with RP will notice a gradual decline in their vision usually struggling to see at night and losing their peripheral vision.

Presenting Symptoms

The first symptoms of retinitis pigmentosa are usually picked up between the ages of 10 and 40, but they can be identified in younger children when both eyes are affected.

- With such a range in the age of onset for retinitis pigmentosa, it can be difficult to predict the extent and timescale of deterioration in someone's vision.
- RP symptoms usually begin with poor night vision as the cells, or rods, that are in charge of seeing in dim light begin to stop working. In most cases, it takes our eyes about 20 minutes to adapt to low-light conditions but with RP it can take much longer or not happen at all.
- Eventually a claimant may be diagnosed with 'night blindness' which will likely restrict their ability to drive to the daytime only.
- As retinitis pigmentosa progresses, the cones (cells which respond to light) will stop working too. Cones are used for peripheral vision - what you can see on the edges of your eyesight.
- Losing the cones will result in what is known as 'tunnel vision' as you struggle to see anything to the sides and above or below when you look straight ahead.
- Although less common, people with retinitis pigmentosa may also lose some of their central vision making it hard to focus on small jobs such as reading.
- **It is important to remember that RP is a progressive condition with no current cure.**

Fluctuations



Because the condition affects the rods at the back of the eye (which are the photoreceptors that we rely on for night vision and detecting movement and periphery) a person with RP will find daily activities can be more difficult during the winter months when the daylight hours are shorter.

It is dark at the beginning and end of a typical working day during the winter months. This means that their eye condition will have more of an impact then than in the summer.

They may also find it difficult going into environments where they cannot control the light levels. Lighting is crucial for people with this condition and therefore brightly lit or very dark environments can be difficult to manage.

What's the treatment for RP?

There's no cure for RP, but low vision aids and rehabilitation (training) programs can help people with RP make the most of their vision. Vitamin A may help slow vision loss from the common forms of RP. But taking too much vitamin A can cause liver problems. Fish oil and lutein supplements may also help slow vision loss.

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?

When considering safety, don't assume no injuries means no restrictions - what adaptations are in place to keep the individual safe in their environment?
Supervision?
Physical assistance - remember this only has to be for part of a task.

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?

Consider that if someone is trying to adapt to functioning with their condition, they may report they are completing activities, but it will take substantially longer due to their limitations.

ACEPTABLE
STANDARD



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

Many people with this condition have developed their own adaptations to their condition because they develop it when they are young. These adaptations may not be identified by them as they are intuitive. This does not mean they are not a significant disadvantage to the person. This might include only travelling to places that they know, and avoiding situations where they might have to navigate unfamiliar areas. Using the same set of shops where they know the layout and the shop assistants to avoid having to go to places that they don't know.

REPEATEDLY



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

You must consider how much more focus it would take someone with a visual impairment to complete activities. This may make it difficult to repeat these activities later in the day. Consider eye strain and the impact of this.

Sensitivities

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

This condition is often diagnosed at a time when the person is starting out as an independent adult; they may have plans and dreams for their future. People with sight loss go through a type of grieving process and this can include stages of anger, depression and denial.

Depending on their stage in the process they underplay the difficulties that are caused by their sight loss or they may be at a stage where they blame spectacles or other causes for their difficulties.

This condition affects younger people and therefore they do not look like a stereotypical blind person. You may not realise that the person has a disability and therefore the condition can be hidden, particularly in the earlier stages. People with this condition can develop ways of coping by avoiding situations and therefore become more isolated. The emotional impact of sight loss is often not taken into consideration.



Customer Care



Face-to-face engagement

Gain the person's attention by speaking first and/or by a gentle touch on the arm

- Introduce yourself and what you do
- Always talk to the person directly, rather than their sighted companion.
- In a group conversation, always make it clear who you are and who you are speaking to
- Use verbal responses, avoid nods and head shakes
- Verbalise your actions
- Inform people when you are moving away from them or leaving the room
 - Remember if someone is blind, it doesn't always mean they have no sight at all
- Ask if guidance or support is required
- Provide information to claimant, if requested, in an alternative format e.g. audio, large print or braille

Remember that when you are communicating with a person with RP they may not be able to see you if you sit to the side of them and/or too close, and they will see you better if you are central and a metre or so away. If they have central vision loss they may not be able to see your facial details and therefore interpret your expressions. Make sure you are clear with your questions and you do not use any facial expressions or gestures to illustrate your meaning.



Functional Impact

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

Activity 1: Preparing food

Not being able to see temperature gauges, location of items, timings, whether a food is in date will impact their ability and this cannot always be mitigated with aids. Some may struggle to chop items safely and many will need support to prepare and cook meals.

Remember in PIP...

Are they safe in the kitchen? Have they had any incidents with cutting or burning? How do they tell if food is cooked or in date? Do they require assistance or supervision or have they adapted to safely using aids?

Activity 2: Taking nutrition

Many are likely to be independent with this task, but this will depend on how they are/have adapted to their sensory loss. Some will be able to make use of aids to support them to manage their restrictions.

Remember in PIP...

Are they able to chew, swallow and bring food to their mouth? Do they regularly spill food that requires them to change clothing? Do they have any aids to overcome this?

Activity 3: Managing therapy and monitoring a health condition

Whilst individuals may have input from therapy services to support with the management and learning skills to manage any changes to their sensory loss, this is likely to be short term.

Some will have medication such as eye drops, but many may have no therapy or medication unless there are other conditions.

Remember in PIP...

If they are prescribed multiple different tablets, can they determine which medication they should be taking at what time? Do they have any aids to support with their visual impairment? Do they receive any therapy in the home environment?

Functional Impact

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

Activity 4: Washing and Bathing

Sight loss in a wet environment can be challenging for many and they will manage this in different ways. Some may struggle with depth perceptions or central vision and rely on aids to guide them and keep them safer in this environment, others may not require this.

Remember in PIP...

How does someone get in and out of the bath? Are they safe? Have they had any falls or do they use any aids? Do they have depth perception?

Activity 5: Managing toileting needs and incontinence

There is no physical limitation unless there is a comorbidity, but many have different ways to manage their sight loss in this environment. For those who have comorbidities and may be incontinent this can be a challenging task which requires support.

Remember in PIP...

Although mobilising to and from the toilet is not considered within the scope of the activity, you must explore how someone sits on, stands from, and cleans themselves after using the toilet. If they experience incontinence, how do they manage this? Do they require support?

Activity 6: Dressing and undressing

For those with no sensory loss it is easy to determine if a garment is suitable to wear, clean, the right way round, and easier to handle fastenings. For many with sensory loss this becomes more challenging.

Remember in PIP...

Explore if someone has the ability to select appropriate clothing for the environment. If they have a longstanding visual impairment, have they established a way to reliably manage this activity? How do they tell if clothes are clean or dirty?

Functional Impact

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

Activity 7: Communicating Verbally

The ability to manage this will be different for each individual. In some forms of RP, a hearing impairment is also present. This means that they may have difficulty with an activity of daily living that involves hearing

Remember in PIP...

Can someone both express and understand verbal information? Do they speak to anyone on the phone? Do they have any hearing impairment? If so, do they utilise aids effectively? If they cannot use aids, how do they manage with BSL/lip reading with their visual impairment?

Activity 8: Reading and understanding signs and symbols

Their ability to read will depend on their level of sensory loss and will vary for many depending on the conditions around them such as lighting.

Remember in PIP...

How do they manage to read? Can they read normal size font? Do they require aids other than spectacles in order to read? Even with these aids, what can they read? Do they have any adaptations to post such as braille or enlarged font?

Activity 9: Engaging with others face to face

Many can find social environments very daunting and anxiety provoking due to their sensory loss and many need support.

This can lead to engagement occurring in more 121 settings for some.

Remember in PIP...

Although a visual impairment alone is not considered within the scope of this activity, we must consider the detrimental impact of the impairment and this leading to potential anxiety. If someone does report difficulties with engaging, who can support them? Who do they engage with on a regular basis? If someone specific supports, why is this? How do they feel engaging with unfamiliar people?

Functional Impact

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

Activity 10: Budgeting

The ability to manage this will be different for each individual.

Remember in PIP...

Visual restriction is not considered within the scope of this activity. However, consider the detrimental impact a visual impairment may have had on someone's ability to learn and consequently manage their finances. Do they do this independently? Could they understand change in a shop? Do they do online banking or shopping?

Activity 11: Planning and following a journey

Retinitis Pigmentosa may have a significant impact on an individual's ability to go out. Sight is extremely important to support a person's ability to navigate around safely.

Remember in PIP...

Within the scope of the activity, someone must be able to plan and follow both familiar and unfamiliar journeys. This must include the ability to follow a diversion. Ensure if someone is safe crossing roads. Can they see traffic? How would they manage a minor diversion? Does their vision change in different lighting? Can they complete journeys at night time? Have there been any incidents when out of the home?

Activity 12: Moving Around

This will depend on any comorbidities the claimant has. A visual restriction alone is clinically unlikely to impact someone's ability to move around within the scope of this activity.

Remember in PIP...

Remember that any safety due to their sensory loss will be covered in A11, here you should seek to determine if there are comorbidities which affect their physical ability to move around on flat surfaces and management of kerbs.

Additional reading or other resources

EXTERNAL

[Retinitis Pigmentosa \(RP\) | Symptoms & Treatment | Specsavers UK](#)

[Retinitis: Types, Symptoms, Causes, Treatment \(webmd.com\)](#)

[Retinitis Pigmentosa](#)

VERSION CONTROL