CONDITION

Retinitis pigmentosa

Retinitis pigmentosa is an inherited condition that gradually damages the retina and reduces vision.

WHAT IT IS
Inherited degeneration of the retina's light-sensing cells

BODY SYSTEM
Eyes and vision

MAIN SYMPTOMS
Night blindness, narrowed vision, glare, slow light adaptation

WHAT CAUSES IT
Inherited gene changes affecting retinal cells

HOW IT IS DIAGNOSED
Retinal examination, imaging, electroretinography, and genetic testing

MAIN TREATMENT
Vision support, complication treatment, and gene-specific therapy for some

CAN IT BE CURED?
No - most genetic forms remain incurable

IS IT AN EMERGENCY?
Sometimes - sudden vision loss or a curtain-like shadow

LONG-TERM OUTLOOK
Progressive vision loss, often with central vision preserved for years

Overview

Retinitis pigmentosa is a group of inherited conditions that gradually damage the retina. The retina is the light-sensitive layer at the back of the eye. It turns light into electrical signals that travel to the brain and allow you to see.

Most forms first affect rod cells. These retinal cells help you see in dim light and notice objects at the edges of your vision. Cone cells, which provide detailed and colour vision, may become affected later.

This pattern often causes difficulty seeing at night, followed by gradual loss of side vision. Some people eventually develop a narrow area of vision sometimes called tunnel vision. Central vision may remain useful for many years, although the course differs widely between people and genetic types.

Retinitis pigmentosa usually affects both eyes. Symptoms can begin in childhood, adolescence, or adulthood. A later start does not necessarily predict how quickly vision will change.

There is no treatment that cures most forms. However, eye care can treat certain complications, help you use your remaining vision, and identify whether a gene-specific treatment or clinical trial may be relevant.

Symptoms

Night blindness is often the first symptom. You may find it hard to walk through a dark room, see outdoors after sunset, or adjust when moving from bright light into darkness. This is more than simply preferring better lighting.

Side, or peripheral, vision often decreases gradually. You may bump into objects, miss steps, or have difficulty noticing people approaching from the side. Finding things in a crowded space may become harder.

Other possible symptoms include:

Because changes are often slow, you may not notice how much your visual field has narrowed. Sometimes a relative, driving assessment, or eye examination identifies the change first.

Some inherited types mainly affect central vision or cause earlier cone-cell loss. Others occur as part of a syndrome that also affects hearing, development, movement, kidneys, or other organs. Usher syndrome, for example, combines retinal degeneration with hearing loss.

- Slow adjustment between bright and dim surroundings
- Glare or discomfort in bright light
- Flashes or shimmering lights without an outside light source
- Difficulty seeing contrast, such as a grey curb against the road
- Reduced colour or detailed central vision later in some forms

Causes and risk factors

Retinitis pigmentosa is caused by changes in genes involved in the health and function of retinal cells. Many different genes can cause a similar pattern of vision loss.

A gene change may be inherited in several ways. It can come from one affected parent, from both parents who carry a gene change, or through the X chromosome. Some changes arise for

the first time in one person.

You can have retinitis pigmentosa without knowing of anyone else in your family who has it. Relatives may have mild or unrecognised symptoms, parents may be unaffected carriers, or the genetic change may be new.

Having an affected biological relative can increase the chance of having or carrying the same genetic change. The level of risk depends on the gene and its inheritance pattern.

Retinitis pigmentosa is not caused by reading, using screens, wearing the wrong glasses, or anything you did. Lifestyle choices do not cause the inherited retinal damage.

Diagnosis

An optometrist or eye doctor may suspect retinitis pigmentosa from your symptoms and the appearance of the retina. Diagnosis usually involves several tests because no single finding gives all the needed information.

A dilated eye examination allows the retina to be examined through an enlarged pupil. Changes may include narrowing of retinal blood vessels, pale areas around the optic nerve, and dark pigment deposits. These signs may not be obvious early in the condition.

Retinal imaging creates detailed pictures of the retina. Optical coherence tomography, or OCT, uses light to produce cross-sectional images of its layers. Fundus autofluorescence imaging can show areas of stressed or damaged retinal tissue.

A visual field test measures how much you can see to the side while looking straight ahead. It can document narrowed or missing areas and track change over time.

Electroretinography, often shortened to ERG, measures the retina's electrical response to flashes of light. It can confirm that rod and cone cells are not working normally and help define the pattern of retinal degeneration.

Genetic testing may identify the responsible gene change. A positive result can clarify the type, show how it may run in a family, and help determine eligibility for certain treatments or research studies. Testing does not find the cause in everyone. Genetic counselling can help you understand the possible results before and after testing.

Hearing tests, blood tests, or other assessments may be suggested if your symptoms raise concern about a condition affecting more than the eyes.

Treatment and management

There is no general treatment that restores vision lost from most forms of retinitis pigmentosa. Management focuses on making the best use of remaining vision, treating related eye problems, and considering therapies designed for a specific genetic cause.

Low-vision rehabilitation teaches practical ways to manage daily tasks. It may include magnifiers, screen-reading software, high-contrast settings, improved lighting, mobility training, or a white cane. These services can be useful before vision becomes severe.

Glasses may correct short-sightedness, long-sightedness, or astigmatism, but they cannot repair damaged retinal cells. Tinted lenses or sunglasses may reduce glare and improve comfort.

Treatable eye problems can make vision worse on top of the inherited retinal changes. Cataract surgery may improve vision when clouding of the eye's natural lens is a significant cause of reduced sight. Swelling in the centre of the retina, called cystoid macular oedema, may be treated with medicines under specialist care. The benefit and side effects need to be assessed for each person.

Voretigene neparvovec is a gene therapy for a specific inherited retinal condition caused by disease-causing changes in both copies of the RPE65 gene. A retinal specialist must also confirm that enough working retinal cells remain. It is delivered by surgery beneath the retina. It is not suitable for most people with retinitis pigmentosa and does not correct other genetic forms.

Clinical trials are studying gene therapies, medicines, cell-based treatments, and visual devices. Participation may offer access to research but cannot guarantee benefit. Eligibility usually depends on your genetic result, retinal structure, age, and previous treatment.

Do not start high-dose vitamin A or other supplements specifically for retinitis pigmentosa without specialist advice. Research has not established a clear overall benefit from nutritional supplements, and high doses can cause harm or interact with other health needs.

Regular eye care can monitor vision, cataracts, retinal swelling, and other changes. The timing of appointments should reflect your symptoms, test results, and support needs.

Complications

Retinitis pigmentosa can eventually limit independent travel, reading, driving, recognising faces, or working in low light. The effect on daily life depends on which parts of vision are affected and what adaptations are available.

Common associated eye problems include cataracts and cystoid macular oedema. These may cause additional blurred or reduced central vision and can sometimes be treated.

Restricted visual fields may make driving unsafe or legally restricted even when the letters on an eye chart remain clear. Licensing rules differ by location. A formal visual field assessment may be needed.

Vision change can also affect sleep, confidence, work, relationships, and emotional health. Anxiety, low mood, and grief are understandable responses. Rehabilitation, peer support, workplace adjustments, and mental health care can help.

Sudden flashes, many new floaters, or a curtain-like shadow are not typical of the usual gradual progression. They may indicate a retinal tear or detachment and require urgent assessment.

Prevention

Inherited retinitis pigmentosa generally cannot be prevented. There is no proven lifestyle change that can stop the responsible gene change from affecting the retina.

Routine eye care cannot prevent the underlying condition, but it can find treatable problems that add to vision loss. Protecting your eyes from injury and using sunglasses that block ultraviolet light are sensible general eye-care measures, although they have not been shown to prevent retinitis pigmentosa.

If a genetic cause is identified, genetic counselling can explain the chance of passing it on. It can also provide information about reproductive options. These are personal choices, and testing does not require you to make any particular decision.

Living with it and what to expect

Retinitis pigmentosa usually changes vision over years rather than days. Night vision and peripheral vision are commonly affected first. Central vision may remain useful for a long time, but some genetic types affect it earlier.

The rate of change cannot be predicted precisely from the condition's name alone. Even relatives with the same gene change may have different ages of onset and levels of vision.

Regular reviews help track your visual field and central retina, identify complications, and update practical support. A new genetic result may also become relevant as gene-specific research develops.

Planning early can make later changes easier. This may include learning accessibility features, improving lighting and contrast at home, arranging mobility training, or discussing workplace and education adjustments. Registering as visually impaired, where available, can provide

access to services and financial or travel support.

Many people continue working, studying, caring for family, exercising, and living independently with suitable adaptations. Others need increasing assistance as their field of vision narrows. Rehabilitation aims to support safety and independence rather than waiting until vision is severely reduced.

When to get medical help

Arrange a routine eye appointment if you notice increasing difficulty seeing at night, slower adjustment to darkness, loss of side vision, or frequent collisions with objects. These symptoms have several possible causes and need a proper eye assessment.

If you already have retinitis pigmentosa, seek an earlier review for a noticeable change in central vision, new distortion, increasing glare, or difficulty with tasks that were previously manageable. These changes may reflect a treatable complication rather than the expected gradual course.

Get urgent same-day eye care for:

Call emergency services if sudden vision loss occurs with weakness, facial drooping, difficulty speaking, severe dizziness, or a sudden severe headache. These can be signs of a neurological emergency rather than retinitis pigmentosa.

- A sudden increase in flashes or floaters
- A dark curtain or shadow moving across your vision
- Sudden or rapid loss of vision
- A painful, red eye with reduced vision
- Significant eye injury

Common questions

Will retinitis pigmentosa make me completely blind?

Some people lose most functional sight, while others keep useful central vision throughout life. The outcome is strongly influenced by the genetic type and age of onset. Tests can show your current vision, but they cannot predict the exact future course.

Can glasses fix retinitis pigmentosa?

Glasses can correct focusing problems, but they cannot restore retinal cells that have stopped

working. Magnifiers, electronic aids, better lighting, and low-vision rehabilitation may help more with tasks affected by retinal damage.

Can I still drive with retinitis pigmentosa?

Driving depends on your visual field, central vision, night vision, and local licensing rules. You may need formal testing even if you can read an eye chart well. Avoid driving when you cannot see safely, especially at night.

Should I take vitamin A or other supplements?

Do not take high-dose supplements for retinitis pigmentosa without specialist guidance. Evidence of benefit is uncertain, and high doses can cause harm. Supplements also do not treat all genetic types in the same way.

Can my children inherit it?

They may, but the chance depends on the gene and how it is inherited. Genetic testing and counselling can provide a more meaningful estimate than family history alone.

Is there a gene therapy for retinitis pigmentosa?

There is an approved gene therapy for people with disease-causing changes in both copies of the RPE65 gene who have enough viable retinal cells. This represents only a small subset of inherited retinal conditions. Other gene-specific treatments remain under study.

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