Kent Association for the Blind

Retinitis Pigmentosa

What is Retinitis Pigmentosa (RP)?

Retinitis Pigmentosa (RP) is the name given to a group of inherited disorders that affect the light sensitive cells in the retina.

The back of the eye is lined with a thin layer of light sensitive cells called the retina and this sends signals to the brain so we can see. RP causes the cells on the outer edges of the retina to deteriorate which initially affects your side (peripheral) vision and how you see in the dark.

Symptoms vary, depending on the type of retinal cell that is affected. Both eyes often experience similar vision loss.

Some cases of RP lead to progressive blindness, but many people still retain some useful vision.

How RP affects sight

RP initially causes a loss of your peripheral vision while your central vision remains normal. The speed of deterioration varies from person to person; the loss of your peripheral vision may progress until you notice difficulties with night vision, glare and how much you can see around you. This is sometimes called tunnel vision.

Even if you can see what is directly in front of you, you may bump into objects that are outside of your central field of vision. KAB can teach you how to use the sight you do have to stay independent, and to help you carry on with everyday tasks.

Spotting the signs

People with RP may not notice any changes in their vision, but other people often initially experience:

- Night blindness; not being able to see at night or in the dark.
- Not being able to see objects to the side of them
- Difficulty seeing in low or dim lighting.
- Difficulty adapting to changes from light to dark environments.
- Glare in bright light.

Diagnosing RP

A standard eye test involves an examination of the retina. An optometrist will be able to detect any changes to this area and refer you to an ophthalmologist for further tests.

If you are aware that a family member has been diagnosed with RP, it is important to share this with the optometrist before the test.

Living with RP

There are lots of ways to stay active and independent if you have RP, such as:

- Compensate for tunnel vision by moving your eyes and/or your head from side to side, and up and down to ensure you see objects around you.
- Allow yourself time to adjust to different levels of lighting, for example pause in the doorway when coming inside from bright daylight.
- Sunglasses (carrying a CE Mark) or a sun visor can help protect your eyes from the glare of bright light.
- Consider using a cane in dim light or in hours of darkness.
- Consider the lighting inside your home. Evenly distributed light makes moving around easier.

Treatment

Unfortunately there are no treatments available at present to slow down or stop the deterioration that RP causes, but research is ongoing. It is, however, important to continue having regular eye tests. RP is hereditary so you should give your eye specialist a detailed history of other family members affected by RP to help the specialist diagnose which type of RP you have.

Help to manage sight loss

KAB's specialist teams provide a range of services to help visually impaired people, of all ages, to be independent, safe and mobile. Our support includes mobility training so you can get around safely, help to learn new techniques so you can carry out everyday tasks like making a drink or cooking dinner.

We can also give you advice about specialist equipment that can help you make the best use of your remaining vision.

KAB also offers help, information and awareness training to professionals, employers, families and carers. This can help them understand the needs of people around them who have sight impairments. Contact us on 01622 691357 or email enquiry@kab.org.uk

Other useful contacts

Retina UK
0300 111 4000
helpline@RetinaUK.org.uk
www.retinauk.org.uk

Sight Research UK
Helpline 0117 325 7757
Open 9am - 5pm (Monday - Friday)
www.sightresearchuk.org

For information about good eye health, visit our help and advice pages on our website: www.kab.org.uk

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To receive KAB Connect, email us at **enquiry@kab.org.uk** or call us on **01622 691357**. It is available in many different formats, including large print, audio, email and Braille.

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