



**Bedfordshire
Community
Health Services**



Albinism

Bedfordshire Children's Eye Services



Bedfordshire adult and children's community health services are provided in partnership by East London NHS Foundation Trust (ELFT) and Cambridgeshire Community Services (CCS) NHS Trust

Albinism

Albinism is a name given to a group of inherited conditions where there is a lack of pigmentation in the eyes, skin and hair. Most people with albinism have a very fair appearance, for example blonde hair and blue eyes. They may also have nystagmus, an involuntary movement of the eyes. The movement is usually from side to side but the eyes can sometimes move up and down or even in a circular motion.

Albinism cannot be cured but your child may benefit from glasses.

Albinism affects people in different ways. The degree of sight loss varies from person to person. Many sufferers are eligible to be registered as partially sighted or blind.

Getting about can be difficult, especially in unfamiliar or busy surroundings. The greatest problems arise on sunny days and in brightly lit places. Crossing roads is more dangerous due to poor vision. Very few people with albinism are legally permitted to drive a car. Advice on mobility issues can be obtained from Social Services when your child is older. Mobility training may also be offered by Social Services.

Depth perception is usually reduced, thus making people appear slower or clumsier than a normally sighted person. As their depth perception is poor, people may need to take care when using stairs or crossing uneven surfaces. Confidence may also be reduced because those with albinism have difficulty maintaining eye contact.

Many people with albinism are able to read small print if it is held close to their eyes. They will find it very difficult to share books with others, as the text will be too far away. Struggling to read small print means they will be slower readers and allowances for this should be made in school, college or work.

As albinism is inherited, a clinical geneticist can be consulted for detailed information as to the probability of having another child with the condition. They can also offer counselling if needed.

Your child may be referred to the Sensory and Impairment Communication Difficulties (SICD) Team. A Visual Impairment (VI) teacher will visit your child at home or school, depending on their age.

What can be done to help?

If your child needs glasses, they will help them to see slightly better and assist with reading, although their vision will still be reduced.

Your child may need to use sunglasses (or tinted glasses) outside as the bright light may cause more problems. The Visual Impairment teacher will be able to help your child use the sight they have to the best of their ability. They will discuss your child's sight problems with their class teacher so that they do not struggle unnecessarily at school.

Your child may need to sit close to the front of the class so they can see the white / black board.

Your child may find it easier to use larger print or a visual aid, such as a magnifier, and will need their own copy of books or worksheets. They may need extra time to complete their work as they may struggle to see small print.

It will be helpful for your child to use a computer as the size of letters can be varied as well as the brightness of the screen.

If you have any questions regarding your child's eye condition, please ask the Orthoptist or Ophthalmologist.

There is a group set up for people with albinism and their carers. Please contact:

The Albinism Fellowship

PO Box 77
Burnley
Lancashire
BB11 5GN

Tel: 01282 771900

This organisation has an excellent website: www.albinism.org.uk

If you do not have internet access, please let us know and we can print information for you.

For further information about this service contact:

Community Eye Service

Enhanced Service Centre
Bedford Health Village
3 Kimbolton Road
Bedford, MK40 2NT

Community Eye Service

Liverpool Road Health Centre
9 Mersey Place
Liverpool Road
Luton, LU1 1HH



Children's Community
Health HUB

**Your one stop
contact point**

Tel: 0300 555 0606

Email: ccs.bedsandlutonchildrenshealthhub@nhs.net



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