

How the National Blind Children's Society Family Support Service Supports Active Lives

Wendy Sainsbury



Wendy Sainsbury is NBCS Head of Family Support and Information Service. Over the past 17 years she has supported more than 5,000 children and young people and their families. Wendy is a highly respected visual impairment specialist, a council member of the International Glaucoma

Association, a former lay adviser to the Royal College of Ophthalmologists and a trained Eye Clinic Liaison Officer.

Summary

The National Blind Children's Society Family Support and Information Service offers immediate and ongoing emotional and specialist practical support and information from first diagnosis of a visual impairment. It is one of five key services whereby the charity can help the estimated 24,000 children and young people in the UK who are blind or partially sighted.

Introduction

The National Blind Children's Society Family Support Service, which was founded in 2004, is widely acknowledged to be the first point of referral for families of children diagnosed with a visual impairment. NBCS will then refer the child, as appropriate, to the local authority sensory support services and other relevant VI support organisations. Many national and regional children's and specialist eye hospitals, including Moorfields Eye Hospital and Great Ormond Street in London and many other centres of excellence, in many cases advise parents to contact NBCS for information and support.

An increasing – and encouraging – point of contact for NBCS is through the families themselves, particularly extended family members such as grandparents. They

are given information and emotional support as well as practical help and confidential advice. NBCS family support officers can take on a keyworker role, to be a single point of contact with the various medical, social and educational professionals the family might be dealing with throughout their child's development.

On diagnosis there may be a sense of loss, anger, confusion or frustration and parents and carers often feel isolated and without crucial information – feeling that there is no one who really understands their situation. NBCS employs a team of experienced family support officers, educational advocates including qualified teachers of the visually impaired (QTVI), an accredited ICT (Information and Communications Technology) assessor, a counsellor and other recognised and highly respected specialists. So far over 3,500 families are being helped with ongoing emotional support, advice, information and practical help at and around the time of diagnosis and at crucial stages in the child's life.

How we can help

Starting with a clear and up-to-date explanation of the child's eye condition, NBCS provides such general and specialised information as:

1. A listening service where parents can talk in confidence about their concerns and receive ongoing support.
2. Programmes to help parents to work with their child during the various stages of the early years.
3. Contact details for national groups for specific eye conditions and other statutory and voluntary support organisations.
4. Suggestions for appropriate toys, equipment and suppliers of them.
5. Ideas for how to respond to the questions and worries of brothers and sisters.
6. Guidelines for completing Disability Living Allowance and other benefit claim forms.
7. A 'who's who guide' to the specialists parents may come into contact with.

8. Help with accessing statutory services, especially in the early years.
9. Parent-friendly information sheets available by post or through the NBCS website (www.nbcs.org.uk).
10. Direction Point – a resource base and comprehensive directory of contacts and information – and other publications.
11. *Tom's Visit to the Eye Hospital* – a free booklet explaining to children what they can expect in hospital.

Children and Families we have Helped

Below are some examples of typical case studies recently handled by NBCS. All names have been changed.

Simon's Story

A grandmother telephoned NBCS when her baby grandson had just been diagnosed with a visual impairment because his mother was too upset to make the call herself.

NBCS forwarded leaflets to the grandmother to pass on to her daughter when she felt ready. The family were unsure of the exact diagnosis and its implications for Simon's future.

His mother then contacted NBCS after she was referred by Simon's medical team. She wanted to discuss her concerns. The NBCS Family Support Service provided emotional support, advice and information through many telephone contacts over the initial weeks after her baby's first diagnosis of visual impairment.

NBCS contacted the hospital which made the diagnosis and instigated additional diagnostic tests and referral to one of the main national eye hospitals.

The mother's support officer forwarded information to the family about Simon's developmental stages, and gave advice on play and how to stimulate his vision.

Advice was given on the statutory benefits available to the family and how to apply for them.

The family was referred to the NBCS Sensory Support Team who discussed their registration with them.

Once Simon's diagnosis was confirmed, NBCS provided information on the eye condition and provided his mother with the contact details of the support group specific to his condition.

Subsequently, the family attended one of the NBCS 'weekends away'* where they met others in a similar situation and enjoyed a very welcome break – with a lot of fun for Simon as well. They continue to receive ongoing support from NBCS.

Donna's Story

Donna's father telephoned NBCS, very upset because his teenage daughter had suddenly lost her vision due to illness.

One of the NBCS support officers, working in consultation with colleagues, discussed the impact of this traumatic news on the family as well as on Donna herself and forwarded information about the services provided by NBCS and the Family Support Service.

They discussed the impact on Donna's schooling and referred her to one of the NBCS specialist educational advocates.

The family support officer talked to Donna's mother and gave her emotional support as well as practical information. Contact continued with both parents, making sure the impact of the diagnosis was clearly understood. Emotional support, advice and information were given at all the crucial stages.

The family support officer discussed benefit entitlements with Donna's mother and forwarded the relevant information to her.

Donna and her parents were sensitively linked to a family with similar experience, and they attended an NBCS family weekend by the seaside.

Donna was put in touch with NBCS's qualified IT assessor who assessed her needs regarding her homework and examination studies.

Sahid's Story

A support worker from a local statutory service referred this family with limited English to NBCS. Because Sahid's elder brother could speak English, one of NBCS's family support officers discussed the family's worries with the elder brother as interpreter, and explained the ongoing support that was available to them.

They discussed Sahid's eye condition and provided clear information to enable the family to understand the implications of the diagnosis and about the support that was available through NBCS and other support organisations.

Sahid's parents were experiencing difficulties with regard to claiming benefits. After extensive telephone work with them, they were sent an information sheet explaining their rights in user-friendly, easy-to-understand words. Ongoing advice and support was given as they completed the benefits application forms. This included a Family Fund application for specialised domestic equipment for Sahid such as a hoist to help him in and out of the bath.

The family's worries about school were discussed and the family was referred to an NBCS educational advocate.

The family enjoyed their first holiday for a number of years in the NBCS mobile holiday home at the seaside. They also joined an NBCS activity day where they met other families in a similar situation and had personal confidential advice sessions with the NBCS Children's Services Team. All NBCS family support officers and educational advocates are members of this Team and are available for free, confidential advice sessions at most NBCS recreational activities, social events and weekends away.

NBCS provided specialised IT equipment for Sahid to use at home, such as a computer magnification device.

Other Services at NBCS

Families may also be referred to any of the other four of NBCS five key services. As well as the Family Support and Information Service, these are:

1. **Educational advocacy** – expert advice and representation to ensure the child receives the most suitable education in the correct environment.
2. **Specialist equipment** – personalised ICT, sensory and other specialist equipment to help children participate fully in the modern world and achieve their potential at home and school.
3. **Recreational activities** – a nationwide programme of day and weekend family events, socialising, holiday and adventure activities.
4. **CustomEyes books** – large-print fact and popular fiction titles, annuals and school revision guides tailor-made to the specific needs of individual children.

NBCS supports the aims of the UK Vision Strategy which is urgently addressing the shocking statistic that 50% of sight loss in the UK is avoidable, and strongly urges parents to take up the free annual eye tests available for children. The UK Vision Strategy is available at www.vision2020uk.org.uk/UKVisionstrategy

* NBCS runs a nationwide programme of day and weekend family events, socialising, holiday and adventure activities. There are parties at Christmas and Easter, audio-described theatre visits, outdoor days at adventure playgrounds or trips to the zoo, and weekends in country or seaside hotels. A disability-friendly mobile holiday home based in a popular seaside holiday park in Somerset is also available for families at a heavily subsidised price. NBCS is now raising funds for another holiday home in North-East England to make this very popular facility accessible to more families.

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For more information about the work of the National Blind Children's Society go to www.nbcs.org.uk
Tel: 01278 764 764.