school activities. For most children, a transition to a more supportive special school environment will be necessary before the end of compulsory schooling.

Forward planning at Annual Reviews plays a vital role in preparing for these transitions. It is helpful for parents to visit the schools they may be considering and to discuss their views at the Annual Review. The Annual Review in Year 5 of primary school is particularly important in deciding on the most appropriate school for the secondary phase and planning for the support that will be needed.

From the age of 14, Annual Reviews must include transition planning for the next stage beyond school. Health, social care and education professionals should be invited to the Transition Reviews and a comprehensive Transition Plan produced. The Transition Plan plays an essential role in collating the relevant information to facilitate a young person's move into adult life. For young people with **JNCL**, forward planning is essential and there often needs to be a 'parallel' planning process with two or more options. The goal should be to offer a continuation at the present placement, with increased support if necessary; or facilitate a smooth transition to a more supportive environment, if the young person experiences a sudden or severe deterioration.

There are a range of post-16 options including local special school, specialist college and specialist residential provision. Some parents choose to support their son or daughter at home, though may access a range of available local services.

Will there be changes to the provision of education for my child?

The new Children and Families legislation coming into force in September 2014 has introduced major reforms in provision for children and young people with SEN. The introduction of the single 0-25 Education, Health and Care should help children, young people and families affected by NCL. There will be the option of a personal budget for children and families which will hopefully extend some choice and control over the support available to them. There will be a 'local

offer' of support by the LA that will include arrangements for short breaks. The reforms are extensive and it is not possible to fully cover the changes in this leaflet.

Will the school provide other forms of support?

The school often plays a central role in helping families to gradually access additional support for their child, including respite care, help with equipment and adaptations at home. Increasing difficulties that are seen through progression of the disease will place further strain on the family, meaning medical support at both school and home will become increasingly necessary. An effective **keyworker** liaising between the school, respite, therapy and medical services can provide support to the family and help them to manage the ever increasing number of professionals involved.

How can the BDFA support us?

The **BDFA** can provide general advice about NCL to schools and identify useful resources available to them. We also offer individualised guidance, support and training (where possible) to school staff and other professionals working with a child or young person through our **Education Advisor**.

The **BDFA** always seek parental consent before discussing individual children with their professionals and assure parents of complete confidentiality. We believe it is important to 'report back' following any conversations or visits, so that parents know exactly what has been discussed and are completely 'in the loop'.

The **BDFA** and our **Education Advisor** can be approached by any parties seeking advice, information or assistance with the educational needs of any child or young person diagnosed with a form of NCL.

To contact us: Tel: **0800 046 9832**E-mail: **education@bdfa-uk.org.uk** or **support@bdfa-uk.org.uk** Website: **www.bdfa-uk.org.uk**

The information in this document is provided on the understanding that it is intended for general information purposes only, therefore the Batten Disease Family Association (BDFA) accepts no responsibility or liability for any other form of use, nor for circumstances arising from any unintended or unsanctioned use. The BDFA have made every effort to ensure that the information provided is appropriate and accurate at the time of publication. All decisions pertaining to meeting the needs of an individual child should be managed, in conjunction with parents or legal guardians, by qualified professionals working for the appropriate health, educational and social services.

Edited by Matt Hobbs (RN Child) with guidance from BDFA Education Advisor Barbara Cole and support from Bluepepper Designs.

© Batten Disease Family Association, 2014(r) Registered Charity No. 1084908

BDFA, PO Box 504, Fleet, Hampshire GU51 9GE Freephone Helpline: 0800 046 9832 Email: education@bdfa-uk.org.uk or support@bdfa-uk.org.uk Website: www.bdfa-uk.org.uk

Supporting the educational needs of children who have a diagnosis of NCL (Batten disease)



How will NCL affect my child's education?

Many families affected by the various forms of **Neuronal Ceroid Lipofuscinoses (NCL)**, commonly referred to as **Batten disease**, will be faced with numerous important decisions about education for their child. The **Batten Disease Family Association (BDFA)** aims to help them get the best possible provision, as well as advising and supporting those professionals working with them.

We are able to provide unique support through our **BDFA Education Advisor** (a qualified teacher of the visually impaired who has worked with many children and young people diagnosed with the various forms of NCL).

This leaflet offers information about support available for individuals who have **Special Educational Needs (SEN)** due to a diagnosis of NCL, as well as providing general advice for families who wish to ensure their child receives the best educational experience possible. We recommend families share this document with all the professionals from education, health, social and other services working with them.

The BDFA recognises that the INCL (infantile), LINCL (late-infantile) and JNCL (juvenile) disease processes impact upon children and young people in varying ways and at different stages of their life. We are developing resources to address issues particularly relevant to each form of the disease e.g. coordinated support from Early Years Practitioners for those with INCL, ensuring medical support is facilitated appropriately and sensitively for those with



LINCL and developing appropriate behavioural strategies for those with **JNCL**.

Each child and family's journey with NCL will differ in some ways to that experienced by others due to many varying factors (e.g. the specific genetic diagnosis, age of onset etc.). However, through drawing upon our experience, insight and knowledge; we aim to offer holistic advice and support regarding the various educational issues that arise at different stages, which will always focus on the individual child and family.

What are Special Educational Needs (SEN)?

SEN refer to the communication, physical, sensory and emotional difficulties experienced by children and young people that require support. Each may need additional or alternative assistance in their education than those children who are not considered to have SEN. Being diagnosed with any form of NCL disease means that a child or young person should be considered to have SEN.

What about planned changes to SEN Law?

The Children and Families Act 2014 introduced changes to the way SEN and disability (SEND) will work in England. **Education, Health and Care Plans (EHC plans)** will gradually replace **Statements** and will bring together all the education, health and care needs of the child. Statements already in place will gradually be converted to an EHC Plan by April 2018. There are differences in SEN law in Scotland, Northern Ireland and Wales. Please contact the **BDFA Education Advisor** for advice on this.

What should I do about my child's SEN?

Following a diagnosis of NCL it should be recognised that your child has SEN and you will need to talk to a relevant professional involved with your family. Depending on the age of your child, this may be a health visitor, someone in their early years' education setting, a teacher or **Special Educational Needs Coordinator (SENCO)** at the school.

You should explain about the diagnosis and share any concerns you have, providing examples of how this could impact on their education. It is important to ask what support can be put in place and consider contacting other support agencies who may be able to assist. Please contact the **BDFA** if you would like assistance or to discuss this.

Freephone Helpline: 0800 046 9832 email: education@bdfa-uk.org.uk www.bdfa-uk.org.uk



Will my child need additional educational support?

Children learn at different rates and in various ways, so teachers differentiate the curriculum in order to meet the range of learning needs in their class. This means they may use alternative teaching methods and/or teach children at different levels. Sometimes additional support is required for the child to be able to access the curriculum. This may mean adapting resources and methods of teaching to take into account visual loss, provide support for physical challenges and ensure that an individual's medical needs are being met.

What educational support should first be offered?

Prior to an NCL diagnosis it is likely that your child will already have an **Individual Educational Plan (IEP)** in place. We advise that you discuss it with your child's teacher if you are not sure about this. An IEP should contain:

- short term targets for your child
- teaching strategies to be used
- provision to be put in place
- when the plan is to be reviewed
- success and/or exit criteria
- outcomes

The IEP should be reviewed two or three times per year. IEPs will be replaced by person centred plans as part of the change to EHC Plans and you and your child will be involved in drawing up and reviewing these plans.

Your child's SEN needs will require a statutory assessment. From September 2014, this will be called an **EHC needs assessment** and may be requested by you or with your agreement by the school, health or care professionals working with you and your child. This will mean that your child's SEN are fully assessed by a range of professionals. The **BDFA Education Advisor** can provide further details about this assessment process.

What is a Education Health and Care Needs Assessment?

This is a statutory assessment of your child's education, health and care needs. Once the request has been received, the **Local Authority (LA)** has six weeks to decide whether to undertake a EHC assessment. You can appeal if this is refused but this is unlikely in such a complex and severe condition. Advice will be requested from parents, the school or early years setting, the Educational Psychologist, the Health Authority and Social Services. The LA can contact any professionals that you have specifically named for advice.

The LA has six weeks to complete the assessment. The LA will issue a draft EHC Plan with copies of all the reports/advice gathered during the assessment. Parents have 15 days to comment on the draft plan. The LA must issue a final plan within twenty weeks of receiving the request for an assessment.

Will we be able to contribute to a statutory assessment?

If the LA decides to make a statutory assessment they must seek parental, educational, medical, psychological and social services' advice – and any other contributions they consider appropriate. They can also contact any professionals that you have specifically named. A statutory assessment, where possible, should also contain the views of your child.

You know the most about your child so your views and the information you provide are very important. LAs must make sure that they are listening to the views of children and their parents throughout the assessment process.

The LA should send you guidelines to help you record your advice. If you are having difficulty writing your views, it is possible to ask your named officer to arrange for someone to record them and also include any information you wish to provide. Your parent partnership service may be able to help you prepare your advice, though the **BDFA Education Advisor** can also offer assistance. Things you may want to consider when giving your advice include:

- the health needs your child has due to their NCL diagnosis
- your child's physical, communication and personal skills
- your child at home, e.g. their hobbies and interests, interactions with family
- your child at school, e.g. what your child enjoys there, problem areas, relationships with peers
- your child's behaviour (both at home and school)
- what help is currently being provided and whether it is working
- what help you think your child needs
- your child's views

It may be helpful to include a description of the likely NCL disease progression to assist in planning for the future.

Various charitable organisations offer advice, information and support in identifying and accessing appropriate specialist equipment. This can be very useful when circumstances are not covered by statutory provision. The **BDFA** can offer assistance in identifying appropriate sources of help and also have a **Small Grants Scheme** that can be utilised.

Can my child's curriculum be adapted?

It is a challenge to adapt the curriculum and school processes to meet the needs of a child with NCL as they may have both deteriorating skills and an awareness of their loss of abilities. Continual monitoring and assessment of the child's learning is essential to provide the best possible support, however this needs to be carried out sensitively so that the child and parents are not constantly reminded of this loss.

Children can and do continue to learn and develop despite the increasing effects of the disease process. They often respond positively to tasks and activities that combine challenge with support and achievement. Support from an **educational psychologist (EP)** can be very helpful in identifying the specific support needed. Schools have developed innovative and imaginative ways of celebrating achievements and this can be extremely important for children and parents.

What educational issues are specific to INCL?

Sadly, due to the early onset of **INCL** and its rapid progression, consideration of a school education is not likely to be a priority amongst the many other challenges that will be faced. However, holistic aspects surrounding development, socialisation and stimulation will continue to be important for the young child and family. These and other relevant issues will require careful thought and significant assistance from the available support professionals and services.

Many **SEN** services have **Early Years and Childcare teams** who can help identify and provide advice regarding the provision needed to support children with complex needs. **Local sensory services** and organisations such as **SENSE** should be able to give additional support. The **BDFA** has expertise in this field and can be approached by any parties seeking information or assistance.

What educational issues are specific to LINCL?

Children with **LINCL** sometimes attend a mainstream school initially, though parents will often need to consider the additional support available at a special school placement. The transition needs to be planned carefully so that the child is able to "link" the two placements. Sometimes the child can attend a special school on a part-time basis, then gradually increase the time spent there.



There is usually a marked delay in the child's development, whilst the onset of seizures, difficulties with balance, mobility and learning mean that significant additional support will be needed. Some children with **LINCL** do not develop spoken language though may use **Makaton** or other forms of signing. Visual impairment tends to develop later in the disease progression.

The SEN of some children with **LINCL** may result in the additional support available at a special nursery or school being recommended immediately.

The **BDFA Education Advisor** has significant experience with these matters and can be approached by any families and professionals seeking information or support.

What educational issues are specific to JNCL?

Most children with **JNCL** attend mainstream schools until their vision begins to markedly deteriorate and other challenges become apparent, including seizures and difficulties with speech and learning. Some children with **JNCL** are able to make a successful transition to secondary school with their peers, yet for others the secondary transfer stage presents a 'natural' point for moving to a special school

Parents may already be concerned that their child with **JNCL** is struggling with the greater demands of their mainstream primary school placement as they approach the secondary transfer stage at 11 or 12 years of age. The mainstream secondary environment is even more challenging, with an increased pace of learning, many more teachers and frequent changes of classroom. For some children there may be the option of a transition to a specialist school for the visually impaired, depending on where they live.

Some children make the transition to a special school at this stage when their peers are also moving on to new schools. Others go on to the mainstream secondary school but need increasing amounts of individual support and adaptations to the curriculum to ensure that they are fully included in all

Can I educate my child at home?

It is possible to educate your child at home, although we recommend that you seek specialist advice as this can be a complex and challenging undertaking. If home schooling is of interest you can discuss the issues with the **BDFA Education Advisor**.

The LA can issue EHC Plans and have issued Statements for children who are being educated at home. If the LA are satisfied that you can provide the help set out in the Statement or EHC Plan, they do not have the duty to arrange it. The Statement or EHC Plan can name the school that the LA considers suitable but will also state that parents have made their own arrangements for the child's education. The LA still has a duty to review the Statement or EHC Plan annually. You can request that the Health Services arrange and provide therapy provision that is identified in the Statement or EHC Plan if your child is being educated at home.

Will my child get support for their visual impairments?

When having a diagnosis of NCL, it is incredibly important that a child's visual impairment (VI) is fully recognised, with support being given both at school and in the home. Around 80% of our learning is experienced through our vision and the loss of this sense affects children in everything that they do. Sometimes a VI teacher is not involved in the support of children with NCL and the loss of vision can be 'overlooked' as other forms of deterioration linked to the condition take precedence.

It is essential that a **VI teacher** is involved in monitoring the vision of a child who has a diagnosis of NCL, as deterioration is often 'masked' by the child's gradual adaptation to its loss. It is important that all those working with your child know what he or she is actually able to see, so they can adapt all school activities to account for this. Learning to use particular types of technology and developing alternative methods for doing things that do not rely on vision are just a few examples of ways to help children diagnosed with NCL adapt to their gradual loss of vision. A VI teacher can provide invaluable support, training and advice to school staff along with parents and carers.

Will my child's communication be supported?

Assisting children to maintain ways of communicating for as long as possible is of the utmost importance. Some children with forms of **INCL**, and possibly **LINCL**, may not acquire any, or only a few, recognisable words. Deteriorating communication skills often result in great distress and frustration, for both the child and those close to them.

Speech and language therapy can play a key role in maintaining skills and in laying the foundations for continuing communication when speech is no longer comprehensible.

Accessing speech and language therapy for your child can be extremely frustrating for parents and may be very difficult if it is not mentioned in their Statement or EHC Plan. If it is not mentioned in their Statement or EHC Plan, it may seem difficult or even impossible. Understanding the complex dynamic between deteriorating learning abilities, short-term memory and language skills will assist schools and families in finding individual solutions that enable the child to continue to communicate through any means possible.

Useful strategies include using:

- key words, symbols or objects in a tactile/auditory calendar or timetable to help 'make sense' of the child's day
- 'memory boxes' of tactile, audio and video material that can stimulate communication as well as maintaining long-term memories through the recording and replaying of events, visits or familiar stories
- laptop computers or iPads, which can enable sharing of these materials between family members and professionals



Will specialist equipment be provided for my child?

Local Authorities or the school may supply certain specialist equipment that a child or young person needs for education purposes. The school should be able to arrange for an **occupational therapist (OT)** to assess your child and may provide aids for use in school and at home. You should contact the Head Teacher or SENCO for further information. If your child has a Statement or EHC Plan, then details of specific equipment required to help your child at school should be included. If you have concerns about your child's needs, then these should be raised with the school.

In Scotland, a child's co-ordinated support plan should detail any equipment necessary to meet a child's educational needs.

What is a draft Education Health and Care Plan?

You will be sent a draft EHC plan that includes essential information, an 'all about me' section and sections on SEN, health needs, care needs, outcomes and target setting, SEN, Health and Social care provision together with the advice and information gathered. Every EHC Plan is personalised to meet the needs and outcomes for each child or young person. The EHC plan may have details of a personal budget that enables families to choose how to support the child. You can express a preference for a particular school.

What should I consider when checking the draft EHC Plan?

It is very important that you check the draft EHC Plan carefully and make sure you are happy with all sections. When reading the draft EHC Plan, try to imagine that a new teacher with no knowledge of your child will be reading the Plan. Will it tell them your child's main learning difficulties and the help needed to meet these challenges? It is sensible to check that the Plan:

- lists your child's difficulties (read through the reports and clarify that each difficulty is included)
- lists all the provision required by your child (make sure that for each need listed there is specific provision to meet that need)
- describes the help to be provided, who will provide it and how often
- gives details of any special equipment that your child needs and who will provide it
- carefully and fully acknowledges the NCL disease process, the nature of the progression and how it affects your child as an individual, now and into the future

You should also:

- make a list of any disagreements or gaps between the professionals' reports and the draft EHC Plan
- highlight any words or phrases that you don't understand and ask for them to be clearly explained



 make a note of anything that you disagree with or that is unclear. (You can include any particular wording that you believe should be in the Plan).

What are the timescales involved?

Local Authorities must make sure that they are listening to the views of children, young people and their parents throughout the assessment process. The LA must make sure that parents and young people have access to independent information and advice and receive support from independent supporters or keyworkers when they need it. Meetings with professionals should be coordinated so that parents do not have to repeat the same information several times to different professionals.

The whole assessment and planning process from the point an assessment is requested until the final EHC Plan is produced must take no more than 20 weeks.

Once the draft EHC Plan has been issued parents have 15 days to comment on any outstanding concerns. This should be done in writing by email or letter. You can also request a meeting.

The LA will ask you whether you want your child to attend a special or mainstream school and you can state the school that you want your child to attend. The LA can refuse your choice of school only on one or more of three clearly defined grounds. If your choice of school is refused you can contact the **BDFA Education Advisor** who will offer advice and will tell you about other sources of support.

The LA will work with you to finalise the plan and identify any additional resources or provision needed. They must issue the final EHC Plan within 20 weeks from the initial request.

Who is able to help me deal with this process?

Friends, relatives or your local Parent Partnership Service can attend meetings with you. You can also ask to meet with any professionals who contributed to the EHC assessment. The **BDFA Education Advisor** can also be contacted to support you.

What are Parent Partnership services?

Parent Partnership services are expected to provide a range of services including access to an independent parental supporter for any parent who wants one. An independent parental supporter is someone who can support you by, for example, attending meetings, encouraging parental participation and providing information about SEN procedures. For details of your local Parent Partnership service Tel: 0207 843 6058, Email: nppn@ncb.org.uk or www.parentpartnership.org.uk

What happens when I receive the final EHC Plan?

There will be a EHC Plan Coordinator who will work with you to make sure that all of your child's individual needs in education, health and care are considered and the provision required identified. Any issues you may have should have been discussed and agreed within this process.

Once the LA gives you the final EHC Plan they must name a school or college and put the educational provision in place. At this point you have the right of appeal to the **SEND** Tribunal if you do not agree with the description of your child's SEN, the special educational provision specified or the school or college that has been named.

If you want to appeal, you have to contact the independent **mediation service** in your LA first. You need a certificate to say that you have done this before you can appeal to the SEND Tribunal. There are strict time limits for this process. Please contact the BDFA Education Advisor for more details.

What happens regarding school transport for my

Children with EHC plans or who have Statements and have a diagnosis of NCL should have free home to school transport as they will meet the LA's eligibility criteria. However, when parents disagree with the LA about their choice of school, 'deals' are sometimes made where the LA agrees to name the parents' choice of school on the basis that the parents will fund the transport costs. Transport arrangements will not be recorded in the EHC plan but may be included within a 'personal budget'. The BDFA Education Advisor can advise you on the complex issues surrounding transport to and from school for your child and suggest other sources of support.

How should I deal with Annual Reviews?

Children with Statements already in place before September 2014 will continue to receive the support outlined in their Statement. However, over the next three and a half years. Statements will gradually be replaced by EHC Plans, usually as part of the Annual Review or when a change of school is being proposed. The LA has to initiate a 'transfer review' and the new EHC Plan should be issued within fourteen weeks of the review.

'Navigating the paperwork' surrounding a child's SEN is often challenging for parents and sometimes schools. Parents have a very clear idea of what they want for their child but are sometimes mystified by the meetings, paperwork and processes involved. There are processes within the SEN legislation that can help parents to access services and support for their child, although parents are



not always made aware of the importance of key meetings and documents. If your child has a recent diagnosis of NCL and this is not already in the Statement, you can ask the LA to begin the process of converting the Statement to a EHC Plan. During this process additional information and provision can be identified and added.

The Statement or EHC Plan must be reviewed every year. You will be able to meet with the school, the LA and all the professionals involved in your child's education, health and care. You will be able to talk about what has happened since the last review and about any changes that might be needed. There will be reports from the school and from professionals such as the VI teacher working with your child. These should be available to you two weeks before the meeting. You can put your views in writing and raise any issues that you want to be discussed at the meeting. A report of the meeting is prepared by the school and sent to the LA who must then carefully review your child's SEN provision and decide if any changes must be made. They must then send their decision to you and the school within four weeks. There is a right of appeal if you do not agree with their decision.

Children with NCL have very complex educational needs that may change rapidly. The Annual Review process is very important in the planning and provision of support for your child over time. Reports and assessments can provide evidence for increased support and more frequent reviews can be requested. The BDFA can offer parents practical and emotional support in preparing for and attending review

Should I consider a special school or nursery?

Children with specific types of NCL sometimes attend a mainstream school initially, though parents may need to consider the additional support available at a special school placement as they navigate their journey with the disease. The special educational needs of some children with forms of INCL or LINCL may result in the additional support available at a special nursery or school being recommended immediately.

It can be very emotional and challenging for both parents and children to come to the realisation that they are no longer

able to attend the same school as their siblings or friends. We can work with families as they make the necessary plans for moving to a more supportive special school and in dealing with the difficult decisions they are likely to face. The BDFA Educational Advisor can offer advice and support to families and the professionals involved, make visits to schools and attend meetings with parents.

Can I influence decisions about my child's education?

Parents often feel overwhelmed by the sudden and intense involvement of a wide range of professionals, with many describing a sense that their child has been 'taken over'. However, there are difficult decisions to be made, with the need for other sources of support to be introduced and coordinated. Schools can, and do, work very effectively with children and families to ensure the best possible quality of life. This can only be possible with a sensitive, open and honest approach that ensures the full involvement of parents and promotes communication and collaboration.

What about support for my child's medical needs?

All schools should have a policy and procedure for dealing with the education of pupils with medical needs. As a result of a diagnosis of NCL and the associated medical needs, your child will benefit from a health care plan being put in place. This will identify the level of support that your child needs and clarifies the help that can be provided. This should be reviewed at least annually, but can be reviewed more frequently depending on your child's needs.



Will NCL affect my child's behaviour and education?

A child's deteriorating skills and behavioural issues may challenge both the family and professionals, possibly putting the educational placement at risk. The complex disease process can result in the child appearing to be "naughty" or "attention seeking" and demonstrating:

- frustration, anxiety, challenging behaviours
- a decreasing ability to cope with changes in routine
- unpredictable behaviour that is resistant to commonly used strategies

The BDFA offer support for children, parents and school staff to help them understand the behavioural issues arising from NCL. This can assist them in formulating effective support programmes.

Can a school placement be maintained as the disease progresses?

Maintaining the child's present school placement whilst planning for inevitable changes is a challenging 'balancing act' for schools and families. It can be very difficult for parents to accept that remaining in their present mainstream school may not be possible for their child. However, the provision of additional one-to-one support, equipment and specialist therapy can help to maintain a placement long enough to plan and prepare for transition to the more supportive environment of a special school.

Many children and young people diagnosed with NCL often retain significant long-term memory, meaning a gradual transition from a mainstream to a special school placement can facilitate 'linking' their original school environment with a new placement. Visits, part-time attendance and building new routines over time can all help reduce anxiety and frustration as well as enabling parents to become comfortable with the new situation. Continued links with the mainstream school (often attended by siblings) can be beneficially maintained throughout the progression of the disease.

When might we consider residential education?

A residential school may be considered when there is agreement that your child has such severe and complex special educational needs that they cannot be met through local day provision. Education, health and social care services are required to work closely together and to jointly agree funding. If a residential school is named in a Statement or EHC Plan, the LA should also agree arrangements for home to school transport with parents.

There will be significant changes for a family to consider and deal with should their child attend a residential school placement. The BDFA Education Advisor can offer support and help you to look at this in a holistic way.