Niemann-Pick type C disease
A practical guide for parents and carers

02:
COPING WITH A DIAGNOSIS
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When your child or loved one is diagnosed with Niemann-Pick type C it can have a profound effect on your whole family. For many families, a diagnosis of NP-C does not happen instantly, and can come at the end of weeks or months of tests and investigations. In many cases this can be the point from which you begin to contemplate the future. During this period of adjustment you may face what feels like a never-ending round of appointments as you begin to meet with the many professionals who will form a network of care around your loved one. You may find yourself having to tell your story time and time again.

Despite her challenges, our daughter had a love of life that was nothing short of inspiring, and a warm sunny character to boot.

Hearing the news that your child or family member has a life-limiting disease, but that no one can tell you the exact path the disease will take, may make you feel that your hopes and dreams have been shattered.

People constantly ask us how we cope and comment about how brave we are, but I don’t think we are brave. We have no choice but to accept that NP-C is part of our lives and that we may never know for sure when the disease will start to show itself fully.
At this time there is a lot to think about. Diagnosis comes at a point when you may not be capable of thinking clearly or taking information in.

We didn’t tell anyone about the diagnosis, only a few family members, and in hindsight we were living in a state of denial.

The NPDG (UK) clinical nurse specialist can help families to make sense of things in the days following a diagnosis. She can work directly with your local health and social care professionals to ensure they understand the medical, clinical and social needs of your child/loved one. Although she is available to give advice over the telephone, she often travels to work with families in their own homes throughout the UK and is happy to accompany them to medical and other appointments as required.

Our son was born in 2003 and within hours of his birth he developed jaundice. I worked as a midwife and alarm bells were beginning to ring. He was quickly transferred to the hospital liver unit and we went through a rollercoaster of investigations, blood tests and hospital admissions. It appeared that nobody could tell us what was wrong with him until, when he was 11 months old, he was finally diagnosed with Niemann-Pick type C. We were completely devastated. Things like that didn’t happen to people like us. But as we all know, they do. I can remember vividly the first conversation with the NPDG (UK) clinical nurse specialist; she really helped to put things into perspective and gave us lots of accurate information about the disease. We attended the first NP-C baby clinic in Manchester and it was a really positive experience to meet other families affected by the condition.
The NPDG (UK) can provide information about the disease that you can distribute to your local healthcare team and also to your family and friends. The Group provides emotional, as well as practical support; if you would like to speak to someone about any aspect of the disease, you can call the 24-hour helpline at any time. It can also put you in touch with other families who know what you are going through. There is also an e-forum, hosted by parents of a child affected by NP-C, especially for parents to share their thoughts and experiences.

To join the forum, visit ‘Hope for Hollie’ at www.hopeforhollie.co.uk.

Our son is gorgeous, funny, full of life and very much part of our family. We don’t know what the future holds for him but in a bizarre way it has taken some of the pressure away from being a parent. Having spent a lot of time with my other sons at rugby and football matches I am well aware of the high expectations that some parents have. I know that he might not be the cleverest or the fastest but we love him just the same and enjoy whatever time we have with him.
**Professionals who will provide support**

**Your local care team**
The NPDG (UK) can provide an information booklet designed to help all professionals involved in caring for your loved one. Please contact us for further details.

**Your family doctor (GP).** Having a good relationship with your GP can be very helpful. Offer to provide them with information about NP-C, so that they can provide appropriate support and medication as and when it is needed.

**Paediatric team and nursing staff.** These are the people who you will deal with directly. Having a good rapport with them can be very helpful as they are often your primary source of support. Paediatric teams generally work in specialist children’s departments at hospitals, with some areas of the UK having specialist community teams.

**Community nurse (district or support nurse).** Responsible for visiting you in your own home, a community nurse will provide support and advice as required.

**Social workers** will help you access the services you require. They can also assist you in completing paperwork for grants and benefits. Your lead professional may be based within a social services team.

**Portage.** This is a home-visiting educational service for pre-school children with additional support needs and their families. It takes place in the child’s own home and aims to equip parents with the skills and confidence they will need to help their child, no matter what the their difficulties may be. Portage offers practical help and ideas to encourage a child’s interests and make learning fun for all the family. For more information and your nearest service visit the National Portage Association website at [www.portage.org.uk](http://www.portage.org.uk) or call 0121 244 1807.
Early support programme. The early support programme supports parents and carers of disabled children aged five and under. It helps to coordinate the services that a child and family receive, bringing together all of the services and support available from different agencies. This can enhance your support network, making it easier for you to access services, advice and information regarding your child’s health, education and social care needs. Early support is currently available in England and Wales.

To find out if the programme is available in your local area, talk to your health-care professional, contact the NPDG (UK) or visit the Early Support website at www.earlysupport.org.uk.

Occupational therapist. This is the person who will assist you in obtaining practical aids and equipment that may be required.

Dietitian. A dietitian will provide advice on nutritional needs, including calories, vitamins and minerals.

Speech therapist. The role of the speech and language therapist is to assess and treat speech, language and communication problems. They can also help when eating or swallowing problems occur and can offer solutions if oral feeding becomes too difficult or no longer safe.

Physiotherapist. A physiotherapist will provide help and advice regarding movement and posture.

Lead professional. Your lead professional can provide a vital link in the care of any child with a disability. This person will work closely with the family and assist them in recognising their needs, liaising with other health and social care agencies to address these needs.
The role of the lead professional

Ideally, this role needs to be taken on by someone local to you, who is familiar with local service provision. Often this person is a social worker or a nurse and they will ensure that the team of professionals involved with your family works together. The lead professional will ensure that they are aware of the role each will play and are kept up to date with developments through regular meetings.

The lead professional is the first port of call for non-medical problems. If they cannot help they will find someone who can. Many hours can be wasted as families phone around trying to find the right person to speak to. This can be stressful on top your other commitments and concerns, so is best avoided.

Specific lead professional arrangements vary by local authority. Your social services department will be able to guide you through local arrangements.

It is important that all of the agencies involved work together to ensure optimum care. The NPDG (UK) clinical nurse specialist can help to arrange multi-disciplinary team meetings to ensure this happens. These meetings would usually be held annually but could be more often if need be.
Carers are people who provide help and support to a family member or a friend who may not be able to manage because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children, or young people who care for another family member.

When our son became ill I faced a number of battles to ensure that he received the treatment he deserved and gained quite a reputation as a ‘stroppy mum’. I really feel that I have a responsibility to act as his advocate and never accept anything that I feel is not in his best interests.

Carers are often so preoccupied with the health and wellbeing of the person they are caring for that their own needs are forgotten. Remember, it is important to look after yourself too, though this is, of course, easier said than done. Yet it doesn’t have to take a lot of time – often just a few minutes of quiet can help. Looking after your own health and emotional needs will mean that you are more able to carry out your role as a carer.

If you are a carer, you may be entitled to receive help and support from social services and other organisations. Your doctor (GP) is a good person to talk to about this or any other issues you may have and will help you to access the information and support that you need.

Some practical hints and tips:

**Try to get enough sleep.** Carers often go short of sleep – either because the person they care for needs attention during the night, or because they have too much on their minds to be able to relax. The following tips might help. If you, or the person you are caring for, still have problems sleeping, speak to your GP.
• if you have trouble getting to sleep, don’t go to bed too early
• don’t snooze during the day unless you know you are going to be kept awake at night
• establish a good bedtime routine. Avoid alcohol, have a warm drink and a bath, and make sure the bedroom isn’t overheated
• if you like to read before going to sleep, choose something soothing. If you like to listen to the radio, play some music rather than listen to the late night news
• after you switch out the light, try some visualisation techniques to occupy your mind. For instance, imagine an idyllic beach scene where the sun is warm, the sea is blue, and you can feel the sand on your bare feet
• if you wake in the night with your head full of worries, try spending an hour or so out of bed, or sitting up with the light on if you sleep alone. You can read, do the ironing, watch television or write down everything that’s on your mind. You’ll find these are preferable to tossing and turning in the dark

**Take time for regular meals.** If possible enlist help from family and friends with cooking and shopping. You may enjoy the everyday things like shopping and cooking but find you are not getting a chance to do them because you are caring for your child. In this case you can ask someone to help to look after your child so that you can do these things yourself.

**Look after your own health needs.** As a carer you need to be as healthy as possible. You probably have a lot to cope with at the moment. Your caring load may be at its maximum now, or it may be gradually increasing. Either way, keeping an eye on your own health will make a real difference to the way you cope and how you feel. Simple things like eating healthily, taking vitamins, maintaining good hand hygiene and keeping distance from friends who have coughs and colds can all make a big difference.

Even when you can’t get out of the house, try to make time throughout the day to rest, exercise, or just take a few deep breaths. You may feel you haven’t the time but if you can create just a 20-minute gap in the day, it will be worth it.
**Take regular exercise.** Exercise is good for you and can combat depression – a regular walk and some fresh air can do wonders for your wellbeing. You may feel tired, but regular, moderate exercise will actually give you more, rather than less, energy. As a bonus you’ll sleep better too. Choose an activity that is right for you – one that you enjoy. Simplest of all is a regular, daily walk – round the block, to the nearest park, or to the shops. The closer to home the exercise is, the easier it will be to do regularly.

Remember there is no such thing as a perfect caregiver – feelings of anger, frustration and guilt are normal. Share your feelings with a friend, relative, doctor, counsellor or support group.

**Further information for carers**
The ‘Caring for someone’ section of the Directgov website provides detailed information about the help and support available to carers, including carers’ rights, employment issues and money matters.

For more information visit [www.direct.gov.uk](http://www.direct.gov.uk) and search for Caring for someone.

**Carers UK** aims to improve the lives of carers and to ensure that they receive the same rights as everyone else. This includes a fair level of income, adequate support to protect their health and wellbeing, and access to the world of work, leisure and education.

For more information visit [www.carersuk.org](http://www.carersuk.org).

**The Princess Royal Trust for Carers** is the largest provider of comprehensive carers support services in the UK. The Trust currently provides quality information, advice and support services to carers, including young carers.

Visit their website [www.carers.org](http://www.carers.org) for information on all the key issues facing carers.
When a child is diagnosed with a rare condition, such as Niemann-Pick type C disease (NP-C), it can have a profound affect on the whole family. For parents caring for a disabled child there are many adjustments to be made. Your hopes and dreams for the future may suddenly be altered as you try to face the fact that your loved one will lead a very different life to the one you had imagined. As the disease progresses, those affected by NP-C can develop complex needs that change rapidly. Many families may struggle to cope with the emotional and financial implications of the condition. The quality of family life may be severely affected.

Relationships, when they are working well, provide us with stability and support. At this time, parents or partners may need to take on new roles, deal with emotional and financial pressures and absorb an astonishing amount of new information. The stress and challenges involved can put a strain on your relationship, as you and your partner adjust to the changes in your lives.

Each of you will do this in different ways and often at a different pace – one of you may want to talk openly about the situation while the other may need more time. It is normal for feelings of sadness, worry, denial, anger, embarrassment, fear, confusion, guilt, concern, resentment, and shock to occur before a sense of acceptance enters your hearts.
Having an ill or special needs child or loved one represents a loss of control. It takes time to reach acceptance and a willingness to adapt. One of the main challenges is striking a healthy balance between dependence and independence. It is important for you to talk about your individual needs and how they are affected, both practically and emotionally. Look at how life has changed for each of you and in what ways. Ask how you can best support each other.

**What can you do to strengthen your relationship?**

- communicate by talking openly about problems and issues when they occur; listen to each other without criticising or judging; try to understand each other’s point of view
- develop a strong family support network – allow friends and family to provide extra support and don’t be afraid to ask for extra help
- realise that there will be disruptions in the course of your relationship now and then, as there can be in all relationships
- maintain physical intimacy. Physical intimacy is an important part of a relationship, but tiredness and stress can take its toll. This is a common issue for many parents and talking about your needs and expectations can help
- be patient with one another, each of you will be under pressure so show support for one another in small ways, such as emotionally by really listening to each other or physically with a hug or a squeeze of the arm
- celebrate each milestone – and hold on to memories of the good times – as a couple as well as a family
- together, learn all you can about your child/loved one’s condition, and seek help or advice that will provide practical and helpful day-to-day solutions
- make time for just the two of you to be together
- think about your lives and how things have changed, talk about the future, share your hopes and fears
- try to emphasise the positive changes. Many couples share their sense of joy, awe and thankfulness as they speak about their special child, and feel that their relationship was enriched through their experiences
Remember, all couples argue. If a conflict occurs, give each other some uninterrupted time to express your feelings. Be prepared to compromise – if you can’t reach an agreement then why not agree to disagree? Often revisiting the issue at a later date will provide time for both of you to consider each other’s point of view and it will then be easier to address. Try to keep your sense of humour. Try to understand that some rows often have an underlying cause – tiredness, stress or feelings of resentment. Again, communication is key to working out the real cause and understanding the feelings underneath. If you are worried about your relationship, there are many resources that could provide help.

Both women and men can be victims of domestic violence. It may be difficult to admit to yourself and others when this is happening, but it’s not your fault and help is available. The police, and your local social services department, can provide help and advice in this area. You will find their contact details in your telephone directory. You can also call the NPDG (UK) for details of other organisations that provide support for victims of domestic violence.

**Useful resources for relationship support**

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<tr>
<td>Premier House, Carolina Court, Lakeside, Doncaster DN4 5RA</td>
<td>18 York Place, Edinburgh EH1 3EP</td>
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<td>t: 0300 100 1234</td>
<td>t: 0845 119 2020</td>
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<td>w: <a href="http://www.relate.org.uk">www.relate.org.uk</a></td>
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**Marriage Care**

Marriage Care helps people prepare for, achieve and sustain successful marriages, supporting them should their marriage break down.

1 Blythe Mews, Blythe Road, London W14 0NW

\[1\] t: 020-7371 1341

w: [www.marriagecare.org.uk](http://www.marriagecare.org.uk)

**Contact a Family**

Contact a Family is a UK charity offering advice and information on many different issues to families with disabled children. They can also provide information on specific conditions and rare disorders.

209–211 City Road, London EC1V 1JN

\[1\] t: 0808-808 3555 (office hours helpline)

e: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

w: [www.cafamily.org.uk](http://www.cafamily.org.uk)

**One Plus One**

One Plus One aims to strengthen and support couples and family relationships through research, information, and by training practitioners to work with families.

1 Benjamin Street, London EC1M 5QG

\[1\] t: 020 7553 9530

w: [www.oneplusone.org.uk](http://www.oneplusone.org.uk)

**Family lives**

Family lives is a UK charity offering support to anyone parenting a child. They run a freephone helpline, develop innovative projects and provide a range of information.

CAM Mezzanine, 49-51 East Road, London N1 6AH

\[1\] t: 0808 800 2222 (24-hour freephone confidential parentline)

w: [www.familylives.org.uk](http://www.familylives.org.uk)

Further details of organisations and services that may be able to help can be found on the NPDG (UK) website on the ‘Useful links and resources’ page at [www.niemannpick.org.uk](http://www.niemannpick.org.uk).
Giving siblings information about their brother or sister’s disability

Parents often ask when they should give siblings information, and how much to give them. They can worry that giving information to siblings will make them anxious or will be a burden to them. We usually find that the opposite is the case: siblings usually feel less anxious if they are kept informed about what is going on. If they are not given factual information they may make up their own incorrect story about what is happening.

Of course the age of the sibling has a big bearing on how much information to give. Think about it like sex education. You can give matter-of-fact information with less detail to young children, and more detailed information and discussion of the issues to older children. In children younger than seven, you will need to gauge how ready they are for information by the questions they ask. Always answer questions honestly and simply. Even young children will detect if you are not being honest and will lose trust in you as a result.

For many parents, the hardest thing about talking about the disability or illness can be dealing with their own uncomfortable feelings when they do so. Try to be comfortable with it – young children will be unlikely to attach these intense emotions to talking about disability. When children get to about seven years of age, they are likely to be asked questions about their brother or sister at school and this will increase their need for information.
Here are some ways to begin talking about disability/chronic illness with siblings:

- with very young children, an easy way to start discussions is by looking at a picture book (about a disabled child) together
- ask the sibling what he or she knows about disability or illness in general and start from there. You may find that he or she is well-informed or might need more accurate and age-appropriate information
- if they seem reluctant to start a face-to-face talk about it ask them if they would like to write down a list of questions about the disability or illness for you to answer. With younger children you could do this together on a big piece of paper
- with older children, you can go on the internet together and look at the information about a particular condition on a website. Some siblings will do this anyway, however it is better if you can be there to discuss things with them. Read the information yourself first before you show it to your child
- next time you have a hospital, clinic or therapy appointment ask the sibling in advance if he or she has any questions to ask the health professional. You may want to invite the sibling along to ask these questions in person, or you can offer to do that on their behalf. The sibling can write them down for you
- explain the role of the professionals who will see your disabled child. As adults we may take it for granted that a child understands who the physiotherapist or the paediatrician or the incontinence nurse is. Siblings may be familiar with the name but not really understand what these people do. It can be helpful to explain the practical ways in which they are helping with their brother or sister’s problems
• with older children, ask them if they would like to know more about the professionals who are involved with the family. Would they like to meet them and ask them about how they help their brother or sister?
• with younger children, you can make a poster with the names of the professionals on it and write down, or draw, or stick on pictures showing what they do. Ask professionals if you can take a photo of them at their work to help a young sibling remember what they do. This will give you a prop for talking with siblings about how they feel about professionals coming into their home. Encourage them to write down questions that you could ask a professional on their behalf – this will help siblings feel a sense of control over the things that are happening in their family

Be aware of sibling issues and their impact at certain stages
Certain issues are particularly relevant for siblings at different stages in their lives. The following is a rough guide and issues will vary from one child to another and depend on each family’s particular circumstances.

Pre-school children 0-5
• receiving less time and attention from parents
• imitating an older child but not understanding unusual or unfamiliar behaviour
• feeling jealous of the child with the disability or illness
• experiencing anxiety due to not understanding a brother or sister’s condition. The sibling may not be able to put this into words
• feeling neglected due to the frequent absence of parent and child for hospital stays or visits. This is most difficult for younger children
School-age children 5-11
- telling friends and others about their brother/sister
- dealing with teasing and embarrassment. This tends to happen from the age of seven onwards
- being involved in caring for the child with a disability/illness
- needing information about their brother or sister’s condition
- not having enough time together as a family
- wanting their brother/sister to have his/her own friends
- feeling that teachers do not understand the pressures at home
- dealing with the possibility that rules or discipline are different for the sibling and the other child
- being frustrated if the children are not able to play together

Adolescents 12+
- dealing with embarrassment
- worrying about being like their brother or sister and the identity issues which this can provoke
- being aware of the influence of disability on their future choice of career
- having enough space and opportunities to develop their own life
- being concerned about their brother or sister’s future
- not wanting to burden parents with their own emotional needs
- dealing with introducing new friends to the family
- feeling responsibility, confusion or guilt about being unaffected by the disease
- expressing concerns about having their own children. This can happen when they start to learn about genetics at school
Grandparents and siblings

Parents often ask how they can get grandparents to help support siblings. Some find that grandparents make themselves available to the whole family for practical help and emotional support. Others can find that since the diagnosis of the disability, grandparents have backed away and therefore the siblings lose out on contact they had in the past.

When a child is diagnosed with a disabling condition, this is often very hard for grandparents to deal with. The way they respond differs from person to person. A good starting point is to read Contact a Family’s fact sheet for grandparents which looks at this area in detail. Visit www.cafamily.org.uk/grandparents.html.

Most grandparents want to help but don’t always know how best to do this. They may also be overwhelmed by the impact that the diagnosis has on their own children, who are now parents themselves. Talk to them about how things are for all of you, and let them know the sort of things that will be helpful. Things like:

- doing an activity with the sibling that you can’t do as a family (swimming, going to the cinema, having a long walk in the park or helping them learn how to ride a bike)
- having the sibling to sleep over so that they can have an evening that is peaceful and relaxing
- allowing the sibling to do homework or a craft project at their house where they will not be interrupted
- getting one-to-one time for attention and nurturing, such as reading them a story, giving help with homework, cooking together
- taking the disabled child for a visit or sleepover so that the sibling gets time with his or her parent(s)
• having the disabled child and sibling visit or sleepover together so that they have this as a shared experience
• being available to chat on the phone with the sibling about things which concern them. This can be really good for siblings aged ten and upwards, whose grandparents live further away
• letting grandparents know that their contact is really important for the sibling, and that you don’t want the sibling to lose this as well as having to deal with other sibling issues

**Dealing with low moods or anxiety in siblings**
Most children go through phases when they feel low or very anxious about things. Low moods or anxiety can arise from many causes. Worries about school and friendships, being ill or over-tired, not having goals to achieve, having food intolerance or going through puberty can all affect children. Parents of siblings are often concerned that low moods or anxiety are caused by things to do with having a disabled brother or sister. Without doubt siblings do have some extra challenges to cope with and some may experience mood problems as a result.

**How you can help**
• reassure your child that you love him or her and that although things seem hard at the moment you will provide support
• let them know that you will listen to them if they want to talk to you, or that they can write down their worries or concerns for you to read if this is easier for them
• provide your child with some ‘looking after’ time, eg provide a favourite meal, run a bath for them, do something for them that they would normally do themselves
• encourage your child to do something they enjoy, something that normally lifts their mood or helps them relax
• take your child out for a walk or a swim – exercise is a great mood-booster
• check whether your child’s mood is related to things that he or she eats, or if he or she is ill
• find another member of the family, or a family friend, that your child will be happy to confide in, and encourage your child to talk to them, if they want to
• tell siblings about things that are happening in the family so they always know what is going on
• find out whether your child’s change in mood is linked to a specific event. Ask the school how things are going there. Talk to your child about possible issues that may be affecting him or her
• encourage your child to talk to friends about how he or she is feeling
• take steps to make sure that your child’s friends can, and are still happy to, come over to your house. It is important that they feel that their social life is something which doesn’t happen entirely elsewhere. This may mean talking to your child’s friends or their parents about NP-C and giving them a chance to ask about anything that might be concerning, difficult or unfamiliar. Sometimes friends might become distant or reluctant to spend time ‘hanging out’ simply because being around a child with disabilities is new and therefore a bit scary
• if you have a gut feeling that your child needs help from a professional then ask your social worker, GP, or child’s school to help you get support for your child. Your area will have a child and adolescent mental health service (CAMHS) which you can contact for more information

For information about anxiety and depression in children, visit the Young Minds website www.youngminds.org.uk where you can download their leaflet on depression in children.
Sibs
Sibs is the UK charity for people who grow up with a disabled brother or sister. It supports siblings who are growing up with, or who have grown up with, a brother or sister with any disability, long-term chronic illness, or life-limiting condition. There are over half a million young siblings and over a million adult siblings in the UK.

Siblings have specific needs that require attention at different stages of their lives. These include combatting isolation, information, and strategies for coping with the situations they find themselves in. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision for siblings throughout the UK. Their long-term vision is that each local authority in the UK will have a dedicated sibling service. This would provide sibling groups and one-to-one support for children who are siblings of a child with an illness or disability.

They believe that siblings have a right:

- to be valued for who they are and what they do
- to be seen as individuals with specific needs
- to access reliable sources of advice and information as well as support services
- to influence the services and policies that affect them
- to reach their full potential
Sibs can help in the following ways:

**Young siblings** are offered advice and ideas for coping with difficult situations and the opportunity to learn about the experiences of other siblings.

**Adult siblings** can get information on planning for the future and on dealing with issues related to childhood.

**Parents** can find out about sibling issues and get tips on supporting siblings at home.

**Professionals** can learn more about sibling issues and how to support siblings through their work with families.

**Sibling group leaders** can get information on running sibling groups and on developing their sibling support service.

To find out more about Sibs visit their website [www.sibs.org.uk](http://www.sibs.org.uk) or call 01535 645453.
One of the most valuable resources for parents or partners is to have an informal support network of people in the community where they live. This includes people who can offer different types of support for you – when you need a break, someone to talk to, or even simply someone to help you do a task like shopping. It is better to have a list of people who can all offer different things, rather than expecting one or two people to take on much bigger roles. Some people may be available to help you on a regular basis, other people may be happy to help when you are stuck or have an emergency. Other parents, friends and older people are often more than willing to help.

Some of the things you can ask people to help you with:

- transport – by car, taking a child on the bus, bringing a child to or from school, giving you a lift somewhere
- shopping – getting a prescription, getting the weekly shop, helping a sibling get a birthday present for a friend
- housework – ironing, going to the launderette, cleaning, preparing a meal
- helping a sibling with homework
- forging links with people with children the same age, so siblings can have their tea or a sleepover there
- sitting – with siblings and/or your disabled child
- playing with your disabled child for an hour while you spend time with a sibling
You should not have to worry about doing something in return – for most people being able to help is reward in itself. Many of us now live away from our extended family or do not live in a community where people automatically support one another. Some people find it hard to approach a family, and although they may be only too pleased to help, they may need to be asked. Helping others in need gives people a sense of purpose and belonging. It also helps other people get a better understanding of your situation. Sometimes you may need to make the first move.

Ask people round for a coffee a few times and get to know them. See if there is any small thing you can do for them (eg helping them with information, a contact with someone, use of a computer, feeding a pet or watering plants when on holiday). Ask them if you can call on them if things are difficult. The worst that can happen is that they say no. If they have come round and want to be sociable it is quite likely they will be happy to help with something.

For further guidance on the subject of relationships, please see Contact a Family’s booklet titled Relationships and Caring for a Disabled Child. You can download this from their website (www.cafamily.org.uk) or you can have a copy sent to you by post. Contact their helpline 0808 808 3555 for more details.
Caring for a child or loved one at home can be a rewarding and positive experience, providing you have the right amount of practical and emotional support, plus the aids and adaptations that will help to make daily living easier.

However, at times, you may feel overwhelmed, stressed, or just tired. At these times you may want to consider enlisting some help that will allow you to have time to relax, catch up with chores or spend some time with your husband/partner or family. There are many options open to you, such as respite care, home carers and your local hospice. NPDG (UK)’s clinical nurse specialist can help you arrange these, and would be happy to discuss the options available to you in greater detail. You can find out more about these options in the third booklet in this set, Living with Niemann-Pick type C disease.

Aids and adaptations
At some point all those affected with NP-C will require some form of aid or adaptation to assist daily living. The aim is to meet increasing needs and to make life as easy as possible for the whole family. Thinking ahead can be traumatic for a family. However, it is advisable to make arrangements ahead of time, aiming to implement the required changes before they become necessary. Understandably, many parents want to hold on to ‘normal’ life for as long as possible. Introducing aids and adaptations is a tangible, and therefore possibly difficult, step in facing up to the impact of the disease. They are designed to help, however, and planning in advance can mean that you are prepared for your child’s or loved one’s changing needs. Exploring the help available may also provide some comfort and help in dealing with your fears.
The priority is to arrange a full assessment as soon as you feel that help would be useful. It is usually the occupational therapist (OT) who will come to the home to discuss your child or loved one’s needs. It is important that this assessment not only takes into account current needs but also considers future requirements.

It can be useful to have the NPDG (UK) clinical nurse specialist in attendance to help during an assessment. It is often difficult to contemplate that you, your child or loved one may need hoists or similar aids in the future. It is also difficult for a person who feels they can be independent to accept that they may be safer with a shower instead of a bath, or indeed be better with a ground floor bedroom. Every individual’s needs will be different. A child will also need aids or adaptations to enable them to continue attending school and these will be considered during an assessment.

Because the OT and NPDG (UK) clinical nurse specialist have worked with many children and adults, they are able to suggest aids to make life as simple as possible for the affected person. One child may need a raised desk at school to angle their books, which makes looking from book to the teacher and the board much easier. Another may work better on a computer. An adult may need handrails throughout the house. Again, each individual’s needs are different.
As mobility decreases, a wheelchair may help with transport for some, or all, of the time. Adaptations to the access of the house may then be required, such as widening the doors and fitting a ramp. There may also be issues with access to the bedroom or bathroom if these are upstairs. In some cases a stair lift may be appropriate, in others a full through-floor lift may be more appropriate. Alternatively, you may want to consider moving the bedroom and bathroom to the ground floor.

Big changes to the home do take time as plans need to be drawn up and grants or other finance sought. It is therefore advisable to make arrangements ahead of time, aiming to implement the required changes before they become necessary. Thinking ahead – especially about the future path of the disease and the increasing needs of your child or loved one – is always difficult. But it is important for the family to talk about future needs with their own nursing team and the NPDG (UK) clinical nurse specialist, even if this is just making a list of the problems you fear the most, and asking for the answers and solutions that may be available when they become needed.

For children there are some aids which are much more fun. A young child with type A or early onset type C can benefit from aids that offer visual stimulation and are calming and soothing. Bubble tubes, fibre optic lights and projected pictures and lights are fascinating for a young child who begins to find handling other toys difficult. The NPDG (UK) clinical nurse specialist can assist families to access aids such as these through grant agencies and other sources. There are also a lot of home-made and low-cost toys and playthings that you can find or make yourself for your child to play with or look at. You might want to make a mobile using foil, shiny paper, fairy lights and Christmas decorations (taking care to keep breakable items out of reach).
Another idea for young children is to put together a ‘treasure basket’ of everyday household things like pan scourers, wooden spoons, pieces of sponge and plastic containers filled with rice or pasta. Inexpensive items such as brightly coloured trinkets, light-up novelty items and torches can make good alternatives to toys and may be more age-appropriate for older children reluctant to play with ‘toys’.

Your child or loved one may also enjoy activities where their own movements, like kicking or rolling, create a noise. Dance mats or floor play mats with noisy or squeaky parts are particularly good for this. This type of play can help a child to maintain a sense of cause and effect and to understand that they can have an impact on their surroundings, as well as helping adults to maintain muscle strength and movement.

It is important that a very dependant person is as comfortable as possible. The OT can advise regarding appropriate seating that will support them safely. An adult or school-age child with NP-C may primarily have memory or communication problems and may benefit from using a computer and email rather than talking to people.

There are many aids and adaptations that can make what is a difficult time easier. The multi-disciplinary team that cares for your child or your loved one will ensure that you and your family access everything you may need.
Asking for help can be difficult for many of us, but particularly when it comes to seeking financial support. Living with a child or loved one with a life-limiting illness can have a range of financial implications. One or both parents may have to give up work or work part-time to become a carer. Day-to-day living for someone with a disability is often more expensive and adaptations to your home and aids to help daily life can be costly. There are various ways to receive financial support to ease the stress associated with these financial commitments.*

**Contact a Family benefits fact sheets**
These fact sheets give an overview of all the main benefits available including the tax credit and benefits system, and focuses on those aspects which affect families with disabled children.

[www.cafamily.org.uk/benefits.html](http://www.cafamily.org.uk/benefits.html)

**The Department for Work and Pensions (DWP)**
The DWP is responsible for a range of benefits and services for people who are sick or disabled, and their carers.

[www.dwp.gov.uk/directgov/](http://www.dwp.gov.uk/directgov/)

**Tax credits**
Tax credits are income-related payments made to people who are responsible for children and to people in relatively low-paid work. The support available to people with children is called Child Tax Credit and the help for those working is called Working Tax Credit. Responsibility for administering tax credits rests with HM Revenue & Customs.

*The information in this section is subject to change. For the latest information and advice in this area, please contact the NPDG (UK) central office.*
Child Tax Credit is paid direct to the person who is responsible for caring for a child or children. It can be claimed both for your own children and any other children who normally live with you and for whom you are responsible. The amount you receive depends on your circumstances and income level. You do not have to be working to claim. Claimants must be at least 16 years old and be resident and present in the UK.

The amount you receive is calculated using several cumulative elements to suit the different circumstances of families. The more elements you qualify for, the more you receive. Those elements include: a family element for all who qualify for Child Tax Credit; a child element for each child within the family; a disabled or a severely disabled child element for any disabled children that you are responsible for.

For further information and to assess your entitlements, visit the HM Revenue & Customs website at www.hmrc.gov.uk/taxcredits.

**Disability Living Allowance (DLA)**

Disability Living Allowance (DLA) is a benefit that is awarded on the basis of the effect that the symptoms of Niemann-Pick disease may have on your daily life. It can be awarded to a child or young adult if they have mobility problems, difficulties with personal care or if they require supervision from another person.

DLA is not means-tested or based on national insurance contributions, and is tax-free. You may claim DLA if you are still working. It is paid on top of any earnings or other income you may have, and is not affected by savings or capital you own. It is almost always paid in addition to other social security benefits and tax credits. DLA can also act as a gateway to other benefits.

You do not need to have a carer, or someone helping you, to qualify for DLA. What matters is the help you need. The payments are made to you and you may spend it on anything you like. DLA is divided into two different components: the mobility component and the care component. You can be awarded one or other or both together.
To claim the allowance, you will need form DLA1. You can get this from your local Jobcentre Plus office or by contacting the Department for Work and Pensions (DWP) Benefits Enquiry Line on 0800 882200. You can also download a copy at www.dwp.gov.uk and claim online at www.dwp.gov.uk/eservice.

Direct payments

What are direct payments?
Local authorities can give payments, instead of services, to allow disabled people and carers to buy in the services they have been assessed as needing. Direct payments are designed to promote the independence of parents and their disabled children who would like to manage their own social care needs. If you have a child who is under 16, direct payments will usually be made to you as their parent. When a child becomes 16 she or he can receive payments in their own right to allow them to buy in the services they have been assessed as needing. In the past parents could not insist on direct payments.

Parents can find out more by searching ‘Direct payments’ on the direct.gov.uk website. Direct payment schemes vary across the UK. For details of arrangements in your area, you will need to click through to your local authority’s website.

With direct payments the amount you receive should be enough to allow you to meet all the costs involved in buying in services. This includes tax and national insurance as well as the fee for a police check (should you employ help directly). Social services will usually deduct an amount from the payments equivalent to what you would have been charged had they arranged the services for you. Alternatively, social services may make the payments in full and ask you to reimburse them any assessed charge. Any payments you receive must be used to pay for services to meet the assessed needs.
Can I get a blue badge?
The Blue Badge scheme (formerly the Orange Badge scheme) provides on-street parking concessions for disabled people in the UK. The badge can also be used in many European countries. You may be eligible if you regularly drive your disabled child and s/he has severe walking difficulties, is registered blind, has severe upper limb disabilities or receives the higher rate component of disability living allowance. To see whether you qualify you should apply to your local social services department.

Disabled facilities grants
The Disabled Facilities Grant (DFG) can help with the cost of work which improves the infrastructure or environment in your home. It covers the costs of building safe play areas, installing a stair lift, adapting a lighting or heating system, or building a new bathroom facility. To be eligible you must be an owner occupier, tenant (private, local authority or housing association) or landlord with a disabled tenant. Usually, an assessment will be carried out by your occupational therapist or local social services department to determine what is needed. Whatever the scale of the proposed works it must be agreed that these are ‘necessary and appropriate’ in meeting the disabled person’s needs and also ‘reasonable and practicable’ taking into account the age and condition of the property.

DFGs are not means-tested in England, Wales or Northern Ireland, so long as the grant is provided to meet the needs of a disabled child.

In Scotland grants for repairs and adaptations to properties are available from local authorities to both homeowners and private tenants. For more information ask your local authority for the Scottish Executive booklet, Housing Grants.
You should always contact your local housing authority to check what help is available before starting work on your home to make it suitable for your disabled child. Contact a Family produces a fact sheet, Aids, Equipment and Adaptations, giving more information about housing grants. This can be found at

www.cafamily.org.uk/benefits.html.

**Family Fund**
The Family Fund can give lump sums for specific items which help provide care for a child or young person with severe disabilities up to the age of 17. Family Fund grants are targeted at low-income families, so social and financial circumstances will be taken into account when an application is assessed.

All requests will be considered, so you can ask for whatever you need most. For example, laundry equipment, transport expenses, clothing, holidays and so on. You should apply in writing to the Fund giving the full name and date of birth of your child, brief details of his/her disability, the type of help you need and whether you have been in touch with the fund before.

The Family Fund, Unit 4, Alpha Court, Monks Cross Drive, York YO32 9WN
t: 0845 130 4542 e: info@familyfund.org.uk w: www.familyfund.org.uk

**Who else can help?**

**Government information on rights for people with a disability**
For guidance on how to find out about your rights as a disabled person, go to www.disability.gov.uk.

**Citizens Advice Bureau**
Access up-to-date, independent advice at www.adviceguide.org.uk.
**Equality and Human Rights Commission**
The aim of the Equality and Human Rights Commission is to end discrimination and harassment of people because of their disability, age, religion or belief, race, gender, or sexual orientation. Find out more about the commission at www.equalityhumanrights.com.

**Benefit Enquiry Line**
Claim forms for all benefits can be obtained from your local benefit office or by calling the Benefit Enquiry Line on 0800 882200 (Monday to Friday 8.30am–6.30pm and Saturday 9am–1pm. Customers who have a textphone can call the Benefit Enquiry Line free on 0800 243355).

**NPDG (UK) Central Office**
The NPDG (UK) can also provide assistance or advice. Please call us on 0191 415 0693 or email niemann-pick@zetnet.co.uk.

The photographs used to illustrate this booklet show people with NPD and their families and friends. They have all been used with permission, but do not generally relate to the text they have been placed alongside.
This booklet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or would like further information, please contact us at the address below.

Note: the information contained in the pack is not a substitute for professional medical care – it is meant to complement the advice and support you receive from your health and social care team.