contact a family
for families with disabled children

Our family, our future















30 NOT OUT
30 years of strengthening families with disabled children

30 families with disabled children tell their stories

Our family, our future

30 families with disabled children tell their stories





30 NOT OUT

30 years of strengthening families with disabled children

Photography by Jeremy Larkin

Our family, our future

“We are celebrating because our teenage daughter recently held an ice cream and ate the entire thing unaided, thrilled because she’s putting her own shoes on, even if she may never do them up herself. Acknowledging and celebrating these achievements is what makes the future bright for our family: the ability to focus on Susie’s unique strengths and gifts”

“Doctors told us Katie wouldn’t live past her first birthday and that she would never walk and talk. Katie is now almost three. She sits up in a chair and her legs are getting stronger every day. She is aware and has learned Makaton sign language. Every day is a bonus and we must live day to day. Our future is today and each hour is very precious. We can’t worry about next year, we just have to think about the here and now”

Contact a Family supports families with disabled children, regardless of the disability or condition.

Families with disabled children have the same hopes and dreams as other families, but are often prevented from achieving them by prejudice and a lack of understanding.

As part of our 30th anniversary celebrations, we asked 30 families from across the UK whose children are affected by a range of disabilities to tell their story. We wanted to give parent carers a voice to talk about their achievements, acknowledge the challenges, reflect on their aspirations and fears for the future, and above all to celebrate their family life.

As this collection of stories shows, families want the best for their children and they dream of a life full of possibilities. But they are met with challenges along the way.

Many talk about the constant battle for support and information, and the bureaucracy they are faced with, which prevents them from enjoying family life. Some of their children have life-limiting conditions and each day spent together as a family is precious, so fighting these battles is all the more frustrating and heartbreaking.

Some talk about their fears, about what will happen in the future when they are no longer able to care for their child. There is great uncertainty about the support that will be available to their children in adulthood and this is adding to the pressures that families are under.

There is acknowledgement of positive changes for families with disabled children in some areas of the country. Parent carers are beginning to be listened to by some local decision makers and recognised for their expertise to help shape services for disabled children. But in other areas the lack of support and help from professionals is a constant source of frustration and anger.

As the stories show, families with disabled children are just like other families. They are making an enormous contribution to society and all they want is a little understanding from decision makers, budget holders and professionals. They would also like recognition from society for the unique gifts and talents that their children bring – because of their disability.

A huge thank you to all the families for sharing their stories.

Contact a Family

Jackie Ambrose, Adam Taylor, Joe (16), Laurie (10) and Caroline (9)

Tynemouth, Tyne and Wear, England

It was a big shock when we first found out that Laurie was autistic. He was nearly three, and initially we feared him needing constant care and never developing. Over time however, we've come to see autism as an important part of Laurie's personality. Without some of the quirky things he does, he just wouldn't be him.

We're lucky to have excellent support, both emotionally and practically, from our families to help us when we need it. In the early days, we benefited very much from attending a 'More Than Words' course, enabling us to meet other local parents in similar situations, and to share in all the ups and downs.

Laurie is now ten, and has higher functioning Autism, which means he can cope with the national curriculum, but his social skills are impaired. Next year, he'll move up to the local secondary school. It's a tribute to the staff at primary, and of course Laurie himself, that we feel confident making this move. We're also keen that he will walk to school, so he'll no longer have expectations of taxis to school every day. We'll have to crack this one together, but we think he'll handle it.

We've been so lucky with his primary school. They have a communication resource base and a strong ethos of inclusion. At first, even getting him into the classroom was an issue. Now he attends all his lessons and has a support assistant available in class, with weekly speech therapy sessions in school. He was even chosen to go on an exchange trip to Turkey. The school was prepared to think he should have a chance. It was a fantastic opportunity to experience a totally different way of life, and given his love of football, Laurie easily found a common bond with the Turkish children.

As he gets older we really want Laurie to be independent, but we know he doesn't read social situations in the same way as other people, and we fear he could end up in a tricky or dangerous situation. He doesn't look disabled, so people might think he's being rude or aggressive, and may not make the same allowances for him as an adult as they might do for a ten year old.

What we would like to see now is meaningful opportunities in the world of work. Employers need to understand the abilities and talents that people bring – because of their disabilities.

Looking forward, we hope Laurie gets the employment he wants, that he gets opportunities, is independent, and has friends and family around to help him if he needs it. There's no rocket science behind it. It's just the same as we want for our other children.


“Employers need to understand the abilities and talents that people bring – because of their disabilities”

> “I know a lot of people who live a more traditional life untouched by disability who aren’t content. Contentment has nothing to do with disability”

Peter, Anne and Helena (4) Bodo

Sedgefield, Stockton-on-Tees, England

Helena was the result of a long sought after pregnancy. My wife, Anne, has Myotonic Dystrophy too. When we found out that the condition was potentially contributing to our difficulty conceiving, Anne went on a list for egg donation. But then she fell pregnant within six months of going on the list. Helena is our little gift from God.

Helena was just four and a half pounds at birth and she couldn't breathe. She was very floppy because her muscles were so weak. In hospital she was on and off oxygen and was fed by a tube, but she couldn't keep the food down. After a series of tests the consultants discovered a kidney disorder and one kidney had to be removed. She was only two and a half weeks old, and she was two months old before we got her home.

All of her motor milestones are delayed, and she also has both a learning delay and a learning disability. She can walk, but not far. And she can talk, but really she babbles. She has a Statement of Special Educational Needs and attends a mainstream nursery with one-to-one help. She is coming on in leaps and bounds though she struggles sometimes. Helena is very popular with the other children, but at present she cries when they hold her hand and this is one of the many things which the staff are working to improve.

No two days are the same. I work in a job with flexitime and, really, I couldn't cope without it. Helena goes by taxi to nursery every afternoon and three days a week we have someone who comes in to help with domestic things. Both of these services are provided by Direct Payments (from the local authority) but due to Anne's condition, not Helena's.

With working at the council, I tend to have a better idea of what services are available. I fear that people who are not in my position can struggle to access these services. Information isn't always easily available and parents with disabled children just don't have time to chase information. They are just busy trying to get through each day.

I do fear for what will happen to my girls if I'm not here. We have no idea how much help Helena will need as she grows up. My wife has a disability herself, and as it's a degenerative condition things are only going to get more difficult.

Above all, we just want a life full of contentment. Playing with Helena is my favourite hobby and we're so lucky in many ways. I know a lot of people who live a more traditional life untouched by disability who aren't content. Contentment has nothing to do with disability.

Karen, Kevin, Daniel (25), Damon (20), Ross (12) and Natasha (9) Brumell

Burnage, Manchester, England

We're just back from Pittsburgh and a conference for families affected by Bladder Exstrophy. Over 300 affected people attended, and my son Ross gained so much confidence meeting others in the same situation. It was great for all the family.

I could see immediately after Ross was born that something was wrong. He was rushed away and I thought he was going to die. After an agonising wait I saw him on the neo-natal ward, but was scared to touch him in case I hurt him. It was such a fearful and emotional time.

Bladder Exstrophy is a rare condition, which causes the bladder to form externally and abnormalities in the pelvic bone and genitalia. Ross needed corrective surgery at seven weeks, and I was led to believe that everything would be normal when he came home. However, a series of health complications followed and Ross spent his first six years in and out of hospital. I never left his side.

One of the hardest things is the constant battle for support. Families whose children have rare conditions just don't fit into government criteria.

When we applied for a grant for an extra bedroom and bathroom for Ross, we were refused because no one understood the condition and its psychological impact around body image. I got legal aid to fight the council using the Convention on the Rights of the Disabled Child. We won, but it was so draining.

I also had a huge battle trying to get Ross into a suitable school. Ross must catheterise at the right time or it can be a life and death situation. The school 10 minutes from where we live has staff experienced in catheterisation, so it's perfect for him. However, the local authority refused him a place because it's outside our catchment area. I fought this, going through the appeals procedure, but lost.

Now Ross attends a school with 2,000 pupils where he struggles with privacy issues and sees a psychologist. Most people don't know about his condition, he knows he's carrying this big secret, which is hard for him emotionally.

As a result of these battles, I had a nervous breakdown last year. A huge scare for everyone and I've had to learn to take care of myself.

Looking forward to the future, I hope Ross will enjoy a relationship and one day have children. At the moment his wish is to join the police force. I hope he finds a career he loves.

Our greatest achievement as a family is that we've worked through the difficult times. We are so proud of our family and of Ross for being the bright, intelligent and caring young man he is.


“...Ross spent his first six years in and out of hospital. I never left his side”

> “...the purpose of life is to be the best you can be, and that’s what we hope for our boys ”

Andrew Caan, Fabienne Libert, Pierre (11) and Jacques (7)

Ilford, Essex, England

I live in Essex with my long-term partner Fabienne and our two sons Pierre and Jacques. Pierre has a very rare condition called Ollier disease, which causes abnormal bone development mainly in the arms, legs and hands.

Like all parents we want our boys to be independent and confident in themselves. We hope that they will look to the future positively and not feel restricted or limited in what they hope to achieve, and that ultimately they are able to live their lives the way they want to.

Pierre is a very bright boy who takes pride in his education and is keen to do well in his exams. He is an avid reader and, like all boys, enjoys playing video games. Both Pierre and Jacques are bi-lingual and spend a lot of time in France visiting their grandparents and cousins, who they are very close to.

Pierre is able to walk normally but has difficulty running. He has had three major operations in his short life, one to straighten his leg and two to lengthen his legs. There have been long periods of rehabilitation following each of the operations, and we are incredibly proud of the brave way Pierre has approached this despite sometimes being in terrible pain.

Pierre understands his condition and is beginning to be aware of differences between himself and his younger brother, such as he can't run as fast as Jacques. Ollier disease restricts bone growth and I have spoken to Pierre about the fact that Jacques will probably be taller than him. Some of these issues are hard for him to deal with and he has been seeing a psychologist to help him cope.

I am a full-time unpaid carer as I gave up my job as a training manager for an insurance company after Pierre was born. We have been fortunate that I can always be here for the boys after school and during holidays.

Our greatest achievement is that we are raising smart, happy and level-headed children. We have organised our lives around them so that we are always there for them.

Looking forward to the future, our hope is that both Pierre and Jacques don't feel limited in any way. We have tried to teach them to have the confidence to pursue their dreams and to achieve whatever it is they want to do. We believe the only limits in life are those in your own mind: if you want something really badly and you work for it, you will achieve it. We believe that the purpose of life is to be the best you can be, and that's what we hope for our boys.

Ruth, Tony, Alice (12) and David (9) Card

St Helens, Merseyside, England

Our daughter Alice has Sturge-Weber syndrome, a rare condition, which is characterised by a birthmark, neurological and eye problems. The condition affects each individual differently but for Alice, it is her learning difficulties which are most challenging.

Alice is very sociable. She loves music and often tries to sing along to the tune. She goes to Girls' Brigade who are brilliant with her as two of the leaders particularly have experience looking after children with additional needs. She also enjoys dancing and swimming.

She has recently started secondary school and is doing half a day supported in mainstream and the rest in a special school. It was really difficult to put all the arrangements in place for this, but we felt it was important that she experienced some time in a mainstream setting. She really enjoys school and the after-school club where she takes part in the singing group, dance group and Boccia (similar to French bowls).

Alice's behaviour at home is becoming an issue and this has made our daily routine more difficult in recent months. I think that it may be to do with teenage hormones and because she can't convey how she feels, she is becoming increasingly frustrated.

Alice is under the care of numerous health professionals and we are forever going to appointments. It used to be worse when she was younger. We were going to so many appointments each month which left very little time for anything else. I strongly believe that professionals should be more co-ordinated. I feel literally run into the ground trying to make all the appointments needed for Alice. We would have benefited so much from having someone else to co-ordinate everything for Alice.

We are often kept waiting in clinic and then the doctor wonders why Alice is being unco-operative when we eventually see them. It would be great if all her health appointments fell on one day, it would take the pressure off me and be easier for Alice to deal with.

We use our Direct Payments to employ a carer to give Alice independence from us for three hours each week. Alice loves being with another person because she's so sociable and enjoys everyday things like eating out.

I gave up my career as a nurse when Alice was born. I now do voluntary work, supporting other parents of disabled children and rely on my husband's income. He works as a school examination admin officer.

Looking to the future, we hope that both Alice and David are healthy and happy and find something they enjoy doing and be supported in that.

> “It would be great if all her health appointments fell on one day, it would take the pressure off me and be easier for Alice to deal with ”

“Our hopes for the future are that Noah will walk and become more mobile and we'd love him to communicate a bit better”

Elaine, Mark, Lauren (9) and Noah (5) Claridge

Cardiff, South Glamorgan, Wales

I work for the BBC in Cardiff and my partner Mark is a primary school teacher. We have two children: Lauren and Noah. Noah has Angelman syndrome, a rare condition which causes severe learning difficulties.

Noah is a very sociable and happy young boy. He is due to start reception at the local special needs school this year and he has really enjoyed going to nursery.

Noah is physically strong and he loves going to the park, playing in soft play areas, and swimming. His communication is poor, but he knows what he wants and is starting to use PECS – pictures for communication. We have had to come to terms with the fact that Noah probably won't be able to work and have a career when he grows up.

Our greatest achievement as a family is that we are still together and are a happy family. I have continued to work – I love going to work and being me – it gives me a break physically and emotionally. I really think there should be more childcare available specifically for disabled children, to help parents who want to work.

Noah attended a nursery last year, which had a policy of including disabled children. However, he came home with dirty and ripped trousers after his first day and when I called to ask if everything was ok, they said they couldn't cope with Noah and that he would have to leave. It was very upsetting and highlighted the need for mainstream services like nurseries to have more disability awareness training.

I think the hardest thing has been finding out about support and services. Parents shouldn't find out by word of mouth. There needs to be good information early on about services. I also think it is wrong that families have to wait for things like speech and language therapy and physiotherapy for their children and adaptations to the home.

We had to wait six months for a special bed for Noah. All the time we were waiting Noah was in danger of injuring himself. At the moment, we are waiting to hear if we can get adaptations to our house. It could be another two years of waiting because of all the bureaucracy, which is very frustrating.

I don't like looking too far into the future, as he is always going to need a level of care. But we really hope that he can gain some independence – things like potty training and feeding himself with a spoon will make a big difference. Our hopes for the future are that Noah will walk and become more mobile and we'd love him to communicate a bit better.

Janet, Paul and Alice (12) Cummings

Durham, County Durham, England

Our daughter Alice has Dyskinetic Cerebral Palsy, which affects all parts of her body, she also has Epilepsy and associated learning difficulties. She's a permanent wheelchair user, she cannot speak and she's totally dependent on others for all aspects of her care.

My husband and I have both reduced our work hours to part time so there's always someone there for her.

Alice was about a week old when we were told she had Cerebral Palsy. Scan results showed some brain damage but they couldn't tell us at that time how severe it was. We felt shocked and went straight into protective mode with our families. It felt quite surreal – as if it was happening to someone else.

She's now 12, but academically functioning at about three or four years old, she goes to a special school. It's a long journey (an hour and a half each way, every day), but she's definitely benefited. The school works around dealing with the needs of the individual and practises conductive education. Basically this means they meet the pupils' physical needs before they start teaching anything. Alice has very definite compartments in her life: school is school and home is home, so we don't often get much out of her about her school day!

She communicates by using eye-pointing for 'yes' and 'no'. She also uses symbols to make choices. We certainly know if she doesn't want to be doing something.

At the moment, she's trialling an eye pointing communication aid at school, but it's very early days.

Alice enjoys swimming, bouncing on her trampoline, camping and being out with her friends.

Accessing the wheelchairs we want can be a big issue. It's a massive postcode lottery and I know it's not as bad here in County Durham as it is elsewhere in the country.

I don't know what it's like to have a 'normal' child, and I worry about Alice's future. Within County Durham, the local authority and health services are changing the way they see and work with disabled children and their families. However, services for disabled adults do not seem to be making these changes and appear to be at a standstill as far as progress is concerned. My feelings are that all adults with a disability are grouped together along with the old and mentally ill, and their individual needs are not always considered.

It might sound corny, but just getting on with life and being as normal as possible is our biggest achievement. We believe that life is for living. Whatever you want to do, in some way it's achievable.


“...getting on with life and being as normal as possible is our biggest achievement”


“There are very few places that I can take Saskia before we are stared at and asked to leave”

Rachael, Scott (18), Hannah (16), Sky (11) and Saskia (10) Davies

Cleator Moor, Cumbria, England

Getting the balance between caring for a child with complex needs, working, being a mum and having a relationship is almost impossible.

I live in Cumbria in a complete mad house, with my three gorgeous daughters and Hannah's baby, who is five months old. My son hasn't lived at home since he was 12, as he couldn't cope with our home situation.

My youngest daughter Saskia, has Polymicrogyria, which causes underdevelopment of the brain. She has mild Cerebral Palsy, severe Epilepsy, Attention Defecit Hyperactivity Disorder (ADHD) and autistic tendencies.

Saskia was 10lb when she was born. She had unusual looking hands and had difficulty sucking. I think I went into denial, but as she got a bit older and was missing her milestones, I began to push for answers. Saskia's dad has never had anything to do with us and so I was on my own dealing with all this.

One of our issues at the moment is the cutback in overnight care in this area. We used to get two to three nights of overnight respite per month for Saskia. That has been cut back to one night. To compensate, we get two carers for seven hours per week through Direct Payments. It is difficult to take Saskia out on my own and can be soul destroying. There are very few places that I can take Saskia before we are stared at and asked to leave. I now have to warn people before I go.

Saskia goes to a special school and loves it. She is learning Makaton sign language and is beginning to understand a lot more. She is a big fan of soft play.

I am currently studying for a degree in social work. I would love to be able to do it full time, but I can't because I would lose my Carer's Allowance! If I get a loan it's classed as income and then I would have to come off income support, which in turn would take me into more debt. Instead I have to do the degree over five years or more!

I do a lot of voluntary work: I run the ADHD support group for Cumbria and am Chair of Governors at our local school. I have recently been asked to be a trustee at the local children's centre.

Thinking about the future is really scary. Saskia can stay at Mayfield until she is 19 years old but I don't know what is going to be there for her after that. I hope that Saskia could live in her own place, supported by carers. It would be good if she could stay nearby so I could see her and make sure everything was ok.

Carrie Davidson, Gary Dicks, Dylan (3) and Jordan (1)

Belfast, Northern Ireland

Dylan is our oldest child. He loves music, massage and sensory activities. He needs a lot of support; he has no speech, is fed by a naso-gastric tube and takes many medications. Dylan has recently started attending a local special needs school and we are very happy with the support he gets.

I became concerned about Dylan's development when he was seven and a half months old. I was reassured by professionals and tried not to worry. When I noticed his eyes flickering and took him to our GP, I was told he would be referred to a neurologist. This didn't happen so I took Dylan to A and E and was told he would be put on a waiting list. I wasn't prepared to wait and saw a private doctor who referred Dylan for blood tests. That was when a diagnosis of Tay Sachs disease was made.

We were given no information about the condition, but were told that Dylan would die before he was a year old. It was later when I looked for information about the condition myself, that I found children with Tay Sachs have a life expectancy of between three and five years of age.

The battle then began for information and treatment. The hospital was reluctant to perform some procedures or provide certain medications. In our struggle to get the best for our son we turned to the local media. I'm sure that the coverage resulted in us beginning to access the right treatment and support for Dylan.

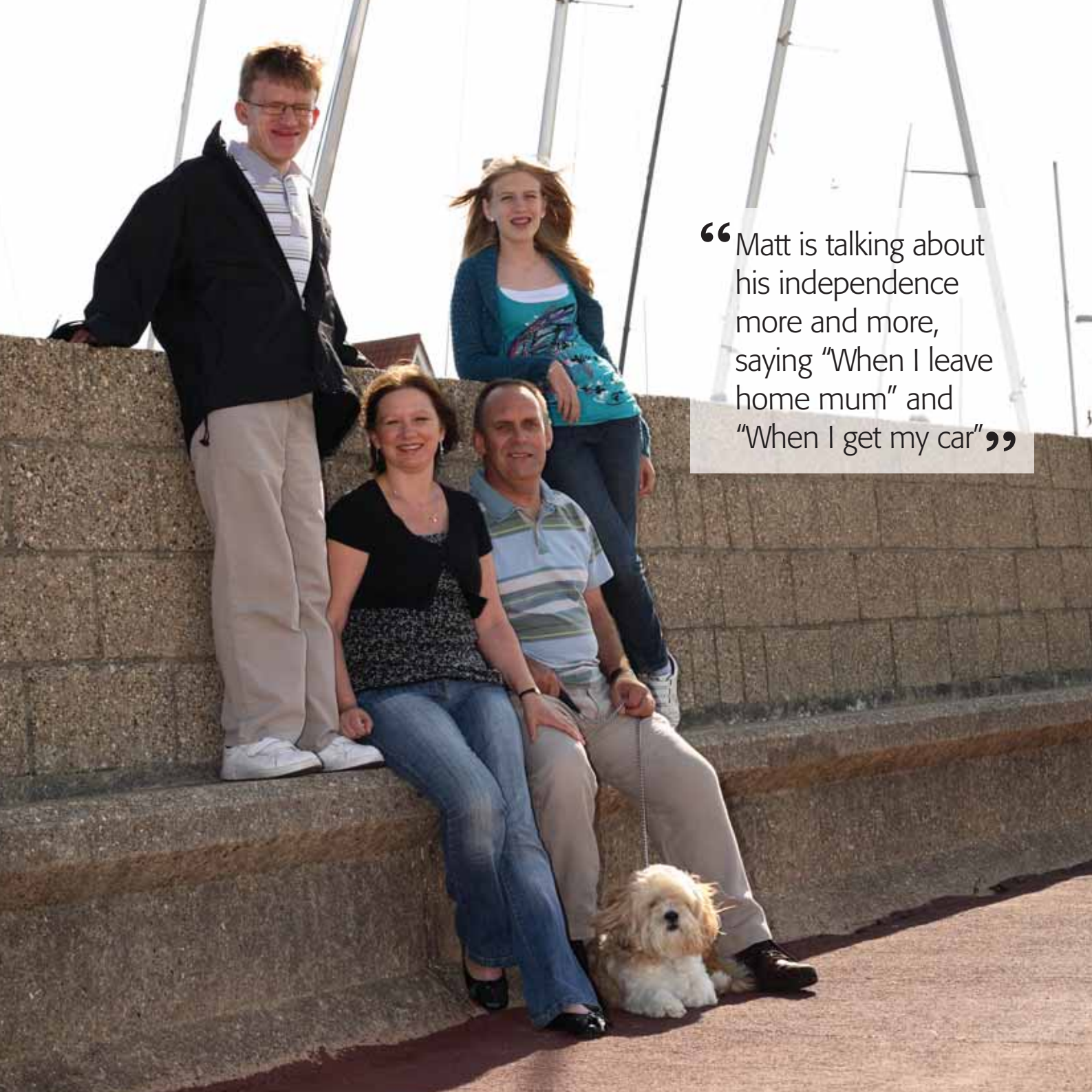
I found doctors with expertise in Tay Sachs in Germany and because nothing appropriate was available locally, we were able to gain a referral. We made several trips to Germany and Dylan was assessed as suitable for a stem cell transplant. This was a difficult time – my husband and I lived in Germany for over three months while Dylan underwent treatment. Neither of us speaks German and we were away from our family, who are an endless source of support.

Last year, when Dylan was very ill, I had to take my concerns to the medical director before Dylan was transferred by air ambulance to Germany. We were told that he could die within 24 hours.

We are very much looking forward to Christmas this year. We don't like looking too far into the future and try to take one day at a time.

I think our family's greatest achievement has been getting through the early years with Dylan and staying together. Our experience has brought us closer together and made our relationship stronger.


“We were given no information about the condition, but were told that Dylan would die before he was a year old”
Barney
GAMES



> “Matt is talking about his independence more and more, saying “When I leave home mum” and “When I get my car””

Carol, Dean, Matt (15) and Emma (14) Dixon

Lee-on-Solent, Hampshire, England

This summer we enjoyed a camping trip in Derbyshire with 50 other families who have children with disabilities. It was fantastic being around people who know what we have been through.

We live on the South coast and have two children. Matt has 17q21.31 Microdeletion syndrome, a rare chromosome disorder, and Emma is undergoing an assessment for Asperger syndrome. I work for the civil service and Dean is a health and safety manager.

Matt was diagnosed with Hypotonic Cerebral Palsy at six months, but doctors also suspected he had an underlying metabolic condition.

Matt now attends a special school for children with moderate learning difficulties, which he loves. We are beginning to think about Matt's transition from child to adult services. It's very difficult to know what help and support will be available in the future, so we want to be as prepared as we can.

There is a college near us which Matt is very keen to attend. There is a residential facility nearby and Matt could live there Monday to Friday, learning life and social skills. He must undergo an assessment to get a place, so we really hope that all works out.

One of our biggest battles was to get Direct Payments for Matt. We needed after-school care so that I could continue working. I had to fight for a carer's assessment and then had to use the Freedom of Information Act to reveal that the assessment had been flawed. Eventually, after making a formal complaint, we were granted the payments. Because of this battle, Hampshire local authority asked me to help put together their revised eligibility criteria. I'm happy to say things have changed under Aiming High for Disabled Children in this area: parents are now equal partners in the decision-making process around changes to disabled children's services.

We use the payments to employ sixth form pupils to spend a couple of hours each day with Matt after school. Matt loves it – he gets the opportunity to mix with young people and do 'normal' teenage things like go to the park together and kick a ball around.

Matt is talking about his independence more and more, saying "When I leave home mum" and "When I get my car". He's said that he would like to be a paramedic or a health and safety manager like his dad. He is very sociable and we hope that he can find a niche in the workplace that he enjoys.

Our greatest achievement as a family is that we are together and have survived. It has involved a lot of battles, but I feel confident we have done everything we can to help Matt reach his full potential.

Elaine, Anthony, Samuel (13), Teresa (10), and Jennifer (9) Doran

Barnsley, Yorkshire, England

We live in Yorkshire and have three children. Samuel, our eldest, has Down's syndrome and is undergoing an assessment for Autism. Teresa is our middle child and has Adams-Oliver syndrome, a rare congenital condition. This resulted in her being born with missing fingers, toes, a club foot and scarring to the scalp. Jennifer is our youngest child.

Inclusion has always been hugely important to us, and we have worked hard to ensure that all the children have equal opportunities of access to activities and services available to others in the mainstream community. Samuel attends the local secondary school and enjoys differentiated mainstream lessons the majority of each day. He is also able to engage in group activities with others with similar educational and social needs. The best of both worlds, you may say! As Samuel has got older, these social groups have become increasingly important to him.

Teresa and Jennifer attend the local primary school. Teresa is becoming more self-conscious about her appearance with age but we have tried to make her confident enough to be open about her condition if any questions are asked.

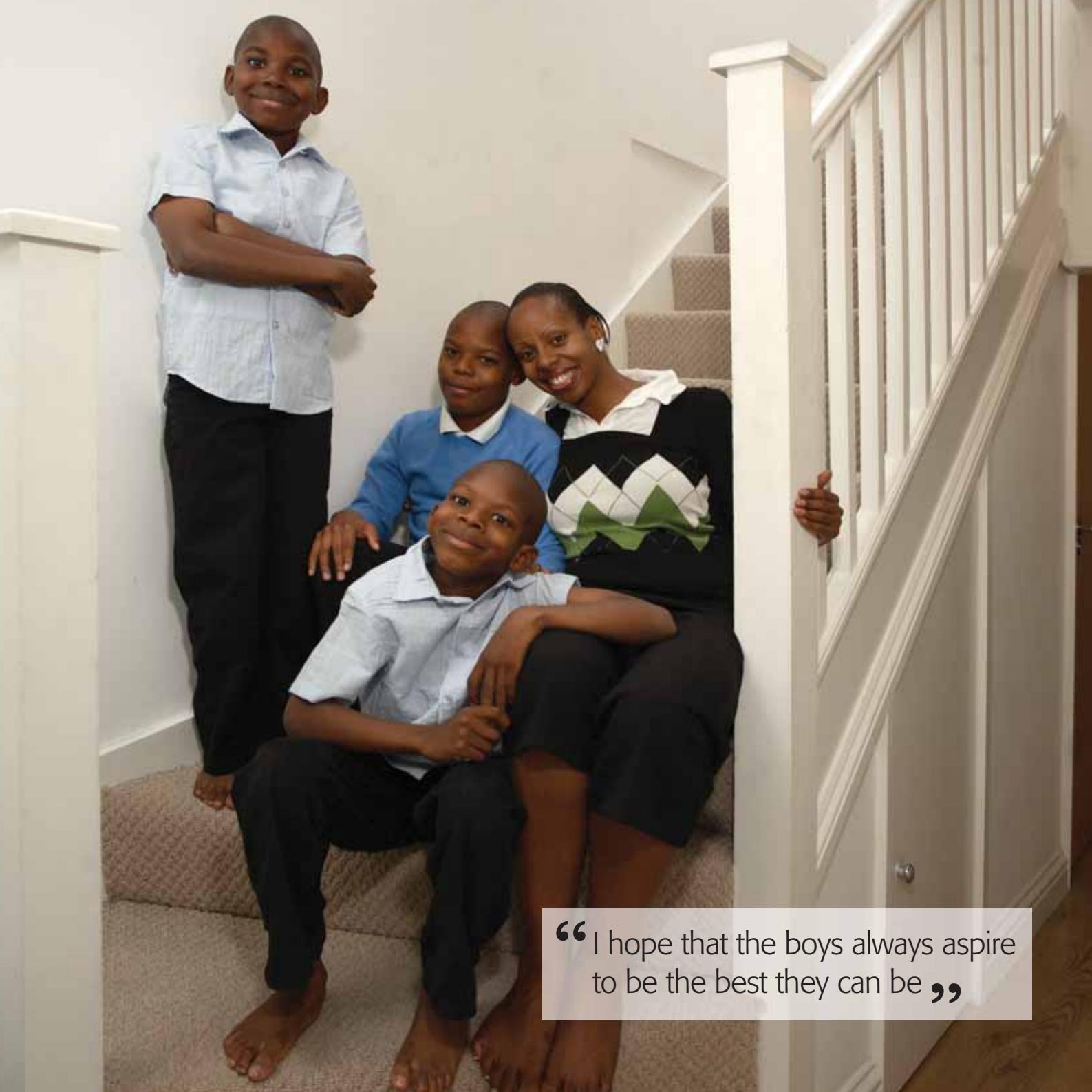
As a family, we are very busy. We both work, albeit part time. All the children play a musical instrument. Samuel enjoys playing the drums and recently played Queen's 'We Will Rock You' at the school concert alongside his teacher. Teresa plays the cornet and Jennifer plays the tenor horn. Swimming and cycling also feature on the family activity list and we are frequently seen cycling the Transpennine routes.

Samuel has always been confident in his own abilities and doesn't want us to always tag along. Unfortunately as he has got older, a number of doors are closing and it is harder to find the opportunities for him to enjoy the activities he chooses.

We have all invested a great deal of time and effort in doing things as a family. What we gained from sharing, caring and being part of that unit must have far reaching benefits for the future. And who knows what that may hold. Our vision is for Samuel to be as independent as possible, to have meaningful relationships, to be happy. While both Teresa and Jennifer are very caring towards Samuel, we have made a conscious effort not to create an expectation that they are ultimately responsible for meeting his needs.

The long-term future will always be a worry to us. All we can do is put in place the structures to ensure all our children continue to enjoy a fulfilling, independent and happy life. We hope we are on the right road in achieving this, having lots of fun on the way.

> “All we can do is put in place the structures to ensure all our children continue to enjoy a fulfilling, independent and happy life”


“I hope that the boys always aspire to be the best they can be”

Daisy, Christopher (10), Michael and Jonathan (twins 8) Etuk

Lewisham, London, England

I love my boys for who they are and am really grateful for my wonderful family. The boys have overcome many challenges and I could not have wished for them to turn out better.

I am a lone parent, living in South London with three boys. My eldest, Christopher, is low-functioning autistic and my twin boys, Michael and Jonathan, are high-functioning autistic.

The boys have hugely different personalities, but we enjoy doing things as a family. Swimming is our favourite family activity as the boys love the water and are excellent swimmers. We also enjoy going to the cinema together, and because boys will be boys they are big fans of computer games.

I was dismissed as a pushy and neurotic mother when I suggested to doctors that Christopher may have complications as a baby. At almost three years old, Christopher didn't have any speech and eventually an educational psychologist got involved. We were soon given a diagnosis of Autism.

Because of Christopher's difficulties, I was given a special needs health visitor when Michael and Jonathan were born. The authorities realised that early intervention with Christopher would have really helped his development. When Michael and Jonathan began missing their milestones, they were referred to the early years centre for support at just 17 months old. This early intervention has had a hugely positive impact on Michael and Jonathan's progress.

Christopher has a dual placement, attending special school three days and mainstream the rest of the week. He is thriving from this balance. Michael and Jonathan go to the local mainstream school. Michael is a character; he has a good sense of humour and likes to imitate people. Jonathan is the more mature and sensible one.

I have worked really hard to provide a good, solid routine for the boys and have worked to improve their behaviour. Three years ago, I could not take them on buses without them getting hurt or causing a scene. Looking back at how hard it was, I don't know how we got through it.

I have Graves disease, which makes me tired all the time, and this has added to my stress. I fought very hard to get support and now a carer takes Christopher out six hours each week and the twins go out for three hours each week. I take the opportunity to get some rest and the boys love going out to the park and visiting local attractions.

Thinking about what the future may hold, I hope that the boys always aspire to be the best they can be. University, college, a job, the opportunity to mix fully in society and make a real contribution, is what I dream for them.

Fiona, Alan, Marianne (16), Jonathan (15) and Katie (8) Fisher

Fife, Scotland

Without wishing disability on anyone, it's been a magnificent journey being the parent of a young man like Jonathan alongside our two bonny lassies.

Jonathan is one of only three males in Scotland with Lowe syndrome. He is registered blind and has the kidney problems associated with the condition. The syndrome can affect people in a variety of ways, but it's Jonathan's learning disabilities which have been most challenging .

We moved to Fife 11 years ago to ensure Jonathan received the best education possible. We were very concerned about the schooling for children with special educational needs in Moray, where we lived when Jonathan was born. We sold and lost £30,000 on our house, uprooted ourselves from our lives and temporarily split the family for Jonathan's education. Jonathan is never going to achieve qualifications but we were determined that he would have a meaningful time at school. It was a difficult move, but definitely the right one.

Jonathan was diagnosed with Lowe syndrome when he was 18 months old. We wanted to know what the future held, but no one had any answers. We thought that the system would help us, but it wasn't until Jonathan was nine years old and we were at breaking point that we got help.

I was really stressed and asked my GP for counselling. We were so desperate, Alan and I thought about pretending to break up to inflate our need. We seriously considered Alan moving to his parents as part of the plan. Fortunately we didn't have to go to such extreme lengths.

I can't underline enough the emotional and financial support of my husband. As a family, we have had to deal with the loss of income that comes with one parent being a full-time unpaid carer.

I am now involved in a group called In Control Scotland, which calls for families with a need to be given an individual budget to arrange care. We want local authorities to buy into the scheme.

I am also the UK contact for the Lowe Syndrome Association (LSA), which is based in the USA. The first time we attended an LSA conference in the USA, it was overwhelming. It was incredible to see other people with the same mannerisms and features as our son and realise that there were other families like us.

We hope Jonathan stays in school until he is 18. We always hope for the best and aim for the best we can for him. We're thinking about extending our house to build a self-contained flat where Jonathan could live. We hope to get a paid carer for him and we would always be on hand to look after him.

“...we were determined that he would have a meaningful time at school”


“People are not tolerant of conditions that they cannot see ”

Gemma, Gregg, Hannah (6), Rebecca (3) and Ellie (2) Gurney

Aghadowey, Coleraine, Northern Ireland

I was concerned about Rebecca from birth. Although she is beautiful and very cute, I knew there was something wrong. As well as my motherly instinct, she had a heart murmur, wasn't feeding, was always sick, slept all the time and wasn't reaching her milestones. She also had a flat head and poor muscle tone down one side. Rebecca had her first seizure at 14 months. It took three months to get the diagnosis of a Chromosome 6 disorder.

It feels like someone pressed the button on a rollercoaster and forgot to stop it.

It frustrates me that professionals always put any problems down to the chromosome disorder, which is so rare there is little information about the prognosis. Rebecca is affected by Hypotonia, Hypermobility, visual impairment, sensory dysfunction and global delay. I am Rebecca's advocate and have to fight for her to receive the best medical treatment.

Last year she screamed seven days a week, had black eyes and head injuries from banging her head and pulling out her hair. Some specialists who assessed her were arrogant and insulting, dismissing our concerns. Eventually a therapist suggested her behaviour was because she was 'sensory seeking'. With appropriate support and equipment Rebecca's behaviour has improved. We have to be respectful to all professionals even when they do not treat us the same way.

I've been pushing to have Rebecca's neurological state assessed. Recently a neurologist from England was visiting Northern Ireland and assessed her while she was in hospital. She thinks Rebecca may have an underlying neurological condition, not part of her chromosome disorder, and has ordered tests.

When it's your child who needs you, you would go to the end of the world for them.

Many people lack compassion and over the years some people's attitudes have made my life hell. I was once reduced to tears at a baby and toddler group. People are not tolerant of conditions that they cannot see.

Rebecca's life is appointments and hospitals. This affects the whole family. Hannah and Ellie miss out on things, and when my husband and I took Rebecca to the UK for assessments we had to leave them behind.

With the possibility of an additional diagnosis it is difficult to think of the future. Additional problems may shorten her life expectancy. We get a lot of strength from our faith.

The greatest achievement for our family is that we are such a close unit and the children are genuinely happy and loved. All I ever wanted when I was growing up was to be a mum.

Jayne, Geraint, Sophie (18) and Isabelle (14) Hill

Aberdare, Rhondda Cynon Taf, Wales

I knew within a couple of months of Isabelle being born there was something wrong. She didn't babble like other babies, didn't make eye contact, and I couldn't bond with her like I had with our eldest daughter Sophie.

Isabelle was identified as having complex learning difficulties from an early age, but it wasn't until she turned 12, just two years ago, that she was diagnosed with low functioning Autism and severe Dyslexia.

From the age of four, Isabelle had a Statement of Special Educational Needs. It set out the support she needed at school, but when she moved to secondary it was clear that Isabelle wasn't getting that help.

I know our experience is not isolated. Children across the UK with learning difficulties are being let down by the education system. Although children are given a statement, schools are not implementing the support properly because there aren't enough trained teachers and speech and language experts. Children's potential is being squandered, which is heartbreaking for their parents.

I was determined to get the best education for Isabelle so she could reach her full potential, as is every child's right, so I took our local authority to tribunal in 2007 and won Isabelle a place at a residential school where there is one-to-one support, and speech and language therapy.

The battle cost us £15,000 in legal fees and two years of stress and worry, but it was the best thing I've ever done. Isabelle has made unbelievable progress: she has gained in confidence, her speech has improved and she is learning new social and conversation skills.

It's a new chapter for all our family. My husband and I are going through a divorce: he has always been financially supportive but hasn't supported us emotionally. My frustrations with what happened to Isabelle at school and the education system in general has made me think about a career change. I am now half way through an MA in special educational needs and I hope to do a teaching qualification next year.

Isabelle is very positive and motivated. She is always on the go and looking for things to do. She excels at activities such as gardening and cookery. Isabelle has said she would like to work in her dad's garage business or start her own.

My concerns for Isabelle and children like her are what future do these children have when they leave education? Are they forgotten? I hope that Isabelle can lead an independent life. She is my biggest responsibility in life and I'm so happy that she is now thriving in the way all children should.


“...what future do these children have when they leave education? Are they forgotten?”

“Now Hope is a very happy girl, she laughs at everything and every achievement is a bonus”

Sarah, Sam, Luke (10), Hope (3) and Imogen (newborn) Hillis

Lisburn, County Antrim, Northern Ireland

Our family's four children were all born prematurely. Luke has a learning disability with borderline Asperger syndrome and Attention Deficit Disorder, Hope has complex medical needs and Cerebral Palsy, and our newborn daughter, Imogen, is currently still in intensive care, being just a few weeks old. Our second son, Connor, died in November 2004.

Within 24 hours of her birth, Hope's lungs collapsed and she suffered brain damage. It was a difficult time, we were still coming to terms with the loss of Connor and we were being asked to make decisions around life support for Hope. We were given a bleak prognosis but, bit by bit, Hope has proved them wrong.

Now Hope is a very happy girl, she laughs at everything and although she has no speech, she gets her message across. We wouldn't swap her. It is scary not knowing what to expect and every achievement is a bonus.

The winter months are difficult for Hope as she has chronic lung disease and is susceptible to recurrent chest infections. She frequently requires oxygen and cannot clear her lungs effectively. We have an alarm to monitor her breathing when she is asleep and we can be up and down all night.

There have been so many difficult things to cope with but my relationship with my husband has survived and become stronger. Sam has a very positive outlook. He was made redundant in December 2008, however, it's been great having him at home to help with the children.

We have help with Hope for two hours a week when someone takes her out and I can spend time with Luke. We also access respite at our local hospice. We were upset when we met the criteria to access this because it confirmed how sick Hope is and reminded us that she is life limited.

Hope has Craniosynostosis, this means the bones of her skull are fused together. While undergoing surgery in October 2008 to relieve pressure on her brain, Hope's heart arrested. She spent many months in intensive care. During that time, part of her bowel died and had to be removed. She almost arrested during this procedure too. Hope will most likely require further surgery in the future but doctors don't know why she keeps arresting under anaesthetic. The decision to undergo further surgery is one we don't want to have to make. Worrying doesn't help and nobody can guess how Hope will be in five years' time.

At the moment, we are concentrating on getting Imogen home and looking forward to settling down as a family – there is always someone in hospital!

Sara, Alex (16), and Ayden (9) Hunt

East Dulwich, London, England

Alex was seven years old when he was diagnosed with Adrenoleukodystrophy (ALD), a life-threatening genetic disorder which causes progressive deterioration of the nervous system. Until then, we had no idea it ran in our family and Alex was a 'normal' healthy boy when his little brother Ayden was born.

A month after we received the diagnosis for Alex, Ayden was tested and found to have the condition also.

It was the worst day of my life getting that diagnosis. You expect doctors to say, this is the problem and here's how we're going to fix it. But instead they said we can't do anything to help Alex, he's got a year to live. Nine years later, he is still here, proving doctors wrong and I am so proud of him for that.

Alex is completely dependent, but stable. We are unsure how much comprehension he has, but at times he tries to communicate using blinking responses. He is home-tutored and enjoys spending time on his exercise bike.

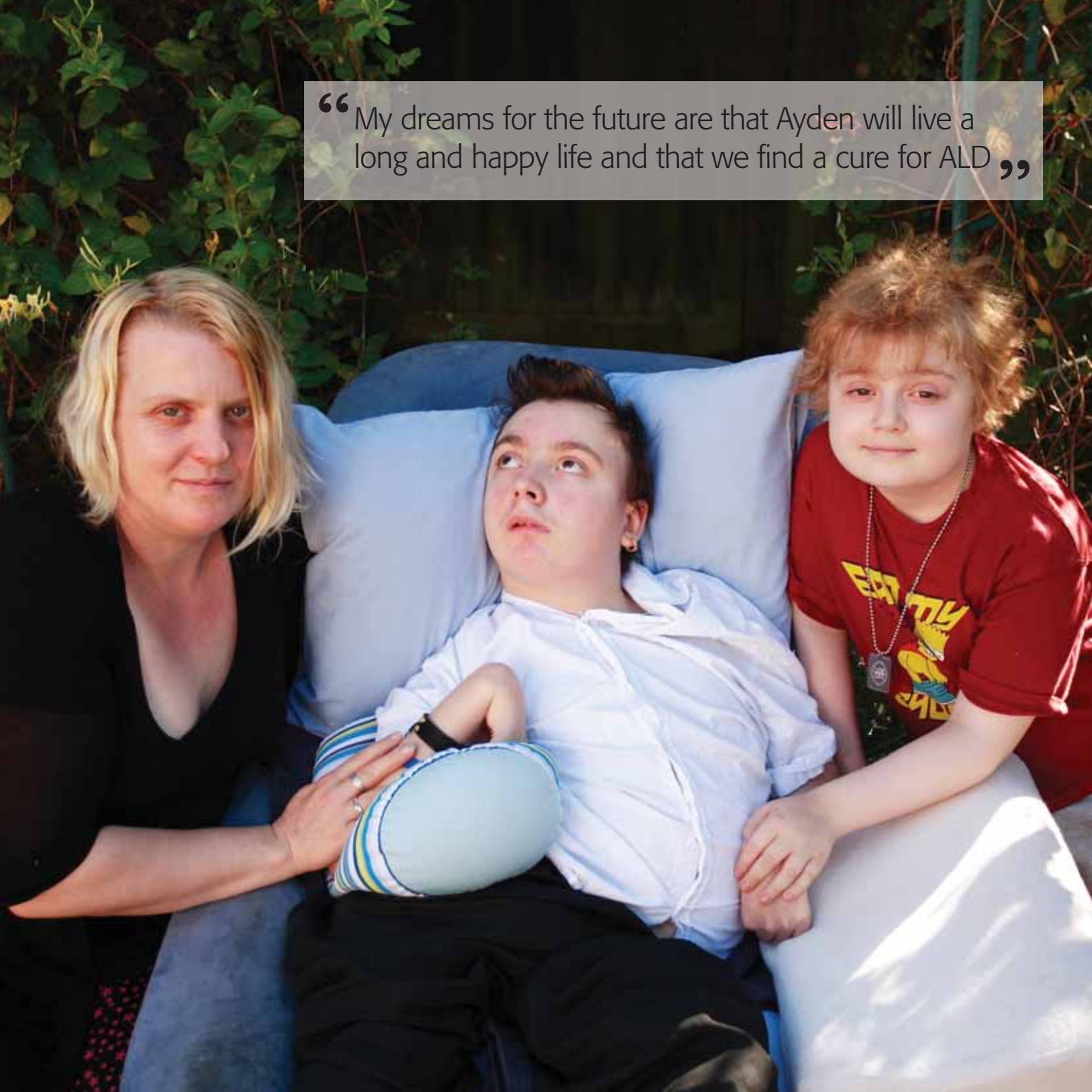
Ayden is happy and healthy and is the life and soul of our house. He loves animals and playing war and computer games with friends. Because the condition was spotted in Ayden early, he has been under the close supervision of doctors. Two years ago he was given a bone marrow transplant, which is the only form of treatment shown to be effective in early ALD. We can almost begin to relax now it is two years since the transplant

Our biggest frustrations are the multiple battles with social services to keep the care package that we have in place. Alex has a progressive degenerative condition and yet, every year the council tries to reduce his care. They claim that these decisions are not budget-led, but it is blatantly about resources.

I would like to see parents invited to social services panel meetings when they make decisions about our children. How can they make informed choices when they are hearing information third or fourth hand? Parents should be involved in making decisions about their child's life.

I run ALD Life, a support group for families in the UK affected by the condition. We hold annual conferences for families, which are hugely successful. As part of my role I fundraise for support work and hope one day to fundraise enough for research into the condition.

My dreams for the future are that Ayden will live a long and happy life and that we find a cure for ALD. Some may say I'm being unrealistic, but you have to live with hope. I will keep fundraising and supporting families and maybe someone out there will have a 'eureka' moment and find a cure.


“My dreams for the future are that Ayden will live a long and happy life and that we find a cure for ALD”

> “We can’t worry about next year, we just have to think about the here and now”

Clare, Derek, Holly and Katie (twins 2) Lally

Clydebank, Dunbartonshire, Scotland

When I fell pregnant with twins, my partner and I were over the moon as we had been trying for a family for some time.

Our beautiful girls, Holly and Katie were born premature weighing just two pounds, 10 ounces. Little Katie came second and, despite difficulties during birth, a caesarean was not offered, and she suffered brain damage.

Katie began life in an incubator. We did not realise how serious her condition was until at three months, Katie was diagnosed with Quadraplegic Cerebral Palsy, Gastroesophageal reflux and Bulbar Palsy which means she is unable to suck or swallow and is fed through a tube in her tummy. Doctors told us Katie wouldn't live past her first birthday and that she would never walk and talk.

Katie is now almost three. She sits up in a chair and her legs are getting stronger every day. She is aware and has learned Makaton sign language.

Every day is a bonus and we must live day to day. Our future is today and each hour is very precious. We can't worry about next year, we just have to think about the here and now.

After Katie was born, Derek and I quickly became experts at administering medication and carrying out emergency medical procedures. Katie must be fed every four hours and does not sleep for more than two, so Derek and I do split shifts and keep a constant vigil. When Derek goes to work, he does 12-hour shifts. I take Holly and Katie to different nurseries, attend appointments, make phone calls and later play with the girls.

It has been a difficult journey. We don't get much support from outside our family. We occasionally go to Robin's House Hospice which is excellent, but the only respite we get.

We spend a lot of time fighting for things for Katie. We had to wait over three months to get a suitable bath seat. It has made a huge difference to our quality of life – why did we have to wait so long? We are in dispute with West Dunbartonshire Council about a flood in our garden which prevents the girls enjoying time outdoors. And we are trying to get adaptations to our house but have been told we will get no assistance, so that is another battle.

Our greatest achievement is that we are together, we have fun as a family, we love and enjoy each other and that Katie is here, proving the doctors wrong. We hope she is here for many more years.

That's why it's so frustrating that I spend my days fighting for support. I know that I'm going to look back and think I have wasted my precious time battling instead of enjoying it with the girls.

Tanya and Carter (8) Latif

Wandsworth, London, England

Carter is just like any other eight year old. He's talkative, loud, bright and loves his friends. He's also very aware of his own disability. We had a huge conversation recently about the word 'disabled' and how appropriate it was for him. Eventually we settled on 'physically challenged'.

Carter has Spinal Muscular Atrophy, which means there are some cells in his spine that don't work properly. The result is profound muscle weakness. Carter gets around in a powered wheelchair and he wears a spinal jacket.

Cognitively he's fine, and his communication is fantastic. He can just about pick up half a plastic cup of water – that's his strength level.

We were given Carter's diagnosis when he was about a year old. First of all, I couldn't quite understand why there were so many people in the room. It didn't sink in – I couldn't work out what 'spinal' and 'atrophy' were doing in the same sentence. I asked about prognosis but at that point I had ceased to take it in. In hindsight, I realise there's no good way to break bad news.

The problem I had in the early days was getting information. I was horrified that I was finding out things by stumbling across them. Later, there was a huge problem in getting assistance at nursery. We finally got the one to one support we needed. But at the beginning, although they had a Special Needs Co-ordinator (SENCO), no one wanted to offer anything and no one had any suggestions.

I can't put up with being pushed around and not having things explained to me. I can't bear to think of how people just accept things and don't get what they deserve or need. I question everything.

We like to focus on things that Carter can do. He joined the school chess club a couple of years ago, and he's recently joined the choir, which he loves. He'll be performing at the O2 arena with his school later this year. He's filling his life with all sorts of things.

The future is a very difficult concept for us because Carter's condition is life limiting. I just look six months to a year ahead. I hope he gets to adulthood and gets to do the things he wants. I've always made sure he can do everything, even if it's in an adapted way.

Everybody thinks Carter's fantastic. He's very cheeky and he's got a great sense of humour. He's a bit wiser than some of his peers. He's aware that he's a burden on me, which I hate. I don't see it as a burden – I love it, though I do get tired. He carries a bit of guilt on his little shoulders.


“I’ve always made sure he can do everything, even if it’s in an adapted way”

“I’ve discovered that taking on Ethan’s mindset means I worry much less. It’s strengthened me as a person...There’s good in everything”

Mandy Le Flock, Lucy (28), Perry (23), James (19) and Ethan (8)

Catford, London, England

People who don't understand Ethan have described him as 'disruptive' and even 'wicked'. But people with Asperger's just see things differently – it doesn't make them evil. His world is a very literal world. There have been some desperate moments, but having Ethan is a gift. He's made me view many things in life more clearly.

Ethan was never an easy baby and as a toddler he became hyperactive and presented signs of Obsessive Compulsive Disorder (OCD). I was continually worn out at the end of each day, and it felt like I was being labelled as a bad parent. It wasn't until Ethan was at school that I got any specialist help, and he was almost seven by the time he got his Statement of Special Educational Needs.

By this stage in Ethan's life, I was feeling stressed and overwhelmed with all the work. My other son, James, was a teenager by then and he didn't understand. I wasn't getting any help and I was becoming quite depressed. This was when I called Contact a Family. They helped me get financial aid and sent leaflets for James, which he could read and understand in his own time.

Asperger's is an invisible condition and people don't realise how much hard work it is. Ethan is eight now, but I have to physically get him to wash and go to the toilet every morning. Then at breakfast if something's not right it really upsets him. We can't run out of bread or sugar – you just can't do that with Ethan. By the time we get to school at 9am I am physically and mentally exhausted.

After school, I have to feed him before I feed everyone else. I'd love to sit down together as a family but it wouldn't be fair on the others. Then, with homework, he'll either do no homework or he'll want to do everything. So if he's got a project to do over a week, he'll want to do it all that evening. It's quite interesting sometimes – I know every dinosaur as that's Ethan's favourite subject!

My son's a lovely child. He does things we would all like to do. Once, he saw a man shouting at a toddler and he went up and said, "Why are you shouting? Look at the size of him and look at the size of you." Don't we all wish we had the guts to say those things?

As adults, we're conditioned by social norms. But I've discovered that taking on Ethan's mindset means I worry much less. It's strengthened me as a person. It's made my maternal instincts much stronger and I can fight my corner. There's good in everything.

Paula McManus, Robert Keatings, Gary (5) and Rachel (3)

Belfast, County Antrim, Northern Ireland

My husband and I are both full time carers for our children. I would like to go back to work but it would be too much. Everything we do has to suit Gary's needs. If he doesn't get the things he needs he'll just be miserable, and then we'll be miserable, but it often feels like there's no one out there who will help you.

Gary has Cerebral Palsy (CP). He's blind, he can't talk or walk and he'll probably never be able to feed either. He has seizures and he's totally dependent on others for his care. We were told that he had CP when he was born – but at that stage we had no idea what it meant. Really, I'd say that things have only started to make any sense in the last couple of years.

Rachel also has health problems: she was born with a massive hole in her heart. Although she had her heart operation last March, she still can't go out and play like the other children. And we have to watch her teeth, because if her teeth decay it could affect her heart. Every day there are things we have to think of.

I work hard to make Rachel feel included by Gary. He brought a biscuit he had made at school home the other day, and I took it out and said "look what Gary made for you, Rachel," and she loves it. They'll have a wee laugh together, or else he'll kick out at her if he wants to… so, in some ways they're just like any other brother and sister. Our main problem is getting Gary a wheelchair to suit his needs. He's in it all the time, but he's always fighting with it. When his shoes are on, he kicks himself out of the chair and when his shoes are off, he just slides down.

I was offered another chair before, but you wait six months for an assessment, then it's another six months until you get the chair. When you do get the chair, your child has grown and it's too small. Sometimes all I do is sit and cry over his chair.

Our greatest achievement was getting Gary his bike. He went to America for treatment after five months of fundraising with our family. So now his daddy takes Gary out on his bike every day and Gary loves it. He gets to pedal and his hands are up, his head is up, he's more relaxed… the difference is unbelievable. But the treatment Gary gets here in Belfast should be first class, too. Sometimes it just feels as if people think he's disabled, so he doesn't matter.

“Sometimes it just feels as if people think he’s disabled, so he doesn’t matter”

“There are times when it has been very difficult but we have retained our sanity and are a happy family”

Stephen, Wendy, Caitlin (11), Sophie (9) and Justin (5) Meek

Lanark, South Lanarkshire, Scotland

We live on a farm in rural Lanark and have two bright and bonny daughters and an amazing son who continually surprises us.

Justin has a Prader-Willi like syndrome. He has the main symptom of the condition, which is constant craving for food. But he also has added complications of oxygen dependency and poor mobility. Justin was incredibly ill when he was born and we spent an agonising year wondering if he would survive.

Our main challenge in caring for Justin now, is managing his food intake. He has a limit of 600 calories per day because his condition reduces metabolism and excessive eating could lead to life-threatening obesity. Justin is hungry all the time and this can lead to him being manipulative.

We control his food intake and reduce temptation by eating home cooked food and sitting down as a family at mealtimes. Everything needs to be meticulously planned and when we go out we must prepare food and avoid people eating – not an easy task!

Sophie and Caitlin are superb with Justin. They play with him all the time and are very close. They have been through a lot and had to grow up faster than most and aren't always able to do the things that they would like such as going to Florida! We are incredibly proud of them for being such caring and intelligent girls.

We have been fighting to get disabled toddlers mobility benefits for several years. We have recently won a judicial review of the government's rule to withhold the mobility component of Disability Living Allowance to children under three. We have argued that the law contravenes Justin's human rights and are supported by a fantastic legal team.

Without the financial help towards a mobility car when Justin was younger, we were left virtually housebound. While Justin is now eligible for mobility benefits, we have continued our fight for other families like ours. If the decision of the judicial review goes our way, it will have significant benefits for families across the UK and would be one of our greatest achievements.

There are times when it has been very difficult but we have retained our sanity and are a happy family. We don't get any respite care: both Wendy and I are full-time carers and gave up our business after he was born.

Our dreams for the future are that Justin and the girls are healthy and happy. Oh and we'd love to get six numbers on the Saturday night lottery! Caitlin would like to be a teacher and Sophie loves looking after people so may become a doctor or nurse. If we could see Justin walking one day that would be a miracle.

Natalie Pearson, Thomas Mason, Summer (7), Seren (4) and Sienna (3)

Llantwit Major, Vale of Glamorgan, Wales

Our youngest daughter Sienna has Opitz syndrome, a rare condition which affects her lungs and heart. She also has mobility problems and developmental delay.

A major issue for us at the moment is finding a suitable and stable home for our family. Our local authority has been unable to find us appropriate accommodation, and we have been forced to move several times in the last three years.

Sienna needs a downstairs bedroom and bathing area due to mobility issues and complex medical interventions. We are currently awaiting a decision from the housing department about building an extension. We are desperate to give the girls some security and stability.

At six weeks old, Sienna stopped breathing and was taken to the intensive care unit at Cardiff Hospital. She stayed there for the next 13 months. Tom and I lived at the hospital, doing shifts so that one of us could be at home with the girls. It affected everyone, our family, friends and, of course, Summer and Seren.

Now our daily routine can only be described as frantic. Sienna has a tracheostomy to help her breathe and is fed through a gastrostomy tube. During the night Sienna is attached to alarms which check her heart and lung function. When the alarm goes off it's all systems go: suctioning her tube and reattaching her monitors up to 30 times a night. As soon as she is awake, we have to get up to give her nebulisers and later do her physiotherapy.

It's difficult to do things together, so Tom and I split all the family activities. I constantly feel guilty trying to balance my time between Sienna and the older girls. And we have lost friends and family because they don't understand why we are so tired and grumpy.

We recently got in touch with a family in Birmingham whose little boy has Opitz Syndrome. We have swapped photographs and chatted online. Sam is now walking and no longer has his tracheostomy, which gives us real hope for the future.

Our greatest achievement was being able to bring our little girl home from the hospital. We learnt all the procedures to care for Sienna and it was a difficult experience. But it's the most amazing feeling waking up in the morning with all the family home together.

Every day is a challenge. We are trying our best to give the girls a normal and happy life, though we sometimes struggle. We went to Blackpool this summer and it was brilliant to spend quality time together – having fun and being normal without having to go to appointments or worry about things. We are incredibly proud of all our gorgeous girls.

> “...it’s the most amazing feeling waking up in the morning with all the family home together”

> “I hope those people whose lives Max touches will become more tolerant and understanding”

Nicola, Joshua (11), Max and Charlie (twins 5) Reid

Gourock, Renfrewshire, Scotland

I am a single mother with three sons. We live in a seaside town west of Glasgow. When Max was three months old, he started having seizures and was diagnosed with Epilepsy. In addition, Max has Cerebral Palsy, is unable to walk, has no speech and has severe developmental delay.

Max's epilepsy is uncontrolled, the seizures are worse during the night and lead to many disrupted nights' sleep. He is on the Ketogenic diet which is restrictive and time consuming to prepare.

I work part-time as a primary school teacher. I am a professional person with a social conscience and I want to contribute to society. However, taking time off for appointments or when Max is ill makes me feel like I am letting colleagues and pupils down. I feel like I have to apologise for needing this time. Requiring more time off than other parents also affects me financially. I want to work, I have a mortgage, and we want to go on holiday and do fun things together.

When Max was first diagnosed, everything felt out of control. I found support from other parents invaluable. Being a parent of a disabled child can be very isolating as peers move on but life can remain static for disabled children and their families. The physical, emotional and logistical requirements increase at a time when other children are becoming more independent. The huge responsibility placed on lone parents with other children can be overwhelming.

It angers me that I cannot get the appropriate equipment or respite for both Max's and my needs using limited money available from the government, and that I have to approach charities and fundraise in order to buy what is required. This puts more pressure on time that is already stretched. I also find this process negative and demoralising, always having to say what Max cannot do and what we don't have – when I want to say I have the most fabulous son who is the sunshine of everyone's life.

I worry about how I will continue to care for Max as he gets bigger, who will care for him when I am ill or… when I am no longer here. I try to take things in stages and not think about the future too much or you won't appreciate today.

I worry that I am missing Charlie's early years because Max gets so much of my attention. Joshua has had to grow up too quickly in many ways and doesn't get the time he deserves.

Before Max was born, I was unaware of disability and the impact it has on a family. I hope those people whose lives Max touches will become more tolerant and understanding.

Dawn, David, Sophie (12), Summer (5), Declan (4), and Scarlett (6 months) Robinson

Stowmarket, Suffolk

Diagnosis for Sophie and Scarlett was very different. Sophie was often ill and given many health tests as a baby, but she wasn't diagnosed with Cystic Fibrosis until she was in school. In contrast, Scarlett was always a high risk baby, as she had a sister with CF and her diagnosis was made when she was a few months old.

When Sophie was very ill and going through diagnosis, I was constantly in and out of hospital with her, leaving my husband David to look after our other two young children. He lost his job as a result of all the time he had to take off and it all really took a toll on our relationship. We've never really had the time to talk about what we went through back then.

Now we're married, have four children with another on the way, we just don't get a chance to sit down. We never go out for a meal or a drink, we just 'pass and go' without ever really getting a break. One of our greatest achievements is making it through, still being a family despite the hard times.

I take it all one day at a time, I am constantly washing, feeding or cleaning someone or something. Sophie keeps me on the go, whether it's going to clinic, problems at school or making a mess around the house. I hope to get a cleaner through the Aiming High for Disabled Children programme – domestic support would mean so much to me. With the extra help I would be able to concentrate on other things like spending time with my children. Just having the time sit down and read them a book would mean the world.

Finding out about support available was very hard. Families should be given information when they receive their child's diagnosis. We really needed someone to talk to at that stage, we knew so little and it was so stressful, I got tired and very depressed.

Although Sophie is now 12 and attends mainstream school, she doesn't go anywhere on her own or have any friends. She needs so much help with personal care and medical treatment I think she will live with us a long time, probably her whole life.

I don't really think about the future a lot. Scarlett is quite a happy baby and still too young to understand much. I worry about the future and Sophie not ever being able to cope on her own and it's pretty scary. She is a very strong character and maybe one day she will be able to live independently with a carer. I'd like to see her grow up and experience the world.

“One of our greatest achievements is making it through, still being a family despite the hard times”

"...we do not have any false hopes about her future, but are able to support her in the best way we can, so that she can reach her full potential"

Julie, Pete, Chloe (12) and Grace (10) Ryan

Willand, Devon, England

We live in a countryside village near Cullompton in Devon and have two daughters. Our youngest daughter, Grace, has the very rare condition Pitt-Hopkins syndrome.

Pitt-Hopkins was identified just 30 years ago and there are only a handful of known cases worldwide. Grace was seven when she received the diagnosis and we were relieved to know the underlying cause of her difficulties. Doctors had told us we may never get a diagnosis for Grace and this uncertainty stopped us having another child.

Before the diagnosis, we had also secretly hoped that Grace would one day catch up with other children her age. Now we do not have any false hopes about her future, but are able to support her in the best way we can, so that she can reach her full potential. We can't believe how much she has come on since she was little. She is now babbling and this is enormous progress and an amazing achievement for her.

Grace loves sensory play and toys. She also loves noisy things like the *Tweenies*. She will sit and watch football and rugby with her Dad and loves travelling in the car. She has attended Riding for the Disabled since she was young and her philosophy seems to be the faster the better. She laughs her head off when the ponies start trotting.

Grace attends special school where she is in her element. She has had excellent teachers who are completely dedicated to the children.

It has been difficult balancing our time between caring for Grace and being a mum to both her and Chloe. We can't do some things that other families do. Chloe is an absolute angel and is very understanding. She has just joined Young Carers, which has helped her enormously. She is very bright and would like to one day be a vet. She has a natural aptitude for sport and is a keen violinist, playing in an orchestra.

I have continued to work as a book keeper for a local firm. My boss has met Grace and realises some of the pressures we are under as a family and is very understanding. I am currently studying for my accountancy exams, so there is literally never a minute to spare.

Our family's greatest achievement is getting through the difficult times and helping Grace to achieve her best. It is absolutely terrifying thinking about the future. As long as we are here it is fine, but who will look after her when we're gone? Will she be put in some kind of home? There is very little information about what happens after she turns 19.

Emma, Steve, Charlotte (6) and Isabelle (8 months) Seager

Solihull, West Midlands, England

I struggle every day with people's reactions to Charlotte. I have even had people coming up to me in the supermarket and saying "can't you control your child?" People just take things at face value – and you can't do that with Charlotte.

Charlotte has Tuberous Sclerosis (TS), which means she has tumours on her brain, kidneys, behind her eyes and on her skin. As a result, she suffers from Epilepsy, Polycystic Kidney disease, a severe learning disability, night time incontinence, sleep arousal disorder, Autism and associated behavioural problems. She is nearly seven now, but she still has what other people would call tantrums – she can lash out at people for no reason and she hits and kicks and bites... But other than a slight rash on her face, there is no outward sign of Charlotte's condition. This is one of the hardest things.

TS is also a very varied condition, so we don't know where Charlotte's potential is. It's very difficult to know what to do for the best. We've just moved her to a special school but she's struggling with the change. There are a lot of delaying tactics in the morning: she wants to change her clothes, then she wets herself in the car… She enjoyed her last school but she couldn't react to the other children like they wanted and it wasn't a suitable learning environment for her.

Charlotte is very smiley and has a really loving and funny personality. She loves the Disney princesses and dressing up. And although she struggles physically, she thinks she's the best dancer in the world! She loves playing with her baby sister, Isabelle, but it's a very fine line keeping Isabelle safe without alienating Charlotte. It's lovely having them both but it's tougher than I ever imagined. I hope things will get easier as Isabelle grows and can fend for herself more.

We really wanted Charlotte to have a sibling – we knew Charlotte would get a lot of joy out of that – but we didn't want to put another child through the same things as Charlotte. There was another pregnancy before I had Isabelle, but at 12 weeks we discovered that this baby also had TS and we opted for a termination. I was then told that any subsequent baby would have a 50/50 chance of getting TS. It was very difficult indeed, but we decided to try one more time.

If anyone had told me six years ago that I would ever have a termination, I wouldn't have believed them. It was the hardest decision we have ever had to make. If anyone questions our decisions, I always say "live with Charlotte for 24 hours then make a judgement."


“ Charlotte is very smiley and has a really loving and funny personality ”

> “He’s very willing to learn and, given the right kinds of instructions, will flourish”

Amanda, Colin and Zak (13) Strowger

Rendlesham, Suffolk, England

We try to bring Zak up as a typical teenager, with his Autism as a secondary consideration. He's grown up with lists and pictures to help him run his life and he's learnt so much, but I still find myself saying "Have you done this?" or "Have you remembered that?" He likes his life as routine and organised as possible.

As a tiny baby, Zak didn't want to be held close. All my friends' babies were reaching milestones and he just wasn't getting there. As he got older, his speech was terribly delayed and he couldn't pronounce things clearly. He also had problems with his motor functions. He didn't want to ride a bike until we found a bike with an L-shaped seat. Then he was able to lean back – and he was well away! All these little things we had to find out.

Zak is a lovely boy and he's extremely intelligent. He has huge problems with spatial awareness but he's done so well. He swims for Suffolk, although he finds it very difficult with the crowds of people. He has adopted various strategies to cope – like playing with a Koosh ball, or just sitting at the back quietly. He's very willing to learn and, given the right kinds of instructions, will flourish.

He's in mainstream school but mainly in the Special Educational Needs (SEN) section where he does extremely well. But whenever he's in the mainstream class, he struggles. He finds it very difficult to get on with the others. He's 13 but he's never had any lasting friendships. That's a long time not to have a special friend.

Zak has grown up with children at church and in his swimming club who understand his foibles. They are very good with him. But at school he has always been bullied. People should be going into schools and educating the children about people with special needs. That's where the government really falls down. The SEN people are fantastic but the other teachers are not equipped to deal with SEN children.

I'd really like Zak to recognise his own self worth. I think he's on the way to doing that. He knows he's really good at swimming and he's fantastic with little children. He says he could be a swimming coach – and he could. That would be really good for him. But he's so intelligent and he could do much more.

There are so many parents I know who allow their autistic children to remain in their autistic worlds. The children miss out on so much. It's harder taking the route we've taken. But when people say "Gosh you do so well", and he's as 'normal' as possible – that's a great achievement.

Anna, Mike, Susie-Jo (15), and Matthew (12) Walker

Redruth, Cornwall, England

We are celebrating because our teenage daughter recently held an ice cream and ate the entire thing unaided, thrilled because she's putting her own shoes on, even if she may never do them up herself.

To us this is real joy, to Susie these are real achievements. It is difficult for anyone who hasn't travelled the same path to understand how often as a parent of a disabled child you feel so much pressure to prove to everyone that your child will amaze everyone by 'overcoming' adversity and prove their value in this world.

When our daughter was born 'bilaterally anophthalmic', as the consultant kindly informed us, or without eyes, as we were soon to discover, our reaction was conventional. We swung from feelings of despair and hopelessness to what we realise now are traditional coping mechanisms when confronted with disability. We weren't going to let this stand in our way. Being blind didn't stop David Blunkett or Stevie Wonder, they achieved beyond all expectations didn't they? Already we were defining achievement for our disabled child in terms of traditional personal success.

But gradually our dreams of a musical prodigy or Paralympic champion faded. Further tests diagnosed Cerebral Palsy, Septo-Optic Dysplasia and a hearing impairment. No one knew to what extent she would be affected by these conditions but we were advised not to set our hopes too high.

As Susie-Jo grew and blossomed into a heart-stoppingly gorgeous child, we learnt an important lesson about progress and achievement and indeed about human value.

Conventional targets such as walking, talking, independence were sometimes never met, milestones on a road she wasn't travelling. But her tears (and often her fingernails) are an eloquent testament to her awareness and frustration, her laughter a song to the joys she feels, her hands clap the excitement that doesn't shine in her eyes.

Acknowledging and celebrating these achievements is what makes the future bright for our family: the ability to focus on Susie's unique strengths and gifts.

Achievement shouldn't be just about what you can do for yourself, but what you can bring to others and we are secure in the knowledge that it isn't what Susie does but who she is, that will continue to make her a great ambassador for acceptance and change.

With her we are creating a vision of the future as one in which she will continue to flourish into a 'grown up' and have opportunities to live her life in the way she does now, full of fun and happiness.

We are aware that achieving this vision may prove difficult for the decision makers, budget holders, case workers and paperwork that gets in the way, but hey, if Susie can achieve so much surely the rest of us can try?

> “Acknowledging and celebrating these achievements is what makes the future bright for our family: the ability to focus on Susie’s unique strengths and gifts”


“I feel like I’m fighting in every corner – when what we really want is to be a family”

Helen, Gavin and Grace (3) Windram

Northampton, England

Grace was always going to be very special. Born two months early and on our two-year wedding anniversary, she has had a massive impact on our lives.

Grace has Cerebral Palsy, which primarily affects her legs but her upper body also. She is unable to sit unsupported, crawl, stand or walk. To do any of these things, she needs support or an adult to help her.

She is a bright girl and very aware of what she wants. Providing Grace with specialist equipment is vital to her development, but getting any has been a real fight. A year after we highlighted something wasn't right, Grace attended a two-day assessment that revealed her difficulties were not simply down to her premature birth. Her diagnosis wasn't confirmed until after an MRI scan six months later. As an Occupational Therapist working for the NHS, I knew that early diagnosis would help with appropriate treatment and funding.

It was eight months from the assessment before the first piece of equipment arrived. People don't realise how important getting equipment quickly is for a child's physical and cognitive development. I still spend a lot of my time ringing up and chasing things. I feel like I'm nagging, but I see people who don't push and they don't get what they need. Many professionals have been great, but the bureaucracy and lack of funding causes unnecessary delays.

Through fundraising and a charity grant, Grace now uses a SnapDragon power wheelchair. We were told that children under five do not have the cognitive ability to use one. That's rubbish! With her chair, Grace can make choices and move independently. It makes a huge difference to how she interacts with others and reduces many of the behaviour problems that come from frustration.

I've managed to keep working (part-time) but it hasn't been easy. Employers aren't always flexible or supportive. Annual leave is taken up with appointments rather than holiday or even a day's rest. Then they wonder why people have time off stressed or ill!

We're now expecting our second child, and I've been surprised at the lack of support. I'm not supposed to be lifting, but need to carry Grace up and down the stairs during the very long process of getting two downstairs rooms converted for her, because there's no extra help.

I feel like I'm fighting in every corner – when what we really want is to be a family. I don't want to get up every day and tell Grace "I've got to do this… so we can't go the park." I only wish that just once when you ask for something you could get it promptly without needing to battle through so much resistance.

Photography by Jeremy Larkin

London based photographer Jeremy Larkin specialises in portraits of people in their environments and film/TV stills. He has worked on many large television productions and several feature films.

Originally from New Zealand, Jeremy spent 10 years as a mechanical engineer before studying photography at the London College of Printing.

His pictures have appeared regularly in the *Radio Times* and he has shot PR campaigns for several feature films, TV shows and band launches. As well as a long running project, photographing protests on Whitehall which has recently exhibited at Orleans House Gallery, Jeremy has regularly worked for Contact a Family.

About Contact a Family

Campaigning
We campaign for rights and justice for all families with disabled children.

Freephone helpline
Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisers. It gives information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

Publications
We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

Linking families
We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking site or using our one-to-one linking service.

Medical information
We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 1000 conditions and related support.

One-to-one support
We offer both practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent representatives and through our local offices.

Local, regional and national offices
Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

Contact a Family is a national registered charity, founded in 1979, providing advice information and support to families with disabled children.

Contact a Family is a leading member of the four nations' campaigns for rights and justice for disabled children and their families:

- Every Disabled Child Matters
- for Scotland's Disabled Children
- Disabled Children Matter Wales
- Children with Disabilities Strategic Alliance Northern Ireland

Getting in contact with us
Free helpline **0808 808 35555**
Textphone **0808 808 3556**
Open Monday to Friday 10am to 4pm,
and Monday 5.30 to 7.30pm

Contact a Family
209-211 City Road
London EC1V 1JN
Tel 020 7608 8700

www.cafamily.org.uk

Registered Charity No. 284912. Charity registered in Scotland No.SC039169
Company limited by guarantee, registered in England and Wales No.1633333.
HM Revenue & Customs charity tax reference No. XN54769. VAT Reg. No. GB 749 3846 82