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Welcome

There’s no denying that the effects of a brain injury extend way beyond the person injured. Whether it’s a child or an adult, the entire family unit will feel the impact, both immediately and longer term.

Families often describe a rollercoaster journey lasting for years, before they settle into a ‘new normal’. Roles and responsibilities and the dynamics of the family group can be turned upside down and inside out by changed behaviours, caring responsibilities, financial constraints, welfare considerations, and communication challenges.

In this issue of Brain Injury News, leading neuropsychologist Jo Johnson looks at the overall impact on family relationships and some of the issues to be aware of (page 3), and Dr Katie Byfield considers how families can be helped to recover in her article (page 13) on resilience.

Some of the practical issues that present themselves in these circumstances are also addressed: we look at family finances on page 7, and dealing with the Court of Protection and deputyship matters, should the injured party be incapable of managing their own affairs, on page 12.

We have first-hand testimony from an inspirational brain injury survivor on page 10, and The Children’s Trust share their experiences of supporting families through the rehabilitation process, including an account of the changing relationship between twin girls on page 14.

The role of carer is often taken for granted, surprisingly even when the carer is a child or young person. Carers Trust provides some disturbing statistics on page 8 and highlights where young people and professionals can get support.

If you have a view on any brain injury related issue, or would like us to cover a specific topic in future issues of Brain Injury News or on our website, please do get in touch. You can find more information and resources on the Brain Injury Group website www.braininjurygroup.co.uk, or please call us on 0800 612 9660 to find out how we can help.

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The Brain Injury Group, a not-for-profit community interest company, is a network of specialist brain injury solicitors and other professionals with proven experience of supporting those affected by brain injury. Our aim is to provide a gateway to support, information and advice for brain injured people, their families and carers.

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Brain injury and family life: dealing with change

When someone sustains a brain injury the effects can be far reaching, causing changes to relationships and family roles that may last a lifetime. Neuropsychologist Jo Johnson takes a look at these changes and what support is needed to help families adapt.
Recent brain injury research has highlighted the importance of thinking about relationships, families and communities when it comes to rehabilitation, rather than focusing solely on the injured individual.

Even years after the incident, when family members recall the memory of finding out their relative had been injured, they experience intense emotions, similar to the symptoms of post traumatic stress. One of the first tasks for health professionals supporting families is to understand how the ‘brain injury story’ started for each person, how that continues to impact them, and the way they respond to their injured relative and everyone else.

**Understanding traumatic life change**

“I was woken up at 3am to find two policemen standing at my door asking ‘Are you the father of Emily?’ That day, life for us, our daughter, her friends, siblings and work colleagues changed forever.”

Peter

Brain injury differs from many other examples of traumatic life changes, such as major illness, divorce and bereavement. These experiences are more common and people are likely to know others who have gone through them, even if they haven’t themselves. There may have even been time to prepare for the challenges they bring, which makes it easier for people to gain support and successfully manage any difficulties.

When someone suffers a brain injury, there’s a sudden transition from a routine life into a world that makes no sense. If the injured person survives, hope emerges and plans are made for the future that include a return to life before the injury. The majority of people expect their injured loved ones to make a full recovery – however slowly – and be exactly the same as they were before.

**Coping with personality change**

“I find it so frustrating. He is suntanned and relaxed. Everyone says ‘I can’t believe Rob has had an accident, he was so lucky to get better.’ Often I am screaming in my head – he is not better and he is not who he was.”

Karen

Many families report a sense that their relative is “different” or their personality has changed after brain injury.

We now understand this is due to a complex interaction of biological, psychological and social factors. For families, it can just feel like their relative has become a different person. The injured person may not share this sense that they have changed and find it confusing and upsetting. This discrepancy may create conflict and feelings of dissatisfaction within family relationships.

A significant challenge for those supporting is to help families understand the changes and to focus on the aspects of their loved one that haven’t changed.

**Feeling ambiguous loss**

The term ‘ambiguous loss’ refers to a situation where a loss is complicated and incomplete, and some people working in brain injury have found this a useful framework to help relatives understand how they are feeling.

Having a sense that the person has changed beyond recognition can produce significant feelings of loss, which have been compared to feelings of grief. This reaction is complicated by the fact that the ‘lost’ person is not only still alive but may not themself feel changed.

Given that many of the changes that follow a brain injury may never resolve, some family members may experience feelings of distress and sadness for many years. This response has been usefully described as ‘chronic sorrow’: the sense that the loss is endless, exacerbated by the exhaustion of all the additional tasks and ongoing changed relationships.

If changes in the family system continue long term, family members may feel forced to take on roles they wouldn’t choose, for example parents who had planned a retirement could be thrown back into active parenting; children may need to be less demanding and take on a more caring role.

Loss of earnings may mean a family has to completely change the way they live. If the injured person is unable to return to education or employment, they may end up requiring care or being at home much more than the family have been used to. If they can return work, they may still have to cope with extreme fatigue leaving no resources for family, or to reduce their hours or level of responsibility causing them frustration.

Changes to pre-injury relationships and lifestyle, on top of residual cognitive, emotional and behavioural changes in the injured person, can make life feel very intense or even intolerable for everyone.

The early literature on family recovery after brain injury is not an encouraging read, concluding that most couples separate, children develop a host of psychological difficulties, and caregivers are mentally unwell. While no-one would deny that a brain injury can result in massive challenges, more recent studies using larger and more representative samples are clear that it isn’t all bad news.
It seems that many people who had positive lives before injury can again feel like life is worth living. Families that are given help can adjust to quite dramatic changes and go on to enjoy different but not necessarily less enjoyable relationships. There is also a growing body of research showing brain injury can bring about personal growth and positive relationship changes that probably wouldn’t have happened otherwise.

Helping children after a parent’s brain injury

In the past, many children would simply have been left to get on with things after a parental injury. Thankfully, how to support children appropriately is a growing area of interest. Research informs us that most children who have not had difficulties before a parental injury cope very well. They may even end up more mature, caring, and independent than other young people.

However, children are likely to experience a range of negative thoughts and feelings as part of a normal response to an upsetting event. Brain injury often changes the way the injured person processes emotion resulting in behaviour that may seem immature or insensitive. It is hard for children to make sense of what is happening. A common theme is for children to feel they are somehow to blame for what has happened or the changes in a parent.

“I don’t think my dad loves me anymore, he shouts whatever I do and never cuddles me now. I miss my old dad.”

Seren, aged 10

Continued on page 6
5 ways to support a child after a parent’s brain injury

1. Make sure they know it’s important to talk about how they are thinking and feeling, that their experience is normal and they’re not to blame. Don’t tell them to keep things secret even if some of the post-injury changes are difficult to manage. Include them as much as possible and give them clear, truthful information.

2. Be open about the situation. Reassure families that it’s OK to show their own negative feelings, acknowledge the confusion and upset they may be feeling, and accept that it will take time for relationships to feel normal again.

3. Don’t pressure children to see mental health professionals if you believe they are coping. Negative feelings in response to an upsetting event don’t routinely require an assessment from a psychologist.

4. Don’t presume a change in behaviour is due to the brain injury. Children are constantly changing and developing, but do seek professional help if the child is experiencing significant symptoms of distress.

5. Encourage usual routines – this may involve families accepting help from friends, or financial and practical support from relevant charities, so children can keep up with the activities they enjoyed before the injury.

For more resources and information to help children and young adults understand a parent’s brain injury, see Useful resources box.

Helping adults look after their mental health
It’s also important to encourage the non-injured adults to actively take care of their own health to increase their chances of staying physically and mentally well.

5 ways to help adults cope with brain injury in the family

1. Manage unhelpful or upsetting thoughts – help people to realise that whilst their situation might be stressful and the future uncertain, constantly listening to unhelpful thoughts like “My life is over” or “The future is bleak” will make them feel less able to cope. There are lots of resources online that might help; for example, take a look at www.getselfhelp.com.

2. Practise mindfulness. Talk to people about mindfulness techniques, which help you focus on the present and what is right in front of you. Research shows that staying in the moment helps our mental health. Search online for practical information on ‘mindfulness’.

3. Encourage gratitude – to help family members focus on the positive things in their lives, suggest they make a note of three things each day that have gone well or for which they are grateful. This can help everyone in the family including the injured person.

4. Teach self compassion. When people feel low, evidence shows that they will feel better if they can learn to be more self compassionate. Encourage people to notice how they treat themselves when they feel unable to cope. Ask them to reflect on what they might say or do for a friend whom is having a hard time. People who can show themselves kindness at times of distress will cope better.

5. Reinforce the need for good food and exercise. There is good evidence that a balanced diet and regular exercise are better than antidepressants for many people. Forgetting to take care of themselves will increase fatigue and the likelihood that their mental health will deteriorate. Encourage people to start by making small changes that are easy to achieve.

Looking to the future
We now know that individuals continue to make progress for many years after a brain injury and appropriate intervention can create change even when it is started many years after the accident. As a result of a more optimistic outlook new models of therapy are being used to help people, models that focus on emotions, relationships, families and the wider system rather than the traditional approach of solely focusing on the injured person. This work is producing encouraging outcomes and specialist professionals working in the field can use this understanding about why some people thrive after a brain injury to ensure families get the most appropriate support.

Useful resources
Books by Jo Johnson
My parent has a brain injury – a book for teenagers about all aspects of coping with a parent with a neurological diagnosis.
My dad makes the best boats and My mum makes the best cakes – books for younger children who have a parent with a brain injury.
Shrinking the Smirch – there are two versions of this accessible workbook about managing emotional distress available, one for adults, one for teens.

Other recommended reading
Head Injury: A practical guide, Trevor Powell
The Selfish Pig’s Guide to Caring, Hugh Marriott
The Reality Slap, Russ Harris

Jo Johnson has worked as a neuropsychologist since 1996. After two decades within the NHS she is now an independent consultant teaching and writing for several national neurology charities, as well as offering clinical interventions to individuals, families and teams impacted by brain injury. She has written several books to meet the needs of children who have a parent with a neurological diagnosis.

Contact Jo on 07891 210716 or neuropsychology@talktalk.net
When a family member suffers a brain injury, family finances almost inevitably take a major knock – even if that injured person is not the main breadwinner. Andrew Warlow from Wolferstans Solicitors looks at some options for helping to relieve the pressure.

After an accident the family’s focus will of course be on providing as much personal support as they can for their loved one. But ongoing visits to a hospital or rehab unit can take its toll on the family finances.

As an experienced personal injury solicitor, when I’m contacted after an accident because a claim is being considered, one of my primary tasks is to attend to financial support and co-ordinate the steps to alleviate financial pressures. This is so that the family can concentrate on what matters most: supporting their loved one and each other. Obviously these steps are just as important for a family affected by an injury whether a claim is pending or not.

Act fast
I recommend that families should contact social services as early as possible for support, whether or not a third party claim is being considered, or if insurers are not forthcoming.

Welfare benefits should also be considered urgently, and I have often found the advice of a specialist financial and benefits adviser to be extremely helpful in providing a guide to this complex and frequently changing area.

If there are going to be court proceedings, these should be started as soon as is practical so that liability can be decided. I have invariably found that courts are willing to determine liability as a preliminary question, before looking in detail at the value of a case.

Get assessed
Local Authority support required by the Care Act 2014 is an area where assistance from, for example, a specialist brain injury case manager, can be invaluable. Whilst case managers are normally appointed by solicitors or insurers in relation to personal injury claims, their services are available to everyone.

For example, in a clinical negligence case where liability was disputed, a colleague called on a case manager to advise. The local authority had carried out the required assessment, but the family found that the support provided was too intrusive. They opted for direct payments in order to manage their own care, but those payments proved inadequate. The case manager was able to take up the matter with the local authority on their behalf and secure substantially increased funding, including for respite, to help get the family back on track.

Seek employment advice
Invariably, employment issues arise after a serious accident, even where the victim is able to return to work following rehabilitation. I recommend consulting specialist employment lawyers for support, direction and reassurance. This may be for the person injured or for their partner or parent who may need extended leave to play an active part in care and rehabilitation. If the injured person has to ultimately give up work, they can recover loss of earnings where there is a successful claim.

Request interim payments
In the event of a claim where liability is admitted, partly or fully, I would expect an interim payment request to the defendant’s insurers to meet with a positive response. The amount might be disputed, however, particularly when it comes to substantial payments to cover the cost of purchasing accommodation or making adaptations.

If a care regime is set up, the interim payments should be obtained well in advance to enable the wages of those involved to be paid, particularly as there can be quite a time lag between requesting an interim payment and obtaining a court order if that initial request is refused and a contested application is required. If the request is agreed but the client lacks capacity there will, in any event, have to be a court order approving the interim payment.

Andrew has specialised in complex, catastrophic injury claims for more than 25 years. He is a Fellow of the Association of Personal Injury Lawyers (APIL), a member of The Law Society’s Personal Injury Panel and features in the solicitor directories of Headway and the Spinal Injuries Association. He is a director of Headway Plymouth.

Contact Andrew on 01752 292267 or awarlow@wolferstans.com
When a family member is ill or injured, young people can end up taking on a caring role they never could have expected. Gail Scott-Spicer from Carers Trust considers the impact – practical and emotional.
Did you know it is estimated that there are two young carers in every classroom in the UK? That’s a staggering 700,000 children and young people up and down the country, caring for others instead of enjoying their childhood.

Many believe this number could be just the tip of the iceberg. Carers Trust knows, from talking to young carers and professionals, that lots of young carers are not identified, slipping under the radar of support services, receiving no help at all.

Official figures reveal that 13,000 young carers are caring for more than 50 hours a week. Some are as young as five or six years old and most care for a parent or other close family member, day in, day out.

What does ‘caring’ look like?
Taking on a caring role can involve:
• Staying in the house a lot to be there for them
• Helping them to get up, get washed or dressed, or going to the toilet
• Doing lots of the household chores like shopping, cleaning and cooking
• Looking after younger brothers and sisters
• Providing emotional support or a shoulder to cry on

As a result of their caring roles, young carers are missing out on their childhoods, education, future life chances and health.

Carers Trust, the UK’s largest charity for unpaid carers, is highlighting the plight of young carers across the country to get them the support they so desperately need, calling on health professionals, teachers and support workers to identify young carers and take action.

We must change this and make sure they all get the support they need so they can thrive and enjoy their childhoods like any other young person.

What health and social care professionals can do
Carers Trust helps almost 30,000 young carers and young adult carers (up to the age of 24) to cope with their caring role through specialised services and centres across the UK. We are improving the identification and support of young carers in schools across the country, so that they get the help they need. We rely on health and social care professionals to also spot the signs of those who are caring.

These care professionals play a vital role in helping to identify young carers and directing them to support services. Our research shows that 39% of young carers do not tell school staff, nurses or teachers that they are young carers, so it is often down to other professionals to notice and take action.

Carers Trust wants to transform those young people’s lives and bing the issue of caring centre-stage so that no-one is isolated and under pressure, caring for someone without support.

Help online for young carers

Babble – for young carers (under 18)
Babble is Carers Trust’s new online community where young carers (under-18) can find others in a similar position, chat, have fun, share experiences and access information and expert support online. Visit babble.carers.org or email youngcarers@carers.org

Matter – for young adult carers (16-25)
An online space for young adult carers and those who work with them, Matter enables carers to post photos, ask for help and share their thoughts and comments. An online community team is on hand to provide support by messaging and email. Visit matter.carers.org or email matter@carers.org

Carers Trust Professionals
Carers Trust Professionals aims to provide those working with carers in health, education or welfare with access to information and resources to deliver the highest quality support. Visit professionals.carers.org

68% of young carers are bullied at school

How young carers are affected
Many young carers don’t even realise they are a carer and that there is support out there for them. Our research indicates over two-thirds of young carers are bullied at school (68%), and nearly half are stressed (48%) and tired (44%).

We know young carers miss on average 48 school days – that’s nearly 10 weeks of school a year – due to their caring role. Those aged between 16 and 18 years are twice as likely to be not in education, employment or training.

Gail Scott-Spicer has 20 years’ experience of working in the public and voluntary sectors. Carers Trust works to improve support, services and recognition for children and adults living with the challenges of caring, unpaid, for a family member or friend.

Contact Carers Trust on 0844 800 4361 or support@carers.org if you are a carer looking for help.
It felt like I was the centre of a ripple, and that ripple effect went outwards, impacting on the lives of everybody who knew me, particularly my family.”

This is how Paul Spence describes the effect of his brain injury on those around him. The 35 year old from Hull was left facing a battle to survive after suffering a brain haemorrhage in 2012. He was the victim of a violent, unprovoked attack on a night out. That one punch changed his life, and those around him, forever.

“Once you leave hospital your biggest challenge is only just starting, and that is adapting to your new life and finding it in yourself to accept your old life is gone forever,” he says.

“Nothing could prepare me or my family for the battle of brain recovery and the difficulties it brought. They were brilliant and did their best for me, but it was a complete change for us all, and a struggle.”

“The injury had completely changed me”

“I didn’t realise at the time, but my bonds with loved ones had become non-existent. It was a really sad consequence of the injury. I was in a complete world of my own. I was functioning, but at such a low level of thought and feeling. It’s probably best to describe me as a shell at that time. I wouldn’t say that I couldn’t love people, but I certainly couldn’t express that love and affection, and that must be a hugely difficult thing for a family to handle.

“Things were really difficult as the injury had completely changed me. The man I was had gone. I was fragile, confused, vulnerable, slow and distant with no deep understanding.

“I also found things extremely hard in front of my children, Shannon and Reece, who were 14 and 13 at the time. I wasn’t able to do normal recreational activities with them or even chat to them like I used to. I wasn’t able to walk to the local shop with them.

“As a dad this really hurts my pride. I had to rely on others, and as I was unable to work I couldn’t afford their maintenance. Not being able to support my children was destroying my fragile mind even more. Gemma, Reece and Shannon were amazing, I just wish they’d had more help and support to understand it all.”

**Road to recovery**

Paul found positivity in physical exercise, slowly building his health and fitness to start setting himself new goals. It led to an amazing story of recovery which has included him completing many marathons across the UK, Europe, and in the US.

He has raised more than £50,000 through his running and community events for brain injury units in hospitals, and last year set up his own charity, PAUL For Brain Recovery, which is now helping others walk the same, difficult road to recovery.

Paul has also become an ambassador for personal injury specialists Hudgell Solicitors, providing one-to-one support for brain injury victims supported by the national firm.

That relationship also helped him open his charity’s own community-based drop-in support centre in his home town, helping those with brain injuries rediscover their place in society, amongst their families, and at work. Providing support to families is one of the key services being provided.
“We’ve tried to focus the centre on providing the support which is lacking in communities for people when they leave hospital and start trying to rebuild their lives; that’s when the really tough part of recovery starts,” he said.

“For every patient that has a brain injury, you may as well multiply that number by five in terms of how many people it affects within the community. “My message is that if you’re caring for a loved one with a brain injury and feeling like you’re not getting anything back, don’t worry.

“It gets better in time. You may be a different person after a brain injury, but you can still have a positive future, and the bonds can be rebuilt. You just have to understand it is a long process which requires Positivity, Awareness, Understanding and Love (PAUL), which is what my charity is all about.”

“Working with Hudgell Solicitors

Paul is supported by Brain Injury Group member firm, Hudgell Solicitors. In turn, he supports their clients going through similar experiences. Senior solicitor, Chris Moore, explains the connection:

“A major focus of our work at Hudgell Solicitors is around supporting people to rebuild their lives after serious illness or injury, and the importance of providing access to vital rehabilitation in the community should never be overlooked.

“We’re delighted to have supported Paul to achieve his goal of opening a new brain injury support centre in Hull, a vital facility for those recovering from serious injury.

“Paul has first-hand experience of walking that difficult road to recovery, and the challenges people face both physically and psychologically; he’s the perfect person to lead this project, and to support our clients who find themselves in the position he was in just a few years ago.”
Losing capacity to manage financial affairs or health and welfare matters can be devastating, for the person and those around them. When a person loses capacity a deputy may be needed to help make decisions on their behalf. Neil Elliott of Novum Law looks at why it’s worth considering someone from outside the family to take on the role.

Many people are understandably apprehensive about appointing a deputy for their loved one, but it is often in the individual’s best interests to appoint someone outside the family, as this avoids altering the family dynamic and can help maintain good relationships.

The responsibility that comes with acting as a deputy should not be underestimated: all decisions must be documented, every financial transaction accounted for, and annual accounts filed with the Office of the Public Guardian. Making decisions can be difficult and some decisions, whilst right, can also be unpopular – which can place a strain on relationships.

What does a deputy do?
The role of a deputy should be seen as one of support, encouraging the independence and empowerment of the person. The deputy should only make those decisions which the person is not able to make, and even then the person should have as much involvement as possible in any decision being made on their behalf. This is an underlying principle of the Mental Capacity Act 2005, which also states that the decision must be made in the best interests of the individual concerned.

Where there are family members involved, the deputy should consider their views and try to put the family back in to as normal a position as possible. A personalised approach is essential – there is no one size fits all solution or a guidebook to follow because every family is unique.

Acting on behalf of a child
The deputy’s role is different when being appointed for a child who lacks capacity, and they should spend time liaising with the child’s parents or carers in order to ensure that any decisions that are made are in the child’s best interests. The deputy must, so far as possible, act in conjunction with parents, and it is important that they take on board the fact that a parent would often be making decisions on the child’s behalf irrespective of any injuries they have because of the child’s age. It is important for the deputy to encourage the parents to have as much input as they want or feel able to, as they need to continue to grow as a family.

Decisions about medical treatment
Circumstances can arise where an individual does not have capacity to make decisions regarding medical treatment. It is not always necessary to have a health and welfare deputy in place in order for decisions to be made; it should be possible in most situations for a “best interests” decision to be made by medical staff and the individual’s family coming to an agreement about what medical treatment they should or shouldn’t be given.

Where there are disputes in relation to treatment either between family members and/or medics, or issues relating to terminating life sustaining treatment, then an application will need to be made to the Court, so that the Court can carefully consider the situation and make a declaration about what choice of treatment should be made.

Neil Elliott is a nationally recognised specialist in personal injury litigation. He has more than 30 years’ experience dealing with complex, high value claims, and is often called on to act as a deputy for clients with severe head injuries.

Contact Neil on 01722 447432 or at nelliott@novumlaw.com
‘Resilience’ is often used to describe how well individuals and families adapt under stress and recover from adversity. Paediatric neuropsychologist, Dr Katie Byard, looks at what research is telling us about the impact of a child’s brain injury on the whole family and how focusing on resilience can inform support and improve recovery.

Families affected by childhood brain injury have suffered a trauma resulting in change that is often devastating and that will likely require family and individual adaptation and adjustment. There is a great deal of data and research defining these effects on the family. We know that families of children with brain injury experience high levels of stress, strain and burden and that this can increase, rather than decrease, over time. We also know that families function differently after an injury because there is a need to adjust and be responsive to what are profound and far-reaching changes over time (Anderson et al., 2011).

This is particularly pertinent when one considers that a child’s brain is constantly growing and developing. This requires the family to adapt and adjust, for example when their child moves into a new developmental phase, such as becoming a teenager, or experiences a transition, such as moving from primary to senior school.

Adapting to the new normal
How a family functions as a unit can be fundamentally altered after brain injury. It can take time, sometimes with support from others, to understand what these changes are and what it means for the family to adapt, and keep on adapting, to the ‘new normal’.

Research, as well as reported experience from families, is helping us to understand how family functioning before the injury influences outcomes after injury. Families considered to be functioning well are good at communicating with one another, and can find solutions together to problems as they arise – in other words they have good resilience. These families are more likely to have better outcomes both as a family and for the brain injured child. (Yeates et al., 2010).

There are also indications that different parenting styles affect longer term outcome (Wade et al., 2011, Micklewright et al., 2012).

Involving the whole family
Research into child brain injury is tantalising because it has begun to focus on the ways families adjust and adapt to their child’s injury and how this affects outcome, and is beginning to identify what works to support families. A key focus is on improving family resilience. Involving the whole family can be helpful both in terms of encouraging family members to be an integral part of the rehabilitation team (Braga et al., 2005) and including the whole family in therapy to learn how to talk and solve problems together (Wade et al., 2006a, 2006b).

Interventions that target parental mental health (Burke et al., 2012) and offer parent training (Brown et al., 2014, Woods et al., 2009) improve family functioning and behaviour in children. It is important to acknowledge that there is a push for interventions to be available to families and to promote access to such interventions whether that is at home, in groups with other parents, or via web-based conferencing.

Research on child brain injury rehabilitation is showing the importance of improving the family’s resilience in order to help the individual child. Improving family resilience after a brain injury should be a key component of a child’s rehabilitation.

What does ‘resilient’ look like?

Dr. Katie Byard is a Consultant Clinical Psychologist, Paediatric Neuropsychologist, and a Co-founder and Clinical Director of Recolo UK Ltd which specialises in providing high quality community neuropsychological rehabilitation to children, young people and their families. She co-edited Neuropsychological Rehabilitation of Childhood Brain Injury: A practical guide.

Contact Katie on 020 7467 8387 or katie.byard@recolo.co.uk

All research references are available on request from Recolo UK or from the Brain Injury Group.
Rebuilding family life
Every day, the UK’s largest residential brain injury rehabilitation unit, part of The Children’s Trust, witnesses how every member of a family is affected when a child suffers a brain injury. Maria Coyle describes how they support and encourage parents and siblings to be part of the rehabilitation process.

Family life is shattered when a child suffers a brain injury. The effects mean families may have to adjust to enormous changes. As well as the sheer emotional strain, parents may face financial pressures whilst juggling the practicalities of looking after other children and going to work.

The families we meet often describe a rollercoaster of emotions: shock, denial, anger, frustration, a feeling of loss for how their child was before, guilt, isolation and confusion.

We provide on-site family accommodation so that parents and siblings can be involved in the rehabilitation process, and learn about their child’s injury. Meeting other parents and siblings and sharing in their experiences also offers support and understanding.

Many family members will experience shock or post-traumatic stress disorder after their child has been injured and there is inevitably a huge amount of new information to take on board at this time. Parents may disagree on a child’s goals or, when the child has returned home, what level of independence to give them. Relationships can, understandably, become strained, but it’s important for parents to be aware that these tensions can surface and that it’s completely normal.

Supporting siblings
Brothers and sisters may face a particularly difficult time. They sometimes have to do things very differently to accommodate a child with an acquired brain injury. Some children feel the loss of their parents’ attention, and it may be difficult for a young child to understand why their brother or sister is treated differently.

Twins Addison and Isabella were the perfect pair. Addison was feisty and boisterous, while Isabella was quieter and tended to follow her sister’s lead. Isabella watched intently as Addison took her first steps, but soon toddled tentatively after her.

Everything changed when Addison suffered a brain injury just before their second birthday and lost many of her new skills.

Addison began an eight-week rehabilitation course at The Children’s Trust. The rest of the family stayed on site and the therapists encouraged Isabella to join in with speech and physiotherapy sessions. It was now Isabella’s turn to show her sister how to talk and walk again. She smiled reassuringly as Addison learnt to walk, gingerly putting one foot in front of the other.

Their mum, Katie, said: “Watching my girls splashing around with other children in the hydro pool, I knew that they’d get through anything. Where once she’d been the leader, Addison now looked to Isabella – and her once timid sister rose to the challenge. The support of The Children’s Trust made this possible. Our ability to stay on site and get involved in sessions was essential to Addison’s fantastic recovery.”

The siblings we meet talk of anxiety, pressure, anger, jealousy, depression and loneliness; some children feel guilty about expressing those feelings, not wanting to add to their parents’ burden.

At The Children’s Trust they get the opportunity to mix with other siblings and take part in activities that give them time to be themselves. They are also welcomed into therapy sessions to learn more about their sibling’s injury and recovery.

We encourage parents to talk things over with children, spend quality time alone with them and give them time to be themselves.

About The Children’s Trust
The Children’s Trust is the UK’s leading charity for children with brain injury. As well as its residential facility at Tadworth, Surrey, it offers a nationwide community service for children and young people with an acquired brain injury. For more information visit: www.thechildrenstrust.org.uk

For advice and support visit: www.braininjuryhub.co.uk

Maria Coyle, Information Editor at The Children’s Trust, works closely with clinicians, the research team and families to create up-to-date, accessible resources to help the families of children who suffer a brain injury. Maria updates The Brain Injury Hub website with tips and strategies and welcomes blogs and news from professionals and families happy to share their expertise and experiences.

Contact Maria on 01737 364318 or mcoyle@thechildrenstrust.org.uk

Recovering together

Maria Coyle, Information Editor at The Children’s Trust, works closely with clinicians, the research team and families to create up-to-date, accessible resources to help the families of children who suffer a brain injury. Maria updates The Brain Injury Hub website with tips and strategies and welcomes blogs and news from professionals and families happy to share their expertise and experiences.
Legal & Welfare Service

Free advice at your finger tips

LAWS Online is a FREE online service for individuals and families affected by brain injury providing access to advice on a range of legal, financial and welfare issues including:

- Mental capacity | Personal finances | Employment
- Powers of Attorney & Court of Protection | Housing
- Personal injury & criminal injury compensation claims
  - Matrimonial & family matters | Education
  - Personal health & care budgets
  - Care or treatment issues

People looking for advice simply complete a brief online questionnaire and one of our member firms will respond to the initial enquiry – usually within two working days.

LAWS Online. Making it simple to access specialist advice from experienced professionals.

For more information, go to braininjurygroup.co.uk/laws-online-support