National Rehabilitation Hospital

An tOspidéal Náisiúnta Athshlánúcháin

Supporting Child Relatives of Adults with Acquired Brain Injury:

A Resource for Rehabilitation Teams

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Foreword

In the NRH Brain Injury Rehabilitation Programme, the interdisciplinary team works with patients with acquired brain injury and helps them to achieve goals in order to improve their quality of life. While some consideration is given to child relatives, the process has been largely client and carer centred. Many injured persons have young children, and there has been an inconsistent approach across the service in terms of helping children cope with and adjust to their brain injured parent or relative. The NRH is not alone in this. A study undertaken to establish the extent of child relatives' involvement in rehabilitation, across approximately 100 UK rehabilitation teams in 2005, concluded that only 19% of participants had reported working with child relatives, indicating that children are not routinely included in interventions.

There has been a new emphasis in recent years on the importance of family focused rehabilitation, with the UK's 'Think Family' policy, as well as research from various authors, such as Audrey Daisley. To date in Ireland, rehabilitation has been more client and carer focussed. The NRH Social Work Department has therefore developed this resource pack, the aim of which is to strengthen the family approach to rehabilitation.

The objective of this pack is to support staff to be more inclusive of child relatives; and to help them see the importance of including child relatives when working with adults with an acquired brain injury. The aim is that, with the aid of this resource, the inclusion of children could be integrated into the rehabilitation programme.

This resource pack has been designed to provide staff with the tools and confidence to work with children. The pack has been developed to serve as a toolkit with suggestions and ideas on how to work with children, and to provide information on the developmental stages of children and how they are impacted by brain injury.

It should also be noted that including children in the rehabilitation process does not necessitate exclusively working directly with the children. Staff can support family members to consider and meet the needs of their children during the rehabilitation process. While the pack is mainly directed at rehabilitation staff, much of the information and tips will be useful for non-healthcare workers also.

Research has shown that children with brain injured parents can have significantly more emotional and behavioural problems than children in the general population. Involving child relatives in the rehabilitation process impacts on their adjustment and consequently has a positive impact on family relationships. Including child and family-centred goals in a rehabilitation programme also has benefits for patients as it can result in their programme being more meaningful and help to motivate them during their rehabilitation.

This pack is divided into three sections: **Introduction** - Involving Child Relatives in Rehabilitation; **Interventions**; and **Resources**. The pack is accompanied by a workbook for children (**"What's the Story?"** *When someone in your family has a brain injury*), which can be given to parents and teachers if deemed appropriate. The workbook contains some information that should be helpful in explaining brain injury to children, while also allowing them to communicate their own experiences.

While this pack was compiled by Phil Butler on behalf of the Social Work Department, it would not have been possible without the invaluable support of the Dr Tom Gregg Bursary Fund.

We would also like to pay particular tribute to Dr Audrey Daisley,Consultant Clinical Neuropsychologist in the Oxford Centre for Enablement, who has a particular interest in the issues facing children who have a relative with brain injury and in 1995 established the first NHS service to specifically support child relatives. Dr Daisley was the inspiration for the project and was extremely generous with her time, resources and publications. The sections entitled 'practical tips' and 'common questions asked by children' are directly based on her research.

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Section 1

Introduction

Involving Child Relatives in Rehabilitation

Introduction: Involving Child Relatives in Rehabilitation

It is widely acknowledged that brain injury does not just affect the person with the injury, but their family also. While efforts have been made in many countries to make rehabilitation more family focussed, and include the needs of family members, the focus is predominantly on the person with the injury. When the family is included in the rehabilitation process, it is often the spouse or partner, and sometimes other adult relatives such as older parents that rehabilitation teams work with. Involving children in the rehabilitation programme does not happen on a consistent basis, and indeed the impact of parental or familial brain injury on children was an area that was not widely researched until recently. This has begun to change, and more work has been done with child relatives assessing their reaction to brain injury and their coping strategies.

Since the late 1980s, researchers began to look at the impact of adult brain injury on child relatives. While the body of research is continuing to grow, most of the research is based on small scale studies, with some citing very negative effects on child relatives, and others pointing to more positive outcomes and opportunities for resilience within families. When compared with the impact on children of other parental illnesses, the effect of parental brain injury does not appear to be especially unique. However, it is an area which requires further investigation, and ideally more large scale studies to determine the impact of brain injury more specifically.

Nevertheless, what the research does tell us is that brain injury presents challenges to both children and parents: the symptoms and sequelae of brain injury affect children, sometimes positively, sometimes negatively, and the age of the child is a contributing factor; brain injury affects the non-injured spouse, which in turn creates an impact for the child; the way children are treated by hospital and rehabilitation staff affects the children but also impacts the whole family; the capacity of the person with the brain injury to parent is affected; brain injury can create an opportunity to develop resilience within the family; and family centred rehabilitation appears to result in positive rehabilitation outcomes.

It is worth reviewing the existing body of research to gain a better understanding of the impact of brain injury on child relatives and to understand the benefits of including them in the rehabilitation process. This review of literature has been undertaken under four main areas: 1) the impact of brain injury on child relatives; 2) the impact of brain injury on parenting capacity; 3) how rehabilitation teams can help to promote resilience to achieve better rehabilitation outcomes; and 4) the benefits of family focused rehabilitation.

1. Impact of Brain Injury on Child Relatives

While some authors focus more on the negative impact of brain injury on child relatives and others focus on the positive consequences, there is general agreement that a brain injury in the family has a long-lasting effect on children.

1.1 The challenges children face

Daisley and Webster (2008) discuss the challenges children can face. They categorise these challenges into four main areas. First, they discuss the “direct impact of post-injury symptoms…that children must try to comprehend and cope with”. This can be particularly difficult if the injured person has emotional or behavioural difficulties.

The second challenge facing children is that of having to “negotiate and redefine their relationship” with their injured family member. There can be considerable role changes within a family where brain injury has occurred. For example, the non-injured parent may have to assume responsibility for household management and childcare, while the injured parent may assume a more dependent role. Or the child may have to take on some care tasks and assume a more adult role within the family.

The third challenge relates to the social consequences of the brain injury. For example, families may have financial difficulties or unemployment resulting from the brain injury. This can lead to feelings of insecurity and uncertainty for children.

The fourth challenge for children is the impact of the brain injury on the non-injured parent or other family members. Daisley and Webster cite Uysal et al. 1998 who reported that "spouses of TBI patients reported fewer feelings of love and acceptance towards their children compared to controls".

Daisley and Webster assert that due to these challenges, "children with brain injured parents had significantly more emotional and behavioural problems than children in the general population". This assertion is based on several small scale studies and therefore it is important to note that this generalisation has yet to be confirmed by further research. Daisley and Webster do however recognise that the impact on children is not always negative and that children can "exhibit positive personal growth".

1.2 Grief and loss

The need for children to redefine their relationship with their injured parent is further alluded to by Butera-Prinzi and Perlesz (2004), who conducted a study on the impact of brain injury on children. Their study found that children reported feeling the loss of their 'real dad', and the authors allude to the ambiguous loss experienced by children, as the loss is not absolute but their parent is changed emotionally and behaviourally. This makes it difficult for children to "mourn the loss of their fathers while they were still alive".

However, it is important to note that this study is very small in scale, based on the experiences of four children living with their injured fathers. In addition, it would seem that children's reactions to their changed parent is influenced by age. In this particular study, the younger child reported the more positive effects of the brain injury, specifically that she could spend more time with her father as he was not working and therefore she felt more connected to him. It is clear then, that research on a wider scale needs to be conducted before more definitive conclusions can be drawn.

1.3 Violent behaviour

A concerning finding of Butera-Prinzi and Perlesz's research was the reported high level of violence experienced by the children, and the authors conclude that clinicians and researchers need to be more "proactive in questioning their clients and families about the level of violence following ABI".

The connection between acquired brain injury and violent behaviour is further explored by Turkstra, Jones and Toler (2003) who conducted research with 20 African American men convicted of domestic violence and 20 African American men with no criminal convictions. This study did not conclude that ABI occurs more often in those convicted of violent crimes. However, the authors did note that "the reported severity of TBI was significantly greater in the batterer group".

1.4 Lack of social support

Another challenge facing children and families following a brain injury is the loss of social support, particularly in the years after the injury. The children in Butera-Prinzi and Perlesz's (2004) research reported feeling abandoned by family friends and extended family.

Brooks (1991) discusses social isolation of families and states it is a marked feature for all family members following ABI, with some having no social contacts outside the close family. This increases "the already high burden on these families".

Brooks then discusses the high levels of subjective burden felt by family members five and six years post ABI, with families becoming lonely, isolated and cut off from support. He also notes that there was a high level of separation and divorce at ten years post ABI. This was also mentioned by Webster, Daisley and King (1999) in which they report that 30% of marriages end in divorce within seven years of a severe ABI to one partner.

The children in Butera-Prinzi and Perlesz's study stated school was their escape from their problems at home, even though "none of the children were approached regarding their fathers' ABI or asked how they were coping". Considerable work therefore still needs to be done on inter-agency co-operation when dealing with children affected by familial brain injury. The children in the study also exhibited signs of emotional distress, such as sadness, anger, ambivalence and confusion. The findings showed that the children were at risk of anxiety and depression.

However, despite these negative impacts on the children, as with Daisley and Webster's research, there were positive signs of resilience in the children, with them citing relationships with their peers and their pets as being of significant support to them. They also stated that social activities outside the home such as horse-riding and going to the cinema helped them cope and enjoy 'normal kids' stuff.

1.5 Life cycle challenges

Another challenge facing children with familial brain injury is raised by Rolland (1999) who states "when illness strikes a parent in the childrearing phase of the life cycle, this crisis is more challenging because it occurs 'off-time' in terms of chronological and social expectation and parenting needs of children". Rolland is therefore stating that children are going through their life cycle transitions, while at the same time the family has to cope with the injured parents' transition to a new level of ability and/or impairment. This can lead to differing demands and stresses on the whole family. Rolland recommends that this be borne in mind when rehabilitation teams work with individuals and families.

DePompei and Williams (1994) allude to challenges in the life cycle of families after brain injury, and give examples of when a stage of the life cycle can be disrupted or even reversed. For example, a person with a brain injury may have to return to live with parents after having lived independently or with a partner. This can be challenging for both the person and the parents, and is further complicated if there are children involved. Children may have to adjust to new living arrangements, such as moving in with grandparents, or their injured parent moving out of the family home.

2. Impact of Brain Injury on Parenting Capacity

2.1 Disrupted parenting

Kieffer-Kristensen et al, (2013) allude to the notion of diminished parental attention and 'disrupted parenting' and define disrupted parenting as "reduced parental support or less nurturing of the child". This reduced support can be from both the injured and non-injured parent, and can include depression and stress of both parents, reduced boundary setting, marital conflicts and other problems. The authors' hypothesis is that ABI families will have disrupted parenting and therefore more stress, and more emotional and behavioural problems in the children. An interesting finding from this study is that the stress in the *non-injured parent* impacted significantly on the child and led to emotional and behavioural problems. They argue that the stress on the non-injured parent, who has to try to fulfil the role of both parents and try to protect the child from further psychological distress, can take its toll on that parent and lead to significant stress levels. This in turn influences the child negatively, and can lead to emotional and behavioural difficulties. The importance of the well-being of the non-injured parent leads the authors to conclude that "one cannot adequately look at parental ABI without taking into account the entire family system".

Pessar et al, 1993 support this and argue that family based rehabilitation should look at depression and parenting behaviour of both parents when assessing the impact of ABI on children and the family.

Vitale Tiar and Dumas (2015) also refer to the challenges faced by the non-injured parent and note that the non-injured parent felt more easily overwhelmed by children and "found the task of bringing children up particularly difficult". They conclude that overall, "both injured and uninjured parents displayed less positive behaviour following ABI…less loving and accepting of their children…showed less interest and involvement in their activities".

2.2 Relationship between injured parent and child

Pessar et al (1993) refer to acquired brain injury as a major family stressor. They state that "psychological and social disruptions within the family may influence children's psychological and social well-being". They report on a study they undertook of 24 families, and found that 22 of the 24 families reported negative changes in children's behaviour since the ABI. The most prevalent problem area according to the authors was the relationship between the children and the injured parents. They highlight that the injured parent no longer fulfilling the parental role caused significant problems for the children. This is further explored by Holloway (2014) who notes that the injured parent's reduced capacity to fulfil his or her parenting role by, for example "poor boundary setting, neglect and lack of attachment to children", can lead to an increased risk of post-traumatic stress symptoms in children.

2.3 Brain injury as a traumatic event

ABI could be defined as a traumatic event as it meets the criterion in the DSM-IV definition of trauma, and therefore can have serious consequences for children. Following an ABI, children may feel neglected and vulnerable and can internalise these feelings. The risk of PTSD in children is a strong recurring theme in the literature. Kieffer-Kristensen et al (2011) concluded that 46% of children with a parental brain injury met the criteria for probable PTSD in the form of "intrusive thoughts, avoidance behaviour and arousal symptoms". They also discovered that parental ABI can lead to additional secondary stressors, which may increase children's risk of developing PTSD symptoms.

These secondary stressors include: 1) diminished parental attention – the brain injured parent is usually less involved in the parenting role, as can also be the case with the noninjured parent who has more demands on their time; 2) tension in the marital relationship – this may threaten the child's feeling of safety and security; 3) changes in daily life and routines – for example, the injured parent no longer collects the child from school. These secondary stressors, in conjunction with the traumatic experience of the brain injury event itself, poses a significant risk of traumatic stress on children. The authors conclude that the impact of trauma in children should be assessed, and that a more child-focused approach is "crucial to decreasing the children's post-traumatic stress symptoms".

3. The Rehabilitation Benefits of Promoting Resilience

3.1 Coping strategies

It is evident from the literature that children can be impacted both positively and negatively by parental brain injury. Tiar and Dumas (2015) identify three methods of coping displayed by children and adolescents. Firstly, some children displayed pro-social coping. For example, they took on more responsibility in the home and in care tasks; and they felt empathy for the non-injured parent. Secondly, some children displayed anti-social coping behaviour, in which they exhibited anti-social behaviour at home and in school, such as temper tantrums, disobedience, anger and hostility. Thirdly, some children displayed asocial coping behaviours. These relate to children displaying depressive symptoms, such as negative mood, poor self-esteem, inability to feel pleasure, as well as feelings of loneliness and isolation.

The importance of peer relationships can help children cope with their parents' ABI. In Moreno- Lopez et al's 2011 study, they highlight the value of peer relationships for adolescents and conclude that "peer relationships appear to have a crucial function as a link between adolescents' lives before and after ABI, enabling them to maintain a sense of normality and continuity". Friendships provided a break for the adolescents from their family and gave them space to be 'normal' adolescents.

3.2 Resilience

A family resilience perspective recognises parental strengths and potential as well as limitations, and as such involves the potential for personal growth and transformation. Walsh (2003) sees a crisis such as brain injury as having the potential to lead to more enriched and loving family relationships, and argues for the potential for family recovery and growth out of adversity. Nine key processes in family resilience are highlighted, and these processes outline the way in which resilience can help support families to 'bounce forward' from a crisis, and maintain positive family relationships. The key processes include:

1) make meaning of adversity – normalise and contextualise adversity and distress;
2) positive outlook – hope, perseverance, accept what can't be changed;
3) transcendence and spirituality – faith, congregational support, healing rituals, finding meaning and purpose beyond oneself and one's immediate troubles
4) flexibility – open to change, adapt to fit new challenges, stability through disruption;
5) connectedness – mutual support, collaboration and commitment, respect differences;
6) social and economic resources – mobilise social networks, balance work/family strains;
7) clarity – clear, consistent messages, clarify ambiguous information;
8) open emotional expression – share range of feelings, mutual empathy;
9) collaborative problem solving – creative brainstorming, resourcefulness, shared decision making, focus on goals, prepare for future challenges.

Butera-Prinzi, Charles and Story (2016) also discuss family resilience. They describe resilience as a dynamic process that can change over time, and at various points in the family life cycle, rather than a 'fixed' family trait. They assert it is the role of the clinical team to look for this resilience and strengthen it in order to support families to adapt to their new life following an acquired brain injury.

The role of the rehabilitation team is further explored by Skippon (2013), who notes the three main dimensions of resilience, focusing on 1) identifying and developing resilience factors within the individual parents and children (such as flexibility and coping strategies); 2) resilience factors within the family (such as attachment relationships); and 3) supporting the family in maintaining social integration and networks". If the rehabilitation team adopts a more family centred approach and adopts a resilience approach to their interventions, it is hoped that more positive outcomes can be achieved for patients and their families.

4. Benefits of Family Focused Rehabilitation

It is clear that acquired brain injury has a significant impact on families in general and children in particular. As we have seen, there are several studies which highlight the effects on children. It is therefore important that not only do professionals support the brain injured person to recover, but also their family, as this will influence rehabilitation outcomes and the family's wellbeing in general.

Holloway and Tyrrell (2016) assert that "goal attainment is noted to be significantly better in families that function and communicate better with each other". They argue that working with uninjured family members has positive impacts on rehabilitation outcomes, and in turn has benefits on parents' ability to parent their children. They report on a study in which they looked at the benefits of supporting parents with an ABI to parent their children. This had benefits for both the injured parent in terms of their rehabilitation and for the child in terms of him or her remaining in the family home in a healthy family environment. They conclude that social work can play a central role in "the effective use of rehabilitation and support by the injured party, monitor risk, and reduce likelihood of harm".

Moreno-Lopez et al (2011) also refer to the benefits of a family focused rehabilitation and state that "family coping appears to have a positive impact on the rehabilitation progress of the ABI survivor". In the UK, there has been a growing emphasis on family focused rehabilitation with their 2007 'Reaching Out: Think Family' document published by the Social Exclusion Task Force. Central to this policy is a belief that "tailored, flexible and holistic services that work with the whole family can turn lives around". It argues that working with the whole family can have preventative qualities by focusing on a family's strengths and recognising problems early on. It promotes resilience and working with parents to help promote positive relationships, and social and emotional skills.

Daisley, Tams and Kischka (2009) support this by stating that "families play a major role in helping people recover from head injury yet the distress they experience can interfere with this". Hence the importance of professionals recognising this distress and helping the whole family in order to help the injured person.

Ceri Bowen (2007) alludes to the increasing emphasis on family focused rehabilitation in the UK and argues for the use of family therapy in this process. He asserts that this new emphasis on the family is based on "a belief that rehabilitation should involve a model for supporting families that is flexibly applied" and that "family support plays a critical role in recovery processes after brain injury".

It is clear from reading the literature that children should be included in the rehabilitation process. This not only helps children, but has a positive impact on a brain injured person's rehabilitation outcomes. All of the reports offer helpful insights into how children are affected by brain injury, and are a useful starting point in looking at how to ensure rehabilitation can be more inclusive of children in the future. They also offer evidence illustrating the benefits of including children in rehabilitation for both the injured person and the whole family.

4.1 Impact of brain injury on parenting

As we know, a brain injury can impact on a person in many different ways. No brain injury is the same, and each person can have very different symptoms. The difficulties associated with brain injury, where present, can have an impact on a person's ability to parent. This does not always have to be negative, as long as people are aware of the impact and how it can be managed.

Below is a list of possible difficulties a person with a brain injury may have when parenting their child. This is an extensive list, and not every parent will have all or even many of these difficulties. It is however important to be aware of any potential difficulties in order to find a way to help both the parent and the child. It is also useful when trying to assess the impact of brain injury on a child and how they feel they are impacted on a daily basis.

The main goal is to support the child to maintain a relationship with his or her parent. It is also important to note that when speaking to a child about possible impacts on parenting, that the list below is used as a guide only, and that the language and words used would be at a level that the child can understand.

Problems arising from brain injury	Impairment	Possible consequence for child. Examples include:
Cognitive	Attention difficulties	When children bring friends home from school, parents may not cope well with the noise and extra demands this entails
	Long term memory problems	A parent may forget the details of important events in a child's life such as their birth or early years
	Everyday memory problems	A parent may forget the route to school, or may forget to give the child a school lunch
	Communication and language skills	A parent may not be able to help their child with homework; it may influence a parent disciplining a child as they may not be able to explain the reason for the disciplinary action; a parent may not be able to 'get the joke' or tell when their child is lying
	Executive functioning difficulties	Young children may not be supervised appropriately; 'play fighting' may become too rough; a parent may leave the house with a young infant and forget to bring nappies or other items
Behavioural	Irritability and temper	A parent may not be able to regulate their temper and become annoyed with children very quickly if they are noisy
	Impulsivity	A parent may change a decision that is important to a child without offering any explanation
Emotional	Depression or low mood	A parent may withdraw contact with a child due to believing s/he is not a good enough parent
	Anxiety or obsession	A parent may worry excessively about a child's safety; a parent may want the house to be immaculately tidy and find it difficult to tolerate children's toys left lying around
Physical	Mobility	A parent may be unable or find it difficult to run and play with the child; there may be limited family activities that the whole family can do together
	Co-ordination	A parent may be unable to help small children fasten buttons or tie shoelaces
Social and practical	Driving	It may be difficult to plan activities with a child if the parent cannot drive; a parent may have to rely on others for assistance
	Epilepsy	A parent may not be able to supervise a small child, depending on the likelihood of seizures

4.2 Children's Understanding of Brain Injury

Depending on their age and stage of development, children have different levels of ability to understand difficult concepts such as brain injury and behavioural symptoms. Below is some information on children at various developmental stages and how they can understand their parent's brain injury, as well as the effects of the injury on their behaviour. It is important to note that some children may not demonstrate any of these effects on behaviour, while others may exhibit different effects not mentioned here. The list is not exhaustive and offers general guidelines. There is also a general table on child development, with information on children's physical, cognitive, emotional and social development at every developmental stage.

Developmental Stage	Level of Understanding	Effects on Behaviour
Infancy (0-2 years)	Understands simple concept of 'hurt' or 'sick'	Unsettled, disturbed sleep, feeding difficulties
Early childhood (2-6 years)	Understands visible symptoms; egocentric thinking – will blame themselves	Clingy, temper tantrums, new fears, loss of skills (bed wetting)
Middle childhood (7-12 years)	Understands all impairments but believes full recovery possible	Sad, withdrawn, increase in fears, anger
Adolescence (13-18 years)	Understands complexities and needs emotional support to cope	Anger, mood swings, fatigue, resistance to rules and boundaries

Babies and Infants (up to age 2)

Babies and infants are unable to understand complex concepts but can understand being 'hurt' or 'sick' from about 6 months onwards. They are also more aware of a parent being absent and can be distressed by this. Babies show problems such as unsettled behaviour, disturbed sleep, and feeding difficulties at times of family stress.

Pre-schoolers (up to age 6)

Pre-schoolers have a better understanding of what an injury is, but will likely struggle to understand 'unseen' symptoms of brain injury such as, for example, poor concentration. They will also find it difficult to understand problems being long term or permanent and will likely expect the adult to make a full recovery.

Pre-schoolers have 'egocentric' thinking and view everything in relation to themselves. They are therefore vulnerable to blaming themselves for the accident, and may believe that their 'naughty' behaviour on a particular day caused their parent's accident.

Some pre-schoolers may also believe that they will 'catch' the injury from their parent and so may avoid them. Pre-schoolers can become clingy, may have more temper tantrums, and may lose some of their previously acquired skills. They may also develop new fears (for example, fear of the dark).

School age children (6-12 years)

Young children have a better understanding of head injury and will understand both 'seen' and 'unseen' symptoms if they are clearly explained. However, they may still need help in understanding the long term nature of head injury, as they are still likely to expect their parent to make a full recovery.

Young children worry about what their friends think as they don't want to be different. They may be teased about their parent being 'odd' and so will need help in knowing what to tell their friends about the injury. Young children, like pre-schoolers, may also blame themselves for the injury, and may not know how to behave 'normally' towards their relative as they believe they must not misbehave at home if they want to help their relative recover.

Young children can become sad and withdrawn, and their school work may suffer. They can show an increase in fears and phobias. They can also show anger towards the injured person, and complain of physical problems, such as stomach aches.

Teenagers (13-18 years)

Teenagers can generally comprehend the complexity of head injury, and can therefore be told about its severity, the extent of recovery, and permanence of injury. However, they will need considerable emotional support to be able to cope with this information.

Teenagers may respond with resentment and anger. They can become tired as they have to take on additional household tasks. They may show an increase in mood swings and oppositional behaviour, and resist family rules and boundaries.

4.3 Stages of Child Development

Developmental Stage	Physical development	Cognitive development	Emotional development	Social development
Infancy (0-2 years)	Learns to crawl and walk Learns to communicate	Intentional goal directed behaviour to solve simple problems Object permanence Categorisation of objects based on perceptual features Deferred imitation of adult's actions	0-12 months: detects emotions by caregiver's facial expressions Anger and fear increase Uses caregiver as a secure base 1-2 years: begins to appreciate others' emotional reactions can differ from one's own Develops empathy	Increased self-awareness Sensitivity to adults' evaluations appears Expressions of pleasure in mastery are evident
Early childhood (2-6 years)	Walks up and down stairs Runs more smoothly Learns to pedal tricycle Learns to throw and catch ball	Increase in representational activity (such as make-believe play) Distinguishes animate beings from inanimate objects Understands cause and effect in familiar contexts Categorises objects based on function and behaviour as well as features Working memory capacity and processing speed increase Attention becomes more focused and sustained	Self-conscious emotions linked to self-evaluation Uses strategies to regulate emotion Improved understanding of consequences, causes, and behavioural signs of emotion As language develops, empathy becomes more reflective	Can categorise self based on physical attributes, abilities, and goodness vs badness Self-esteem is high Sense of achievement appears but is undifferentiated

4.3 Stages of Child Development

Developmental Stage	**Physical development**	**Cognitive development**	**Emotional development**	**Social development**
Middle childhood (7-12 years)	Increases running speed Increases throwing and kicking speed Learns to ride bike	Thinks in more organised logical fashion about concrete information Displays more effective spatial reasoning Working memory capacity and processing speed continue to increase Attention becomes more selective and adaptable Memory strategies become more effective	Self-conscious emotions linked with inner standards of excellence and good behaviour Uses internal strategies to regulate emotion Empathy increases Increased awareness of people's mixed feelings and that expressions may not always reflect true feelings	Emphasises personality traits and both positive and negative attributes in self-concept Makes social comparisons among multiple individuals Self-esteem becomes hierarchically organised
Adolescence (13-18 years)	Sexual maturation Growth spurt Voice change in males	Reasons abstractly and can deduce hypotheses Can engage in propositional thought – evaluate the logic of propositions without referring to real-world circumstances Displays imaginary audience (belief that they are the focus of everyone else's attention and concern) and personal fable (belief that others are observing and thinking about them) Improved decision making Working memory capacity and processing speed increase but at a slower pace Attention & memory strategies continue to improve	Self-conscious about physical appearance and early or late development Body image rarely objective Emotionally labile Engages in activities for intense emotional experience Relies on peer group for support Identity includes positive self image comprised of cognitive and affective components	Unifies separate traits, such as 'smart' and 'talented' into abstract descriptors such as 'intelligent' Combines traits to create an organised self-concept New dimensions of self-esteem are added (close friendship, romantic appeal, job competence) Self-esteem continues to rise

Section 2

Interventions

Interventions

5. Helping Children Cope with Brain Injury

The following is a list of practical tips and advice on how to help children adjust to and cope with their parent or relative's brain injury. It is important to note that a lot of work can be done with the family rather than the child, as it may not always be possible or appropriate to meet with children directly.

Assessment

- **Ask patients/families about their children and gain information on the names and ages of patients' children as part of assessment**

  It is helpful to know which of your patients has children, and details about them if they do. Photographs of children or the pictures that children have drawn could be hung up over their beds. Engaging with people about their children has many benefits: it helps develop rapport; it helps patients feel like people rather than clients; it helps both patients and therapists acknowledge the potential impact on children and consequently develops awareness of the need to develop goals around them.

- **Assess parenting ability as part of normal assessment and treatment**

  It is important when working with a parent with a brain injury to assess their ability to care for their children, and to include practical parenting tasks as part of treatment. When parents leave the rehabilitation setting they are usually returning to the family home where they share responsibility for the care of their children. It is therefore essential from a safety as well as emotional perspective, that they are able to do as much as they physically and cognitively can with their children.

Goal Setting

- **Include parenting and childcare goals in goal planning**

  Parenting and childcare can be a large part of an injured parent's life, particularly if their injury has led to them having to stay at home more with the children, while their partner may have to work more outside the home and take on the financial responsibility within the family. Rehabilitation goals should therefore reflect this.

  It is important that rehabilitation goals focus on the needs of patients to fulfil their role as parents as well as other life roles. Having goals that are meaningful to patients can be very motivating and encourage them to work harder to meet these goals. For example, having a goal around helping a parent be able to sit on the floor and play with their child and then be able to get up off the floor unaided is a meaningful goal for the patient, and a practical and therapeutic goal for the therapist.

Communication with Children

- **Give honest age-appropriate information to children to help them understand brain injury, and an opportunity to express their feelings and concerns**

  Children's understanding in general, and understanding of brain injury in particular, varies at each developmental stage. It is therefore important when explaining symptoms to children that they are addressed at a level they will understand. The importance of giving children honest information has been documented in the literature. Sometimes the most upsetting thing for children is not the brain injury itself, but the feeling of not knowing what is happening and feeling they are being excluded.

  Children who are not given enough information will usually assume the worst and will have created an image in their head of the future, which is often far worse than the reality. Giving children the opportunity to express their feelings is also important in helping them to adjust to their relative's injury, thereby reducing potential future behavioural or other difficulties for the whole family.

- **Work with parents and partners to prepare information that they can either deliver themselves to the child or together with a staff member**

  Empowering parents to speak to their children directly about brain injury has benefits for both the children and the parents. Honest communication fosters an open loving relationship between child and parent, and helps the child to feel respected and loved. When a family member has a brain injury the other members, particularly the partner, can often feel a lack of control over events. Helping a non-injured parent to have the knowledge and ability to explain the situation to their child can give them some of that control back, and reinforce their continued role as parent.

- **Keep children up to date on progress, by giving them regular information and feedback**

  Giving children regular updates helps to ensure they feel included in the process, and ensures they have an understanding of their relative's condition and progress. Children can often have misconceptions about brain injury symptoms, and would benefit from regular updates on how their relative is doing. For example, fatigue is a common symptom of brain injury, but children can sometimes feel that their relative is just a little tired and will be ok after a short rest. The full impact of fatigue should be explained to children in order to avoid them putting pressure on their relative to engage in activities they are unable to complete.

- **Reassure children they are not to blame for the injury**

  Many children, particularly young children, blame themselves for their relative's brain injury, and think their behaviour on a particular day contributed to the accident or event. This impacts on their subsequent behaviour towards that relative, with some trying to be perfectly behaved all of the time, or some not knowing how to act 'normal' around their relative. This affects everyone in the family and can affect the bond between children and injured parents.

- **When speaking to children about their relative's brain injury, follow this structure:**

» Gain a picture of the child's understanding of brain injury and its causes

» State what a brain injury is (at an age appropriate level)

» Say how the brain injury specifically affects their relative

» Reassure the child that the brain injury is not contagious and they are not to blame for it

» Focus on the injured person's strengths and abilities, to make sure a balanced picture is given

» Discuss recovery and the likelihood of some long-term problems. Balance this with an optimistic statement about the future and reassure the child that the relative will still be involved with them

» Acknowledge that the child may be feeling sadness and fear, that this is normal, and that it will improve

» Ask the child to repeat what you have said (so you can check for any misunderstandings)

- » Ask the child if they have questions
- » Ask the child if they would like to speak to someone, either in the NRH or outside.

Communication with Families

- **Encourage adults in the family to model positive coping strategies for children**

  Children look to adults to gain a sense of the world and how to react to events. If children see other members of the family coping well and adjusting to their relative's injury, this will help them to also try to deal with the injury in a positive way.

- **Encourage family to try to keep children's daily routines as 'normal' as possible**

  Family life will undoubtedly change once a member has a brain injury. In the initial acute hospital stage, it is likely that children have been looked after by various family members and friends. Children may also have been taken out of school for hospital visits.

  During the rehabilitation stage, it is important that life for children returns to some form of normality, with a return to school, and if possible only one or two 'main' carers. Any change is difficult for children as they like routine and boundaries. While some changes are unavoidable, it is important to instil some routine and return to boundaries in order to help them adjust to a 'new normal' life.

  It is also important they continue to engage in any afterschool activities, as research has shown that peer support is beneficial to children's sense of wellbeing.

- **Encourage family to tell the school what is happening – they may be able to offer some extra support**

  Children spend a significant amount of time in school. The influence of friends and teachers can be considerable. There is therefore the potential for a huge resource within the school to provide support and an outlet for children. Teachers are also well placed to observe any changes in children and can alert family to the need for extra supports such as counselling.

Inclusion of Children in the Rehabilitation Process

- **Encourage regular visits to the relative, as well as telephone calls, emails, letters, skype, children's pictures**

  As with the need for regular updates, children will also benefit from regular contact with the injured relative, either through hospital visits, email, skype and facetime calls. If children can see their relative and engage with them, this will help to reduce their fear and anxiety, but it will also help to maintain the bond between them.

- **Invite children to observe and participate in therapy sessions where appropriate, but be careful to ensure children don't feel they need to be mini carers or therapists**

  Attending therapy sessions can really help children to understand the nature of their relative's disability as well as giving them the opportunity to learn how to help their relative on a practical level, thus feeling useful and important. It is important however, to make sure children do not feel they have to become carers or 'mini-adults' in the family.

Hospital Environment

- **Try to create a friendly, relaxed environment for children when they visit**
  When a child is not familiar with the hospital environment in which their parent is staying, they can be very concerned and worried about it and can have ideas that it is not a friendly or nice place. It is always helpful for the child to visit and see their parent, and if possible meet some nursing and therapy staff. Even a little chat with staff members in a non-therapeutic capacity can put the child at ease and feel reassured that their parent is being looked after when they are not there.

Resources within Hospitals

◇ Books ◇ Games ◇ Websites	} see booklist in Section 3.8 of this manual

◇ Social work/psychology individual sessions with children

Resources within The National Rehabilitaton Hospital

◇ See above list
◇ NRH Paediatric team (for advice and guidance)
◇ Family room (including facilitating family visits)
◇ Valentine’s fund (for assistance with travel and accommodation expenses)

Onward Referrals

- **If a child requires more intensive support, liaise with the social work department, who can either work with the child themselves, or refer to the relevant support services**
  In some exceptional cases, the social work department may have to refer to the relevant Child and Family services. While this is not the norm, it is important to note that if there is any indication that a child is not being adequately protected or cared for, there is a legal obligation to report this. It is important therefore to be mindful of this.

6. Common questions asked by young children (up to age 12 approx) and how to answer them

See workbook (**“What’s The Story?”** *When someone in your family has a brain injury*) which is part of this resource pack, and serves as an accompaniment to these questions. The workbook can aid in direct work with children, and help to explain brain injury to them, while also allowing them the opportunity to discuss their own family situation and their feelings.

For more in-depth direct work with children, and particularly children experiencing feelings of anxiety and anger, there are many helpful books which can be used (such as ‘The Creative Journal for Children: A Guide for Parents, Teachers and Counsellors’ by Lucia Capacchione, 1989; and ‘Think Good – Feel Good: A Cognitive Behaviour Therapy Workbook for Children and Young People’ by Paul Stallard, 2002).

6.1 Common questions asked by younger children, and answers to these:

What is a brain?

The brain is like firm jelly inside your head. It is like a command station of a space ship. The brain controls the body just like the command station controls the ship. It controls how we move, feel, think and talk.

Who can get a brain injury?

Anyone can have a brain injury. Men and women and girls and boys can all have a brain injury.

How does a brain injury happen?

A brain injury is when the head and the brain get hurt. When a brain injury happens it is like a meteorite hitting the command station, and the ship may lose control. After a brain injury, the brain may not be able to send signals to the body and the person may have trouble walking, talking, seeing or hearing.

Most people have a brain injury because of an accident. They might be in a car accident, or fall from something high, or be hit on the head by something. Many children worry that they might have caused the brain injury by being naughty or causing trouble. It's normal to worry about this but, REMEMBER, a person's injury does not happen because of anything you did and your family would not want you to worry about this.

What happens when someone has a brain injury?

Most people go to hospital when they have had a brain injury. If their injury is very bad they might have to go in an ambulance. When a person goes to hospital, doctors take x-rays and do other tests to try to see if the brain is very damaged. They will also give medicine to the person to try to help them.

Sometimes people might be in a 'coma' for days, weeks, or even months. A coma is like a deep sleep and allows the brain to heal. When a person is in a coma, you can't wake them up.

After a person wakes up from a coma, they may be unable to do things like talk or walk. They may not remember things, such as their children's names. Therapists in the hospital help the person learn how to walk, talk, eat and remember things as best they can. Therapists are like teachers trying to help the person to learn how to do things.

Trying to get better can take some people a long time, and some stay in hospital for months, while others get home quite soon. For those in hospital a long time, they may miss their family and friends. So it is a good idea to visit them, and to draw pictures, and bring in their favourite things.

What kinds of problems can people with brain injuries have?

A hurt brain is different to a broken leg. The person with the brain injury may look the same but usually they will act differently than they used to. They may walk slowly or use a wheelchair. They may get tired easily or sleep a lot. They may not remember things. They may not be able to speak properly or at all. They may get angry easily or say strange things.

Do brain injury problems get better?

Lots of problems can get better. But it can take a long time for things to get better, and sometimes even after many years people still have problems. It is very hard for doctors and therapists to know who will get better and how long it will take. Usually we have to wait and see what happens.

Some people have problems that never go away, and the hospital will try to help families find new ways of doing things. This can be very hard for families. Sometimes people with brain injuries have to be looked after by people who are specially trained, and they may have to live away from the family.

How does it feel to have a brain injury?

Sometimes people can feel very sad and be upset about their brain injury, especially if they can't do some of the things they used to do. Other people can get confused about everything, especially if they have memory problems. And some people can feel angry and get mad about the brain injury.

What can help?

Talking to an adult about your worries can help. They will help you find a way to feel better about things. It can also help to write down worries and feelings. Every day, try to do some things that you like to do. This will your brain a break from worrying. And try to remember that even though your relative had a brain injury, they still love you. Even if they seem sad or mad sometimes, try to remember that this is caused by the brain injury and that they still love and care about you.

7. Common questions asked by teenagers, and how to answer them

For teenagers it is important to allow them to come with questions and give them the opportunity to express their feelings. The questions below are just a guide. Teenagers may want to research brain injury themselves, and some books can be very helpful, such as Jo Johnson's (2011) 'My parent has a brain injury: a guide for young people'. Teenagers should also be encouraged to speak directly to staff, and depending on their age, should be given the opportunity to see staff on their own as they may feel more comfortable asking questions without their parents being present.

7.1 Common questions asked by teenagers, and answers to these:

What is a brain injury?

A brain injury is when the head and brain get hurt or damaged. A brain injury can also be called a head injury, a traumatic brain injury (TBI) or an acquired brain injury (ABI).

Who can get a brain injury?

Anyone of any age can have a brain injury.

How does a brain injury happen?

Most brain injuries happen because of an accident, such as a car accident, a fall, or if a person is hit by something. Many children and young people blame themselves for the accident and feel that somehow the accident happened to 'pay them back' for things they had done wrong. They also sometimes think that they might have been able to prevent the accident happening (for example by having done something differently on the day). It is important to know that your relative's injury did not happen because of anything you did and they would not want you to worry about this.

What happens when someone has a brain injury?

Most people with a brain injury go to hospital, where staff will assess how severe the injury is and decide on the best way to treat them. Some people can go home quite quickly if their injuries are not serious. Those who have more serious injuries will have to stay in hospital. They will usually need more tests (such as brain scans), be monitored and maybe have an operation on their brain. They might spend some time in intensive care before moving to a ward. During this time, they may be unconscious, confused, or attached to lots of equipment. This is a normal part of recovery but can be upsetting and frightening.

Some people with brain injuries remain in hospital for weeks or even months. They may have rehabilitation in another hospital before going home, or attend hospital clinics from home. Recovery usually takes a long time.

Unfortunately some people do not recover completely and continue to have problems when they get home. A small number of people do not recover from their injury and are unable to return home to live. Instead they have to live in a facility such as a nursing home where they will be cared for by trained staff. This can be very sad and difficult for all of the family. Most people do not die because of a brain injury, but a small number do. This is very hard for everyone in the family and they need a lot of support to cope with this.

What kinds of problems can people with brain injuries have?

People can have a wide range of problems such as:

Physical – for example, being unable to walk or use their arms

Cognitive – a person may have poor memory or concentration

Emotional – this can include sadness, worry, depression, anger

Behavioural – such as being more aggressive, shouting, sitting still and doing nothing

Relationship problems – for example, arguing with relatives, ignoring others.

Sometimes these problems can be very severe, and the person cannot go back to work or look after the family like they used to. It can be very difficult to understand these problems, as the person can look exactly the same but behave differently. Their behaviour can be upsetting, or cause embarrassment or anger, and you might not want your friends to visit the house and see them like this. Try to remember that they have changed because of the accident and that they still love you, even if it doesn't always seem like it.

Do brain injury problems recover?

Lots of problems after a brain injury can improve. It can help if you can find ways of 'getting around' problems – such as helping someone remember things by using a mobile phone.

However, recovery from brain injury can take a long time, and even after many years, people can still have problems. It is very hard for doctors to know who is going to get better and how long it will take. Usually we just have to wait and see what happens.

How does it feel to have a brain injury?

We cannot know for sure how someone with a brain injury feels if we haven't had one ourselves. But from what we can see, people with brain injuries are often upset and distressed about what has happened to them and if they will get better. They can also be sad or angry about it all. If they have memory problems, they can be quite confused about what is happening. Some people don't appear to worry at all about their brain injury. This could be because they don't fully understand what has happened to them, or it could mean that they have found a way to cope with it.

How do young people feel when someone in the family has a brain injury?

Everyone reacts differently to brain injury. Some young people feel ok about it and get on with their normal life. Others get very worried and sad and find it hard to get on with their normal activities. For example, some people find it hard to go to school and do their homework. They may not be able to concentrate because they are worried. And sometimes friends can ask difficult questions that are hurtful or hard to answer.

Some young people argue more with others in the family, as they feel worried or angry about what has happened. They might be asked to do extra jobs around the house or 'look after' their injured relative, which can be annoying. The family might have less money so there might be less money to go out with friends, or buy things. This can be upsetting, or even embarrassing with friends.

Sometimes people can feel sad one day, and worried the next. All these mixed feelings can be difficult, but they are very normal, and the good thing is that they don't last forever. It is helpful to talk to someone about them. Sometimes going to school or spending time with friends can be a break from all the worries, and that can be helpful too.

What can help?

Talking to someone about your feelings and your worries always helps. If you can talk to an adult you trust that would really help. But even confiding in close friends will help you to feel better. Learning more about how the brain works and brain injury can help. Knowledge about brain injury can help make it easier to cope with. Also, remember that none of this is your fault.

Section 3

Resources

Resources

8. Resources for Children of Parents with Acquired Brain Injury (ABI)

Compiled by Anne O'Loughlin, Sheila MacGowan, and Bronwyn Stephenson on behalf of the International Network for Social Workers in Acquired Brain Injury.

Books

- **A Kid's Guide to Brain Injury** by Headway (www.headway.ie)
- **A Kid's guide to the brain** by Sylvia Funston and Jay Ingram-produced Greey de Pencier Books, Toronto ISBN: 1-895688-19-1
- **Your Amazing Brain** by Jenny Bryan. A Joshua Morris Book from reader's Digest Young Families, Inc. ISBN: 1-57584-032-4
- **Coma Boy and Superwoman: Two kids with Brain Injuries beat the odds – their true stories,** 1998, backhouse, Montrose Society, Brisbane, Australia
- **The Human Brain** (Science Action Book) produced by Quatro Children Books LTD- Running Press, Philadelphia ISBN: 0-7624-0491-4
- **Karing Kids**, a book by kids for kids about head injury. Brain Injury Association of Ottawa Valley, Ottawa, Ontario, Canada
- **Pook The Hamster wants to know what's wrong with Ben and Lucy's dad** by Laura Bach (Headway UK)
- **My Dad's had a brain injury** by Katie Field and Parenting after Brain Injury by Headway (www.headway.org.uk)
- **My mum's had a Stroke** Junny turnstall, 2001, Griffith University, Neuropsychology Unit, Brisbane, Australia
- Jo Johnson has also written **My mum makes the best cakes and My dad makes the best boats.** These are actually MS specific but are a great way of starting a discussion. They are available from the MS Society. http://www.mssociety.org.uk/downloads/Our_mum_makes_the_best_cakes_-_web.716694bd.pdf
- **I Know You Won't Forget by Truly Blessed Ink**. A book for readers age 8 and up. Story about a young boy whose mother suffers a TBI.
- **Why Did It Happen On a School Day? My Family's experience with Brain Injury**, BIA of Maryland, Washington DC, USA 1995

  A book written from the perspective of a young boy whose father has sustained a brain injury-a tool for helping children understand what is happening to a parent with a brain injury and the subsequent recovery process. The authors suggest that while the story is about a child's experience after a parent's brain injury, the suggestions should be helpful regardless of the relationship between the child and the person with the brain injury. There's no age range recommended for this book but the boy in the book is an 8 year old.

- **After a Head Injury G. Banks,** 1995 Gore and Osment Pubs, NSW Australia
- **Grandpa's Crooked Smile:** A Story of Stroke Survival by Mid-Michigan Medical Center.
- **Brave Mrs Koala** by Robyn Densley,
- **Sparky goes to Grandma's Cottage** by Mathilde Backhouse
- **Susan's Dad: A Child's Story of Head Injury,** Leif E. Leaf. 1998, Meadowbrook Rehabilitation Group, Emeryville, CA
- **Elvin The Elephant Who Forgets** by Heather Synder
- **'A little book of suggestions...'** - A book of suggestions for children whose parents have a brain injury: produced by Regional Community Brain Injury Services, Ontario
- **When a parent has a Brain Injury;** Sons and Daughters speak out, 1993 M. lash Massachusetts HI Association
- **What's up Tamara;** Medikids
- **Tim - Tron**, Heads Up – CBIT

Websites

- Website: **Neuroscience Resources for Kids**
- Lash and Associates Publishing / Training Inc has a catalogue of resources for children and adolescents, you may find this useful. The material is available on line **www.lapublishing.com**
- A very good online book that might help children of around five 5 years **http://www.strokecenter.org/kids/**
- The Acquired Brain Injury Outreach Service in Queensland Australia have a group programme called Brain Crew **www.health.qld.gov.au/abios/asp/braincrew.asp**
- **http://kidshealth.org/kid/grownup/conditions/stroke.html#**
- BIRT (Brain Injury Rehabilitation Trust) print 2 leaflets for children aimed at promoting safety, these may also start a conversation. “Look After Your Head” **http://www.birt.co.uk/content.asp?page_id=508**
- Medikidz **www.medikidz.com** is a UK website which has accessible literature in comic type format for children on topics about medical conditions such as breast cancer, epilepsy, insulin pumps and so on.
- Website: **www.brainline.org**

Games

- **Rachel’s Brain Game**
  This is a board game to help children share their feelings and thoughts about a loved one who has a brain injury. Two to four players, ages five and up (available via BI Association of America)

Toolkits and Other Resources

- Family and Adult Tool Kit on TBI, Lash Publications includes “The Get Well Balloon….When a Parent is Injured”
- Working with Child Relatives – A Resource Pack for Teams: G Webster, A. Daisley and K Cardoso, Oxford Centre for Enablement (formerly the Rivermead Unit) U.K.
- Hunter Brain Injury Service has produced a DVD programme for children that was made quite a few years ago but still has some good information on it. It needs updating to run on newer computers and they are currently trying to obtain some funding for this, which may take some time. The Hunter BI Service SW’s will let the INSWABI know when it is available

Practice Examples

- Liverpool BI Unit has run a Kidz Club – a kids’ educational group for children with a family members with a TBI. The person to contact is Tina Khandu, Inpatient SW
- Valerie (Val) Lusted from Holland Bloorview Kids Rehabilitation Hospital in Canada works on the Family Support Service that supports individuals and families of people with BI who are 16-25 years old/younger at the time of injury. This programme also does excellent workshops and programme for children and youth across Toronto whose parent have had a BI. The link for this service is http://www.hollandbloorview.ca/programsandservices/rehabcomplexcare/familysupport.php and Val is at vlusted@hollandbloorview.ca
- Recolo Organisation, UK working with children and young people who have had ABIs and their families in a community based context and is led by three neuropsychologists, Katie Byard, Jonathan reed and Howard Fine. They are due to publish an article of Paediatric ABI and their model
- Oxford Centre for Enablement: Dr. Audrey Daisley, Consultant Clinical neuropsychologist. audrey.daisley@ouh.nhs.uk

Professional Books and Articles

1. Burke, Peter (2010) Brothers and Sisters of Disabled Children; The experience of Disability by Association in British Journal of Social Work 40 1681-1699
2. Daisley, A and Webster, G (2008) Familial Brain Injury: Impact on and Interventions with Children in Psychological Approaches to Rehabilitation after Traumatic Brain Injury, Ed by Andy Tyerman and Nigel King. Blackwell Publishing. ISBN 978-1-405-11167-6
3. Daisley, A (2009) Helping Children Cope with Head Injury in the Family in Daisley, a, Tams, R and Kischka, U (eds) Head Injury : the Facts, OUP
4. Daisley A, and Webster G (2005) A staff resource pack for working with children affected by familial acquired brain injury. Clinical Psychology, 46, 26-29
5. Lieffer-Kristensen, R., Teasdale, T., and Bilenberg, N (2011) Post-traumatic stress symptoms and psychological functioning in children of parents with acquired brain injury in Brain Injury 25(7-8) 752-760
6. Moreno-Lopez, A. Holttum, S and Oddy, M (2011): A grounded theory investigation of life experience and the role of social support for adolescent offspring and their parental brain injury in Brain Injury, 25(12): 1221-1233
7. Pessar, L., Coad, M., Linn, R. and Willer, B (1993) The Effects of Parental Traumatic Brain Injury on the Behaviour of Parents and Children. Brain Injury Vol. 7 no. 3 231-240
8. Rolland, John has written a lot on Families, Illness and Disability from a Systems perspective including parental disability.
9. Urback, J (1989) the Impact of Parental Head Trauma on Families with Children. Psychiatric Medicine 7 (1), 7-3
10. Webster, G and Daisley, A (2007) Including Children in family-focused acquired brain injury rehabilitation: a national survey of rehabilitation staff practice in Clinical Rehabilitation 21: 1097 1108

9. How a child may be affected when a parent or close relative has a brain injury

How a child may be affected when a relative has a brain injury

Children and young people may not understand or have been told why their parent seems different and what to expect. They may blame themselves or try to take on too much responsibility

There are likely to be changes in the family's roles

The injured parent may now be out of work while their partner is working more often. They may not be able to parent alone. Other relatives may be caring for the children

The child may have a sense of heightened anxiety and be worried that something will happen to other key adults in their lives

They often protect the non injured parent by not sharing their worries

Many other aspects of the child's life can change because of a serious family illness

Finances, time for family outings or events, holidays, having friends to the home can all be more difficult. The family is more likely to be socially isolated

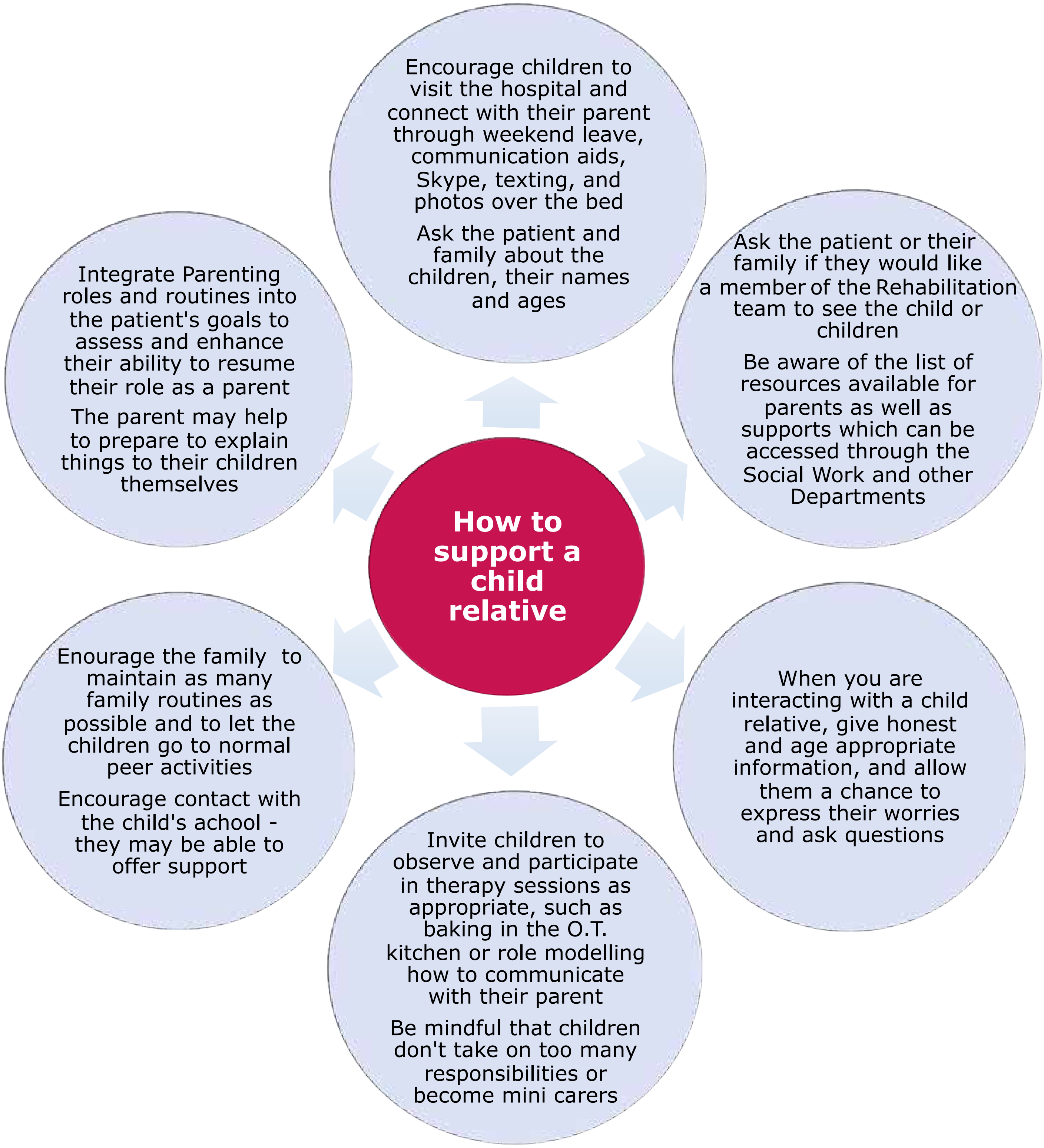
A child or young person may notice changes in the non injured parent

The other parent is likely to be tired, distracted and worried and therefore less emotionally available to the child

The child may be missing the previous relationship they had with their parent or relative

They may express distress or anger through challenging behaviour, bed wetting, low mood, poor school performance

10. Tips to support a child relative



How to support a child relative

Encourage children to visit the hospital and connect with their parent through weekend leave, communication aids, Skype, texting, and photos over the bed

Ask the patient and family about the children, their names and ages

Ask the patient or their family if they would like a member of the Rehabilitation team to see the child or children

Be aware of the list of resources available for parents as well as supports which can be accessed through the Social Work and other Departments

When you are interacting with a child relative, give honest and age appropriate information, and allow them a chance to express their worries and ask questions

Invite children to observe and participate in therapy sessions as appropriate, such as baking in the O.T. kitchen or role modelling how to communicate with their parent

Be mindful that children don't take on too many responsibilities or become mini carers

Enourage the family to maintain as many family routines as possible and to let the children go to normal peer activities

Encourage contact with the child's achool - they may be able to offer support

Integrate Parenting roles and routines into the patient's goals to assess and enhance their ability to resume their role as a parent

The parent may help to prepare to explain things to their children themselves

11. Benefits of including children in the rehabilitation process

Why involve children in the rehabilitation process?

Encouraging children to visit the hospital can reduce their fear about what is happening to their parent and demystify fears and misinformation

It can also give the team valuable information in terms of assessment

It is important that children see that other people can be involved in the care of their parents and that the parent is safe and well cared for

Preventing children becoming mini carers is also important

It gives an opportunity to link children with members of the Rehab team or relevant community services to explain about brain injury and to support adjustment and coping

Children can learn practical skills such as how to resume baking with a parent in the O.T. kitchen or how to chat using a communciation aid

Involving children has been shown to help the whole family to cope better

The Rehab team can assist with maintaining child-parent relationships, even if the child is not present in the NRH

Weekend leave, photos, Skype and days out for special family events can all support family coping

A parent with a brain inury will be more motivated to work on meaningful goals such as being able to pick up a child from school

This can enhance their ability to resume their role as a parent

12. Child Support Services in Ireland

Support Service	Website	Contact
Tusla	www.tusla.ie	info@tusla.ie
CAMHS	www.hse.ie/camhs	hselive@hse.ie
Pieta House	www.pieta.ie	info@pieta.ie
Rainbows Ireland	www.rainbowsireland.ie	ask@rainbowsireland.ie
Sibshops – Siblings Support Project	www.siblingsupport.org/sibshops	
Barnardos Family Support Services	www.barnardos.ie	info@barnardos.ie
Children's Grief Project	www.childrensgriefproject.ie	info@childrensgriefproject.ie
Parenting Plus	www.parentsplus.ie	admin@parentsplus.ie
HSE Counselling in Primary Care (CIPC)	www.hse.ie	hselive@hse.ie
School counsellors		Contact individual schools
HSE Child and Family Psychology Service	www.hse.ie	hselive@hse.ie
YAP – Youth Advocate Programmes	www.yapireland.ie	info@yapireland.ie
ISPCC – Irish Society for the Prevention of Cruelty to Children	www.ispcc.ie	01 6767960
Jigsaw	www.jigsaw.ie	dublincity@jigsaw.ie

Appendices

Supporting Child Relatives of Adults with Acquired Brain Injury

Parents’ Information Sheet - 1 of 3

NRH
National
Rehabilitation
Hospital

An tOspidéal Náisiúnta Athshlánúcháin

How your child may be affected when a relative has a brain injury

How your child may be affected when a relative has a brain injury

A child may not be able to understand why the person seems different

The parent or relative may look the same but react in different ways

There may be role changes in the family that your child has to get used to

You may have to go back to work, for example, while your partner or relative is the person at home

The child may be worried that something will happen to you or other key adults in their lives

They may be protecting you by not sharing their worries

Aspects of your child's life can change because of a serious family illness

You may be unable to afford outings or have the time to bring your child to usual activities

A child or young person may notice changes in their other parent

You are likely to be tired, distracted and worried yourself

The child or young person may be missing the 'old' relationship they had with their parent or relative

They may have to become used to this new and changed relationship

Supporting Child Relatives of Adults with Acquired Brain Injury

Parents' Information Sheet - 2 of 3

NRH
National Rehabilitation Hospital
An tOspidéal Náisiúnta Athshlánúcháin

How your child may react when a relative has a brain injury

How your child may react when a relative has a brain injury

Your child may be confused about why the injury happened

They may blame themselves or fear you will also get sick

Your child may feel angry or resentful and their behaviour might be challenging

You may be less able to deal with difficult behaviour due to your own worries

Your child may be worried or anxious but may not be able to explain their feelings

Older children may protect you by hiding fears and worries

Children or young people may not want their friends to know what has happened or to know others are talking about it

They may be embarrassed about the situation

A child or young person may appear uninterested in activities and not seem to care about anything

Their mood may be low

The child or young person may be showing signs of upset or challenging behaviour at school

They may lose interest in their school work and their grades may be affected

Supporting Child Relatives of Adults with Acquired Brain Injury

Parents' Information Sheet - 3 of 3

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Why involve children in a rehabilitation process?

Why involve your child in the rehabilitation process?

Allowing children to visit the hospital can reduce their fear about what is happening to their parent and if they are safe

It is important that children see that other people can be involved in the care of their parents and that they do not take on the role of a carer

This can help them to get on with their own lives

A member of the rehabilitation team can see your child or children to explain about brain injury and answer any questions

The team can advise about community supports for your child

Children can learn practical skills such as how to resume baking with a parent in the O.T. kitchen or how to chat using a communication aid

Involving children has shown to help the whole family cope better

The rehabilitation team can help with ways to connect with children even if they cannot visit; such as weekend leave, photos, Skype, and days out for special family events

A person with a brain Injury will be more motivated to work on goals such as being able to pick up a child from school

This can enhance their ability to resume their role as a mum or dad

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Notes

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