



Resources for Children of Parents with ABI

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with suggestions from INSWABI members

**On behalf of the International Network for
Social Workers in Acquired Brain Injury**

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Books and fact sheets

- ◆ 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, 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 Stoke Junny Turnstall, 2001, Griffith University, Neuropsychology Unit, Brisbane, Australia
- ◆ I Know You Won't Forget
A book for readers age 8 and up. Story about a young boy who's 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. No age range recommended for this book but the boy in the book is an 8 year old.
- ◆ Big Boss Brain by Shannon Maxwell and Illustrated by Liza Biggers 2012. For children 7-11 to understand TBI. ELKurdlya Publishing LLC, 16211 Oxford Court, Bowie, Maryland 20715 USA ISBN 978-1-61751-006-9
- ◆ A Kid's Guide to Brain Injury Laura Taylor et al. National Resource Center on TBI, Virginia Commonwealth University. Copies available www.pmr.neuro.vcu.edu

- ◆ 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
- ◆ The Road Ahead – Next Exit Hope! – A Look at how brain injury affects the whole family (for 5-10 year olds and a new booklet for 11- 17 years) developed for the Fraser Valley Brain Injury Association by Jodie Millward and carol Paetkau, 2006
e-mail: infor@fvbia.org or www.fvbia.org (Tel 604-557-1913)
- ◆ Brave Mrs Koala by Robyn Densley, Phone 061883732577, PO Box 221 Unley South Australia 5061 Australia (unsure if still current)
- ◆ Sparky goes to Grandma's Cottage by Mathilde Backhouse, last phone number was 61 7 33799200
- ◆ Helping Children Cope with Head Injury in the Family. Reproduced on the Brainline website with the permission of Oxford University Press, © Oxford University Press, 2009. **THE FACTS: HEAD INJURY** by Audrey Daisley, Rachel Tams, & Udo Kischka (2008) Ch. 10, pp.121-130.
- ◆ 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
- ◆ Susan's Dad – A Child's Story of Head Injury by Leif. E. Leaf and Illustrated by Lisa Widucki. 1988, Meadowbrook Rehabilitation Group, 2200 Powell Street, Suite 800, Emeryville, Ca 94608 (tel 1-800-828-7740)
- ◆ "My parent had a brain injury. A guide for young people. 2011. Jo Johnson. Copies can be purchased www.headway.org.uk
- ◆ My mum makes the best cakes and My dad makes the best boats. Jo Johnson
These are MS specific but great for starting discussion. They are available from the MS Society.
http://www.mssociety.org.uk/downloads/Our_mum_makes_the_best_cakes_-_web.716694bd.pdf

Websites

- ◆ Neuroscience Resources for Kids <http://faculty.washington.edu/chudler/neurok.html>
- ◆ Lash and Associates Publishing /Training Inc has a catalogue of resources for children and Adolescents, you may find this useful. You can look at the material on line www.lapublishing.com
- ◆ When Grandpa comes home. A very good online book that might help the 5 yr old: <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/brain_crew.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" They also have a tipsheet "The family following ABI" by Ian Fussey and Michael Oddy http://www.birt.co.uk/content.asp?page_id=508
- ◆ www.lifesupports.com.au/rehabilitation has a fact sheet on "Children or Adolescents with a Parent of Sibling with ABI – advice for Parents and Carers". Life Supports Counselling Service (specialist counseling for people affected by ABI), Level 1, 401 Whitehorse Rd., Balwyn, Victoria, Australia (Tel 1300 73 50 30) e-mail: info@lifesupports.com.au
- ◆ Medikidz www.medikidz.com A UK website which has accessible literature/comic type format for children on medical conditions such as breast cancer, epilepsy, insulin pumps etc
- ◆ www.childrens-mercy.org has a list of useful resources, books, and videos for family members affected by BI including children

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 Assoc of America)

ToolKits/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
- ◆ Keamer Family Resource Center, Children’s Mercy Hospitals and Clinics, 2401 Gillham Road, Kansas City, MO 64108 (Tel 816-234-3900) www.childrens-mercy.org The center has a list of useful resources, books, and videos for family members affected by BI including children
- ◆ Parent Education – Helping Children to Understand Disability. List of Resources available at the rehabilitation Resource centre, Chedoke Hospital, USA (2005)

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 ABI’s 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 Paed ABI and their model
- ◆ Oxford Enablement Unit: Dr. Audrey Daisley, Consultant Clinical neuropsychologist. audrey.daisley@noc.nhs.uk

Professional Books/Articles

1. Burke, P. (2010). Brothers and sisters of disabled children: The experience of disability by association. *British Journal of Social Work, 40*, 1681-1699.
2. Daisley, A., & Webster, G. (2008). Familial brain injury: Impact on and interventions with children. In A. Tyerman & N. King (Eds.), *Psychological Approaches to Rehabilitation after Traumatic Brain Injury* (pp. 475-507). doi:10.1002/9781444301762.ch19
3. Daisley, A. (2009). Helping children cope with head injury in the family. In A. Daisley, R. Tams, & U. Kischka (Eds.), *Head injury: The facts*. Oxford: Oxford University Press.
4. Lieffer-Kristensen, R., Teasdale, T., & Bilenberg, N. (2011). Post-traumatic stress symptoms and psychological functioning in children of parents with acquired brain injury. *Brain Injury, 25*, 752-760
5. Moreno-Lopez, A. Holttum, S., & Oddy, M. (2011). A grounded theory investigation of life experience and the role of social support for adolescent offspring and their parental brain injury. *Brain Injury, 25*, 1221-1233.
6. Pessar, L., Coad, M., Linn, R., & Willer, B. (1993). The effects of parental traumatic brain injury on the behaviour of parents and children. *Brain Injury, 7*, 231-240.
7. Urback, J. (1989). The impact of parental head trauma on families with children. *Psychiatric Medicine, 7*, 17-36.
8. Webster, G. & Daisley, A. (2007). Including children in family-focused acquired brain injury rehabilitation: A national survey of rehabilitation staff practice. *Clinical Rehabilitation, 21*, 1097-1108.
9. Butera-Prinzi, F., & Perlesz, A. J. (2004). Through children's eyes: Children's experience of living with a parent with an acquired brain injury. *Brain Injury, 18*, 83-101.
10. Charles, N., Butera-Prinzi, F, & Perlesz, A. (2007). Families living with acquired brain injury: A multiple family group experience. *NeuroRehabilitation, 22*, 61-76.