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FAMILY MATTERS: Understanding and Addressing Family Needs after Acquired Brain Injury

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There are 9 sessions included in this online resource package. Each presentation has the slides included in the video however you may also access the slides separately.

Session 1 (14 minutes)**The Lived Experience**

This presentation was created with gratitude to the many family members of people with ABI, who were interviewed by Mark Holloway for his doctoral thesis. Their narratives have been adapted and are presented today by Kate Tym.

Kate Tym, Performance Poet

Session 2 (41 minutes)**Family Transition: the first year**

Dr Whiffin will present her research findings on how family members benefit from support to recreate a narrative, to tell their story to help them understand the changes that have taken place to them as a consequence of the brain injury to their relative. Dr Whiffin will identify the narratives created by non-injured family members in relation to themselves and their family in the first year after head injury. She will also examine the relationship between narratives and the construction of self and explore the use of narrative inquiry to examine post-injury change following Traumatic Brain Injury.

Dr Charlotte Whiffin, Senior Lecturer in Nursing, University of Derby

Session 3 (43 minutes)**Family Needs and Transformations: Research Perspectives and Clinical Insights**

This presentation will provide an outline the international academic literature in relation to the impact of acquired brain injury on family members, setting the scene for what follows.

Dr Giles Yeates, Principal Clinical Neuropsychologist & Couples Therapist Community Head Injury Service, Buckinghamshire Healthcare NHS Trust & NeuroFlow (Independent Practice)

Session 4 (18 minutes)**Family Breakdown and Childcare: The Legal Framework**

This talk will aim to provide some insight into the process of divorce; the law's approach to the resolution of family finances on separation, and in particular the treatment of Personal Injury damages; the status of spouses who have acted as carers, and the approach to on-going periodical payments. We will also touch upon the relevant provisions of the Children Act 1989 that deal with arrangements for children following separation, Special Guardianship and the approach to grandparents and other members of extended families.

Toby Hales, Partner & Head of Family Law, Irwin Mitchell, London



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Session 5 (35 minutes)

Family Needs: first-hand experience

Family panel - During a facilitated discussion, family members will share their experiences of acquired brain injury, focussing in particular on what they found worked for them. You will have the opportunity to learn from many years of hard-won knowledge, gaining a greater understanding of the wide ranging and complex impact upon family members.

Session 6 (10 minutes)

East London Headway Choir

Session 7 (40 minutes)

Post-traumatic Stress

Post-traumatic Stress is now more widely recognised to affect those that have sustained a brain injury but what about family members? Some relatives witness the traumatic event when their loved ones are injured, but most sustain unremitting stress from the acute trauma and their subsequent experiences.

Dr Julius H Bourke, Consultant Neuropsychiatrist, Re:Cognition Health & Clinical Senior Lecturer in Neurophysiology & Clinical Neuropsychiatry, QMUL

Session 8 (47 minutes)

Keep it in the family: practically strengthening the capacity of family members to provide support to each other during neurorehabilitation

Where a brain injury has occurred for a child/young person/adult, this will often have occurred in a traumatic way. Trauma is therefore very much part of the injury and provides an important narrative role in what the individual and family have to process. This requires a careful approach, bearing in mind the impact upon the individual, the parent/carer/siblings and for the family as a complete unit. Dr Fine will discuss this topic, looking at evidence-based approaches for therapeutic input for this, how trauma affects the rehabilitation process and in turn, how this can impact complex MDT type processes. This will include practical suggestions to help engagement and successful on-going working for traumatised and/or complex families.

Dr Howard Fine, Consultant Clinical Psychologist & Paediatric Neuropsychologist, Recolo

Session 9 (31 minutes)

Addressing our human needs when supporting family members

Caroline will examine the potential role of the "expert companion" to support family members through the trauma and perpetual uncertainty that life post brain injury brings for family members, focussing on the need for professionals to "humanise" their approach and allow new narratives and possibilities to develop that support family members to adjust to and manage the demands of their changed role. Caroline has a particular interest in humanising practice through taking a lifeworld approach. With this approach, service providers recognise the human needs of service users and staff through understanding what 'life feels like from the inside out'.

Dr Caroline Ellis-Hill, Occupational Therapist & Senior Lecturer, Bournemouth University

This conference took place on 16th September 2019

BIOGRAPHIES

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Dr Mark Holloway

Brain Injury Case Manager, Expert Witness and Post-Doctoral Researcher

Mark is a UK qualified and HCPC registered social worker with over 25 years experience of working with people with an acquired brain injury. His research interests include the neuro-functional approach to rehabilitation and support, family response to and experience of brain injury, the use of motivational interviewing and the impact of executive impairment and reduced insight upon functioning. He has provided evidence for the UK House of Commons and House

of Lords regarding the impact of brain injury. He is an advanced member of the British Association of Brain Injury Case Managers, is a National Institute of Health Research School for Social Care Research Fellow and a former member of the National Institute of Clinical Excellence guidelines writing committee in relation to supported decision making. He is a member of the leadership group for the National Mental Capacity Forum, Trustee of the Brain Injury Social Work Group and an Honorary Assistant Professor in the School of Sociology & Social Policy (University of Nottingham).



Kate Tym

Performance Poet

Kate Tym is a writer and spoken-word artist. She spear-headed a project working with people who had survived strokes and putting their narratives into poetry. She is interested in seeing 'medical conditions' in a non-medicalised way. Hence the title of her stroke-related poetry pamphlet was titled 'How Are You Feeling?'. She lives in St Leonards, also works as an Independent Celebrant - conducting weddings and funerals and has three teenage daughters.



Dr Charlotte Whiffin

Senior Lecturer in Nursing, University of Derby

Charlie Whiffin is a registered adult nurse and worked clinically on acute neurosurgical wards. Charlie is a highly respected senior lecturer and senior researcher at the University of Derby with over 14 years' experience in higher education. Charlie's research interest include a range of clinical and pedagogical topics but Charlie has maintained a specialist interest in TBI. Charlie pursued this specialist interest through a doctoral study with the University of Southampton and

was successfully awarded a PhD in 2012 entitled "A study of family transition in the first year post-head injury: perspectives of the non-injured members".

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Dr Giles Yeates

Principal Clinical Neuropsychologist & Couples Therapist Community Head Injury Service, Buckinghamshire Healthcare NHS Trust & NeuroFlow (Independent Practice)

Dr Giles Yeates is a clinical neuropsychologist and couples therapist working in the Community Head Injury Service, Buckinghamshire, and in private practice. His clinical work focuses on emotions and relationships following acquired brain injury (such as traumatic brain injuries and strokes), working with individuals, couples, families and groups. As a researcher he studies the impact of both neurological damage and social factors on emotional connections between people (the "Social Cognition, So What?" research programme) and as a clinician he uses this research to develop and adapt individuals, couples, family and group therapy approaches to increase closeness and connection following brain injury.

He is an internationally-invited and keynote speaker on this topic and a past International Neuropsychanalysis Fellow. He has written several articles, chapters and edited books, and is co-author of "A Relational Approach to Rehabilitation: Thinking about Relationships after Brain Injury", one of the first relationship-orientated texts on brain injury, editor of the Routledge Brain Injury book series, and is editor of Neuro-Disability & Psychotherapy journal/book series.



Toby Hales

Partner & Head of Family Law, Irwin Mitchell, London

Toby has practiced Family Law throughout his career since he qualified in 1995, dealing with all aspects of divorce, financial arrangements and issues concerning children. Toby spent 8 years heading up the Family team at Hodge Jones and Allen, and joined IM in January 2019. He was a member of the Law Society Children Panel for some 14 years, so have experience representing children at all levels of Court. A number of my cases have also involved a crossover into the Court of Protection.

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Nicola Hughes

Family Member

Nicola (49) was a Senior Executive, managing the European organisation of a global company, when her husband Alwyn sustained a severe frontal lobe brain (SAH) injury in 2011. When Alwyn was discharged from hospital without any plan or support, she gave up her career to manage his 'rehabilitation' and create a local charity, that she continues to Chair, to fill the gaps that statutory services do not provide for survivors and families.

She now describes marriage in two parts. Before his injury (10 years) – and after it (8 years). She says: "I lost my husband, my marriage, our hopes and dreams in 2011. I also lost a huge part of myself over the isolating and relentless journey from 2011 onwards."

Nicola continues to fight the system and help to change the status quo for survivors – particularly for families affected and isolated by their loved one's brain injury.

She is currently in the process of writing a book describing her story of survival and is about to self-publish the books written for their daughter (now 8) about a little girl trying to understand her Daddy's brain injury and her Mummy's reaction to it!



Eliza Fricker

Family Member

Eliza Fricker is one half of Baines&Fricker, an interiors company that designs and makes furniture, wallpaper and art. They have worked for Liberty London, Heals Urban Outfitters, designing products for their stores.

Eliza Fricker illustrates wallpapers for Baines&Fricker as well as working as a freelance illustrator. She was taught to draw by her father who is a political cartoonist and illustrator. Her work is influenced by her upbringing in the suburbs of London.

She has written a novel called "Just Getting Old" about the devastating effects of long term illness on a family. For many years her mother was ill- this was a subtle and perplexing time as her family tried to fathom what was going. At one time her mother was a passionate and excited woman who had many interests, she was quick witted and striking however over the period of her decline she lost all her interests, she was unable to react to those around her, she lost her job as a bookshop manager and eventually her marriage of 42 years to Eliza's father. After several years they received an MRI scan for her mother which revealed a large brain tumour that had been growing slowly over a long time and altering her along way.

BIOGRAPHIES

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Lorraine Currie

Family Member and other things!

Lorraine Currie is the MCA Professional Lead for a local Authority and a Visiting Lecturer at Wolverhampton and Keele Universities.

Lorraine Chairs the West Midlands Region and the National DoLS Leads groups. She also carries out MCA Consultancy work which to date has mainly been for ADASS and the LGA including leading the review of DoLS Forms and National Guidance.

Lorraine is also engaged in providing significant support to her 25 year old daughter following an accident in 2010. Although this was a family tragedy it has contributed to a greater understanding of the need for personalised care and responsive services.



Dr Julius Bourke, MBBS, MRCPsych

Consultant Neuropsychiatrist, Re:Cognition Health and Clinical Senior Lecturer in Neurophysiology and Clinical Neuropsychiatry, QMUL

Dr Julius Bourke is a Consultant Neuropsychiatrist with a specialist interest in post concussion syndrome, chronic pain, chronic fatigue and their biological interplay with mood and anxiety disorders. His NHS clinic is based in East London and provides a specialist service for chronic fatigue and chronic pain. He is a Senior Clinical Lecturer in Neurophysiology and Clinical Psychiatry at QMUL, where his

research has focussed on the neurophysiology of chronic idiopathic pain. At recognition health, he sees TBI cases clinically and for medicolegal reports, as well as patients with unexplained symptoms and syndromes.

BIOGRAPHIES

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Dr. Howard Fine

**Consultant Clinical Psychologist & Neuropsychologist
Recolo UK Limited**

Dr. Howard Fine BSc (Hons) MSc PsychD C.Psychol AFBPsS, is a Consultant Clinical Psychologist and Paediatric Neuropsychologist, and co-founder and Director of Recolo UK Ltd, specialising in providing high quality and effective community neuropsychological rehabilitation to children, young people and their families. As well as holding a clinical caseload, as a Director of the practice, Dr. Fine holds senior clinical, supervisory, and management roles. He is also committed

to delivering regular input and dissemination of skills at national conferences, through publications, and teaching, including providing specialist Paediatric Neuropsychology and Developmental teaching to Doctoral Clinical Psychology courses at the University of East London (UEL), Royal Holloway University of London, Salomons Centre for Applied Psychology (Canterbury Christ Church University), and the University of Surrey. Dr. Fine also contributes to the UCL MSc Clinical and Applied Paediatric Neuropsychology Training Programme (accredited by the British Psychological Society) at the Institute of Child Health. Dr. Fine has also co-authored an essential reader on childhood brain injury intervention - Neuropsychological Rehabilitation of Childhood Brain Injury: A Practical Guide.



Dr Caroline Ellis-Hill

Occupational Therapist & Senior Lecturer, Bournemouth University

Caroline is a Senior Lecturer at Bournemouth University. Having a clinical background in occupational therapy and a PhD in psychology, she has a long standing interest in the lived experience of acquired brain injury. Caroline's research focus is humanising practice and considering what makes us feel human. Using this approach Caroline has completed two major research projects involving the use of arts following ABI and looking at how we can develop humanising

services in acute care. Through this research Caroline and her colleagues are developing a new approach to rehabilitation: that of lifeworld led rehabilitation where the subjective, lifeworld experience of both service users and providers are combined to form the basis for understanding and service delivery, allowing a fully human response within care and rehabilitation services.



“ Once you are pushing the boundaries, when you are dealing with something that is so difficult to deal with, you need the best... we need help, everyone needs help, and from someone who has seen it before... ”



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