

ALEX JELLY, ADEL HELMY,
AND BARBARA A. WILSON

LIFE AFTER A RARE BRAIN TUMOUR AND SUPPLEMENTARY MOTOR AREA SYNDROME

Awake Behind Closed Eyes



AFTER BRAIN INJURY: SURVIVOR STORIES



“This remarkable book shares Alex’s lived experience of a rare type of meningioma and the perplexing effects that dramatically altered her sense of reality and control over her thoughts, behaviour, speech and body. Part I charts her journey spanning life prior to the illness, symptom onset and diagnosis, treatment, experience of psychosis, rehabilitation and adjustment to the new normal. Part II is written by a leading neurosurgeon and a world-renowned clinical neuropsychologist and provides the clinical context for understanding Alex’s illness and the rehabilitation that was integral to her recovery. Over time, Alex has managed to put the pieces of the puzzle together to find meaning in her illness with the support of family, friends and professionals. This beautifully written, candid and touching account will appeal to other people and family members affected by neurological conditions and cancer, and will inspire anyone facing major life challenges.”

*Tamara Ownsworth, School of Applied Psychology,
Griffith University, Australia*



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Life After a Rare Brain Tumour and Supplementary Motor Area Syndrome

This book offers a personal insight into the experience of Alex Jelly, a professional fundraiser who developed a rare brain tumour, a papillary meningioma, which was successfully removed. She was left with Supplementary Motor Area Syndrome and associated problems including motor and speech impairments and a temporary psychosis. Discussing Alex's struggles and triumphs throughout her rehabilitation, this book offers an honest account of her journey from diagnosis to recovery.

Part I introduces Alex's early life and employment, symptom onset and diagnosis, treatment and rehabilitation. Part II presents her neurosurgeon, Adel Helmy, and a clinical neuropsychologist, Barbara A. Wilson. Adel provides a medical context by explaining Alex's successful surgery and her post-operative experience. Finally, Barbara concludes with a comprehensive view of Alex's recovery and gives a voice to the therapists and psychologists who worked with Alex throughout her inpatient and outpatient rehabilitation journey.

This book provides support, understanding and hope for patients who have suffered a brain tumour, and their families. It is valuable reading for any professional involved in neurorehabilitation, students of clinical neuropsychology and those touched by brain injury.

Alex Jelly was a professional fundraiser for charities for many years in London and then a fundraising consultant for UK and international charities. In the summer of 2016 she started to feel odd and that led to the discovery of a brain tumour, which has in turn led to this book.

Adel Helmy is a University Lecturer in the Division of Neurosurgery, University of Cambridge, and an Honorary Consultant Neurosurgeon at Cambridge University Hospitals NHS Trust.

Barbara A. Wilson is a clinical neuropsychologist who has worked in brain injury rehabilitation for 42 years. She has won many awards for her work, including an OBE for services to rehabilitation and five lifetime achievement awards.

After Brain Injury: Survivor Stories

Series Editor: Barbara A. Wilson

With this series, we hope to expand awareness of brain injury and its consequences. The World Health Organization has acknowledged the need to raise the profile of mental health issues (with the WHO Mental Health Action Plan 2013–20) and we believe there needs to be a similar focus on psychological, neurological and behavioural issues caused by brain disorder, and a deeper understanding of the importance of rehabilitation support. Giving a voice to these survivors of brain injury is a step in the right direction.

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The Invisible Brain Injury

Cognitive Impairments in Traumatic Brain Injury, Stroke and other Acquired Brain Pathologies

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Awake Behind Closed Eyes

Alex Jelly, Adel Helmy and
Barbara A. Wilson

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This book is dedicated to the memory of Polly Higgins, a friend who died tragically and suddenly of cancer at the age of just 50, while this book was being written. Polly was an inspirational champion for the Earth, a barrister who researched, drafted and campaigned for an international crime of ecocide. She did not survive to see this law put into practice but it now, thanks to her work and vision, has every hope of becoming a reality.



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Preface

This book is one of the Survivor Stories, a series of books which offers a personal insight into the experience of a survivor of brain injury. This one tells the story of Alex, a professional fundraiser, who developed a rare brain tumour, a papillary meningioma, which was successfully removed. Alex was left with SMA (Supplementary Motor Area) Syndrome. This syndrome can occur after neurosurgery for a lesion in the SMA. Clinical symptoms can vary from none to a global impairment of voluntary movement, with preserved muscle strength and loss of speech. Typically, these symptoms completely resolve within weeks to months, leaving only a disturbance in alternating bimanual movements.

We learn about Alex's early life and employment together with the early signs that something was wrong. Her neurosurgeon tells us about the successful surgery and the post-operative journey. Alex recalls her early problems including motor and speech impairments and a temporary psychosis. We hear about the neuropsychological rehabilitation she received at the Oliver Zangwill Centre in Ely near Cambridge and her gradual return to health. We learn about Alex's struggles and triumphs along the way and the main messages she wants to give to readers of the book.

Part I of the book is about Alex and her story while Part II by her neurosurgeon Adel Helmy and a clinical neuropsychologist, Barbara A. Wilson, provides background information on meningiomas and Supplementary Motor Area Syndrome, together with reports from people who worked with Alex during her recovery and rehabilitation.

Note: Please note that Alex's story illustrates her perceptions at the time and her views do not necessarily represent those of other patients, the care staff or the clinical practice.

Acknowledgements

Alex would like to thank all her family and friends who have seen her through this time. She sends special thanks to her surgeon, Mr Adel Helmy, and also to her neuro-oncologist, who prefers not to be named, and all the dedicated staff on the ICU, A ward and Lewin Unit at Addenbrooke's, with particular thanks to the hugely committed and capable staff at the Brain Injury Rehabilitation Trust (BIRT) and the Oliver Zangwill Centre, both in Ely. And, of course, to my fabulous, untiring editor, Professor Barbara Wilson, without whom this book would never have been written.

We would all like to acknowledge and thank Mick Wilson for his insightful comments and proofreading of the book and Jessica Fish for her comments and help with references. Thanks, too, for all those who have given permission for their names and reports to be used.

Foreword

As lead psychologist at the Oliver Zangwill Centre for Neuropsychological Rehabilitation (OZC) from 2010 to 2018, I had the opportunity to get to know personally many people whose lives were suddenly and unexpectedly disrupted by a life-altering brain injury. Our mission was to support and accompany these people on their journeys from experiencing the brain injury as a central defining and damaging event in their lives, to putting the injury and its consequences in the background and moving on to recapture their confidence and enjoyment of life, albeit with some quirks and new ways of doing things. This book captures one such journey from the perspectives of survivor Alex, her neurosurgeon, and her psychologists and therapists.

Readers of this latest book in the Survivor Stories series will learn about Alex's full and fascinating life before her diagnosis with a papillary meningioma, a rare and cancerous brain tumour. They will hear her tales of experiencing early post-surgery life when she was unable to communicate her thoughts and her surreal interpretations of the world around her. Her neurosurgeon, Mr Adel Helmy, contributes a clearly written chapter on brain tumours, adding a vital piece of knowledge so the reader can start putting Alex's experience into a medical context. Finally, we hear from the therapists and psychologists who worked with Alex throughout her inpatient and outpatient rehabilitation journey; their voices as given to us by Professor Barbara Wilson round out a comprehensive view of Alex's recovery.

There is something very special about a book that narrates a personal journey through brain injury and beyond. And when that story is told with wit and intelligence, it is even more special. Add to this a professional understanding and explanation of the disease and its progress and rehabilitation, and you have a very full story of the inner workings of an injured brain on its road to recovery. The Survivor Stories series has offered a

wealth of insight and knowledge about life with a brain injury from the perspectives of the survivors and their health teams as well as clues to the impact of rehabilitation on recovery and eventual adjustment. In particular, the series, and this book, highlights the value of neuropsychological rehabilitation in helping the injured person not only learn cognitive strategies but also gain a true understanding of their brain and the consequences of damage to it. Good neuropsychological rehabilitation helps people regain their own unique sense of identity and confidence in themselves as whole people, even with an injured brain. Alex's story gives us a rich sense of who she is as a person, her strong values and passions, her determination, and her use of a vast range of resources as she glues the pieces of herself back together again.

As one of the authors of the original *Survivor Stories* book, I was delighted to read this newest addition to the series. I know Alex personally from her time at the Oliver Zangwill Centre, and I can attest to her bright and curious mind, her determination and persistence, and her wry sense of humour. Her stories of her early days after surgery when she misperceived and misunderstood things around her are filled with humour, but also poignantly help us understand how incredibly difficult, lonely, puzzling and scary these experiences were for her. All of us who routinely encounter patients in their early days will surely have enhanced empathy and understanding for these patients.

One of Alex's most striking experiences in the early days was to misinterpret the world around her and this resulted in anecdotes such as this one:

I thought at one point that I was the first human in all of history to consciously create HGH or Human Growth Hormone. We all produce it naturally or our pituitary gland does, especially when we're babies and children, but it slows down in production from middle age. I could feel the HGH pulsing through my arms at night, like blood.

I then "realised" that the bags of liquid feed that were delivered through the NG tube contained HGH, and that nurses were trading this (in other words stealing from the hospital and selling it to a range of private individuals who wanted immortality) as bags were always going missing and nurses could never find them when they wanted them.

Alex's neurosurgeon, Mr Helmy, writes a very cogent clinical description of brain tumours, putting Alex's experience within the wider context of this potentially devastating diagnosis: a brain tumour is at once life

threatening and also damaging to the very organ we use to cope with life's challenges, the brain. Both lay readers and health professionals will appreciate the clear and straightforward description of the various types of brain tumours and their management.

Professor Wilson adds the voices of the various therapists and psychologists who worked with Alex throughout her journey. It is fascinating to compare their views on Alex's disturbed thoughts and behaviour with her own description of how she felt and thought at the time. The weaving together of the patient experience and the professional outlook and care gives a uniquely well-rounded picture of the injured brain and its healing.

Jill Winegardner, PhD

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Centre, Ely, UK)



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Part I

Alex's story
