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Dear Medical Provider,

The Neurocritical Care Society (NCS) is pleased to announce the release of A Guide to Traumatic Brain Injury: The Intensive Care Unit. This unique book is intended to help families of patients with severe traumatic brain injury (TBI) in your neuroscience intensive care unit (NICU) navigate their personal crises by delivering comprehensive medical, technical, and practical information in a compassionate, empathetic, and reassuring way.

With shared decision making and patient/family-centered care in mind, the book is designed to empower your TBI patients' families by assisting with their understanding of their loved ones' condition, prognosis, and medical interventions. This guide is meant to create a common language for families and NICU practitioners and to facilitate effective communication on a range of topics, including sensitive ones such as transitioning to comfort care. The tone of the book is optimistic and supportive but also focuses readers on realistic expectations about recovery.

A Neuroscience Clinical Nurse Specialist writes, *"This book was so well written it allowed me to have a better understanding and feeling of what it is like to be a family member with a loved one in the ICU. It will help me to engage with family members that can be so overwhelmed with the neurological injury their loved one has experienced. I feel this book will help many families organize their thoughts and empower them to ask questions and make decisions. This book provides families with realistic expectations of what the day to day struggles could be while their loved one is in the ICU. This book has reminded me of how overwhelming the ICU environment can be, how devastating a brain injury can change the lives of so many people, and how I, a nurse can be there for both the patient and family to help them get through this difficult period in their lives."* Cynthia Bautista, PhD, RN, CNRN, SCRn, CCNS, ACNS-BC, FNCS, Yale-New Haven Hospital, New Haven, CT

This book is the result of a partnership among David Y. Hwang, MD, a neurointensivist at Yale-New Haven Hospital; Dayla Maisey, BSc, whose brother was critically brain injured in a motorcycle accident; and the Neurocritical Care Society.

We are confident that this guide will be an asset in your NICU and will help you utilize your time with families more effectively—both at the bedside and during formal family meetings. We encourage the families of your patients to read it and appreciate your help in getting this resource into the hands of those who may find it most helpful in your NICU.

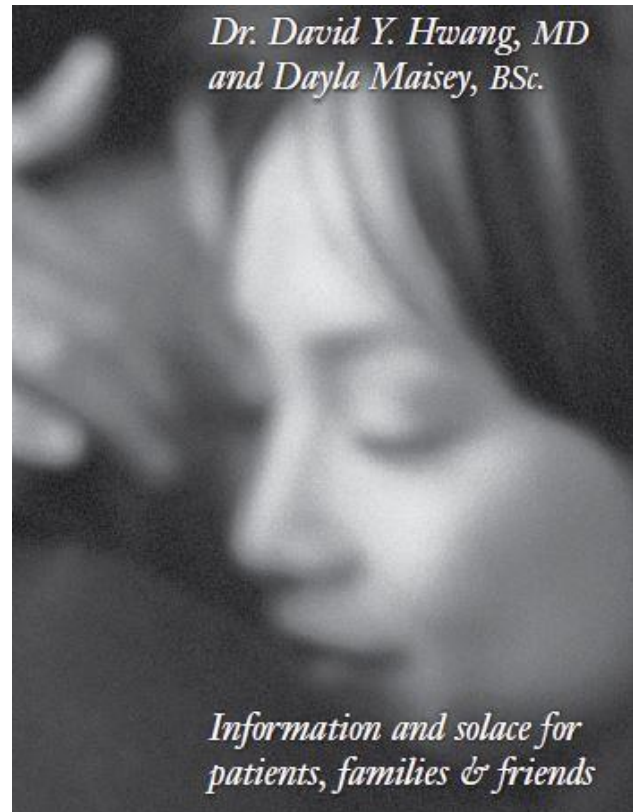
Sincerely,

Alejandro Rabinstein, MD, FNCS  
NCS Educational Products Co-Chair

Wade Smith, MD, PhD, FNCS  
NCS Educational Products Co-Chair

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A GUIDE TO TRAUMATIC BRAIN INJURY  
*The Intensive Care Unit*

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For Theo, Julia  
& Janice

Don, Dean  
& Graham

*Angels who light our way*



*Like a lighthouse*

*I cannot make your journey easier*

*I cannot stop the storms*

*I cannot calm the seas*

*I cannot chart your course*

*Rather*

*I offer direction, guidance and hope*

*May it light your way*





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# Introduction

I am sorry someone close to you has sustained a traumatic brain injury.

*I have been where you are now.*

I remember the call: the disbelief, the numbness, the uncertainty, the desperation.

I had no idea what to expect.

Yet, I knew I must act. Very important decisions lay ahead – for my injured loved one and for our family.

*I began searching for answers.*

What I needed, besides a miracle, was a wise and supportive confidant; someone who could answer my questions, acknowledge my fears, understand my feelings and help me find my way.

I wanted someone who knew when to share their knowledge, when to nod with validation and when to say nothing.

*Often, there is nothing to be said.*

I hope this book becomes that someone to you.

No matter how terrified you feel right now, trust that within you exists the

*courage, wisdom, strength and love  
to make it through.*

Know there will be moments every day when you feel frightened, hopeless, angry and overwhelmed.

Take a deep breath and continue on...

Later, when you reflect on the events of the next few weeks and months, you will be in awe of yourself and what you have accomplished.

*You are stronger and more capable  
than you realize.*

I was.

*So are you.*

What follows is a collection of insights and experiences.

It is what would have been helpful to me, as I navigated my way from that terrible moment when I first learned the news, until we left the intensive care unit (ICU).

*You are an important and valued member of the team.*

Do not be afraid to be actively involved.

You may be in unfamiliar territory, but

*You are capable.*

Ask questions. Learn as much as you can.

While you may be surrounded by state-of-the-art equipment and skilled medical professionals, those who are closest to the patient remain the expert on their loved one; their values, their fears, their beliefs, their priorities, their hopes and their dreams.

*You are now their voice.*

Do not under estimate your abilities or the importance of love and vigilance.

*"I remember the moment, the telephone call that changed my life... so many lives.*

*Shock, denial, disbelief...*

*yet some intelligent and capable person who lives inside of me took control.*

*Unrelenting waves of panic and terror and nausea were kept at bay as the practicalities and demands of the moment dominated my thoughts.*

*Everything was unreal... somehow detached from me. While still holding tightly to the belief that this could not be true... I acted.*

*What is the fastest way to the hospital? How do I get in to see him?*

*Parallel thoughts.*

*Perpendicular realities.*

*No distinction between the two."*

Thinking back, I struggle to remember how much information I would have been able to absorb at the time.

I remember feeling totally overwhelmed, and at the same time, desperate for information.

I have tried to find a balance and provide enough detail for you to make informed decisions...

Yet not be overwhelmed.

For me, the fear of knowing was always easier to bear than the fear of not knowing.

Over and over I would learn,

*Knowledge is power.*

When I understood what to expect, I was more prepared and proactive rather than being surprised and reactive,

I was better able to participate in discussions about medical care options and advocate on my loved one's behalf.

Information makes the intimidating... understandable.

The overwhelming... bearable.

*There is much fear in the unknown.*

*True courage isn't  
not feeling scared.*

*True courage is being terrified,  
and doing it anyway...*



The information within these pages unfolds in the same sequence I asked the questions myself (and family and friends asked the questions of me).

My immediate priority was to understand what was happening to him. What machines is he connected to? What are the medical personnel doing to him? For him?

### *What can I do to help?*

Next, I realized it was important to learn about the brain, what a coma was and how a brain is injured. I also needed to understand the basics about how brain injury is medically managed as well as how prognosis for survival and quality of life issues are assessed. This helped me to understand what the medical personnel were saying and allowed me to ask more informed questions as we discussed goals of care and potential treatment options.

The next focus was practical. I needed to let others know what had happened and gently prepare them for this painful reality.

### *It is vital to come together to support your injured loved one and each other.*

Day to day tasks still must be attended to. Colleagues and teachers need to be informed.

The future is uncertain. Many challenges and important decisions lay ahead.

Later, as the initial panic and terror began to subside and emotions I had not allowed myself to feel began to find their way to the surface, I started to question what emotional impact this crisis would have on my family, my friends, my injured loved one and myself.

It was much later before I had the strength to consider the long term implications of traumatic brain injury and how it would impact our family.

Everyone's needs and experiences are unique.

*So...*

You decide how much you want to be involved.

Make conscious decisions about what is important and what is no longer a priority.

*Take in what you can,  
when you can.*

Listen to your own voice.

Navigate your own path.

Honor your own pace.

Take one step at a time.

*Make this book your own.*

Skip around these pages.

Use what works. Ignore what does not. Revisit as circumstances evolve.

*Consider keeping a journal.  
Record the challenges,  
the routine, the miracles.*

Document information for health care professionals; it is important.

Preserve memories to share with your loved one, for children still too young to understand, for those who live far away. Being part of the process is invaluable.

*Write for yourself –  
to help you to remember,  
to allow you to forget.*

*This is now your story:*

an unchosen chapter,

*an unknown ending.*

It is about strength and courage and resilience and hope.

It is about fear and anger and frustration and fatigue.

But mostly, and always,

*It is about love.*

# The Intensive Care Unit

Walking into the intensive care unit (ICU) is a terrifying experience. Your senses are bombarded with countless details. It is immediately evident real trauma is not as romantic as on TV: the smells, the lights, the blood, the noise, the energy, the tears...

Reality seeps in as you come face to face with the person you love attached to unfamiliar machines and tubes.

It becomes more and more difficult to deny the seriousness of the situation.

This person may die or never regain their quality of life.

The entire focus of your life shifts. There is now only one priority.

While nothing can prepare you for the flood of emotions you feel when you first walk into the ICU, it is helpful to know what to expect.

A multitude of machines and tubes will be attached to the patient. Most seem to beep or gurgle at will, with little provocation. Once you understand their function and purpose and meaning of the sounds, it will be less intimidating.

Soon, believe it or not, the ICU will seem almost normal, a part of your everyday life.

Learn the basics about the equipment and what the patient will look like.

*Do not be afraid to ask questions.*

The ICU provides the comprehensive monitoring and support required after a critical injury. Immediate and aggressive interventions can be performed, if necessary. Each nurse is specially trained and cares for only one or possibly two patients.

The following descriptions will help explain some of the more common equipment used in the ICU. Not every patient will have all the equipment described, while some may have items not discussed below. If there is additional equipment you are curious about, or if you have questions regarding the ones identified below, write down your questions and check with the nurse.

*You are an integral member  
of the team.*

## **A Guide to Traumatic Brain Injury: The Intensive Care Unit**

### *Testimonials*

**The following are excerpts from unsolicited cards and letters received from families, survivors and medical professionals who have read the book.**

*"I found your book not only informative and inspirational, but extremely familiar---were you sitting on my shoulder throughout our ordeal? ...I believe your book would be very helpful to anyone experiencing the devastation of acquired brain injury. They are easy and quick to read, but packed with much important information, as well as uplifting advice. It is good to know during this terrible time that one is not alone---that others have travelled the same path and made it through."* Valerie B. Mom, British Columbia

*"I love your book. I cried all the way through it. I believe this book should be in every critical care hospital in North America."* Tom D. Dad, Nova Scotia

*"The words of hope, fact and inspiration you have compiled together are a comfort to all that must endure the new, lifelong journey of the entire family. You bring hope and sanity to those that experience the "end-of-the-rope" feeling."* Jennifer, Survivor, Ontario

*"Your words have been a confirmation of my sanity and given me great strength to carry on."* Joy S. Wife, Ontario

A Neuroscience Clinical Nurse Specialist writes, *"A Guide to Traumatic Brain Injury: The Intensive Care Unit"* was so well written it allowed me to have a better understanding and feeling of what it is like to be a family member with a loved one in the ICU. It will help me to engage with family members that can be so overwhelmed with the neurological injury their loved one has experienced. I feel this book will help many families organize their thoughts and empower them to ask questions and make decisions. This book provides families with realistic expectations of what the day to day struggles could be while their loved one is in the ICU. This book has reminded me of how overwhelming the ICU environment can be, how devastating a brain injury can change the lives of so many people, and how I, a nurse can be there for both the patient and family to help them get through this difficult period in their lives." Cynthia Bautista, PhD, RN, CNRN, SCRNP, CCNS, ACNS-BC, FNCSS, Yale-New Haven Hospital

*"I have been reading and re-reading your book today and am reassured that my family and I are not alone in our journey. The light of your experience has helped me to find my way, as you hoped. Thank you for sharing your knowledge to make that possible."* Norene S., Alberta

*"...an inspiring book that will help a family through the intensive care unit when they are caring for a family member with traumatic brain injury....should be required reading for anyone dealing with the grief and emotional turmoil of brain injury."* Book Review in No Boundaries Newsletter, Springfield, Missouri

*"You are an inspiration to me....all trauma units should have copies of your books. They are invaluable."* Mom, British Columbia

*"The book has a wonderful impact on families in the ICU."* Heather Macdonald, RN, BScN, CCN(C), Nova Scotia

*"I like to give your stuff to new staff to give them a base as to what the personal issues are."* Teresa D.

*"...your personal experience gives credibility and genuine awareness to your writings."* Norm Jackson, Social Worker, Alberta

*"...book is comprehensive, meaningful, informative, and far from being over-whelming. It can be referred to over and over again at any point of the journey. The book has been an inspiration and guiding light of insight."* Lisette S., British Columbia

*"You had the courage to put your head, heart, soul and gut together and let it shine through your words so that it warms and sustains others. Thank you."* Christine, Family Member

*"...the book is a source of comfort and is kept at arm's length by my bedside."* Melanie E., Nova Scotia

*"...the book has been hugely meaningful to our large family. Intuitively, we were on the right track, but grasping. The sharing of your insights and experience with facts and information is a gift. Thank you."* Ann B, Family member, British Columbia

*"...this book has sustained our family through this roller coaster of love, fear and hope."* Roberta H. Aunt, British Columbia

*"...readable and easy to comprehend. ...written with compassion, concern and love....an invaluable tool."* Creta M. Wife, Alberta



*"...very valuable resource for family members in the ICU – their feedback is always positive."*  
Sandy F. Clinician, Victoria General Hospital, British Columbia

*"Your book has been a tremendous source of comfort. Your courage and insights are truly admirable."* Adria, Friend, Alberta

*"Your book is so easy to read and informative at the same time. You have no idea how much you have helped me through this time....My husband went through all the stages and the book helped us realize that was not unusual for traumatic brain injury....the agitation, bad language, confusion...." Wife*

*Information and solace for  
patients, families & friends*

**A GUIDE TO**

**TRAUMATIC BRAIN INJURY**

*The Intensive Care Unit*