

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.*