

A GUIDE TO TRAUMATIC BRAIN INJURY

*Information and solace
for patients, families & friends*

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THE INTENSIVE CARE UNIT

NEUR  CRITICAL
CARE SOCIETY

A Guide to Traumatic Brain Injury

The Intensive Care Unit

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ISBN: 978-0-9909917-9-3

*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.

The **Neurocritical Care Society** believes that those with traumatic brain injury receive the highest quality of care when families and medical professionals work together as partners in shared decision making to develop treatment plans that respect your loved one's values and priorities.

This book exemplifies the Neurocritical Care Society's commitment to promoting patient-family centered care and the shared decision making process. The foundation of this book is a partnership between neurointensivist, Dr. David Y. Hwang, MD, FAAN, FCCM, FNCS and family member, Dayla Maisey, BSc., BComm, Honorary Masters (Intensivist). This effort reflects the contributions of numerous health care professionals and family members as well as the endorsement of several medical organizations. Importantly, the narrative is inspired by Dayla's personal experience with the Intensive Care Unit after her younger brother was critically brain injured in a motorcycle accident. For this reason, some of the narratives are written in the first person, reflecting Dayla's voice in the moment.

As a key part of our mandate to empower families during a neurotrauma crisis and provide compassionate, high quality, patient and family-driven care, the Neurocritical Care Society is providing this revised version of ***A Guide to Traumatic Brain Injury: the Intensive Care Unit*** as a **free** download.

Please share this information with anyone who may benefit from the material.

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1. Introduction

I am so sorry that 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 - or what to do.

Yet I knew I must act.

Critical 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 compassionate 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 support 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 you possess the courage, wisdom, strength and love to navigate through.

While you may be surrounded by skilled professionals and state of the art medical equipment, those closest to the patient remain the expert on their loved one - their philosophy about life, their faith, their spiritual beliefs, their values, their priorities, their passions, their pastimes, their hopes, their fears.

You are now their voice...their surrogate.

Do not be afraid to be actively involved. Ask questions. Learn as much as you can.

Help the medical team to see their patient through your eyes - to know your loved one, who they were only days ago...before the accident.

The more the team understands your loved one, the better equipped they will be to provide treatment that is in alignment with your family members wishes.

You are a critical and valued member of your loved one's medical team.

You may be in unfamiliar territory but

You are capable.

There will be moments everyday when you feel frightened, hopeless, exhausted and powerless.

Find a quiet space, take a deep breath, re-group and continue on...

Later, when you reflect on the events of the next few days and weeks, 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.

Courage isn't not feeling scared.

*Courage is being terrified, and
Doing it anyway...*

Thinking back, I consider 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.

Early on I grasped that being a surrogate would be one of the most important and challenging roles I would ever be called to play.

*This understanding gave me courage...
a type of courage I had never known before...*

Decision by decision, through quite victories and debilitating setbacks...I learned

Love is more powerful than fear...and a deep resolve resides within us all.

I have tried to provide enough detail to empower you to make informed decisions... yet not be overwhelmed.

Over and over I would learn,

Knowledge is power.

Having a comprehensive and realistic understanding of the process, the prognosis and the treatment options is essential to effectively participating in discussions regarding goals of care and potential medical interventions.

When I knew what to expect, I was able to be more prepared and proactive rather than surprised and reactive. I was better able to advocate on my loved one's behalf.

*Information makes the intimidating...understandable.
The overwhelming...bearable.*

There is much fear in the unknown.

The information within these pages unfolds in the same sequence as 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?

Is there anything the health care team needs to know about my loved one including allergies, medications, medical history, lifestyle choices?

What is my role on the team?

What can I do to help?

Next, I recognized the importance of learning the fundamentals of neurotrauma care, the technical and medical terminology used and common procedures in the Intensive Care Unit (ICU).

Knowing each member of the medical team and their function helped me to better understand what each specialist was saying and allowed me to ask more relevant and informed questions.

*As you learn more, you will begin to feel more at ease
in this once foreign environment.*

As our family began to grasp the seriousness of our loved one's injuries, we learned more about how the prognosis for survival and quality of life issues are assessed.

Having a realistic understanding about the range of possible outcomes given our loved one's injuries helped to provide us with the perspective and background necessary in our new role as surrogate decision makers.

Our family discussed many things...including the possibility of transitioning to care and comfort and organ donation.

Our guiding question was always the same – “What future would he want for himself? What decisions would he make?”

I quickly realized the importance of learning about the brain, what a coma was, how a brain can be injured, and the basics of how brain injury is medically managed - both immediately after an injury and over the next several days as swelling increases and the secondary brain injury continues to evolve.

Next, I needed to let others know about what had happened and gently prepare them for this difficult reality.

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

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

Later, as the initial panic began to subside and feelings I had not allowed myself to process began to find their way to the surface, I started to learn about the longer-term implications of traumatic brain injury and consider what impact this crisis would have on my family, my friends, my injured loved one and myself.

Everyone's needs and experiences are unique...

You decide how much you want to be involved and what is best for your loved one and your family.

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

Listen to your own voice. Navigate your own path. Honor your own pace.

Make this book your own.

Skip around these pages.

Embrace what works. Ignore what does not.

Re-evaluate as time passes and new information becomes available.

Consider keeping a journal.

Record the challenges, the routine, the miracles.

Document medical information - include the names and roles and recommendations of healthcare professionals.

Write down your questions and the answers for future reference.

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.

My heart aches knowing many of the challenges you, your loved one and your family will face over the next several days and months and years.

My hope is that these words will reach out across the pages and touch your heart...and your head.

You will need both.

This is now your story;

An unchosen chapter,
An uncertain 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.

"I remember the moment, the telephone call that was to change my life forever... so many lives.

Shock, panic, disbelief, denial...

*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."

Each of us has our own tolerance for these types of situations.

*Don't force yourself
(or anyone else)
to enter the ICU unless you want to and
feel ready.*

2. 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 that real trauma is not as glamorous 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, unconscious and attached to unfamiliar machines and tubes.

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

Your loved one may die...the life you shared will never be the same again.

The focus of your world shifts.

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, guided by some unseen force. Once you understand their function and purpose, and the meaning of the sounds, it will be less intimidating.

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

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

Do not be afraid to ask questions.

You may not realize it at first but...

You are a key member of the team.

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 two patients.

A patient's neurological function and medical status are continuously monitored. Nurses are alert to any changes and will contact the doctor if necessary.

Being aware of subtle changes may help to prevent or minimize complications.

Clinical information is documented within the patient's file and available to multiple specialties to facilitate collaboration regarding medical interventions and treatment plans.

Your loved one may have sustained additional injuries from the accident including internal injuries, broken bones, cuts and bruises. Medications or medical interventions may cause additional bruising or an increase in swelling. Stitches or staples may have been used to close wounds caused by injury or incisions from surgeries.

The following descriptions will help to explain the more common equipment used in the ICU. Not every patient will have all the equipment described, while some may have items not discussed.

If there is additional equipment you are curious about, or if you have questions regarding the ones identified below, write down your questions in your journal and check with the nurse.

Equipment used may include:

Ventilator or Respirator (breathing machine, vent, being on life support or intubated)

People in comas (or those who have difficulty breathing) generally have a breathing tube as a life-supporting measure. A ventilator, sometimes called a respirator, helps to ensure that the brain and the rest of the body receive sufficient oxygen and expels carbon dioxide.

A plastic tube, about $\frac{3}{4}$ of an inch in diameter (called an endotracheal tube or ET tube), will be inserted through the patient's mouth into the windpipe and attached to a ventilator. Patients are generally sedated prior to intubation to facilitate insertion. Humidified oxygen is pumped into the lungs. The patient's blood stream then transports the oxygen throughout the body. Carbon dioxide from the bloodstream then travels back through the lungs and out through the tube.

A ventilator can provide either extra support to a person who initiates the breathing process on their own or, if needed, control the entire breathing process, including the rate and the amount the lungs are inflated. For patients who are unresponsive, the tube helps to prevent oral secretions from going through the patient's windpipe and into their lungs, which helps to protect against lung infections ("airway protection"). Even if the patient is awake, a ventilator will prevent the patient from using their voice.

The respirator will beep if it senses that the patient is not breathing at the desired level. In practice, this may happen frequently.

There is no need for concern every time the machine makes a sound.

If a patient begins to initiate the breathing process on their own and can protect their airway, they may be weaned off the ventilator by slowly reducing the amount of assistance the ventilator provides.

This happens at different speeds for different patients. Should a patient stabilize and meet certain criteria, a **S**pontaneous **B**reathing **T**rial (SBT) may be performed to determine if the patient is able to manage the breathing process without the assistance of the ventilator. The SBT also provides an opportunity to evaluate respiratory patterns, which may provide additional detail regarding a patient's neurological function.

Some people with severe brain injury never regain the ability to breathe safely without the assistance of a breathing tube and / or a ventilator.

If the patient is expected to need airway protection or ventilator support for an extended period of time, your doctors may talk to you about whether a tracheostomy (trach) should be performed so that a plastic tube is not persistently inserted in the patient's mouth. During a short surgery, a tube is inserted into the windpipe (trachea) through a small incision in the patient's throat to create an artificial airway in the neck. This tube also provides infection and airway protection. When needed, the respirator is attached to the trach.

If the patient improves enough to be able to leave the ICU, "talking" trach tubes are sometimes used as a bridge to eventual trach removal. However, people who remain persistently on breathing machines require a high level of care that is most commonly available through long-term care facilities, rather than in the community or home based.

Ventricular Drain (External Ventricular Drain (EVD), Ventriculostomy)

IntraCranial Pressure (ICP) may be continuously monitored for certain patients in the ICU.

A ventricle drain is a monitor used to measure **IntraCranial Pressure** (ICP). This instrument may be placed on the surface of the brain, in the brain tissue itself, or directly into the ventricles (small cavities inside the brain filled with **CerebroSpinal Fluid** (CSF)).

Refer to Brain Basics on page 76 to learn more about the brain. You will find two diagrams of the brain for your reference – one of the outside of the brain, one of the inside of the brain.

IntraCranial Pressure (ICP) is a measure of the pressure inside the skull. Increased ICP is an important measure of brain swelling and the progress of secondary injury within the brain.

Reduction and stabilization of ICP is an important priority.

CerebroSpinal Fluid (CSF) is a clear fluid that circulates within and around the brain and spinal cord. CSF cushions and protects the brain, delivers nutrition and removes wastes. CSF is continually being manufactured inside small cavities within the brain (called ventricles) and reabsorbed through bloodstream. Injuries to the brain may disrupt this process leading to an increase in intracranial pressure.

An **E**xternal **V**entricular **D**rain (EVD), which is placed directly into ventricles to evaluate ICP, may also be used to release cerebrospinal fluid from within the brain to reduce the pressure inside the skull.

A surgical procedure is required for this monitor to be inserted, which means some of the patient's hair will be shaved. While this may look shocking, it is not cause for additional concern.

For additional detail regarding ventricular drain placement, refer to Potential Surgical Interventions on page 83.

The head of the hospital bed may be inclined slightly (about 30 degrees) to help decrease intracranial pressure, if needed. The increased elevation may help to facilitate the reabsorption of CSF. The incline may also reduce saliva flowing into the lungs, which may reduce the risk of lung infection.

Spontaneous Breathing Trials and other tests will not be performed unless ICP is stabilized at an acceptable level.

Catheters

A catheter is a general term used for various types of plastic tubes, drains, or lines that may be inserted into the patient. Catheters can be used to deliver medications or other fluids, draw blood or measure blood pressure. Catheters may also be used to remove fluids including urine, excess blood, or other fluids.

Intravenous Lines (IV)

Patients are generally attached to a number of intravenous (IV) lines. These narrow tubes are inserted into peripheral veins (which refer to veins typically in an arm or leg versus the core) and can be used to administer medications or nutritional support and maintain fluid balance.

IV pumps will beep regularly as reminders to the nursing staff that the fluid is almost finished or to alert them if the fluid is not moving freely. Again, do not be alarmed every time the machine beeps.

Central Line [femoral line, internal jugular (IJ) line, subclavian line]

A central line is a catheter (narrow tube) inserted into a major vein in the neck, chest or groin (into the trunk or core of the body versus the peripheral). For certain patients, a central line may help to reduce damage to smaller peripheral veins in the arms or legs. A central line allows special medications to be administered to the patient as needed [especially those that regulate blood pressure (vasopressors) or intracranial pressure].

A central line may be required to administer **Total Parenteral Nutrition (TPN)**, which is a special nutrition supplement for some people in the ICU.

Peripherally Inserted Central Catheter (PICC) Line

A PICC line is an IV catheter that is inserted into the patient's arm and intended for longer-term use.

Arterial Line (art line, A line)

Arterial blood refers to oxygenated blood as it is pumped away from the heart and lungs. An Art line is inserted into an artery in the patient's arm or groin.

An arterial line continuously monitors Arterial Blood Pressure.

Arterial Blood Gas (ABG), which identifies the concentrations of oxygen and carbon dioxide in the blood, can also be measured.

An art line may also be used to draw blood.

Chest Tubes

Your lungs sit inside a cavity within your chest. Sometimes during a trauma, punctures or tears occur in the lungs, allowing air to escape and collect in this space. Blood from other injuries (fractured ribs, for example) may flow into this cavity as well. If too much air or blood accumulate in this space, breathing may become difficult.

Chest tubes are inserted between the ribs and into this space to remove any excess fluid or air that may build up. Chest tubes are attached to a large bubbling apparatus that contains colored water and hangs below the bed. The water helps to accommodate the natural pressure changes that occur within the chest during regular breathing. This gurgling often becomes a very comforting sound.

Urinary “Foley” Catheter

A Foley catheter empties urine from the bladder and allows for accurate monitoring of fluid balance.

Electrocardiogram (ECG or EKG)

An electrocardiogram measures the electrical activity of the heart. Leads (electrical sensing devices) on the chest relay information about heart rate and rhythm.

Electroencephalogram (EEG)

An electroencephalogram measures brain wave patterns and the electrical activity of the brain. Electrodes placed on the skull may detect changes in brain activity, sometimes in response to certain stimuli. An EEG is may be included as one part of a comprehensive neurological evaluation.

Enteral Feeding Tube

It is vital that patients receive sufficient nutrition and fluids to support the rebuilding and healing process. An enteral feeding tube may be used to provide the patient with concentrated nutrients including protein, vitamins, and minerals.

A small, soft tube is inserted into the stomach through the nose (nasogastric tube – NG tube) or the mouth (orogastric tube – OG tube). In addition to artificial nutrition, medications may be given through the tube. A special pump is used to regulate the flow and rate of tube feeds. This machine beeps to let the nurse know when the feeding is almost complete or that the tube is not working correctly.

Should nutritional support be required for a prolonged period of time, a Percutaneous Endoscopic Gastrostomy (PEG) tube or catheter may be inserted through the abdomen wall and directly into the stomach during a short surgery. Approximately 6 to 12 inches of the tube remain outside of the body and is easily accessible to provide nutrients, medications or other fluids directly into the stomach, bypassing the mouth and nose. There is a cap on the end the catheter so it may be closed when not in use. A PEG tube can be removed without surgery should it no longer be required.

Oxygen Saturation Monitor (pulse oximeter, pulse ox)

Oxygen is transported through the bloodstream via red blood cells. The oxygen saturation monitor records pulse rate and measures the percentage of red blood cells carrying oxygen. An oxygen saturation monitor looks like a clothespin and is attached to one of the patient's fingers or toes. This too beeps often, so do not be alarmed.

Sequential Compression Devices (SCD)

Sequential Compression Devices (SCDs) are air filled plastic “stockings” that may be placed on the patient's legs to improve blood circulation back to the heart. SCDs help to reduce venous blood clots (sometimes referred to as **deep venous thrombosis**, or DVT). SCDs are attached to a pump that operates in cycles and makes popping sounds.

Some patients wear long white stockings called anti-embolism stockings (TEDs) to help prevent blood pooling in the legs. For additional detail about DVTs, refer to Potential Complications on page 84.

Traction Apparatus, Staples, or Casts

Broken or fractured bones may be stabilized and aligned using a system of pulleys and weights. The traction equipment is generally mounted to the frame of the bed. Sometimes, metal rods are inserted into the bones. Casts are commonly used to set breaks or fractures.

Incisions or wounds are stitched or stapled closed.

Cooling Devices

When a patient has a high fever, sometimes doctors consider interventions to maintain normal body temperature and brain metabolic requirements. During this carefully controlled process, a patient's body temperature may be slowly lowered by circulating cool water through pads on the patient's skin. Should the patient shiver during the cooling process, special medications may be administered to reduce or eliminate the shivering.

Write down any questions that you may have.

*"For me,
I needed to see him, to touch him before I could exhale.*

*Only then could I begin to absorb additional information or
consider next steps."*

"I started taking in all the details my brain could tolerate at the time.

He was in a coma, his hair was half shaved off, and there was a drain tube inserted into his head with a faucet (to reduce the pressure inside his brain, I later learned).

He was on a ventilator.

There was a seven-inch line of staples down the middle of his stomach as well as down one arm.

He had "balloons" on his legs (to aid in circulation).

He was naked except for a small towel and was still covered with dried blood and mud from the highway and yellowish antiseptic from the surgery.

A plastic bag with his hair was attached to the foot of the bed.

He looked beautiful to me because he was still alive."

3. What is a coma?

When most of us imagine someone in a coma, we picture the person as being in a deep, motionless “sleep” - completely unconscious.

The strict definition of coma is a state of unresponsiveness when the patient’s eyes are closed and they are unarousable, lasting for at least several hours.

This is often not the reality.

In the ICU, a patient may display a wide range of altered levels of consciousness or awareness, including varying degrees of spontaneous eye opening, physical movement or even verbal responses.

*A “coma” diagnosis is not black or white...
rather many levels of altered consciousness often exist.*

Understanding the depth of the coma helps the medical team to assess the extent of the damage in the brain and evaluate the likelihood of survival or range of potential long-term functional outcomes. This information helps the medical team to recommend the most appropriate medical interventions and treatment plans for the patient.

Formal neurological exams are performed regularly to evaluate the depth of coma and identify any changes in neurological status.

To learn more about Neurological Assessments and how they are performed, refer to page 36.

A patient’s reduced consciousness may be temporary, long-term, or permanent.

Unfortunately, some people remain in an unresponsive or minimally responsive state indefinitely, and are reliant on a ventilator to breathe and a feeding tube and formula for nutrition.

For many patients who arrive in the ICU in a coma after a traumatic brain injury, a “wait and see” approach must be adopted.

It is still too early to fully assess how severely the brain has been injured and the impact of the evolving secondary injury.

Damage to the brain occurs in two stages: primary and secondary.

The primary injury occurs at the time of the initial trauma (car accident, fall, being shaken or hit, etc.). A direct blow to the head is not necessary to cause injury. Sudden acceleration or deceleration is sufficient to cause a brain injury.

Secondary injury continues for several days after the initial trauma due to brain swelling and a complex cascade of biochemical, electrical, cellular, and molecular processes within the brain.

These processes can cause further damage despite treatment.

For additional detail refer to Brain Injury Mechanisms on page 81.

4. ICU Care

The primary focus of the ICU medical team is to monitor and evaluate the evolving secondary brain injury and provide the best available medical treatment to minimize the impact of the secondary injury process to the brain.

The medical team must also manage and treat other injuries that your loved one may have sustained, requiring the team to continually manage multiple priorities. Additional injuries may further increase the risk of death and compromise long-term functional outcomes for the patient should they survive their injuries.

Complications are a constant concern.

Understanding the routine care and terminology used in the ICU will allow you to ask more relevant questions, make more informed decisions, and if necessary, advocate on your loved one's behalf.

Being familiar with the various procedures helps you to be more actively involved with your loved one's care. It also prepares you to explain to your loved one, as well as other family members and friends, what is happening.

Routine care may provide early clues to a change in neurological status--as a patient may spontaneously respond by opening their eyes, turning their head, or trying to make a sound.

Interacting with the nurses and other members of the medical team on a regular basis helps facilitate conversations, strengthen relationships, and better prepare you to communicate during bedside rounding or family meetings.

Every hour or two, the nurse will reposition the patient to ensure they are as comfortable as possible and to reduce the risk of bedsores (by relieving pressure on the skin). Care will be taken to maintain neck alignment to optimize fluid and air flow. Shifting the patient also helps to support their breathing process.

The nurse regularly monitors and records vital signs (temperature, heart rate, breathing rate, blood pressure, oxygenation levels). Brain injury can impact the body's ability to automatically regulate these fundamental processes.

Temperature is taken regularly, as a change in temperature is one of the first indicators of a possible infection. Temperature may be measured externally (temporal artery) or internally with an internal catheter. External temperature is measured using a small machine that is gently moved across the patients' forehead to behind their ear. The machine beeps when an accurate measurement has been recorded. Critically ill patients may have fever without infection because the brain injury itself can affect body temperature regulation.

The External Ventricle Drain (EVD) will be monitored and cleaned (if necessary) to ensure it continues to operate properly and provides accurate information regarding the pressure inside the brain.

If your loved one is on a ventilator, they may be suctioned regularly to maintain a clear airway and to reduce the risk of infection. Awake patients who are coughing and breathing normally can generally do this on their own.

The Respiratory Therapist (RT) may use a vibrating machine or “clap” on the patient’s chest to loosen phlegm in the lungs prior to suctioning. The patient may be temporarily disconnected from the ventilator prior to suctioning. This is an opportunity for the RT to further evaluate the patient’s respiratory patterns, which may provide additional detail regarding neurological function.

Sometimes, while the patient is off the respirator, the nurse, the RT or even a family member may manually inflate the lungs by squeezing oxygen from a compressible delivery device (it looks like a face mask with a balloon attached) into the breathing tube (“bagging” the patient) to ensure there is always sufficient oxygen available to the brain and other vital organs.

Participating in your loved one’s care can help to build your confidence - and competence.

During suctioning, the nurse or RT may test to see if the cough reflex is intact. The presence or absence of this reflex provides additional detail regarding brainstem function and neurological status.

If a tracheotomy (or trach) has been performed, regular cleaning to remove excess sputum, mucus or other fluids from the trachea and / or stomach is required. Trach care helps to reduce the risk of upper airway or lung infection. Cleaning the trach may be unpleasant for the patient, so it is not uncommon to witness one of the first signs of “lightening” from a coma during this procedure.

If your family member continues to stabilize and meets certain criteria, **Spontaneous Awakening Trials (SAT)** and / or **Spontaneous Breathing Trials (SBT)** may be performed. The SAT helps to assess if a patient is progressing neurologically. The SBT provides feedback to determine if the patient is capable of breathing without the assistance of a respirator and if weaning from the ventilator may be further evaluated. The goal is to minimize interventions as soon as is medically prudent.

The Spontaneous Breathing Trials (SBT) and Spontaneous Awakening Trials (SAT) are often coordinated. Breathing patterns may be evaluated at this time to further assess the neurological status of a patient. Sedation medications may be reduced prior to breathing trials or other assessments so patient’s reactions can be evaluated more accurately.

Many hospital schedule procedures and testing to provide the patient with as much quiet, uninterrupted time as possible to allow for rest and repair.

Ensure the medical team knows the following about the patient so they are able to provide the best care:

- Allergies

- Medications
- Supplements
- Drug and alcohol use
- Relevant lifestyle choices
- Previous conditions
- Prior surgeries
- Family doctor or other specialists seen

*Prior to any medical intervention being performed,
explain to your loved one what to expect and
why the procedure is necessary*

Ask all members of the medical team to do the same.

*"I discovered if I held his hand and talked to him during suctioning,
his heart rate and intracranial pressure would remain more stable.*

He would remain calmer...his vitals more stable.

It was one of the few things I could do to make this more bearable...

For him.

For me."

A nurse will regularly assess for and treat pain, agitation, and delirium to ensure your loved one is as comfortable and calm as possible without being over medicated.

Effective pain management is a top priority.

Untreated pain can sometimes lead to an increase in agitation and delirium.

The goal is to find an optimal balance where pain is effectively managed with the minimum dose of pharmaceuticals, allowing the patient to be as aware and conscious as possible.

Assessing pain in someone who is in a coma or non-verbal can be a challenge.

Ideally your loved one would be able to explain the level of pain they are experiencing, where the pain is, what it feels like, and whether it is increasing or decreasing. However, when someone is unconscious or unable to communicate, that is not possible.

Behavioral assessment tools may be useful in assessing the pain level in these situations. Vital signs can provide additional cues but are verified using other methods.

It is common for a family member to be the first to notice a change or something unusual.

Share your observations with the nurse.

Those closest to the patient are often most adept at recognizing subtle, non-verbal clues that their loved one is experiencing pain.

Families frequently spend considerable time at the bedside and immediately pick up on a furrowed brow, a certain tenseness in the jaw, rubbing or favoring a certain area.

Trust your instincts. Be assertive.

Non-medical forms of pain relief are often very effective - a familiar voice, soothing touch, cold packs, warm face cloth, music etc. You know your loved one – be creative.

Ongoing pain (baseline) may be managed with a continuous infusion of pain medication (called analgesic). A combination of opioids and non-opioids are sometimes used to ensure effective pain management while minimizing adverse side effects.

Common non-opioid analgesics include: acetaminophen (aspirin), ibuprofen (Advil / Motrin) and ketamine. Common opioid analgesics include: fentanyl, morphine, methadone and hydromorphone.

Additional pain medication may be administered prior to certain potentially painful procedures being performed, including turning, wound or trach care, blood draws, or art line insertion.

Every decision in the ICU balances the risks and benefits of medical interventions with potential short and long-term adverse consequences.

For additional detail regarding potential long-term complications, including **Post Intensive Care Syndrome (PICS)**, refer to Potential Complications on page 84.

Ask your nurse or physical therapist for recommendations about **Range of Motion (ROM)** or other exercises that can be performed safely at the bedside.

When possible, range of motion exercises help to ensure joints remain supple and muscles maintain their elasticity. Preserving joint and muscle mobility helps to reduce the likelihood of complications including contractures (stiffening of a joint due to wasting away or shortening of the muscle fibres) or foot drop (a condition where the ankle joint becomes immobile). Even with exercises, some patients require special splints on their hands and feet to help prevent contractures.

Your loved one will benefit from the interaction and added stimulation of touch as well.

Simple activities like wiping their face, washing their hair, brushing their teeth (suctioning will likely be required) go a long way in helping your loved one maintain their humanity and dignity. It also provides you with another opportunity to actively engage in their rehabilitation process.

Learning to navigate day-to-day activities within the hospital is key.

Some hospitals utilize white boards in the patient's room to facilitate communication between families and the medical team. Details could include tests or procedures scheduled, medication administered, names and functions of your core medical team, who is providing care today, etc.

Shift changes offer a great opportunity to get a summary highlighting any events that occurred over last several hours. Generally, an outline of the plan looking forward is also discussed.

Formal family meetings are scheduled regularly in many hospitals and may be requested at any time. Family meetings are generally interdisciplinary and include key members of the medical team and the family.

Many hospitals have multidisciplinary rounds at the bedside in the morning, which may provide an opportunity for regular, two-way communication between families and multiple members of the medical team.

Your nurse may be able to advise you when the daily rounds are scheduled and help you to prepare to actively participate. Write down any questions or concerns you have in advance.

"For me, being involved with his care helped keep me sane.

Instinctively, I talked to him, stroked his hair, wiped his face.

I was lucky (and determined) to stay with him in the intensive care unit.

I slept in a cardiac chair by his bed.

He was so vulnerable, more helpless than a newborn.

I could only imagine what it must be like for him.

Sometimes, while still deep in coma, his intracranial pressure would increase and his heart would race (this is quite common and called "storming"). I could soothe him by gently putting my head next to his head, my cheek next to his cheek, stroking what was left of his hair, and whispering gently into his ear.

*With the innocence of a child, I would reassure him,
making promises I had no way of keeping.*

Often I would be rewarded by decreased pressures and reduced heart rate.

My heart and hopes would soar.

*I truly believed that my love could pull him back
into the life we had once shared.*

It is hard to express what joy I experienced based on something (like a reduction in intracranial pressure) that had not even existed in my mind only 24 hours before...."

5. Neurological Assessments

Structured neurological assessments may be used to gather objective, consistent, and reliable information about the depth of a coma and neurological function. Neurological evaluations are performed regularly to monitor changes in neurological status (stable, improving, or worsening) and evaluate the progression of the secondary injury.

Detail gathered during a neurological evaluation is used in conjunction with other information--including ongoing monitoring, imaging, test results, and the clinical judgement of the medical team--to clarify the prognosis and guide treatment options.

The **Glasgow Coma Scale (GCS)** is the most commonly used measure of a patient's responsiveness and level of consciousness (LOC) used during the acute stage of brain injury. It evaluates a patient's best response in 3 areas: eye opening, motor response, and verbal response.

Each of the 3 elements is tested, scored, and reported independently. A combined Total Score is also calculated.

Modifications are made if the patient has difficulty hearing, eye or facial injuries, is on a respirator etc. The assessment is conducted with as much care and compassion as possible and in a language the patient understands. Sedation may be temporarily reduced prior to performing a neurological assessment to ensure the most accurate results.

Eye Opening (Scored E1 to E4)

The Eye Opening component score ranges from a low of E1 to a high of E4. Adjustments are made if the patient has an eye injury, difficulty hearing or other condition.

If a patient spontaneously opens their eyes, they would receive the highest score, which is E4.

If a patient does not spontaneously open their eyes, the nurse or doctor will call a patient by name or touch their arm requesting that they open their eyes. If the patient responds, their score would be E3.

If the patient does not respond to touch or sound, intense pressure is applied to the patient's fingernails for up to 10 second to determine if the patient will open their eyes. If the patient responds, they receive a score of E2.

If there is no response, the score is E1.

If eye opening cannot be evaluated a Non testable (NT) score is applied.

Verbal Response (Scored V1 to V5)

The Verbal Response component score ranges from a low of V1 to a high of V5. Adjustments are made if the patient has an endotracheal tube that prevents the patient from talking or other conditions that may impact scoring. Written responses are acceptable.

An orientated patient would receive a score of V5. For a patient to be considered orientated, they must know their name, the date and where they are.

If a patient is able to communicate but their responses are confused (they may not know where they are or what year it is), their score would be V4.

If the patient is only able to respond with single, understandable words, their scoring would be V3.

If the patient can only moan or make sounds that are not understandable, their score would be V2.

No sound is scored as V1.

If Verbal Response is Non Testable, an NT is applied.

Best Motor Response (Scored M1 to M6)

The Best Motor Response component score ranges from a low of M1 to a high of M6. Again, modifications are made if required.

To receive the highest score of M6, the patient must be able to reliably follow a command, like “squeeze my hand” and then “let go”. This is to ensure the response is not a reflex.

If the patient does not respond to the initial request, the nurse or doctor will increase the stimulus in an attempt to provoke a reaction. They will pinch the trapezius (base of neck) or press on the supraorbital area (above the eye) maintaining firm pressure for a minimum of 10 seconds. This allows adequate time for the patient to react in a purposeful way, like moving their hand above their collarbone to try to stop the painful stimulus. This reaction is considered “localizing” and is scored as M5.

The next level of Motor Response is called Withdrawal. In response to a stimulus to their arm or leg, the patient moves their arm or leg away from the area of pain. This response would be scored M4.

If a patient bends their arm at the elbow and moves with their wrist curled inward and a clinched fist, the reaction is considered Flexion. The legs may extend (straighten) during this response, which is scored as M3.

An M2 response is recorded if both the arms and legs extend (straighten).

M1 is recorded if there is no response.

If Motor Response is Non Testable, an NT is recorded.

The scores from each component (Eye Opening, Verbal Response, Motor Response) are recorded, both individually and as a combined total between 3 and 15.

The lower the number, the less responsive the patient and the deeper and more life-threatening the coma is considered.

Glasgow Coma Scale (GCS)

I. Motor Response (Score ranges from M6 to M1)

Obeys Commands fully.....	M6
Localizes to Stimuli.....	M5
Withdraws to Stimuli.....	M4
Flexes to Stimuli.....	M3
Extends to Stimuli.....	M2
None.....	M1

II. Eyes Open (Score ranges from E4 to E1)

Spontaneously.....	E4
To Speech or Touch.....	E3
To Pain.....	E2
None.....	E1

III. Verbal Response (Score ranges from V5 to V1)

Alert and Oriented.....	V5
Confused but coherent speech.....	V4
Inappropriate words or jumbled phrases.....	V3
Incomprehensible sounds.....	V2
None.....	V1

Motor Response.....	M6 to M1
Eyes Open.....	E4 to E1
Verbal Response.....	V5 to V1

Total score - Glasgow Coma Scale (GCS)..... (M6+E4+V5=15 to M1+E1+V1=3)

Severe brain injury.....	3-8
Moderate brain injury.....	9-12
Mild brain injury.....	13-15

Originally developed by William Bryan Jennett CBE, MDFRCS (1974),

The Paradox of Pain

Every day will be filled with quiet, desperate struggles.

Time will help you make sense of most.

*"When the doctors and nurses first started checking to see
if he would respond to pain,*

he remained perfectly still, motionless as reality raged on about him. They would pinch his neck or squeeze his fingernails. I did not think much about it.

Finally, he responded. He pulled his foot and leg away.

We all rejoiced....

perhaps he was lightening from his coma.

But the days dragged on and on...

the doctors and nurses inflicted pain almost hourly to test his neurological status...

sometimes he responded, often he did not.

I was no longer so excited to see him move.

Intellectually, I understand...but

I am still bewildered by what we do in the name of recovery."

The ICU is an extraordinary place.

Do not try to understand it within the parameters of normal life.

Full Outline of UnResponsiveness Score (FOUR Score)

Some hospitals may supplement the results of the GCS score with an additional assessment called the **Full Outline of UnResponsiveness Score (FOUR Score)**.

The FOUR Score includes four components: eye response, upper body (hands or arms) motor response, brainstem reflexes and respiration. Each component is scored and reported individually with a minimum score of zero and a maximum score of 4 in each area.

Again, the lower the score the more life-threatening the coma is considered.

A total score of 4 or less may identify a brain injury as not being survivable.

The FOUR Score provides additional detail regarding brainstem reflexes and respiratory patterns, which is most informative for patients with a lower GCS score.

The FOUR Score assesses three additional reflexes that help to evaluate brainstem function: Pupil reactivity, the Blink (corneal) test and breathing patterns.

The brainstem is the part of the brain that regulates the most fundamental processes of life including breathing, heart rate, blood pressure, swallowing and other reflexes. To learn more about the brainstem refer to Brain Structure on page 79.

Pupil Reactivity (pupillary reflex)

Pupil reactivity (pupillary reflex) is an autonomic (automatic or involuntary) reflex that adjusts the size of the pupils to accommodate an increase or decrease of light in the environment. The pupil is the dark part of the eye that is surrounded by a band of color called the iris.

Unequal, abnormal or absent pupil responses may suggest brainstem damage and generally indicate a more serious injury.

Blink (Corneal) Reflex

The blink (corneal) reflex is an autonomic (automatic or involuntary) blinking response that occurs when the cornea (clear protective outer layer of the eye that covers the pupil and iris) is stimulated. Saline eye drops are most commonly used to perform this test, although sometimes a cotton swab is used to lightly touch the cornea rather than eye drops.

Each eye is tested independently. A normal blink reflex is recorded if both eyes blink when a saline drop is placed in either eye.

Respiratory Patterns

Observing breathing rhythms and initiation may provide additional detail regarding brain stem reflexes and neurological status.

Breathing patterns are evaluated based primarily on the rate (number of breaths in and out), the depth of each breath (length of time in and out), and the time between breaths.

Watching the chest move up and downs is one way to assess breathing patterns. It is not possible to properly evaluate the breathing pattern of a patient while they are on a ventilator.

See below for a summary of the FOUR Score framework and the evaluation process.

FOUR Score

Eyes Response

Eyelids open and tracking, or blinking to command.....	+4
Eyelids open but not tracking (following a finger or a person).....	+3
Eyelids closed but open to loud voice.....	+2
Eyelids closed but open to pain (noxious stimulus).....	+1
Eyelids remain closed with pain (noxious stimulus).....	+0

Motor Response (upper extremities)

Thumb-up, fist, or peace sign.....	+4
Localizing to pain (noxious stimulus).....	+3
Flexion response to pain (noxious stimulus).....	+2
Extension response to pain (noxious stimulus).....	+1
No response to pain or generalized myoclonus status (uncontrolled twitching).....	+0

Brainstem Reflexes

Pupil and corneal reflexes present.....	+4
One pupil wide and fixed.....	+3
Pupil OR corneal reflex absent.....	+2
Pupil AND corneal reflexes absent.....	+1
Absent pupil, corneal, and cough reflexes.....	+0

Respiration Pattern

Not intubated, regular breathing pattern.....	+4
Not intubated, Cheyne-Stokes (abnormal) breathing pattern.....	+3
Not intubated, irregular breathing	+2
Breathes above (more frequently than) ventilator rate.....	+1
Breathes at ventilator rate	+0

Developed by Dr. Eelco F.M Wijdicks, MD, PhD

6. Diagnostic Tests

Various diagnostic tests will be performed.

Ask about any assessment you are not familiar with.

What information will be learned?

Why is it important to know this information?

How will it influence how we proceed with medical intervention?

Does it provide additional certainty regarding prognosis?

Is pain medication or sedation required prior to the procedure?

Will sedation be stopped or reduced prior to testing being performed?

Gain an understanding of how the test is performed and how the results will be interpreted.

You can record the name of the test, dates, outcomes, and subsequent interventions in your journal for future references.

7. Working with the Team

The ICU can be a frantic place, with an atmosphere that is ripe for misunderstandings.

During those first critical hours, some families have expressed that this already horrifying experience was made more difficult by being physically separated from their loved one. Others have spoken of being isolated by technical jargon, or worse, the deafening silence of being ignored.

Medical professionals will now be a constant in your life. It is vital to establish and maintain a positive partnership between you and the other members of the healthcare team.

Strive to create a win-win-win scenario where the professional's role is meaningful and rewarding, the family feels empowered, confident and valued, and most importantly, the patient benefits from the skills of both groups and receives the best possible care.

*You will more than recover the time and energy
you devote to nurturing this relationship.*

Learn the names and specialties of doctors, nurses and other key staff members. Gain an understanding of their positions and roles and what each individual contributes to the team so you know whom to approach for what. It may be helpful to record these details in your journal for future reference.

Introduce yourself to all members of the team.

It is important that they know who you are and how much you care.

Identify one or two close family members who are able to maintain open lines of communication with a staff member who can supply complete, timely, understandable, and practical information. These details can then be relayed to other family members and friends.

*Ensure the medical team understands the level of involvement you would like regarding decisions
about medical care and treatment options.*

Nurses often know when doctors go on their rounds and may be able to advise you on the best time to speak with a specific specialist.

There may be:

Intensivists: doctors who oversee and coordinate the care of the patient in the ICU. Intensivists lead the multidisciplinary care team.

A **neurointensivist** is an intensivist with special training in neurologic diseases and disorders; these specialists are trained to balance and integrate complex medical treatments for the brain while managing the care of other body systems.

Neurosurgeons: doctors who perform surgery on the brain.

Neurologists: doctors who specialize in the medical treatment of the brain and nervous system.

In general, there will be one doctor who is the “attending of record” and who is ultimately responsible for coordinating your family member’s care. For patients with traumatic brain injury in the ICU, this doctor is often a neurointensivist or a neurosurgeon.

There may also be:

Internal Medicine Physicians: doctors who consult as needed about the organs and systems inside the body.

Ear, Nose, Throat Doctors (ENT): doctors who specialize in treatment of the head and neck.

Orthopaedic Surgeons: doctors who specialize in bones and the musculoskeletal system.

General Surgeons: doctors who perform surgery on the internal organs and the abdomen.

Trainee Physicians: physicians who have earned their medical degree and are at various stages of postgraduate clinical training. They work under the direction of the “attending of record” and the consulting attending. This group includes: “Interns” who are in their first year following medical school graduation, “Residents” who are training in a particular specialty (e.g. neurosurgery, neurology), and “Fellows” who have completed residency training and are pursuing training in a specific sub-specialty (e.g. neurocritical care).

Advanced Practice Providers: nurse practitioners and physician assistants work closely with the physician teams to evaluate patients, write orders or prescriptions, and give updates to families.

Nurses: professionals who provide around the clock bedside care that is guided by doctor’s orders. Nurses monitor a patient’s condition, administer medications, perform treatments, and help to educate patients and their families.

Clinical Nurse Specialists: expert nurses who support other nurses and clinicians in the management of the brain injury patient and their family members.

Respiratory Therapists (RT): health care professionals who manage breathing tubes, ventilator settings, and chest physiotherapy. These professionals are responsible to perform and interpret Spontaneous Breathing Trials (SBT) and other respiratory pattern assessments.

Physical Therapists or Physiotherapists (PT): health care professionals who focus on maintaining and optimizing Range of Motion (RoM) and other physical functions of the patient.

Social Workers: professionals who help the family navigate through the medical system and answer questions about insurance or disability, provide education, counselling and practical assistance. They often make referrals to community resources that may assist both the family and patient.

Case Managers or Care Coordinators: professionals who work with the patient (and their support system) as well as other members of the health care team to assess needs and develop an individualized plan to facilitate discharge from acute care. Care coordinators are knowledgeable about existing services and are able to access and connect these resources to provide coordinated support both in a hospital setting and in the community.

Palliative Care: professionals whose focus is on maximizing patient and family quality of life. Palliative care is appropriate whether a patient is *receiving life-sustaining or curative treatment or focusing exclusively on comfort care*.

These professionals have special expertise in managing patient discomfort and empowering families as they navigate the shared decision making process. They may help the primary ICU team with regards to helping surrogates to understand their loved one's prognosis, clarify the *goals of care* available given their loved one's injuries. Whenever possible, palliative care attempts to obtain a family consensus.

Palliative care is equipped to help a family come to terms with the potential death of a loved one, as well as help them navigate through the dying process. Alternatively, palliative care can help a family grasp the multiple challenges they may face if their loved one survives the ICU.

Most hospitals also have chaplains available for spiritual and emotional support.

It is common to see medical and nursing students, especially in teaching hospitals.

Later, there may be occupational therapists, physiatrists (physicians who specialize in rehabilitation medicine), dietitians, recreation therapists, speech and language pathologists, and neuropsychologists...the list seems endless.

Keep asking questions until you feel confident that you understand how the system functions and who does what.

Every professional will express their commitment to you and your family member in their own unique way.

"We received more bad news today..."

The brain swelling was increasing again, and little else could be done; we would just have to wait and see.

This was a terrible moment, yet something wonderful happened as well.

His nurse started to cry.

Her tears revealed that she cared about him, not as a patient or statistic but as the beautiful and vibrant person I loved.

I have never been more confident in the care he received."

8. Tips for Strengthening the Team

Express how much you appreciate the work the staff does.

Say Thank You in as many ways as you can.

Inquire about their interests outside the hospital; you may have more in common than you think.

Remember the staff members are human. They have their own personal stressors and life outside the hospital. Do not take their every action personally. Most care deeply.

Share information with them about yourself and your loved one. Bring in pictures and tell great stories. Your love for the patient will be contagious.

Ask for their advice about dealing with stress or other issues that may arise; they have many areas of expertise.

Search for compromises so that everyone's needs are met. Check to see if there is anything you can do to make their job easier. Offer to get them a coffee or snack when you get one for yourself.

Remain calm; do not take your fear, anger or frustration out on the staff. If you are abrupt, apologize.

In an emergency, they must act quickly. Give them the space they need to do their job.

Always remember the big picture.

Focus on patient care...that is what is truly important.

*Do not underestimate your abilities or
the importance of love and vigilance.*

9. Shared Decision Making

Shared Decision Making is a collaborative partnership between the medical team and informed, engaged and empowered family members (who have become surrogates for their injured loved one).

This newly established team works together to determine realistic *Goals of Care* and develop an appropriate treatment plan that is aligned with the patient's belief system and priorities and consistent with the recommendations of the medical team.

During the early stages after a brain injury, *Goals of Care* are often very general and must be revisited regularly.

Initially, a “wait and see” approach must be adopted before a more definitive diagnosis can be made.

Talk openly and honestly with your medical team about their prognosis and their reasoning.

The medical team will discuss with you the realistic range of probable functional recovery outcomes given the severity of your loved one's injuries, their age, medical history, improvement since the primary injury, response to interventions to manage secondary injury, imaging and their neurological assessment.

They will make recommendations regarding what procedures and treatment options to pursue and the relative benefits and risks associated with each intervention.

It is critical that family surrogates comprehend the long-term physical, emotional, social, spiritual and financial realities that their loved one and family now face.

Providing balanced and realistic information to family surrogates demonstrates respect for the shared decision-making process and confidence in a family's ability to make wise decisions on behalf of their loved one.

Knowledge empowers surrogates with the tools they need to make valuable contributions to the collaborative partnership.

Honest communication requires courage and compassion – it informs the kindest and most gentle path forward.

Even with the best medical treatment available and intensive rehabilitation, ***more than half of those who survive a severe brain injury will never live independently upon discharge from hospital.***

While this may seem inconceivable, it is the reality.

It is important that each family member grasps the range of realistic functional outcomes given their loved one's injuries.

We all wish the accident was a nightmare that we could awaken from and everything could go back to the way it was before...but it serves no one, especially the injured person and their family, to hold to unrealistic and unachievable expectations for recovery.

Family conferences can be organized to facilitate effective communication and ensure family surrogates have the resources and support they need to effectively navigate the shared decision making process.

Achieving consensus within a family helps establish a firm foundation for healing and moving forward -- regardless of the outcome.

Depending on your hospital, these services may be delivered through the ICU team, social work, palliative care etc.

*No one ever feels
prepared to **be** a surrogate decision maker
for someone they love.*

10. Becoming a Surrogate Decision Maker

A Surrogate is someone close to the patient who, in partnership with the medical team, contributes to decisions regarding goals of care and medical treatment options on behalf of their loved one.

Surrogates are guided by the questions:

Are my decisions aligned with our loved one's belief system?

Their faith ? Their spirituality? Their character and personality? How they lived their life?

Discuss how treatment decisions will be made within your family.

Who will provide input?

How important is it important to achieve consensus within the family?

Is one person ultimately responsible to make the final decision?

Ideally, your injured loved one has a written directive outlining the level of medical care they would want given a range of circumstances. Even if this specific scenario was not considered, a directive helps to clarify your family member's wishes about what medical options and level of intervention they would have chosen.

Most individuals, especially young people, do not have formal medical directives.

Even if families have not addressed medical directives and goals of care directly, many have a sense of what their loved one would want should a situation arise where they are unable to speak on their own behalf.

Specialized resources are available to help to empower surrogates and facilitate communication as families navigate through the complex and often heart-wrenching discussions necessary to arrive at *goals of care* and treatment decisions that are aligned with their loved ones belief system and values and consistent with the recommendations of the medical team.

Being part of an inclusive and comprehensive shared decision making process increases a surrogates confidence in their contributions and will ultimately help them to feel more at peace with the wide range of potential outcomes – including profound disability or death.

Do your best to consider goals of care from your loved one's perspective rather than focusing on your own grief and fear.

It is important to be realistic regarding what level of independence your loved one will be able to achieve given their injuries.

Seek out a wise friend or trusted family member to help you to talk through the details, clarify the options, and make decisions.

Before information becomes a useful tool, it must first be processed through the head...and the heart.

"My hope was for a complete recovery...

maybe a limp, some slurred speech, difficulty finding words when he was tired.

I didn't yet grasp that outcome was no longer achievable for him.

From the moment of impact, given the significance of his injuries, he would never regain the quality of life or independence he had prior to the accident.

I now know that survival, a heartbeat, was the initial hope of his medical team.

I didn't understand that we defined success differently."

11. How Do People Wake Up From a Coma?

One of the first signs someone may be “lightening” from a coma is that they begin to go through cycles of being “asleep” and “awake”. During “awake” periods, patients are more likely to make spontaneous movements or respond to stimulus.

Mirror your loved one’s sleep and wake cycles as best you can.

Support these circadian cycles, if they are present, by opening or closing the curtains or reducing stimulation (no talking or music, close the door) at appropriate times,.

It is very subtle.

Be as sensitive to their needs as possible.

As a patients’ brain injury evolves, they may make more purposeful movements, like withdrawing from pain, pulling at their tubes, or fully opening their eyes.

At this stage, should your loved one open their eyes, they often do not “see” but stare without focus.

Initially, your loved one’s reactions may be inconsistent and slow. It is often difficult to link a stimulus (pain or light or the sound of a familiar voice) with the response the patient makes (changing vital signs, moving a hand or foot, opening their eyes, or trying to make a sound).

Some patients make repetitive, non-purposeful movements, sometimes even rubbing themselves raw. If this happens with your loved one, you may wish to bring them a soft scarf or pillowcase and put it under their arm or leg so they can rub without hurting themselves.

Tube pillows make great supports and protectors. Consider buying a couple if your hospital is open to it.

If your loved one continues to improve, it may become easier to link the stimulus and reaction and establish a cause and effect relationship. They may begin to “track” or follow certain stimuli or movements with their eyes.

Responses may become more consistent and appropriate.

Talk to your loved one in a calm and soothing voice.

Let them know you are there and how much you love them.

Speak in short, understandable sentences.

Explain that they have been in an accident (or whatever the truth is), and that they are in hospital.

Reassure them constantly.

If your loved one is forming memory, it is likely very fleeting, perhaps lasting for no more than a few moments at a time.

Try and imagine what that must feel like...by the time you have finished reading this sentence, you can no longer remember how it began. The memory has already evaporated.

Depending on the extent of brain injury, some people appear to be able to hear and recall things that happened while they were “unconscious”.

Tiny improvements are often followed by plateaus, complications, and setbacks – and then, as always, more waiting.

Some people continue a slow process of improvement for days, months, or even years.

Some people never regain a greater level of consciousness and remain in a coma or near comatose state indefinitely.

There are no guarantees. The future is uncertain.

Only in movies do people flicker their eyelashes, stretch and ask “What happened?”

12. Sedation and Chemically Induced Coma

Some patients may be sedated and / or chemically paralyzed after a brain injury.

When a patient is receiving sedation, it may be difficult to know how much of the coma is medically induced and how much is the result of the brain trauma.

If the patient meets certain criteria, sedation may be lightened or stopped to enable the doctors and nurses to more accurately assess a patient's neurologic function. Refer to Neurological Assessments beginning on page 36 for additional detail.

For some patients, a chemically induced coma can help reduce agitation and mitigate additional injury to the brain due to swelling.

Physical motion may increase the pressure inside the skull for certain patients. In some cases, eliminating or reducing movement can help minimize the pressure.

Sedative medications may also lessen the oxygen requirements of the brain by reducing brain metabolism in certain situations.

Sedatives may be used to calm a patient or reduce their agitation and are commonly used prior to certain procedures being performed.

Patients who are experiencing agitation are sometimes physically restrained to ensure they do not further themselves by pulling out their tubes or ventilator.

Common sedatives include: propofol, lorazepam, midazolam, and dexmedetomidine.

*Be realistic about the amount of power and control
you have over your loved one's recovery.*

"I understand that a helicopter (*air ambulance*), an entourage of the best and the brightest doctors and specialists, and a hospital full of state of the art medical equipment can't completely heal his damaged brain....

*But I cannot stop myself from thinking....
Why can't I?"*

13. Family Presence During Resuscitation Attempts

If you and your family make the decision that your loved one would want every effort made to resuscitate them if their heart were to stop beating,

Consider if you want to be present if a code is initiated for your loved one.

Full Code is the default status for all patients admitted to hospital. This status remains in place, unless the patient or their surrogate revises the directive.

Full code means that all available medical interventions will be used to prolong or sustain your loved one's life, including chest compressions and electric shocks [referred to as Cardiopulmonary Resuscitation (CPR).]

It also means that if the patient is not currently intubated and develops difficulty breathing, a breathing tube would be (re)placed.

Contrary to how CPR is portrayed on television, few people who receive CPR in hospital will recover sufficiently to return home and to their community.

For some patients, the decision to be intubated means a lifetime of having a trach in place or even being dependent on a ventilator.

Ask your medical team how effective CPR and / or intubation would be given your loved one's condition.

Ensure the medical team is clear regarding the level of involvement you are comfortable with during CPR.

If you make the decision that you would like to be present during a resuscitation attempt, should the situation arise, ask the hospital what resources are available to support your choice.

"I didn't have time to think...it felt like I was watching myself respond.

Time unfolded in slow motion...and a million miles a second...he wouldn't stop seizing...and then, all at once, I understood...the "code blue" I heard overhead was for us...for him...the team swooped in and started to whisk him away...

With a courage and conviction I didn't know I possessed, I asked to stay with him.

"I promise to stay calm. I will stay out of your way...

We had come too far.

I didn't want him to die without me, or someone who loved him, by his side.

If he is dying, he is dying with me watching."

I am forever grateful that I was present to witness the efforts and commitment of the entire medical team.

Sometimes, the gift is being proud of the way you behave...then,

Regardless of the outcome, there will be a sense of peace.

14. Informing Others

The phone calls to tell others what has happened will be among the most difficult calls you will ever make.

Remember, the moment someone learns devastating news about a loved one will be etched in their consciousness forever.

Be as calm and gentle as possible.

You may not realize it now, but these first few minutes are laying the foundation of a new and challenging period...

the "After the Brain Injury" era.

Each person who learns the "news" will go through periods of shock and panic and disbelief.

It will be difficult for them to "take it all in".

They will not be thinking as clearly as they could be.

- Make it as easy as possible for them to get to the hospital
- Is it better to take a cab or have a friend or neighbor drive them?
- Remind them of the quickest route to the hospital
- Tell them what entrance to use, where to park, and exactly how to find you once they enter the hospital
- Explain where you are (the first family room on your left when you get off the elevator) and how the telephone or intercom in the ICU waiting room works, if there is one where you are.

From the moment you first learn the news, you are thrust into unfamiliar territory: emotionally, intellectually, spiritually, physically.

Each person will respond in their own way.

Some people cry, others express no emotion.

Some are practical and pragmatic, others philosophical.

Some need to be with their loved one immediately, others need time to prepare before they feel ready to face the trauma. Some feel numb, others are physically sick.

There is no right or wrong way to react.

Be prepared for and supportive of all responses.

Consider:

- How much medical information do they need to know right now? How much are you able to provide? Saying that your loved one is very sick or badly injured is often all that is necessary or appropriate.
- Will they need a ride to the hospital? Help to book a flight?
- Is it okay to text or telephone this person or would it be better if they receive the news in person?
- If they live out of town, can someone else tell them? A friend? A relative? A neighbor?
- Should this person have someone else with them when they hear the news?

Each person will have slightly different needs when hearing the news.

Elderly grandparents, teenagers, and children require an individualized approach based on their backgrounds, experiences and relationship to the injured person.

Everyone will process the information from their own perspective, their own point of view.

Do your best to anticipate each person's unique needs and appreciate the individual contributions they are able to offer.

It is essential to maintain and strengthen existing relationships.

Building a resilient network of support is critical to ensuring the best long-term outcomes for everyone involved.

Allow others to support you through this experience.

When friends and family ask

"What can I do?"

Answer:

- Make a frozen casserole for dinner at home - I have no time to cook.
- Bring a plate of home-cooked food, muffins, fruit or cut vegetables to the hospital - we spend most of our time here.
- Take care of my kids; it gives me a break and gives them some undivided attention from an adult.
- Take my mother / father / in-laws / aunt / cousin, etc. out for coffee, they need support, but sometimes I feel too overwhelmed to give it.
- Phone others to keep them informed of what is happening - there are so many people who care, but going over and over the details of the story is exhausting.
- Bring in a tote bag from home with a toothbrush, deodorant, a change of clothes, a warm sweater, coins for vending machines, a charger for the phone...
- Bring in his favorite music or pictures that I can put up in his room.
- Pick me up at the hospital and take me for coffee or dinner. Do not be offended if I suddenly feel overwhelmed with fear and want to return to his bedside.
- Come and just sit with me, or walk with me. Even if I hardly seem to notice, I appreciate your presence.
- Cut my grass, water my plants, shovel my walk, feed my dog, bring in my mail...
- Bring in a thermos of coffee, herbal tea or hot chocolate - the cafeteria is not open all night.
- "No spill" travel mugs make great "I was thinking 'bout you today" gifts. So do pocket flashlights. They allow you to read at the bedside when the lights are turned down.
- Bring in a light book, magazine, knitting...anything to pass the time at his bedside.
- Come and sit with him so I can take a break and feel confident that he is not alone. Sometimes a "tag team" approach works well.
- Just listen as I go over and over the details of the trauma...trying to comprehend the incomprehensible.

Allow me to cry or be angry or be silent.

Please do not judge me.

Give me a hug.

Remind me how much you love them too.

15. What is the Prognosis?

It is difficult to grasp the impact that brain injury will have on your loved one and your entire family...for a lifetime.

While it may seem inconceivable, this young and vibrant person, who was just launching into life, or fully independent only yesterday, may likely require some form of life-long assistance or need to live in a supportive-living arrangement.

The future is unknown, but there are ranges of potential functional outcomes that can be predicted with a reasonable degree of certainty.

Optimism must be tempered with realism.

Ask the medical team to explain the potential range of outcomes given your loved one's injuries, their Glasgow Coma Score or FOUR Score, their age, their medical history, their improvement since the initial injury, their response to interventions to treat the secondary injury process, imaging results, etc.

Brain injury is often cumulative. If your loved one has sustained a previous brain injury or has a history of brain disease, the consequences of this injury may be more serious.

Once the prognosis is clarified, as well as the level of certainty around that diagnosis, realistic *goals of care* can be developed and treatment options can be discussed.

Understanding quality of life challenges and the range of possible long-term outcomes is critical to being an informed surrogate decision maker.

It is important comprehend the physical, emotional, financial, and social realities your family will face as you navigate through the next several years. The impact of a brain injury on a family is multi-generational.

Work with the resources available within your hospital to ensure you and your family have the tools and skills necessary to flourish into the future - regardless of how it unfolds.

*"I am eternally grateful
to those compassionate professionals who bravely sat with us....
and with raw honesty and integrity helped us to grasp
the range of outcomes and the quality of life challenges
our loved one and our family would face if he survived his injuries.*

*These open and sincere discussions increased
the trust and confidence we had in our medical team...*

*and were especially treasured on days when
the only treatment options available ranged from bad to worse."*

Consider:

What is the level of certainty regarding the prognosis? Are there specific indicators that increase or decrease their level of certainty?

How confident is the medical team regarding the prognosis? What criteria is the prognosis based on?

What treatment options are available given the severity of the injuries and the prognosis?

Given that your loved one requires treatment in the ICU, it is *very possible* that they will not recover the level of independence that they enjoyed prior to the injury. Family celebrations, traditions, upcoming events will likely evolve to reflect this new reality.

It is *very possible* that your loved one will not have the ability to return to the occupation they had before their injury, or work at the same level.

If the patient is a parent of young children or teens, additional assistance or paid care may be required to provide ongoing physical and emotional support for the family.

Some people with moderate brain injury may be able to live with support in the community, in a group home or with attendant care. Who will be part of their day-to-day support network?

Some may learn to drive again, maintain employment, or volunteer in meaningful ways.

Many are able to participate in low risk sports such as golf or hiking, but higher risk sports such as skiing and bike riding may not be recommended.

The definition of meaningful activity may likely be revisited.

Depending on the seriousness of the injury, asking specific questions may help to clarify:

Will they wake up? Will they be aware of and able to respond to their environment?

Could they remain in an unresponsive or minimally conscious state indefinitely?

Will they walk? Will they talk? Will they be able to feed themselves? Manage their own bathroom and other hygiene related needs?

Will they have a quality of life and level of independence that is acceptable to them?

Will they remember who I am and the relationship we once shared?

Could they return to school or work at the same level as before the accident?

Will they be able to financially support themselves (and potentially their family)?

Will they be able to manage their own finances?

Will they be able to drive a car?

Will they be able to cook for themselves? Grocery shop?

Read and comprehend a book? A magazine?

Able to engage in and maintain an intimate, committed relationship?

Care for their children?

Participate in sports?

What is the likelihood that they will be able to live independently? What types of additional support will be required from family and friends or paid service providers?

Is it possible they could live in a supportive living arrangement in the community?

Is it likely that they will require full-time support in a long-term care facility?

Some people with severe brain injury live well in supportive care for many years. How will these support requirements evolve as they age?

Who will be responsible to ensure my loved one is protected and safe in their new living arrangement and reality?

In the short-term? For the long-term?

As parents (or spouses) age, families must consider who will assist the person who has been the primary support provider and who will assume that responsibility into the future.

In time, this support role often falls to the younger generation including siblings, spouses, or children.

It is important to understand the physical and cognitive challenges, as well as the less apparent emotional and social impacts of brain injury.

What types of personality changes may be anticipated?

Changes in temperament are very common after a brain injury.

How will my loved one function socially? Emotionally? Psychologically?

Emotional and social challenges are often more subtle and the most difficult issues for those with brain injury and their families.

Some people with severe brain injury struggle with both short and long term memory, never regaining their memory of those they loved prior to the accident.

Will they recognize me? Will I recognize them?

Refer to the section Possible Effects of a Brain Injury on Survivors on page 108 for additional detail.

16. Treatment Plan

The medical team and the family work together to develop a mutually agreed to treatment plan. Treatment plans generally include multiple alternatives based on response to treatments, test results, and targets achieved within a given timeline.

Treatment plans are generally updated regularly.

*Speak openly with the medical team
to ensure they understand the level of input you would like
regarding decisions about medical care and treatment options.*

Are you and your family most comfortable accepting the doctor's recommendations and asking questions for clarification?

Would you prefer to be a more active participant in a shared decision making process?

Questions to discuss with the team regarding treatment options include:

What are the pros and cons of each treatment option? How much uncertainty or risk is associated with each procedure or option?

What is the time frame for each option before we can understand if the intervention will be beneficial or not? Does the procedure improve functional outcomes?

If we choose one strategy, will it make other interventions less effective?

If the treatment is not effective within a certain time frame, is there a plan to discontinue or withdraw the intervention?

When do we meet again to review and re-strategize?

Process as much information as you can.

Be patient with yourself. Take breaks. Re-evaluate regularly.

There are no perfect solutions. Do your best and surrender.

*Sometimes Love is holding tightly.
Sometimes Love is letting go.*

Wisdom is knowing the difference.

Peace is acting on that knowledge.

17. Care and Comfort

I want to gently broach a very sensitive and difficult topic...likely one of the most difficult decisions you will ever face.

Take a deep breath. Find a quiet space.

Let's talk through this together.

Sometimes, despite the most advanced technology and science available and the best efforts of the medical professionals, the wonderful, vibrant person that you knew may never return.

When an injury is severe and the prognosis poor, your loved one may not benefit from continued aggressive, "curative" medical treatment.

The most loving and compassionate choice may be to transition from prolonging life with medical interventions to focus exclusively on the care and comfort of your loved one – with an understanding that their brain is too severely injured to be survivable.

Their injury is life-ending.

My heart aches remembering how it felt to be sitting where you are now.

I want to ever so tenderly reach out to you and, with love and empathy, gently walk with you through this unimaginable decision.

I cannot tell you what choices are best for your loved one and your family.

I can help you navigate your way through the decision process.

You are not alone.

The medical team will support your loved one and your family through what ever treatment options you choose – continuing life sustaining treatment or transitioning to care and comfort.

They will be available to answer your questions and provide the most comprehensive information available.

Know that your loved one will be kept comfortable and will not suffer. You and your family can be present with them throughout the dying process.

This is not a decision that needs to be made immediately.

Sit with your loved one. You know them best.

*“What future would my loved one want for themselves...
for their family?”*

How would they want to proceed? What is in their best long-term interests? Would this quality of life and level of dependence be acceptable to them? Would they have wanted this amount of intervention?

Achieving consensus among key family members goes a long way to developing a strong foundation going forward into the future - regardless of the outcome.

*Take some time to work through the various scenarios –
with your head and with your heart.*

Be realistic about how much influence you have over your loved one's recovery.

Love cannot heal a damaged brain.

*Holding tightly to unrealistic expectations is destructive...
for your loved one, for you and for your family.*

“Chaos continued to rage about us...the bright lights glared down...the machines continued to whirl.

I was at a loss. I didn't know what to do. I could not imagine my life without him.

I just wanted him back like he was before

...so we could carry on with our lives and grow old together.

I could not comprehend that this warm, breathing man lying beside me,

may already be technically gone...

I can hold his hand but his life, our life together,

may have slipped away on the side of the highway.

I racked my brain for every conversation we ever had that might give me some insight into his wishes given the unimaginable – from movies to news reports to discussions about organ donation.

I took his hand in mine, stroked what was left of his hair and rested my head gently on his chest – listening to his still beating heart.

I quietly asked him what I should do.

What future do you want for yourself?

From a place of peace, the answer revealed itself.

I knew in my heart how to proceed...

What choices he would make for himself.”

"I so desperately wanted him back – for his brain injury to be "cured".

*Please let him just wake up and come back to me...
make this nightmare end."*

Yet, at the same time, on some level that I was yet unable to fully acknowledge, I was beginning to grasp that keeping him on "life support" would not heal his damaged brain.

No matter what we did, or how much I loved him, we were unable to bring him back.

His quality of life would forever be extremely compromised.

He would never be the same...walk again...talk again...laugh again.

From the moment I first heard about the accident, I understood that he might die.

I hadn't comprehended that he may "live" but never recover again."

Brain injury is unpredictable.

It is almost impossible to know what to hope for, when to hold tightly and what to relinquish forever.

"I surrendered....

Please, please do what is best for him....

And give me the

Courage

Strength and

Grace

To accept the future with dignity...

precisely as he would have wanted..."

18. Medical and Technical Information about the Brain

Most of us take our brain for granted. Stop and consider for a moment what your brain is doing at this exact moment.

Your brain is regulating your heart rate, your breathing, your temperature, your balance. It is automatically filtering out subtle noises (like the whirl of a machine in the background) so you can focus on reading and comprehending these words. It will tell you when and how to turn this page (or advance the computer screen).

Your brain is continually integrating every thought, emotion, impression and experience into your memory. Your brain is the most important organ in your body.

Everything you think, feel, say, or do is dependent on your brain.

It is exhausting to consider what a complicated system we are.

Brain Basics

A brain weighs approximately 3 pounds and is the consistency of gelatine. It is enclosed in a strong protective covering called the dura and floats inside the skull in **Cerebrospinal Fluid (CSF)** that provides cushioning, nutrition and support for the brain.

Inside the brain are cavities called ventricles, which are filled with CSF. CSF is constantly being produced in the lining of the ventricles. CSF flows from your brain, down the entire length of your spinal cord and back again, delivering nutrients and removing toxins. CSF is reabsorbed through multiple systems in the brain.

A brain is composed of billions of tiny brain cells called neurons. Neurons are linked together by connective fibres, or axons, that form complex pathways within the brain. Impulses travel along these routes to communicate information from neuron to neuron within different centers in the brain and throughout the entire body via the spinal cord. Special chemicals called neurotransmitters also transmit messages throughout the brain.

While neurons do not regenerate after being damaged or destroyed (although exciting research is being pursued), different neuronal pathways may be re-established or re-routed as skills are relearned.

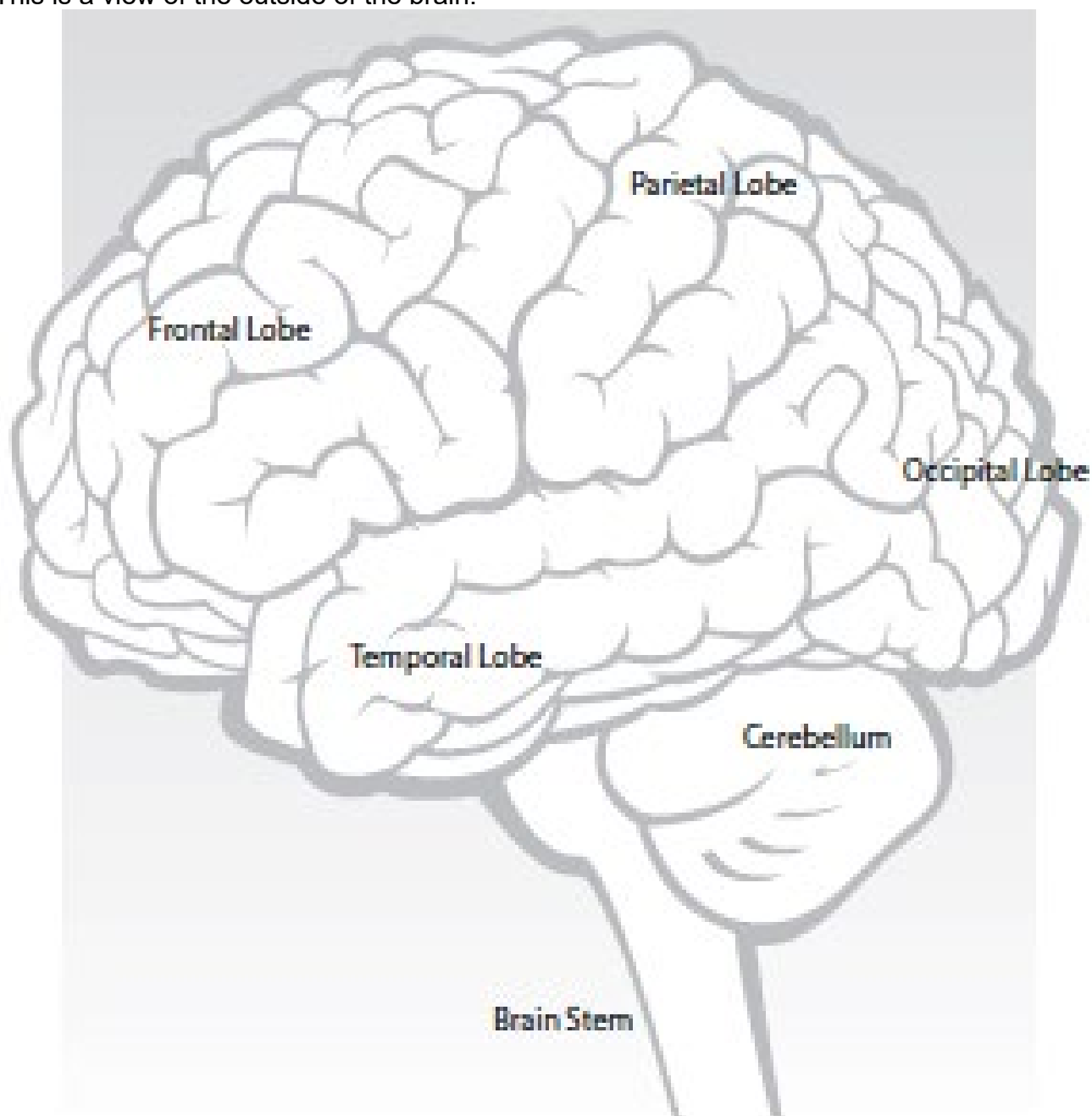
Brain Diagrams

These pictures may be helpful as you talk with your healthcare team about your loved one's injury.

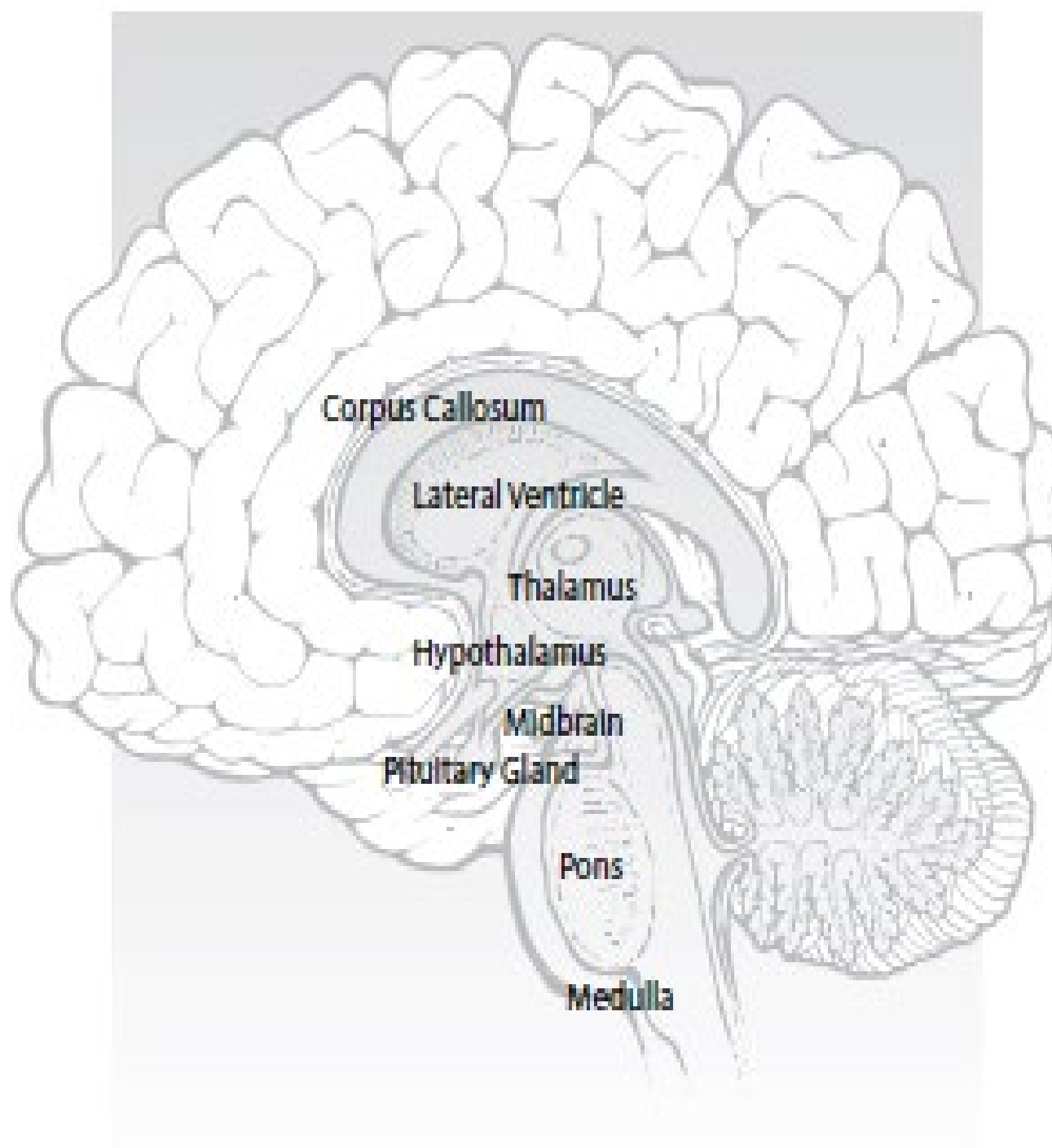
The doctor or nurse can color or write on the diagram to help you understand the location and extent of the injury within the brain.

Not only will this be useful for you, it will help you to explain what is happening to family and friends.

This is a view of the outside of the brain.



This is a view of the inside of the brain.



Brain Structure

The following provides a brief overview of various areas of the brain and their functions. It may help you to understand some of the terminology the doctors and nurses use.

The brain can be divided into the cerebrum, the cerebellum, and the brainstem.

The **cerebrum** is the larger, upper portion of the brain and is responsible for more complex functions including communication, reasoning, emotions, music and art appreciation. This portion of the brain organizes information collected from our five senses (vision, hearing, taste, smell, touch) integrates these details, and initiates appropriate responses.

The cerebrum is divided into two parts: the right and left hemispheres. A neuronal tract called the corpus callosum connects these two halves. The **corpus callosum** facilitates information transfer between the hemispheres.

The left hemisphere controls the right side of the body. The right hemisphere controls the left side of the body. For most right-handed people, the left hemisphere also controls speech and comprehension. The left hemisphere is “dominant” in these situations. The majority of people are right-handed and left-brain dominant. However, there are a few left-handed people who happen to be right-brain dominant.

The **cerebellum** is the smaller, lower section of the brain and is located at the back of your head. It also has two hemispheres: the left and the right. The cerebellum is responsible primarily for coordination of muscle movements and balance.

The **brainstem** connects the cerebrum and cerebellum to the spinal cord and is responsible for the nerves to the face and head, as well as for many automatic involuntary functions – including breathing, heart rate, blood pressure and wakefulness. All information processed in the brain must pass through the brainstem to various areas in your body, making it a particularly critical structure.

The brain is divided into four lobes:

Frontal Lobes

- Responsible for executive functions, planning, personality, humor, insight, judgment, behavioral control, verbal expression, emotions and integrating information
- Responsible for main movements of extremities, trunk and eyes, spatial perception

Temporal Lobes

- Responsible for hearing, smell, and taste, interpreting written and spoken language (dominant hemisphere), and long-term memory formation

Parietal Lobes

- Responsible for spatial awareness, recognition of body parts and physical sensations

Occipital Lobes

- Responsible for vision and interpretation of written language

Brain Injury Mechanisms

Approximately 50% of traumatic brain injuries are the result of motor vehicle accidents. Other causes include falls, sporting and recreational injuries, assaults, etc.

Damage to the brain occurs in two phases: primary and secondary.

The initial trauma (primary) may be the result of a direct impact, such as the head hitting the windshield of a car or being hit by an object such as a baseball bat or a bullet.

Secondary injury to the brain continues for the next several days and sometimes weeks after the trauma, due to swelling and a complex cascade of biochemical, cellular, molecular and electrical processes within the brain.

A brain injury can occur even if the head does not hit something directly. Rapid acceleration and deceleration causes the brain to be whipped and twisted around inside the head and to bounce off jagged bones located on the inside of the skull. This can cause widespread or “diffuse” injury to nerve fibers throughout the brain, disrupting neural pathways and tearing communication “wires”. The frontal lobe (behind the forehead and along the sides) is especially vulnerable in these events.

The injury to the brain may be “coup” and “countercoup”. Coup (pronounced “coo”) refers to the damage caused by the initial impact, while countercoup refers to the damage on the opposite side as the brain rebounds off the inside of the skull.

Secondary swelling (edema) and bleeding (hemorrhage) are both cause for concern as they may increase the pressure inside the skull causing additional (secondary) injury. Because the skull is an enclosed system, there is no natural place for the excess fluid to expand to or escape (like there is with a swollen ankle or other extremity). Instead, the pressure from the excess fluid builds inside the skull. If this pressure increases too much, death will result.

Bleeding inside the brain is dangerous for two reasons. First, the specific area of the brain that is damaged may receive an inadequate supply of blood and oxygen. Second, the haemorrhage may increase the pressure inside the skull.

Bleeding may occur between the skull and the dura, the protective covering of the brain. This type of bleeding is called an epidural hematoma (“epi” means above, and dural refers to the dura). Bleeding occurring between the dura and the brain is called a subdural hematoma (“sub” meaning under). If the bleeding occurs inside the brain tissue, it is called an intracerebral hemorrhage (“intra” means within, “cerebral” refers to the brain) or intreparenchymal hemorrhage (“intra” means within, “parenchymal” refers to the brain tissue).

Secondary injury also occurs at a microscopic level due to a complex cascade of biochemical and electrical interactions. These dynamics are still not well understood and cannot be measured using the common tests such as a Computed Tomography (CT) scan or Magnetic Resonance Imaging (MRI).

Common Tests

The most common tests used to diagnose brain injury are the Computed Tomography (CT) scan and Magnetic Resonance Imaging (MRI).

A CT scan is an “x-ray” image that takes pictures of cross sections or slices of the brain. A CT scan can be performed relatively quickly and while a patient is connected to other medical equipment. CT scans can be effective at identifying areas of bleeding, swelling, and bone injury. It does not, however, show microscopic damage or the impact to electrical impulses and chemical pathways.

An MRI uses a high-powered magnet to construct a picture of the brain. While an MRI provides additional detailed structural information, it does not provide detail regarding microscopic damage or the impact of the injury to electrical impulses and chemical pathways.

An MRI requires a much longer period of time to complete than a CT scan. An MRI is generally not an option until the patient is stable and able to be away from the ICU for a couple of hours.

19. Potential Surgical Interventions

When someone who has sustained a brain injury arrives at the trauma unit, the primary focus of treatment is to prevent and minimize secondary injury to the brain. For additional detail, refer to Brain Injury Mechanisms on page 81.

The medical team will focus on:

- Detecting, preventing, and/or minimizing the pressure within the skull (intracranial pressure or ICP)
- Maintaining blood flow to the brain (Cerebral Perfusion Pressure – CPP)
- Stopping any bleeding in the brain

Common brain surgeries / procedures include:

ICP monitor placement: During this very common surgery, a small burr hole is made in the skull and through the protective dura. Depending on the type of ICP monitor utilized, the ventricular drain could be placed either on the surface of the brain, within the brain tissue, or deeper within the ventricles (External Ventricular Drain, or EVD).

Bone flap removal (decompressive craniectomy): During this procedure, a piece of bone from the skull is temporarily removed to accommodate brain swelling. The scalp is then laid back on top of the dura (internal protective covering on the brain) and reattached to provide some protection to the brain.

The area where the bone is removed is very vulnerable until the bone flap is replaced. The bone will be put back when the swelling subsides and any ongoing medical issues with the brain have been resolved. This could take several weeks or even months. A helmet may be provided to protect the area of the brain that is no longer protected by the skull when the patient is transported or mobilized.

The piece of bone that was removed may be temporarily placed in a secure location with the patient's name on it or stored in the patient's abdomen. The patient will have a visible indentation in their skull until the bone flap is replaced.

Craniotomy: During this procedure, a piece of bone from the skull is temporarily removed to allow the neurosurgeon access to the brain to remove any damage (including blood clots and bone fragments) or to repair damaged tissue. The bone is replaced during the surgery, and the scalp is reattached.

Burr holes: During this procedure, a small opening is made in the skull to drain fluid from the surface of the brain and to allow surgical access. A burr hole is required for ICP monitor placement.

20. Potential Complications

Deep Venous Thrombosis (DVT)

A deep venous thrombosis (DVT) is a blood clot in a major vein, most commonly, those in the legs. DVTs can be dangerous as the clot can dislodge from the leg and travel to the lungs. This can be fatal. Blood clots are common in people who are sedentary (inactive or bed bound).

Common, necessary interventions performed in intensive care units (such as central lines) may increase the risk of blood clots.

Keep an eye on your loved one's lower legs and toes.

A lack of circulation due to a DVT may cause one leg or foot to swell, to feel hotter or cooler than the other, or to lack color.

Sequential Compression Devices (SCD) or small doses of blood thinners may be used to reduce the risk of DVTs. Early mobility and range of motion exercises also help reduce the threat of DVTs.

Infections

It is common for someone with a brain injury to get infections including pneumonia, bladder infections, bloodstream infections, or infections in the brain or cerebrospinal fluid. One of the first signs of infection is an increase in body temperature. The presence of an infection is generally confirmed by sending a sample of the relevant body fluid (blood, urine, sputum, CSF) to the lab for analysis.

The medical team evaluates fevers should they occur and orders antibiotics when necessary and appropriate. Antibiotics are often used to prevent or treat infections, but may have side effects.

Acute Kidney Injury (AKI)

Acute kidney injury (AKI) is a sudden decrease in kidney function. When the kidneys are unable to filter sufficient waste products from the blood, toxins accumulate within the body potentially causing an electrolyte or fluid imbalance impacting multiple systems including the brain, heart and lungs.

AKI impacts approximately 10% of people who have sustained a serious brain injury. While the exact mechanism is not clearly understood, lesions in the brain appear to create a chemical or electrical imbalance in the kidneys.

Short or long-term dialysis may be required to filter the toxins from the blood system.

Acute Respiratory Distress Syndrome (ARDS)

Acute Respiratory Distress Syndrome (ARDS) is an inflammatory process within the lungs that causes fluid to accumulate inside tiny sacs inside your lungs (alveoli) and the neighboring blood capillaries. Lungs may become stiff, a problem that reduces the amount of oxygen exchange and decreases the oxygen that is available to be pumped through the bloodstream to support brain and other organ systems.

ARDS may trigger an immune response causing systemic inflammation throughout the body.

ARDS is typically a complication of a pre-existing condition and is most common in people who are already very sick.

ARDS is especially difficult to manage in people with brain injury. Intervention strategies must be carefully considered, as common treatments for ARDS may increase ICP and decrease MAP (Mean Arterial Pressure), resulting in decreased CPP (Cerebral Perfusion Pressure).

Seizures

Seizures are common after a brain injury.

Sometimes, seizure activity begins immediately after a brain injury. Sometimes, it takes months or longer to present.

Seizures arise when a group of neurons “short circuit” and begin firing uncontrollably.

Seizures may remain localized (called partial seizure) affecting only a portion of the brain. Symptoms of a partial seizure include staring, twitching on only one side of the body or experiencing strange tastes, smells, or flashes of lights

Some seizures are “non-convulsive” meaning that there are no visual signs of seizure activity. In these cases, the patient may have a blank stare and be unresponsive.

Seizures may be more generalized within the brain. Symptoms of a generalized seizure are more visible, often with full-body convulsions of all extremities. With little or no warning, a person with a seizure disorder may drop to the floor and experience jerking movements throughout their body.

Should this happen, ensure there is nothing close to the person that could injure them. Protect their head as much as possible. Do not try to put anything in their mouth in an attempt to open an airway.

If the person starts to throw up (which is common), gently roll them on to their side so they are less likely to choke (aspirate). It is common for someone to bite their tongue during a seizure, so don't be alarmed if there is a small amount of blood.

Seizures generally last only a minute or two, but

it can seem like an eternity when you are present.

Observe as much behaviour as possible. Time the seizure.

Call for help if you are in a hospital. If you are outside the hospital and a seizure continues for more than 5 minutes, call 911.

Remain calm.

A doctor, nurse or Emergency Medical Technician (EMT) will likely ask you for all the details of the seizure you can recall.

People are more vulnerable to seizures when they are tired, hungry or under stress.

Seizures can often be controlled with medication.

An electroencephalogram (EEG) may be used to detect seizure activity (especially non-convulsive seizures). For additional detail about an EEG, refer to page 22.

Sepsis

Sepsis is a life threatening condition where the body's immune system is overwhelmed by a severe bacterial, virus or fungal infection, which may cause low blood pressure and lead to multiple organ failure.

Early intervention is critical.

Initial symptoms of sepsis may include a high heart rate, fever, and fast breathing.

Sepsis is treated with antibiotics and intravenous fluids. Broad spectrum antibiotics may be initiated immediately. Cultures from body fluids (blood, urine, sputum) may be analyzed in the lab before more specific antibiotics can be identified and administered.

Delirium

Delirium is the result of a fundamental change in the way the brain is functioning. Delirium can begin suddenly or increase incrementally over the course of several hours.

Certain drugs, electrolyte or fluid imbalances or a build-up of toxins may cause delirium.

Delirium is often reversible.

People with delirium may not think clearly, experience hallucinations (see things that are not there), and be disoriented and confused about where they are—even about what time period they are in. They struggle to make sense of what is happening in the world around them and sometimes act aggressively or alternatively, withdraw into their own unseen world.

Family members are often effective at calming and orientating the patient.

Assessing delirium for someone with a brain injury is especially challenging as many of the symptoms of brain injury and delirium overlap.

Common medications for delirium include: haloperidol, quetiapine, and risperidone.

Delirium is a strong independent risk factor for adverse long-term outcomes, including Post Intensive Care Syndrome (PICS).

Post Intensive Care Syndrome (PICS)

Post Intensive Care Syndrome (PICS) is a constellation of symptoms exhibited by some patients after they are discharged from the ICU.

The symptoms may be divided into three main categories:

1. Cognitive symptoms include memory, problem-solving, and concentrating challenges, as well as difficulty communicating.
2. Emotional symptoms include depression, anxiety, and post-traumatic stress disorder.
3. Physical symptoms include fatigue, pain, weakness, insomnia, and shortness of breath.

Ongoing challenges from PICS can persist for several months or years after discharge from the ICU and are often severe enough, independent of the patient's recovery from the initial injury, to reduce a patient's quality of life, their independence and ability to function in work or social situations.

PICS is a relatively new diagnosis and is thought to be the result of a combination of factors including the use of invasive, life sustaining interventions, extensive use of medications to manage pain, agitation and delirium, and complications associated with critical illness (including sepsis for example).

Every decision in the ICU balances the risks and benefits of medical interventions with potential short and long-term adverse consequences.

It is estimated that more than half of those who survive the ICU will experience at least one of the major symptoms of PICS.

The impact of PICS may be reduced or prevented by working with the medical team in the ICU to optimize the amount of medications required to manage pain, agitation and delirium.

Do everything possible to actively ensure that your loved one is conscious and as oriented and involved in the rehabilitation process as possible.

Help your loved one to maintain their connection to the life they had before they were hospitalized including friends, pets, pictures, music, clothing, and hobbies.

Initiate physical therapy as soon as possible. Maximize movement, including being upright, sitting on the bed, and walking. While it may seem like a small thing, being upright and physically engaged is linked with a remarkable improvement in long-term outcomes.

Simple "range of motion" exercises are a good first step.

There are no perfect solutions – medicine is both art and science.

There is an increasing recognition that family members sometimes experience PICS symptoms including anxiety, depression, post-traumatic stress disorder, sleep difficulties and unresolved grief. Recognizing and supporting families with these issues may help to improve overall patient outcomes and mitigate the longer-term impact of critical illness.

*With your every action
Choose
Not to add any more pain
to this world.*

*Increasing another's suffering
will not lessen your own.*

21. Family and Emotional Support

Family Matters

Periods of great stress and uncertainty can bind people together...or tear them apart.

Strained family relationships will not magically correct themselves during times of crisis. Often, the opposite is true – the added pressure may make an already tense situation more volatile.

However, in this time of crisis, it is more important than ever to come together to support the person who is injured and each other.

Maintaining strong relationships is critical for the long-term survival of your family as well as ensuring the best possible outcome for your loved one.

Make the decision that this experience will strengthen the foundation of your close relationships. Begin today to deepen your intimacy and draw closer together.

Sometimes we feel so vulnerable and raw, we turn away from those who can support us best. Do not allow the fear of loss and pain to isolate you from those you love and those who want to support you.

Remember to say “I love you”; hug, touch, laugh, compliment, soothe, nurture and make time for each other every day.

Learning Moments

This is going to be a difficult time. It is also an opportunity to teach.

What would you like your child or teen to take away from this experience?

They can learn that they are a vital part of a family that comes together to love and support each other, especially during times of crisis.

They can learn about emotions and how people are able to be both tender and strong.

They can learn they can be capable, competent, and compassionate—and frightened at the same time.

Commit to helping them grasp the valuable lessons this experience has to offer.

Children

Learning that a sibling, friend, or parent has been brain injured will be a defining moment for many children.

They remember where they were, what they were doing, who was there, what was said, what the weather was like...and that life after that was never the same.

Children are often the forgotten victims during this type of trauma.

Sometimes adults do not know what to say; so they say nothing at all.

Children lack the life experience to comprehend what is happening and the skills to integrate the complexities of the situation.

Ensure each child receives some undivided attention from a calm, centered adult who they know and trust. Encourage special relationships with a favourite uncle, aunt or friend. Spending time in a soothing, non-judgmental, and safe environment will help to create an atmosphere where a child can open up, share their thoughts and feelings, and begin to start healing the trauma. Initiate this process as soon as possible.

Treat each child as an individual.

Encourage them to ask questions.

Be sensitive to their unique needs and reactions. Allow them to have their opinions and viewpoints.

Listen to what they say without reproach. Children sometimes offer incredibly accurate insights.

It is okay to say that you, as an adult, do not have all the answers.

At the same time, reassure the children that they will be taken care of and that you love them.

Children often focus on physical concerns.

Maintain a concrete routine as much as possible. Ensure children know who will take care of them, where they will eat and sleep, how they will get to school, and how they will get back home. Pets are often a source of comfort.

Children often have difficulty articulating their fears – listening to their concerns often illuminates their thought process. Ask a question and suggest that they draw a picture, paint or even play-act in response.

Help them to express themselves in any way they can.

Listen with your eyes, ears, and heart for verbal and nonverbal clues about how they are coping.

Choose your moments...

We all process information better when we are well rested, fed and in familiar surroundings.

Use simple, concrete terms to explain what has happened.

It is okay for children to see you cry. Remind them that it is okay for them to cry too. Sometimes roles get reversed, and children try to “be strong” and comfort their parents.

Ask if they would like to see the injured person and listen to their response. Do not pressure them to visit or to be more involved than they feel comfortable with. If they choose to visit, give them a brief explanation about what the person will look like and what the machines are for.

Do not say the person in coma is “sleeping”. Children sometimes become frightened to fall asleep in case they, too, do not wake up.

Introduce them to the doctors, nurses and other healthcare professionals. Give them age-appropriate tasks like choosing their favorite photos for an album or drawing a picture. Allow them to be active participants on the team.

Do not expect children to be responsible beyond their years.

Inform the school what has happened; a supportive teacher and friends can make all the difference. A school counsellor may be able to provide additional resources and encouragement.

Concerts, school plays and sports events should remain as significant as ever. It is important to continue to celebrate the achievements of all of your children, encouraging each to shine and have fun in spite of this crisis.

Maintaining these commitments helps to preserve the foundation and stability of your family and acts as a pathway to the future as you create a different but fulfilling life post injury.

Make dates with your children so you can spend at least a little time alone together.

Cuddle lots, cuddle often.

Children sometimes believe that when something bad happens, it is the result of something they did, or didn't do, said or even thought.

Relieve them of the unearned guilt.

Reassure them that the accident was not their fault.

Keep them updated. Be as honest as possible – what you don't explain, they will make up.

Their imagination is often worse than the reality.

Inquire if Child Life Services are available. These professionals work with children and teens to help them effectively cope with trauma and related stressors. They provide age-appropriate information and help to prepare each child for what they may see and experience in the ICU and beyond. These specialists collaborate with other members of the health care team to provide resources, support, and guidance to parents and other family members.

If a formal Child Life Services program is not available, work in conjunction with the intensivist, the nurse, or the social worker to ensure that the children and teens receive the specific support they require.

As time passes, support groups for siblings or children of people with brain injury may be helpful.

Cries for Help

Be aware of any change in a child's typical pattern.

Signs that a child may not be working through or coping with their emotions include:

- Hyperactivity
- Withdrawing from family, friends or activities
- Aggressive behavior with friends, family or pets
- Becoming unusually sensitive
- Nightmares
- Outbursts of anger or temper tantrums
- Phobias
- Prolonged crying episodes or alternatively, not expressing any emotions
- Eating or sleeping disturbances
- Bed-wetting
- Clinging to family members and friends
- Being too perfect

Teens

Teens (and young adults) are one of the groups most commonly impacted by brain injury – and the least prepared to deal with it.

Young people are especially vulnerable at this stage in their lives, as they are becoming more independent from their families and are beginning to form supportive and intimate relationships with their friends.

This may be their first exposure to trauma. Some will have never faced the possibility of death or the loss of someone they care deeply about. Many will have never seen the inside of an ICU.

This may be their first insight into the fact that they may not be invincible or immortal.

It is a difficult lesson.

If your teen is catapulted into this experience, be especially sensitive to their needs.

Remember how challenging these years can be.

Acknowledge their conflicting feelings. They may be frightened of saying or doing the wrong thing, of being too emotional, of being an adult, of their own mortality.

Survivor's guilt is common.

“Part of me is grateful that his life until now has allowed for his innocence,
but it leaves him so unprepared for the devastation of today.

He is no longer a child, not quite a man...

He stands before me acting the way he believes he should – silent and strong.

He is tortured inside, wanting to see his childhood friend...

They grew up together, as close as brothers...

But even more, he wants to run, to escape the pain, the fear, the panic.

He remains motionless, paralyzed, transfixed by the conflict within...

until I take his hand in mine and together we ease our way closer to the bedside...

Stopping frequently for breaks as he squeezes my hand ever more tightly...breaking my heart more than hurting my hand.

No need to do this today...I reassure.

*But he remains insistent as inch by inch
he bravely strides into adulthood.”*

*If your teenager is injured,
it is extremely important to nurture and support their teenage friends.*

Ensure each one feels welcome.

Invite them, as a group and individually, to visit as often as they like. Support often comes from unexpected places.

Explain to them what to expect so they are not surprised or overwhelmed. This will help to increase the chances of a return visit.

Maintaining and strengthening these friendships will be critical to achieving the best possible long-term recovery. A sad statistic is that survivors of brain injury lose 90% of their existing friends within two years of the injury. The relationships that remain are often radically altered.

Teens often travel in pairs or small groups. Gaining insight into the group dynamics may assist you with preserving or strengthening existing relationships.

Ask for and respect their opinions. Listen to what they say. Accept that their viewpoint may be different from yours.

Teens have sometimes been known not to tell their parents everything.

Keep them informed with appropriate detail. Express your appreciation for their support.

Remember that this is likely their first experience with such a life-altering event –

It will be a defining moment for many.

Regardless of the outcome, the lives of every young person who was part of the circle is now forever changed.

Give them permission to continue to pursue their dreams. Do not underestimate the importance of your encouragement.

Minimizing the trauma of the group serves everyone.

As an interim measure after a brain injury in the family, teenagers may help out by caring for younger siblings or being responsible for meal preparation.

Do not allow this to become a pattern so as to catapult them into early adulthood. Let them live their teenage years as teenagers.

Balance additional responsibilities with additional privileges.

Many of the “Cries for Help” previously listed for children are also relevant for teens.

Additional signs that teens are struggling to cope include:

- Slipping grades
- Ignoring rules
- Curfew infractions
- Experimenting with smoking, alcohol, drugs or sex

Some teens react by doing their best to be perfect on the outside while screaming on the inside.

Listen carefully for what they are not telling you.

Grandparents

Grandparents or older relatives often require more practical or physical types of support. They may need rides or additional help to find their way to the hospital.

Often, because they have been through crisis before, they have a better understanding about what to expect. This may provide them with a level of insight, or it could make the process more frightening and difficult.

Because the person injured is likely much younger than they are, it can increase their sense of the unfairness of the situation and complicate their emotional response.

*"I watched helplessly as she pressed her wet cheeks
into her grandson's comatose body.*

She continues to sob. She would not be consoled.

"It should be me. He is too young. It should be me..."

She repeated those words over and over...

She has experienced pain and loss.

She knows the difficulties that lay ahead."

"I am not sure which is more difficult to watch; the devastation of knowing what is to come or the terror and disillusionment of not knowing."

Older relatives have been through loss before, they know what to expect, they can grasp the consequences.

*They understand they will continue to exist
independent of this utter devastation.*

But the absolute shattering of innocence in their younger siblings and friends is unbearable.

They cannot take it all in. They are lost. They have no truth, no prior experience

to help them comprehend that whatever happens, it will be okay again.

Whatever that may mean...

Brain injury impacts the very essence of who you are.

*It affects the way you think,
feel, react, and experience the world.*

It shapes every relationship and every interaction.

It leaves nothing untouched.

22. Feeling it Through....

When someone you love is brain injured, you are bombarded with many complicated and contradictory emotions.

Many people are surprised by the intensity, unpredictability and complexity of their reactions.

Your emotions may change moment to moment.

You are required to function on multiple levels, managing diverse demands while integrating the physical, emotional, mental, and spiritual areas of your life.

It is exhausting.

Initially, many people, consciously or unconsciously, put their emotions “on hold”. It is often easier, and effective in the short term, to be “too busy” to feel rather than experience our emotions and face our fears.

Shock and disbelief allow us to physically and intellectually function while keeping our emotions at bay.

Many explain that they feel like they exist within a protective numbness or dreamlike state that enables them to maintain a delicate balance between doing what needs to be done and preserving their sanity.

“Just two weeks ago, I could not have imagined where my life (all of our lives) is today.

And yet, at this moment, all I feel is calm, an eerie calm, born of being so overwhelmed, so often, that I had to take a step back, a step away from myself in order to continue to function...

*It is not a comfortable feeling,
knowing how detached I am and how far there is to go and
that we can never go back again...”*

However, if your loved one becomes more medically stable, do not be surprised if a flood of your suppressed emotions begin to find their way to the surface.

You will pass through multiple layers of insights and reactions as you begin to comprehend how these events will impact your life and shape your future.

There are many questions and few answers.

Much remains unknown about the brain and brain injury.

No one knows what the future holds...

This uncertainty complicates the healing process.

*Time will help you integrate this experience into your world,
into who you have become.*

Be patient with the process.

23. Grief After a Traumatic Brain Injury

Each person will experience their own unique path through grief.

Often, after someone you love sustains a traumatic brain injury, the initial reaction is being in a state of shock, followed by denial, sadness, anger and eventually reengaging into your new reality.

This is not a simple sequential path. Do not be surprised if you move back and forth between phases or if one person is numb with shock while another is feeling the full intensity of grief or anger.

One person may feel the need to talk over every detail or find themselves constantly teary, while the other may deny a problem exists at all.

Grieving differently or being in different phases of the grief process can put an enormous amount of stress on any relationship.

Do your best to allow others to recharge or grieve in whatever way they need to.

Sometimes, solitude is a gift.

Agree that only one of you can be unreasonable at a time...and that everyone gets a turn.

Promise yourself you will take a deep breath...and then another rather than lashing out.

Apologize if you slip.

There is often much kindness in silence.

People make mistakes. Issues must be discussed, but a cooling off period may be required.

Words, once spoken, cannot be taken back.

Be gentle with each other.

Brain injury impacts an entire family.

Grief is experienced individually.

24. What Happened at the Scene of the Accident?

After a serious accident, there is a “golden hour” when medical interventions will yield the most positive outcomes.

Every effort is made to ensure a patient arrives at a trauma unit as soon as possible.

At the scene of the accident, the emergency medical team begins to stabilize the patient so they can safely be transported to the intensive care unit.

If the accident occurred outside of town or is exceptionally serious, a helicopter may be called if one is available and if it will decrease transportation time.

Before transportation to the hospital:

- The neck and spine are immobilized to ensure no additional damage occurs to the spinal cord. It is standard procedure to put the patient in a neck brace and on a spinal board.
- It may be necessary to establish an airway and to ventilate the patient to ensure the brain is receiving an adequate supply of oxygen.
- An IV may be inserted to give fluids and administer medications.
- After a brain injury, seizures are common and may further compromise the condition of the patient. Sedating medications may be given at the scene to stop these seizures.
- A basic neurological assessment will be done on scene using the Glasgow Coma Scale (GCS). Refer to page **Error! Bookmark not defined.** for a description of the GCS.
- The patient will then be transported to an emergency room.

Details you may want to record in your journal include:

- The names of police officers, witnesses, and emergency medical personnel on scene.
- Insurance information from those involved (depending on the situation and where you live, an insurance adjuster may contact you).

Do not sign any financial or legal papers without talking to a lawyer who is representing the patient or you.

You may feel a need to revisit the scene of the crash.

I did.

It was the first time we had ventured away from the hospital for any length of time since the day of the accident. We needed to gather his things, the clothes they cut off him, his wallet, what was left of his motorcycle...

Yet we all seemed drawn to the scene of the crash.

We needed to see the spot; to try and comprehend how such a tragedy could have occurred.

It was almost as if, on some level, we believed if we could understand what happened, we could reclaim his lost life...that somehow, these insights would

give us the power to capture and alter that one moment in time that changed our world forever.

I am not sure it helped.

I am really glad we went.

You will make many such private excursions along the road to recovery.

It takes a long, long time.

Do whatever it takes to find the peace and serenity you are searching for.

25. Possible Effects of a Brain Injury on Survivors

The following is not intended to provide an exhaustive explanation of brain injury and its impact.

Sadly, if your loved one survives their hospital stay,

you will have a lifetime to learn about brain injury.

This is a brief overview so you will have some idea what to expect.

Brain injury is complex, difficult to define and on some days almost impossible to comprehend.

Every brain injury is unique.

No two people respond in exactly the same way.

Some symptoms are obvious – easy to measure and quantify.

Others are subtle and much more difficult to grasp.

These are often the most devastating.

Simply identifying the functional areas of impact does not allow someone to comprehend the true implications of a brain injury.

It is, however, a place to start.

*Recovery is more about loving what remains
than regaining what is lost.*

Brain injury can impact a patient's:

1. Cognition and Executive Function
2. Emotional and Social Behavior
3. Communication Abilities
4. Physical Abilities

1. Cognition and Executive Function

Cognition refers to our thinking process – our ability to pull together and make sense of our surroundings.

Every moment of every day our brains are collecting, processing, and integrating information. Some processes are almost unconscious, like filtering out unimportant “white” noise (like a ticking clock). Some processes are more complicated, like reading, calculating math, or taking care of daily activities (personal hygiene, cooking, cleaning, shopping).

Some activities are even more complex like abstract reasoning, creative pursuits and philosophical concepts.

The **Executive Function** of the brain helps us “pull together” and makes sense of the data collected by our senses and the results of our cognitive, social, and emotional analysis. The executive function helps to identify and utilize intact skills after a brain injury. It also allows us to monitor and regulate our own behavior.

Deficits in executive function magnify all other losses.

The area of the brain responsible for executive function is located behind the forehead in the frontal lobes. The frontal lobes are particularly vulnerable to injury due to their proximity to protruding bones on the inside of the skull in this area.

Executive function allows us to:

- Initiate, plan, and follow through
- Be self-aware and insightful
- Regulate impulses and self-correct
- Be empathetic and considerate

People with brain injury may have challenges with:

- Short and long term memory
- Awareness about date, time, location, names, and relationships
- Problem solving
- Organizing and integrating thoughts
- Attention span – being easily distracted
- Perseveration – becoming “stuck” on one concept and being unable to extinguish the thought process
- Confabulation – making up details to fill in holes or gaps in their memory – this is different than lying, as there is no intention to deceive
- Responding to questions or requests in a timely manner
- Sequencing tasks

2. Emotional and Social Function

Emotional and social skills impact how we express our feelings and interact with other people. These skills impact every relationship we have – including the one with ourselves. Difficulties in this area are generally the most challenging for family and friends to comprehend and are may prevent those who have sustained a brain injury from utilizing their intact skills and achieving full community integration.

Cognitive processes generally have a “right” or “wrong” answer, making it easier to structure support around deficits in this area. In contrast, emotional and social exchanges are based on identifying and integrating hundreds of seemingly cryptic pieces of information. Almost automatically, we are able to simultaneously think and feel through a concept, compare it to our memories of past experiences, weigh potential alternatives, consider how our actions will impact the situation and then make a reasonable decision.

This is an overwhelming task for someone with a brain injury. The challenge is compounded given their struggle with memory.

Emotional and social difficulties include being:

- Irritable and argumentative
- Quick tempered, volatile, and impulsive
- Inappropriate or immature
- Emotional labile – survivors may laugh or cry or anger easily. Their emotional reactions generally are not reflective of, or proportional to, what they are actually feeling. They are prone to “flip flop” emotions quickly and often without warning.
- Egocentric – not to be confused with being selfish – there is a childlike absence of insight into how their behavior impacts others

Survivors of brain injury may have:

- Limited affect – flat or no emotional response
- Lack of inhibition – sexually inappropriate comments or behavior
- Rigid and repetitive personality
- Inability to understand and interpret even basic body language and other non-verbal cues
- Lack of empathy
- Tendency towards suspicious and/or paranoid behavior

Suspicion is often the result of memory loss and the increased anxiety a survivor feels. It is not uncommon for survivors to accuse loved one's of stealing from them or of infidelity.

3. Communication

Communication is our ability to express ourselves to those around us and includes verbal and non-verbal forms.

Communication difficulties may include challenges with:

- Organizing words and ideas into sentences
- Understanding basic sentence structure – substituting verbs in place of nouns, etc.
- Retrieving words and names – often substituting incorrect ones
- Following and comprehending conversations
- Reading and writing
- Expression of needs, wants and feelings

4. Physical

The initial focus after a brain injury is often on the physical. However, the impact of physical challenges on the survivor, and their family, usually pale in comparison to the “invisible” symptoms of brain injury. It is common for survivors to focus on concrete physical issues.

Physical challenges can include:

- Headaches
- Hemiparesis – weakness or complete paralysis (hemiplegia) on one half of the body
- Spasticity – extremely tightening of muscles, which can lead to overactive reflexes and muscle tremors. Spasticity sometimes causes fingers to clench into a tight fist
- Seizures
- Reduced range of motion
- Body neglect – lack of awareness about where a body part is in space or even that the body part belongs to them

- Fatigue and reduced endurance
- Balance difficulties
- Difficulty swallowing or excessive drooling
- Lack of coordination and dizziness
- Disruption of circadian clock – days and nights may be switched
- Insomnia
- Incontinence – loss of bowel and bladder control

Brain injury can impact all five senses:

Vision

- Blurred or double vision
- Perceptual difficulties
- Gaps in seeing complete visual field (the right or left side of space)

Hearing

- Reduced hearing
- Ringing in ears
- Increased sensitivity to noise

Smell

- Inability to smell
- Being overly sensitivity to certain odors – sense of smell impacts taste as well

Taste

- Food has no taste or tastes strange – this can be very dangerous as a survivor may eat spoiled food or sour milk without knowing it
- Change in preferences for certain foods

Touch

- Numbness – may increase anxiety as the survivor may not realize they are being touched
- Heightened sensitivity to touch – a gentle brush may feel like a scrape
- Inability to sense or regulate body temperature – survivors can burn themselves or get frostbite without being aware
- Unaware when they are hungry or full

By asking questions about the function of the parts of the brain that are injured, you may gain some insight into what the long term challenges may be.

For additional detail refer to Medical and Technical Information about the Brain starting on page 76.

Brain injury will challenge

Your truths,

Your faith,

Your endurance.

Do not allow it to consume your world.

26. What Comes Next?

Should your loved one continue to evolve through their injury, I want to gently prepare you for the next stage of reconnecting after a brain injury.

It will stretch you still further beyond your physical and emotional limits.

While it may not be helpful to explain the challenges of the next stage in detail, I feel it is important for you to have some idea about what may lay ahead and to give you a few suggestions to help you through.

Preserve your strength.

During the initial stages after the injury, you rejoiced at any reaction your loved one made.

This may not be true during this next phase of recovery.

You may wonder what has happened to the person you love when a stranger, who in many ways bears little resemblance to the person you once knew, begins to “emerge” from their altered state of consciousness.

They may not recognize you.

They may experience periods of hallucinations and delirium. They may alternate between being terrified of you and then, moments later protecting you from a danger only they can see.

They may swear and kick and yell and spit.

They may be tied to the bed for their own protection (to ensure they do not further injure themselves by falling out of bed or by tearing out their tubes).

This will be a terrifying time – for them and for you.

I tell you this not to frighten you, but so you will pace yourself and not be surprised by this anticipated and very taxing part of the recovery process.

Just do the best you can.

Reassure and re-orientate your loved one...over and over again.

Remind them where they are and what has happened to them.

If they are restrained, continually tell them that they have done nothing wrong and are tied for their own protection.

*Do everything within your power to safely
minimize the use of restraints.*

People with brain injury often have very limited short-term memory and, if they can talk, ask the same questions over and over.

Every survivor is different.

Often you must try several different things to calm them.

Something that worked in the morning may no longer work by that afternoon or the next day.

Work with the staff to find a balance between freedom and safety.

Family members of other patients often become a great source of support.

"Seeing him is excruciating.

Not seeing him is worse."

Suggestions include:

Decorate their room with posters, cards, favorite photographs and other familiar items. A hospital room can be much more welcoming with a little effort and imagination. Increasing your loved one's sense of safety and control helps to create a more calming environment.

Bring in clothing from home. This helps the survivor to re-establish their identity and reminds them of their once familiar world outside of hospital. It also allows the staff to relate to their patient in a different light.

Put up a large calendar in the room to help orientate the survivor to time and place. Mark off the days together.

Encourage visitors to write a message in a Guest Book. Sometimes the patient won't remember who stopped by to visit.

It is fun and reassuring to sit together and read the entries in the book.

Video conference with those who live far away or are unable to visit. Protect your loved one's privacy – snapshots in time and stories can spread very quickly in the electronic world (and remain accessible for a very long time).

Simple games like X's and O's or board games can be fun and help pass the time. This also supports rehabilitation.

Read them the newspaper, the sports section, light books or e-mail and texts from friends. Keep them up to date with the local stories.

Play their favorite music.

Pain may increase agitation. It is common for people awaking from altered consciousness to have intense headaches but be unable to communicate their pain. If this is the case, often basic pain medication will soothe the agitation. Maintaining a baseline of analgesic may be important, with increased dosages prior to potentially painful interventions or even day-to-day activities, including eating or going for a walk.

Some survivors go through periods when they are extremely sensitive to touch and light and noise. Be aware of their non-verbal responses.

Allow for as much privacy and autonomy as possible.

We all need some space of our own.

Recovery is an Art as much as it is a Science.

You must continually balance

Hope with Acceptance,

Doing with Being,

Preserving with Surrendering.

Take control of the things you can – exercise, eat a balanced diet, rest, manage the daily errands that build up.

Do not expend your energy trying to change the unchangeable.

Pay attention to how you feel.

When the tension starts building, take some time to decompress.

Breaks are not just okay; they preserve you.

Learn techniques to calm yourself - meditation, breathing, going for walks, yoga, biofeedback, going for a work out, taking a nap....

You must make time for yourself or you will burn out.

Have dinner or coffee with someone who can support and nurture you.

*Caring for a brain-injured loved one is a life-long marathon...
not a sprint.*

Start today to bring balance to your life.

*A strong, healthy, balanced YOU is what is best
for your loved one, your family and yourself.*

Strive for at least one moment of peace and comfort each day.

Take time to experience:

- A sunrise
- Lunch with a friend
- Fresh flowers
- Good coffee
- Cozy fireplaces
- Bubble baths
- A massage
- Candles
- Good books
- Naps
- Solitude
- Music
- Walks
- Bike rides

Do not underestimate the importance of remembering that beauty continues to exist.

Do not become discouraged if you have trouble during this initial stage of the trauma.

*Most people with severe brain injury will
require additional support for the remainder of their life.*

There will be many opportunities for you to support those you love in the future

Do your best. Contribute by doing whatever feels right for you.

Brain injury is now part of your life...not for a week, a month, a year or even a decade.

Brain injury is forever.

You have begun one of the most difficult challenges that any family can face.

Take one moment at a time.

Soon you will learn more than you thought possible about doctors and trauma, technology and terminology, comas and brains.

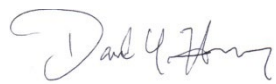
You will also learn more than you can imagine about heroes and hope, commitment and compassion, strength and love.

Our deepest hope is that this book will empower you, encourage you, inspire you and ultimately, bring you to a place of peace.

While this is now your path...

You need not walk alone.

You will find your way.

A handwritten signature in cursive script, reading "David Y. Henry".A handwritten signature in cursive script, reading "Dayla Maioy".

A lighthouse

*Beaconing in the distance
Powerless to calm the seas*

*Strong
Silent
Serene*

A sign from those who have gone before

And made it through

You will too...

For additional information and support, or to inquire about a local brain injury association, please contact:

Neurocritical Care Society
<http://www.neurocriticalcare.org/>

Brain Injury Association of America
<http://www.biausa.org/>

Traumatic Brain Injury Survival Guide
<http://tbiguide.com/>

About the Authors

David Y. Hwang, MD, FAAN, FCCM, FNCS

David Y. Hwang is currently an Associate Professor in the Division of Neurocritical Care and Emergency Neurology at the Yale School of Medicine and a neurointensivist at Yale-New Haven Hospital. Beginning in September 2022, he will be the Division Chief of Neurocritical Care at the University of North Carolina School of Medicine.

A native of Memphis, Tennessee, he earned his BS in Chemistry at Emory University and his MD at Harvard Medical School. He completed his residency in neurology at the Brigham and Women's Hospital and Massachusetts General Hospital, serving as chief resident in his final year. He then completed a fellowship in neurocritical care at the same institutions before joining the Yale faculty in 2012.

David's academic and professional interests include outcome prognostication for severe acute brain injury patients and family support in ICUs. He is a past recipient of the American Brain Foundation Practice Research Training Fellowship, the Neurocritical Care Society (NCS) Research Training Fellowship, the Robert G. Siekert New Investigator Award at the International Stroke Conference, the First-Place Patient and Family Support Abstract Award at the Society of Critical Care Medicine (SCCM) Critical Care Congress, and an Outstanding Oral Presentation Award at the NCS Research Conference. He is a recent Chair of the American Academy of Neurology Critical Care and Emergency Neurology Section, a current member of the NCS Board of Directors, and a recent Chair of the SCCM Patient and Family Support Committee.

Dayla Maisey, BSc., BComm

Dayla's own journey inspired this book. She was moved to write after her younger brother was critically brain-injured in a motorcycle accident. As the narrator of the book, she integrates the technical, the practical, the emotional and the spiritual to help you navigate your way through the intensely stressful, fast-paced, high tech environment of the ICU and beyond.

Dayla presents nationally and internationally at conferences, hospitals and retreats to a variety of audiences including physicians, nurses, lawyers, social workers, family members and those with brain injury. She has worked with various levels of government as an advocate for those with brain injury, their families and their friends. She has contributed to numerous councils, boards and committees and presented at the *"Visionary Leadership that Makes a Difference at the United Nations"* conference in New York City.

Her formal education includes a Bachelor of Science and Bachelor of Commerce. Dayla was also awarded an Honorary Master's Degree (Intensivist) from Sociedade Brasileira de Terapia Intensiva (SOBRATI – the Brazilian Society of Critical Care) based on her work on behalf of families and humanization of the intensive care unit.

Authors' Acknowledgements

This book would not have been possible without the support and inspiration of so many people.

Thank you to the Society of Critical Care Medicine and to the Neurocritical Care Society for providing platforms for us to learn about each other's work and for this opportunity to work together.

This book is the product of interviews with hundreds of people living with brain injury, their families and their friends as well as experts in the field including: Ellen Boelcke, M.Ed., Eileen Bona, M.Ed., Diane Duff, PhD., Heather Macdonald, RN, BScN, CCN(C), and Janet Nastiuk, BN.

We would especially like to express our gratitude to those who shared their stories with us. Your inspiration is priceless.

Thank you all...especially

Mary, Dean, Neil, Rick, Ron, Ruth-Anne, Laura, Ines, Dale, Sheldon, Robert, Jennifer, Diane, Linda, Kari, Lisa, Stace....and Kenny.

Testimonials from Family Members, Survivors and Medical Professionals

The following are excerpts from unsolicited cards, letters and e-mails 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 any one 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 a devastating 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, Yale-New Haven Hospital
PhD, RN, CNRN, SCRn, CCNS, ACNS-BC, FNCs

"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

“...the 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

“...before I read your book, I knew 10% of what happened to me (in the ICU). After I read your book, I understood 50% of what happened to me. Then I talked with my family, and they said 90% of this happened to me in the ICU. It was a painful process, but you gave me back a piece of my life. Thank you.”

Dale, Survivor and engineer

“Your book has been a tremendous source of comfort. Your courage and insights are truly admirable.”

Adria, 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

Updates in Revised Version

To further the Neurocritical Care Society's formal vision and foundational principles which include:

- providing and advocating for the highest quality care for critical neurologic illnesses
- obtaining uncoerced, informed consent of the patient or appropriate surrogate decision maker to support the right of self-determination in health care (autonomy)
- respecting the patient – centered values and patient and family driven care

Key revisions in the spring 2022 edition include:

- Introduction of the basic concepts identified in the ABCDEF Bundle including assessing and managing pain prior to sedation, optimum utilization of pharmaceuticals, minimizing delirium and early mobilization.
- Revising the Glasgow Coma Scale to reflect reporting each component individually
- Addition of a summary of the Full Outline of UnResponsiveness (FOUR) Score neurological assessment
- Increased focus on the Shared Decision Making process and the vital role of empowered and knowledgeable Surrogate Decision Makers.
 - Special care was taken to help surrogates prepare for their new role and help them to understand that their key contribution was to help the medical team understand what treatments and level of interventions their loved one would choose if they could speak on their own behalf. This is an important distinction that provides perspective and helps to alleviate the stress of contributing to treatment choices.
- Additional detail was added regarding the importance of a realistic prognosis and honestly communicating a range of potential functional outcomes and likely quality of life issues that the patient and the family could likely face if the patient survives their injury.
 - Topics included potential longer-term living arrangements and formal and informal support requirements.
- Additional discussion around transitioning to care and comfort as well as family presence during resuscitation attempts.
- Added discussion regarding potential complications including sepsis, Acute Respiratory Distress Syndrome (ARDS) and Post-Intensive Care Syndrome (PICS)

Contact the Authors

May the light of our experience help you to find your way...

To share your comments or suggestions regarding this book, please contact:

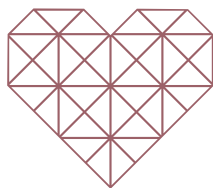
education@neurocriticalcare.org

Correspondence will be forwarded to the authors for a personal response.

A GUIDE TO TRAUMATIC BRAIN INJURY

*Information and solace
for patients, families & friends*

It may begin with a telephone call, a text or a knock on your door — however it begins, nothing will ever be the same again. You and your family have been catapulted into the unfamiliar world of Traumatic Brain Injury.



ISBN: 978-0-9909917-9-3