

THE FIGHT FOR SURVIVAL



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My book of poems celebrates the miraculous and extraordinary journey I experienced when my husband Tony acquired life changing brain injury in 2011 resulting in a 5 month hospital stay and a challenging time in intensive care.

In my previous life I worked for 30 years full time until undergoing extensive major surgery myself in 2009. I am now Tony's Full Time Carer and the Secretary of ICUsteps Tees where I have the unique opportunity to support others who have experienced critical illness.

The lasting impressions of Intensive care inspired me to express my thoughts and experiences through poetry which I hope will offer comfort to families on the critical care journey. I have recited my poetry at conferences and workshops and will continue to do so in order to raise awareness of the patient carer voice.

“The excellent medical care and intervention we received and continue to receive is our reason for being alive”

*This booklet has been produced by North of England Critical Care Network
on behalf of Diane Bousfield.*

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Ode “Facing the Storm”

Without warning there was a furious storm
All consuming into which you are drawn
You feel as though you're starting to drown
Situation out of control pulling you down
Your life takes on a different dimension
When your loved one's life is in suspension
Here's a selection of poems to share
For all who've experienced ICU care

Ode "Two Worlds Rolled into One"

Dedicated to the James Cook University Hospital medical team who gave Tony the opportunity to "Fight for his Survival"

Two worlds running side by side
Reality and Normality nowhere to hide
What started out as a normal day?
Has changed our lives in every way
Two parallel universes exist
Extreme differences continue to persist

We'd just returned from Tony's pre op
In a couple of days his surgical slot
Tony feels his head is going to explode
I need to react in emergency mode
Try not to panic and stay calm
Dial 999 and raise the alarm

Paramedics arrive in next to no time
Immediate medical attention a positive sign
Admission to hospital the contrast begins
The bells of change start to ring
Outside it's a cold frosty night
Inside the smell of disinfectant and fright
The stars are shining brightly down
Tony's moving hospital to a different town

The house feels empty it missing his soul
How I long again to feel complete and whole
Back in HDU Tony's started to lash out
He's trying to knock the neuro-surgical team out
I receive the dreaded phone call is your husband a violent
man
If not you need to be at the hospital as fast as you can

Lane closures make the journey slow
Above silhouettes of birds display an Ariel show
The department of Transport are over keen
There's bollards everywhere to be seen
Will I manage to arrive in time
And escape from this never ending line

A photo at the base of neuro stairs
Looks surprising like the neighbour caught unaware
There's only one person in HDU
Fighting with life and the neuro team too
A battle of wills in HDU
I watch the curtain move without a clue
Of what I will see on the other side
As Tony's health continues to slide

The image of James Cook is printed on the curtain
I'm sure Tony's behind there can't tell for certain
I need to see Tony before they operate
Braced for anything whatever the state
I need to reassure and give peace of mind
Tell him I'll be waiting when he wakes on the other side

His eyes are raised gasping for breath
Confused and desperate he's still has strength
I ask him to let the medics operate
There's a mass in the brain they need to evacuate

The pastel colours on the curtains relieve tired eyes a treat
I'm beginning to count how many times the landmarks
repeat

I enter the office to sign the forms
And have time to make those important calls
The large tumour located in his brain
They suspect a cyst waiting to be tamed
Tony's off to the operating theatre his life in their hands
Mum and I are eating chocolates we're in a different land

I pace the corridors know all the pictures off by heart
Committing the hospital layout to memory each and every
part

The fabric of life is being torn apart
Tugging on the muscles of my heart
He's in the operating theatre my head is reeling
I'm struggling to decipher how I'm feeling

I visit the bathroom for a well-earned break
And pull the emergency cord by mistake
That certainly added to the confusion
And somewhat destroyed my composed illusion
I keep gelling my hands with liquid soap
Its antiseptic odour makes me want to choke

I'm informed the operation will take some time
I should take a few hours out from the surgical line

My body is unable to rest
Mind subjected to the ultimate test
Memories of my own surgery start to flood back
Empathy is a thing I do not lack
My Mum and I travel back for a change of scenery
It's a welcome relief to see some greenery
Traffic fly's past at an intense pace
People travelling to their destinations part of life's race

My inner strength keeps me going
From deep inside not waning ever growing
Later that evening the telephone rings
Tony's survived the surgery my heart starts to sing
His condition is critical he's in ICU
I need to drive through it's the only thing to do
My Dad escorts me on the night shift
Making a great effort our spirits to lift
With Dad as co-pilot we return to James Cook
Wearing his Russian fur hat it's a particular look

The lights of oncoming traffic flash by
Expectations are not running high
On our arrival we scrub our hands put on over shoes
Adorn plastic aprons to give the germs no clues
He's in with a chance machines are keeping him alive
Tony's still fighting for his life with tremendous drive

There he lays in an induced coma
In a world of his own he's currently a loner
Life's in the balance we'll just have to see
If he'll ever return to his life with me
Reality of what's happened starts to sink in
His fight for survival has started to begin

Ode "The Fight for Survival"

Dedicated to Professor Kane and all the Clinical Team involved in Tony's care at James Cook University Hospital

Thank you

Brain abscess evacuated Tony's in ICU
No knowledge of his situation he hasn't a clue
Thoughts of his survival race round my head
I don't want to leave the side of his bed
He's in a coma brain in emergency mode
A few neurons are active but only the bold
Radio silence prevails amongst the rest
Minimal stimuli the ultimate test

Will his brain be able to repair?
Are new cells forming connections really there?
The equivalent of a power cut has taken place
Not a hint of expression upon his face
He's lost control over body and life
In a form of suspension from the surgeon's knife
There is no logic to his situation
Not of our making or creation
Like everyone else in ICU care
We're all really wondering how we ended up there

I talk continually and hold his hand
He's in a coma a distance land
I'm hoping the memories are being taken in
There's not even a twist of my wedding ring
Recalling our lives together implanting the facts
Whilst machines constantly monitor his stats
Is my conversation getting through
What else can a loved one do?
But be there and support at this difficult time
And hope for a positive sign

The medical staff are caring and kind
Reassuringly giving me peace of mind
Other families loved ones are fighting for survival
Some in tears on their loved ones arrival
It's out of my hands I haven't a clue
Which strategies to apply or what to do
I need to stay strong so how does that work
It's a role where the darkness lurks

Blind and speechless unable to move
All these functions yet to improve
I feel in a vacuum a type of cocoon
Like I could be walking on the moon
Will he live or will he die
How did this happen and the big question WHY
Questions spinning around my head
While Tony lies in an ICU bed
He lives motionless in a peaceful state
His chest still moving my soul mate
In an induced coma to help heal his brain
Will he ever wake up again?

I drive to the hospital every day
My brain automatically navigates the way
A crash course in neuroscience will keep me going
My thirst for knowledge not ebbing but flowing
I'm living each day on remote control
Part of my life no longer feels whole
A different Tony will emerge if he survives
Which will I know drastically change our lives
I will be a carer for the rest of my days
Gaining knowledge and confidence along the way
Determined to strive as hard as can be
To ensure Tony has a quality of life with me

The room where he lays is white and bright
Not able to tell if its day or night
There's also a surreal feeling of calm
Coupled with fright panic and alarm
Confident the machines will prevent him from dying
No pain visible tears or crying
Life continues round me at its usual pace
While Tony life's suspended in space
Will his body ever heal?
Is this reality is it real

Then comes the breakthrough Tony awakes
Will he speak how long will it take
"Don't go iane" the most powerful words ever spoken
I felt overwhelmed his silence was broken
Fingers now working, food tubes fall from grace
As he pulls them continually out of place
Pulling of wires is a good sign
As long as someone stops him in time
Hoping he misses the staples in his head
His mind is wandering easily led

Every day I visit and wonder what awaits
As Tony reels through incredible states
Thrombocytopenia and deep vein thrombosis were diagnosed
He certainly was keeping us all on our toes
Deceased people appear hallucinations started
Family and friends long since departed
Each day I visit he has a different occupation
Incapable of anything in his current situation
From Bank manager, steelworker to driving a steam train
Pleasant confusion continues to reign

Not sure how much or if he can see
He's squeezing my hand he knows it's me
My inner strength starts to grow
His fight for survival begins to show
Normality's become a thing of the past
A different life has now been cast

There's pressure increasing hydrocephalus in the brain
We're off to the operating theatre again
Shunt in place we're back on course
Once again the medics have discovered the source
The abscess makes an appearance once more
Back to square one we know the score
Another craniotomy it's a continual battle
With drips and medication I'm sure he'll rattle
Operation over not like the first
The shock to the system had to be the worst
Abscess evacuated but at what cost
Have any other brain functions been lost

I'm meeting kindred spirits faces from the past
All in the same boat how long will it last
Each successful operation is a step forward to me
Feels less like I'm drowning in the sea
It's down to me to strive and be strong
Although I need to get some sleep before too long
Eating's automatic systematic and routine
Ham and Egg Panini echo from the James Cook canteen
I pass neighbours friends and dogs on my morning walks
I struggle to recall any of the talks
Exchanged as I prepare for the day
And the forthcoming challenges along the way

I'm starting to feel confident he will come home again
Although our lives will never be the same
Five months hospitalisation takes its toll
He's not seen much daylight just like a mole
Multiple operations kept the medics busy
Keeping up with it all makes you positively dizzy
His disabilities significant I was well prepared
Ready to tackle them head on no time to be scared
Visual cognitive and physical conditions will always remain
But I will support my husband just the same

On the long road of discovery
Acceptance is half the way to recovery
The images of events are imprinted in my brain
In a special way so if I ever feel the strain
I can look back to see just how far Tony has progressed
Even on the days when he is really stressed
Tony's brain injury will never pull us under
It's created a bond so strong let no man put asunder
Stories of survival need to be heard
In those immortal words "Welcome to our World"

Ode "The Collage of External Images"

Dedicated to Tony's imaginative Brain

Hallucinations where do you begin?
To describe a world created from within
As far as Tony's concerned it's definitely real
Seeing hearing tasting smelling and feel
They don't exist outside his mind
Visual stimuli of every kind

There's lights colours shapes and objects
Many form into more complex projects
Lifelike images people and scenes
Reality is intermingled with dreams
There's a woman in the corner with a flower pot on her head
"Oops I've just squashed Elizabeth in the bed"
Deceased relatives make an appearance once more
They're standing beside you next to the door

I'm part of an experiment did you know?
Its top secret keep your voice down low
There's a crowd of people in the room
It's getting congested I feel entombed
The logical brain that was previously there
Appears somewhat confused and needing repair
Could it be the brain abscesses, epilepsy or drugs?
Disorientation imbalances or bacterial bugs

The controls on the bed have turned into biscuits
And the oximeter is repeatedly pulled off his digits
Idle visual brain cells waiting for appropriate signs
Still relaying but no longer synchronised in line
Some of the medics are wearing costume hats
Then comes chains of binary stats

Malfunctioning occipital lobe floods of signals begin to trickle
Reduced electrical signals leave the brain with very little
But a great imagination which is running very wild
In its present condition he could compete with any child
Signals it can't receive it makes up any way
An enterprising way of spending the day
Filling the gaps giving relatives surprises
People shapes and objects in different disguises
It's all so convincing and logical to him
This collage of external images conjured up from deep within

Complex pathways have taken a vacation
From a relatives perspective a bizarre situation
He's convinced these images really are there
I'm the one losing the plot and possibly my hair
The hallucinations are real created in his mind
It's hard to communicate with images of this kind
They're false perceptions in absence of stimuli
But very real through the patients mind's eye
Central processing unit in overdrive creating elaborate illusions
For the unsuspecting relative there's no instant solution

Elizabeth's the topic of conversation once more
At the top of his list is my Mum's high score
She's got on her hot head she needs to cool down

Take her shopping trolley off to town
Tony's legs are causing problems will I take them off?
How do you answer that best just to cough?
He's been at work driving a steam train this morning
On the North Yorkshire Moors railway as the day was dawning
He's managed to convince the man in the next bay
Explaining the route of his journey everyday
He's persuaded a nurse he's working in a bank
Not quite sure for that who to thank
He's telling them all he manages a branch
Its tops yesterday riding horses on a ranch

Then there's the sensitive question of age
He could utter anything at this stage
I'm looking good for one hundred and two
As appear to be the rest of the crew
Tony's amazingly remembered his age
Everyone else is in the centurion stage
Not to mention the fact that he's now a chain smoker
Never lit up in his life he's more of a choker
Always more prone to a pint or three
Now seems to prefer a cup of tea
He also wants sugar with his cuppa
Along with curry for his supper
Quite an achievement with a Hickman line
Constant cravings help pass the time
You're in a hospital James Cook and its dark
Oh no he isn't he's at St James Park
Which for a lifelong Liverpool supporter is a change of course
Definitely now backing a different horse

A member of Tony's staff visits once or twice
And informs me he's been given excellent advice
My mind starts to boggle at what it could have been
His intended course of action remains to be seen
He wasn't quite sure what to do
What Tony advised I haven't a clue
He left delighted from the side of his bed
Leaving Tony to recover from surgical procedures to the head
The delusions were obviously not plain to see
Unless you spent time with Tony like me

From this barrage of hallucination and delusion you're left
confused
However sometimes I can't help being somewhat amused
It's reassuring to know that whatever lies ahead
Robert my Dad is always at the end of the bed

Nothing can prepare you for the hallucinogenic world
It's never expected and can make straight hair curled
As a relative bewilderment and amazement roll into one
And what a relief when the images have gone
Out of sight out of mind tomorrows another day
Tony's brain is incredible and that's how we'd like it to stay

Ode "Brink of Life in the ICU lobby"

*Dedicated to Professor Stephen Bonner and all the clinical team involved in Tony's care at James Cook University Hospital
Thank you*

The external manifestation of emotion is affect
Everyone's different with the mode we select
A variety of expressions fill the room
Grief, worry, fear, depression and gloom
Emotion wells up I want to cry
Will Tony my soul mate live or die?
A stream of adrenaline secretes through my body
As I wrestle with my mind-set in the ICU lobby
A conscious experience of intense mental feeling
Which I battle to fight to prevent me from leaving
Positive and negative influences begin to run wild
Life's in suspension nowhere to hide
I try to evaluate the pathway ahead
The emotional roller coaster on which I'm being led

I need to absorb information I don't want to hear
A willingness to learn accompanied by panic and fear
It's an alien situation for me and you
My optional escape route is via the loo
Survival is key at this stage of play
Remaining positive and realistic the order of the day
Hoping and praying for a quality of life
If Tony recovers from the surgeon's knife
Families of loved ones express a haunted dimension
Pleasant emotions subside into suppression
Acceptance of circumstances are hard for me to swallow
My inner strength and courage giving hope for tomorrow
Desperation and uncertainty total powerlessness
An incredible experience of helplessness
Normality has been turned upside down
The reality of ICU now holds the crown

Tony's treatment is tailored to his every need
In the ICU lobby we forget to feed
I'm in a time warp no way forward or back
Hour by hour life's taking a different track
Fight or flight I know what's right
To guide me through this indescribable plight
I can't prepare for what lies ahead
If Tony escapes from an ICU bed
But for now I focus on the minute the hour of the day
And pray as a family we'll be able to stay

Admission to ICU care has no preparation or warning
It was a normal day when I woke up this morning
Survival and life quality challenges are now immense
Out of my comfort zone I can't sit on the fence
Without the intervention of ICU care
Tony would no longer be there
Waiting for the ICU doors to open
For news of Tony through the consultant spoken
The raft of emotions roll through you like waves
Until you make it to the next day
I'm not giving up support and strength every growing
A boldness to survive forever glowing
Tomorrow in the ICU lobby we'll all face it again
Courageous strong and fearful women and men

Ode ICU Passage of Time through the Mind's Eye

Hypothetical site of visual recollection
The mind's eye visualises images by selection
A mental picture so easily conceived
Up to the individual how to be perceived
An imaginative imprint of the ICU world
Where your loved ones future waits to be unfurled
Confronted with unfamiliar sights and sounds
Your heart embarks on a journey to race and pound
Intensive care all-inclusive and embracing
Painstakingly scrupulous a safety net in the making
Suddenly you're in the eye of the storm
Prolonged deep unconsciousness becomes the norm
I perceive you're trapped in your body I'm out of sight
In a twilight world unresponsive to light
A motionless existence no response or feeling
A state of oblivion sends you reeling
Coma signifies "deep sleep" in Greek
Overwhelmingly motionless it's peace we seek
Critically ill at risk of death
Currently unable to draw his own breath
Continuous monitoring of basic bodily fluctuations
Infusions sedation intubation and ventilation
Enormity of crisis point devouring emotion
A heart rending feeling full of devotion
Shadows from the past stream into my mind
The silver ghosts in the machine I search to find
The intricate web woven throughout our lives
Hold those thoughts and pray he survives
Compartmentalising images restores control
Enabling you to feel more complete and whole
Mental time travel I start to rewind
ICU the world in which you've become entwined
Kaleidoscopic surreal dreamlike unreal

When waking from coma how will he feel?
Phantasmagorical fantastical hallucinations run wild
Figments of imagination have nowhere to hide
Delirium, visual apparitions' loss of control
Outer shell of body intact what about the soul?
Patience is a virtue so hard to possess
When the nucleus of your family is deep in distress
Comfort and commitment overcome grief
Faith hope and love encouraging belief
Fresh green shoots of life begin to appear
Nourishment for the soul overcoming fear
The kindness of strangers who do become friends
On their understanding and compassion your soul mate
depends
Who encourage and nurture safeguard and assist
To cultivate and preserve life they endeavour to persist
True acceptance and discernment allow you to see
Clearly through the windows of what will be
Our lives are both in suspended animation
Mind bending experience of re-orientation
This state of limbo is yours and mine
Normality and reality a very fine line
An invisible vapour encasing your heart
An unbreakable bond till death do us part
Obstacles and challenges lie along the way
Endurance ensures survival for today
I'm conjuring up future concepts to view
Memories past and present cascading through
Each moment in ICU passes by
Through the passage of time in my Mind's Eye
The riches of hope are there for the taking
Forming a connection a plan in the making
The Alpha and Omega have occurred in reverse
Our inner flame still burning thanks to all in ICU who
nurse

Ode "Sentiments of the Heart in ICU"

An aura of apprehension anxiety by the hour
Blissful unawareness I'm burned out no power
Crushed by compassion I crumble by his side
Determined and drained my inner spirit glides
Emptiness empathy and exhaustion energised by fear
Foreboding flavour of fatality the futures unclear
Gravitas of grief a gruelling path we'll follow
Haunting but heart warming with hope for tomorrow
Impassioned by intuition our life will move along
Jolted and jostled but we're still hanging on
Kindred spirit entrusted in safe keeping
Life and love so precious even when he's sleeping
Motivated by memories all is not lost
Natural negation is a heavy cost
Optimum opportunities occupy the soul
Partners in suffering and comfort life's puzzles not whole
Quenching to move forward quashing the scene
Radiance relentlessly reflecting my being
Sentimentally selecting segments of our lives
Trauma and turbulence invigorating strength and drive
Understanding the ultimatum of ICU care
Vivid vibrant images I retain at every layer
Wisdom and worthiness overcome weakness
"X" our unknown destiny we'll overcome bleakness
Yearning for years ahead our love continually refilling
Zeal and zing to survive belong to the living

Ode Compartmentalising the moment in ICU “Respite Adspice Prospice”

Unfathomable I'm in the ICU lobby waiting for news
Neurosurgeon's on the way to present his views
Hourglass of time is slipping away
My foundations are shaking by the minute today
Respite the defining time before the moment
Palm's sweating like an oily component
Poised in expectation awaiting a diagnosis
Desperately praying for a positive prognosis
The prognostication hits you like a slab of lead
Tony's in a coma in an ICU bed
The fight for his survival is underway
Patience is the order for the day
Adspice the defining moment in time
The brink of life and death a very fine line
Fear temporarily paralyzing my frame
A unique boldness and courage compete to reign
Unresponsive and unaware of his predicament
Life without my soul mate would have no embellishment
Kept alive by a network of wonderment
An overwhelming wave submerges me in bewilderment
In a level of depressed consciousness undeterred
Motionless the sky's falling in on our world
Prospice time to examine the future
Both of our lives now need more than a suture
Survival and life changing disabilities lie ahead
A future to be embraced not filled with dread
A second chance at life after the storm
Thunder and lightening have become the norm
Visual cognitive and physical deficits will be a permanent fixture
Medical and medicinal a positive mixture
Tony's survival my richest blessing will always be
The most bountiful of gifts so precious to me
Faith hope and love will see us through
Accompanied by his life saving team and ICU

Ode "The Oscillating Pendulum of Survival"

The pendulum of survival oscillating through the seasons
ICU care providing life fulfilling reasons
Tony's physical shell in a stage of decline
Glowing sun setting on his life its autumn time
His body's in "the fall" functions slipping away
Fragility of form life support ensures he'll stay
Pale sun starts weakening time for hibernation
An arctic glacial chill runs down my spine of contemplation
Coma bleak winter frozen to the bone
Deep sleep immobilisation no response to tone
As the leaves and limbs of a tree are bare and stark
Tony's life's extinguished he's alone in the dark
Communication zero closed shutters on the world
Environmental awareness yet to be unfurled
A cauldron of emotion wells up inside my brain
Life needs rejuvenation with cool refreshing rain
Emergence from darkness fear and despair
A beacon of light and gust of fresh air
Awakening of the senses the phoenix rises from the ashes
Release from constraints through clouds the sun crashes
Healthy green foliage sprouts by the squeezing of my hand
He's fixating on the ceiling purposeful movements become grand
Spring has arrived the roots provide support and care
ICU the nurturing system for keeping Tony there
Life begins to flourish delirium and psychosis have no place
Radiating summer sun reflecting upon his face
The tree of life bursts forth with budding greenery
Time to evolve for a change of scenery
Acceptance courage wisdom hope and vitality
Treated with dignity respect and humanity
Incredible fight for survival Tony's one of the fortunate few
Annual seasonal ring completed time to leave ICU
Restoration and victory we can embrace the challenges ahead
Tony's life hung in suspension between the living and the dead
He'll never remember how close he came to leaving this world behind
Vivid images of life changing events will remain imprinted in my mind
The seasons have turned the pendulum keeps swinging
Onto precious life we're determined to keep clinging
Life's drought has passed waters of heart and soul remain
The miracle of renewal our lives together again

Ode "The Extraordinary Critical World of ICU"

Dedicated to all who work in Intensive Care Unit at James Cook University Hospital

There's an art to visiting intensive care
It can send a chill through every hair
Your loved one lies there in wait
You rush to arrive for this special date
There's hundreds of obstacles which lie ahead
They can fill your heart with fear and dread
Emotion plays an integral part
Preventing information being absorbed from the start
You listen but distraction prevails
Your concentration fades and trails
Trying desperately to take it all in
You'd love to put the lid on the tin
Body's not functioning vital organs need support
Visual cognitive physical dimensions what a cohort
Some problems are easy to identify
Others not so visual to quantify
Anxiety depression and post-traumatic stress
Psychosocial problems are difficult to assess
The outer shell of the body remains
Internal organs and soul now take the strain
Helpless and vulnerable on life support
ICU the safety net in which your loved ones been caught
No amount of preparation can help with how you feel
Your loved one in ICU is bound to make you reel
You can be reassured though they're receiving constant care
24 hours round the clock even when you're not there
Your mind processes different stages of what lies ahead
Will they wake, speak or ever sit up in bed
Will they ever really know who you are?
Questions at present way to complex by far
Life is not a recording you can't turn back time
The long winding path ahead is definitely a fine line
A Consultant and team of doctors lead your loved ones care
They plan the treatment at every layer
Nurses provide significant overall care needs
While Dieticians calculate nutrition through drip feeds
Physiotherapist ensure movement in legs and arms
Strengthening lungs so breathing is calm
That's all for your loved one lying in the bed
As the next of kin your head is positively in the shed
The atmosphere is captivating warm to breathe
You always need to roll up your sleeves
Your back starts to ache with all the bending

As over your loved ones body you are tending
Intrigued by coloured lights flashing on the machines
Wires supporting life running into the teens
Drips and tubes in arms chest and feet
Dust free environment constant heat
It's a one way form of communication
Normal response for the current situation
Loved ones sentences fill the air
A strange form of normality no-one stares
Relatives desperately trying to stimulate a reaction
Even if it's only a fraction
At this stage you'll settle for a blink
A squeeze of the hand would really make you think
Noise levels constant from monitors and drips
Punctuated by ventilators bleeps and clicks
ICU has become your world
As into it you have been hurled
It's a waiting game no one knows
Life's in the balance no longer on show
You ring the unit morning and night
It really is an incredible plight
You prepare for the worst but pray for the best
It's an unimaginable situation an endurance test
Emotion the sense so hard to control
Obscuring reality facts and goals
What if the heart can no longer take the strain?
How do you know they're not feeling any pain?
You can't imagine the outcome if they're brain stem dead
An inconceivable prognosis filling your head
Does your loved one really know what's going on?
When you're not at their bedside do they wonder where
you've gone?
Go and eat chocolate it pacifies the brain
And for a while makes you feel human again
Your body's flight and fight system automatically kicks in
It's definitely not flying let the fighting begin
You're loved one could not be in better hands
If they stand a chance of remaining in this land
It's an alien world to the relative outsider
After time in ICU your horizons become wider
You acknowledge your loved one's only still there
Thanks to the extraordinary world of ICU care

Ode "The A-Z Conundrum of ICU Care"

Anaesthesia Brain abscesses anguish and strife
Breathing and believing the balance of life
Cognitively cushioned in a coma at the crossroads he lays
Delirium drips and drugs is how he spends his days
Exhaustion and emotion the shield's lost its crown
Fountain of fear flourishing pummelling you down
Guidance great medical accomplishments exalt dread
Hemianopia's Hydrocephalous hidden health horizons lie ahead
Imagination incredible inner strength an insider in ICU
Jewel and jurisdiction of precious life preserved for me and you
Knowledge of life and death predicament appears to grow
Level highways lost lucidity begins to show
Mental endurance and miracles through medical lenses
Neutropenia nurturing and nutrition awakening the senses
Oracles of health overwhelming oblivion identified
Penalties psychological physical yet to be quantified
Quality no qualms of care second to none
Reassurance and reasoning refreshingly haven't all gone
Survival of seizures strength of spirit and searching the soul
Thrombocytopenia tranquillity life's treasure time lapsing out of control
Understanding and resilience the ultimate choice
Ventilation and vigilance the patient carer voice
Wisdom's wealth calms the whirlwind in your head
X-rays Xanthoma patches of yellow not red
Yesterday is history yearning to live persistently growing
Zest and determination ensure our precious river of life continues flowing

Ode "Putting Back the Pieces"

Dedicated to all those involved in ICU & Rehabilitation after Critical Illness

It's the basics of life after critical care
Things we take for granted until they're not there
Tony's in the wrong house someone's moved the stairs
Was the bathroom really always there?
It's so exhausting just to exist
He hasn't the energy to write a list
Food is a thing he really doesn't need
After being too long on drip feed
The stairs are a mountain a challenge to climb
I have to climb with him every time
Tony concentrates so hard on each step he takes
And tries to think through each move he makes
Going to sleep is a thing of the past
Nights of tossing and turning continue to last
His brain won't switch off it doesn't seem to know
When it's time to sleep or get up and go
Legs are restless they continually move
As though they feel they have something to prove
Tony's no recollection what happened in James Cook
To him it's a completely closed book
I help Tony try to piece facts together
Cognitive deficits make it heavy weather
Who are these people who live next door?
He doesn't think he's ever seen them before
Not really aware of what's going on
The days and nights just roll along
Tony struggles to hold a knife and fork
Let alone to even try and talk
Sentences come out in quite a muddle
Body hunched up in a huddle
As eating a meal is a major event
On my dinner plate his meat and veg are sent
Half way through he'll drop off to sleep
Slumped over his plate body in a heap
He has no idea which tablets to take
And has eaten his hearing aid battery by mistake
Pausing live TV is essential for Tony and me
He needs to rewind each programme we see
As often he has lost the plot
Or sometimes just plain simply forgot
Decimated images affect his sight
Tony's eyes visualise the world in flashing lights
His Physio's work to a singular point
To help him to strengthen his weakened joints
They will go to any lengths
In order to give his body more strength
After a session legs feel like lead
He needs to rest again on the bed

His head is swimming exhaustion prevails
There's no longer any wind in his sails
Speech and language therapy is going well
As long as he's not asked how to spell
Tony's verbally fluent he can con the best
Then the conversation is stored with the rest
Lost in the vaults deep in his brain
Never to be retrieved again
His conversation is not necessarily correct
It all depends what his brain selects
Dysphasia contributes to the confusion
Which somewhat destroys the fluency illusion
Decisions are impossible for him to make
Extreme frustration fills their place
Tony's bodily functions have a life of their own
New pathways and ideas have been grown
Tony's epileptic seizures are a very complex story
Attempting to explain they would steal all the glory
Tony's no longer able to drive a car
Legs unfortunately won't travel far
I am both guide dog and chauffeur
So he need not spend much time on the sofa
A power chair has given him a new lease of life
At top speed cutting through the air like a knife
Waterproofs allow him out in the rain
It's great to travel together again
How refreshing to feel raindrops on his cheeks
Even when the weather is really bleak
As we travel along Saltburn Pier
Tony needs to go up a gear
Reminders of our walking days
Happy memories from years ago appear to stay
ICUsteps has given Tony the confidence to share
His life with others after critical care
Giving help and encouragement along the way
And the opportunity to revisit the ICU unit one day
He eventually plucks up the courage to go
Not sure what will be on show
At James Cook we revisit ICU care
To find out if he remembers being there
Another patient lies in his place
All wired up a fight for life to face
Beside his bed Tony's memory is blank
It's the ICU medics we need to thank
For nurturing him through this incredible phase
They all deserve the ultimate praise
The ICU is extremely clean
The friendly staff very keen
To show him where on his arrival
He fought with their help for his survival

The ICU is filled with wires and pipes
Machinery and medication of all different types
It's like a scene out of science fiction
No words to describe it in our diction
Tony's so sorry he can't remember any faces
The bed machinery or any of the places
His memory has been totally erased
It's all a very blank phase
Not so unfortunately for me
Vivid memories I will always see
Wondering if he was going to pull through
Totally oblivious he hadn't a clue
Everyone has their share of troubles
With Tony's brain abscesses he made it a double
His life's now taken on a different twist
Not a conventional bucket list

He has two speeds slow and stop
It's a major achievement to travel to the shop
A different path now lies ahead
Without medical intervention he would have been dead
The Intensive Care Unit kept Tony alive
Now he has the opportunity to thrive
Rehabilitation and support keep us going
Our life journey continually flowing
Positivity is a state of mind
A way to move forward and leave the past behind
We are both now content with the simple things in life
Grateful to be alive and blessed to be husband and wife

Ode "Electrical Power Surge"

Dedicated to a strong courageous man My Husband Tony

Suddenly there's a thundering bump
Body convulsing on the floor in a hump
Communication system has broken down
No facial expression smiling or frowns
Pupils elevated like a scene from Halloween
Iris's hiding unable to be seen
Jaws are clashing teeth on show
Unfortunate tongue has nowhere to go
It all gets down to damage limitation
Seizures of this velocity have increased animation
Intensity increases foaming at the mouth
Legs kicking violently trying to move south
A personal battle has broken out
No control just a permanent pout
Head throwing aggressively from side to side
Wrestling and swimming against the tide
He's lashing out at Tara the cuddly tiger
Keeping him from harm is like climbing the Eiger
Obeying commands is a thing of the past
For however long the seizure lasts
Neural connections are out of sync
Wiring and firing to find the missing link
Files in the brain are out of place
Temporarily located in outer space
The lights are on but there's no one at home
A bit like looking at a garden gnome
Cuts and bruises on the body stain
Accompanied by excessive muscle pain
Muscles spasm into tight knots
As they manipulate the body into incredible spots
They contract rhythmically then relax
Placing stress on the limbs a heavy tax
The elixir of life is draining from his body
He's starting to act extremely oddly
A teddy bear transformed into a street fighter
Preventing self-harm the stakes become tighter
Confusion prevails we're in for a fall
Sometimes there's no pre-warning at all
Central Processing unit malfunctioning and stumbling
Fingers jerking constantly fumbling
The calm voice at the end of the 999 call
Says I'm doing a grand job don't take your eye off the ball
Hands free has a different meaning
As towards the stairs his body is reeling
Seizures can be volatile but never the same
Some positively wild in comparison some moderately tame
Millions of nerve cells control the way we think
When seizure occurs they've had too much to drink
Signals are interrupted or can't switch off
Mimicking the signs of a very bad cough
Symptomatic cryptogenic idiopathic what a choice
Thresholds low and high they all have a voice
Those purple torpedoes can work a treat

As long as side effects don't send you off to sleep
Triggers stress alcohol lack of sleep and medication
It's enough to make you take up levitation
Occipital lobe seizures hallucinations and flashing lights
Temporal lobe seizures confused if it's day or night
Frontal lobe seizures cycling movements and kicking
Complex focal seizures repetitive movements records sticking
There's petit mals and grand mals what a selection
Tonic atonic and myoclonic we need to know prevention
Seizures come in all shapes and sizes
Manipulating vision and cognition into different disguises
1 million miles of white matter connect in our brain
Although none of us function exactly the same
Some are short and some are long
And some have just completely gone
So what exactly is happening right now?
I can't begin to understand how
I'm doing well don't lose your head
Stay calm and controlled and try to keep the thread
Paramedics at last the reinforcements arrive
There's three of us now to control those thighs
Which have far more power when they're on the floor
Especially when they're trying to rearrange the bedroom doors
He's starting to lose power rotating subsiding
Bodily movements adjust into gliding
Eventually neurons have burnt themselves out
They've lost momentum and considerable clout
Neurological overload has flicked the switch
Muscle movements reduced to a twitch
Paramedics and I left counting our bruises
Overcharged nerve cells ready for snoozes
Confusion prevails language restricted
Electrical overcharge gradually being lifted
Life returns to the face once more
Washed out bruised and very sore
"What's going on" as awareness returns
And we are all left soothing our carpet burns
This legacy can occur any time of day
An intrinsic part of life which will always stay
As a critical care survivor it's a small price to pay
And it's certainly a lively way to start the day
We refuse to be filled with fear or dread
On this electrical charged battle that lies ahead
Like all power failings eventually they reconnect
Brain starts to function operations re-select
After being able to cut through the air like a knife
We can once again return to a quality of life
Back to an open playing field again
Specific cognitive deficits will always remain
You never return exactly to how you were before
As each seizure stipulates the score
Neurological challenge over for the day
Seizure free until the next time we hope we'll stay

Ode "Moving Mountains"

ICU survivors and relatives have a different perspective
Empathy and understanding not predicted or selective
The impact of critical illness is here to stay
Survival is the challenge for the day
Quality of life follows survivorship
At ICUsteps Tees you develop fellowship
The road forward is long and winding
A journey for some which is still hiding
We share experiences anxieties stresses and strains
Trials and tribulations and everyday pains
From survivors and their families we gain strength and drive
We're all battling on and very much alive
Cognitive visual emotional and physical functions are no longer the same
Some lost forever others to be regained
A new life lies ahead completely different from the old
Our ongoing story will continue to unfold
But in the meantime all is not lost
Life's really worth living despite the heavy cost
It takes friendship courage and empathy to help move the mountain
To give us strength and determination to flourish in life's great fountain

Ode ICUsteps supporting Life after Critical Illness

ICUsteps support groups provide a welcoming place to meet
Offering critical care survivors a non-judgemental seat
After critical care health complexities can be overwhelming
The challenges ahead seem never descending
The cost of survival impacts on family life
Patients carers partners children husband and wife
Sharing experiences during and after surviving critical care
Can be both therapeutic and healing to all who've been there
Debilitating impacts of health on life are here to stay
ICUsteps offer empathy and friendship gaining confidence to face the day

Ode to ICUsteps Tees

Dedicated to Michael Power & all the Team who established ICUsteps Tees Group

Empathy is a complex word
Not understood by all until it's been learnt
Don't judge me until you've walked my path
Gradients so severe it's off the graph
Positivity from others helps deal with the pain
And gives us the strength to face the strain
It's impossible to imagine unless you've been there
At ICUSteps Tees there's the opportunity to share
Stories of survival fear and dread
And the challenging times that lie ahead
Patients Carers Relatives and Medics can see
There is a way forward for people like me
We gain inner strength when experiences we share
A friendly face and someone who cares
So if you've escaped from an ICU bed
We'd love to meet you and help on your journey ahead

Thank you to ICUsteps Tees

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Thank You
Diane Bousfield