

I Am Still Me!

Brains are Injured, Hearts are Mended
Third Edition



Angela Hunt

Author of Am I Still Me?

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Another Collection of Recovery Helps for Stroke
and Traumatic Brain Injury Survivors,
Their Caregivers, and
Anyone Else Asking, "Am I Still Me?"

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I Am Still Me!: Brains are Injured, Hearts are Mended: Another Collection of Recovery Helps for Stroke and Traumatic Brain Injury Survivors, Their Caregivers, and Anyone Else Asking, "Am I Still Me?"

By Angela Hunt

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Dedication

To James Thomson, Ph.D., L.P.
of Miland E. Knapp Rehabilitation Center,
Hennepin County Medical Center,

Who believed this little engine could.

Author Notes

Just like you, I've always *had* something to say. It's just that twice in my life I couldn't reach in and pull out what I wanted any more. In January, 1985, I suffered an acquired brain injury during surgery, and on February 14, 2005, I fell on the sidewalk. Simple things, really, that happen to a lot of people: 1.7 million a year have traumatic brain injuries, in fact. For me, both events resulted in aphasia, the inability to retrieve words for speech; and cognitive deficit, to delay the act or process of knowing.

Fortunately both effective events in my case were considered of mild to medium intensity, and I was able to recover functionality. Yet both times, ability to properly communicate, and the feeling that something was profoundly and fundamentally wrong with my world left me with the concern that others must also be experiencing similar circumstances and may appreciate a tool to help communicate, especially emotionally.

This book is for you,
As you find in yourself not only
The strength to survive, but to recover,

As you uncover the *you* you were
And move toward
A stronger mind and body again

May you discover with hope,
Reality, pragmatism and some delight
The *you* you will become.

This book is about overcoming the angst and frustration of concussion, brain injury or stroke, assessing and naming changes, as well as coming to terms with new skill levels. It is about acceptance of, and adaptation to, a new way of life.

Who knew at age twenty-nine I would have
A drooling mouth
Dragging right leg
Right arm weakness and numbness
Speech difficulties
Short-term amnesia

Who knew 20 years later
A simple fall on a sidewalk could net:
Second injury syndrome
Fractured ocular bone
Accordion nose
Crushed ethmoid sinuses
Right shoulder damage
Meniscal tear, right knee
Cracked soft tissue in rib area
15-90 minutes unconsciousness
Brain Bleed

The process of recovery, in each instance, occurred in emotional, as well as physical, stages and plateaus. I've arranged the book by these stages of my recovery. Due to setbacks like knee surgery, re-entry into the workforce, fatigue, and new life demands, many of the stages were revisited throughout the 14 months of formal recovery with speech, occupational and physical therapists. Therefore, poems are arranged earliest to latest in each section.

Along the way there were flares of emotion, celebrations of success, the grind of the hard work of recovery; sleep and more sleep.

If there seems to be quite a bit of material expressing angst, it is because on frustrating days I learned to set the stove timer, allow myself some mire-time—perhaps enough to write a poem—before moving on back to the business of life when the timer rang. Of course, I didn't want to limit elation on good days, so wasn't always as studious about writing down happy thoughts.

Until word retrieval improved, in my case, I was able to use the written word faster than the spoken word, but vocabulary in both cases improved over time. For those reacquiring vocabulary, I have reintroduced some words that right now might seem unfamiliar, but I've included them more than once for context and recall practice.

This is a record of my own experience, and reflections and observations from 40 people who also have had brain injuries (see page 156 for a partial list). With some I had lengthy discussions. Others provided an anonymous phrase. Thank you to each one.

I hope you'll use the blank spaces in the book to record your own thoughts (with a date—very important to your recovery!). As you move through the sections, back and forth and back again, may you also feel encouraged by your journey over time, find a-has, notice progress, see resourceful adaptation in yourself, and develop new skills, just like me.

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1

It Begins



“Touch helps bear the weight of beauty
Too much for sight alone.”

– Florence Jacobs, author of Colors of Time

“I house a brain.
It is a permanent record of my past,
Even if I can’t get at it right now.
It is a single continuous strip including sound,
Of my whole waking life.
One day I’ll relive each event,
Feel the same emotions,
See what I saw and thought and did.”

– Pastor Don at Marietta Korpi’s funeral

Evolution of a Brain Trauma Recovery

At first I did not know that
I was missing what I knew.
I was *naïve*.

For a short time
I did not know that I ever knew;
I was innocent.

Then I did not know, but thought I knew
—Though everyone else already knew I was
different than before.
I should have felt apprehension, but had
no feeling at all.

Then I realized I did not know,
But I didn't know that I *should* know.
It was bliss!

I learned that I did not know,
But I had known once.
I felt perplexed.

I thought I should know names of faces around me—
Especially those I woke up to and worked with—
And I felt lost.

Then I did not know and knew that I did not know
And I was afraid I would never know.
I had grief of loss.

I did not know,
But thought I should know again by now.
I was frustrated.

There were things I knew I knew
But could not access, recall or express.
I felt helpless.

I thought I *should* know
But I didn't
And I was ashamed.

I thought everyone else thought I should know,
But I didn't know, and feared I would never
 know again.
I was paranoid and heartbroken.

So I pretended I knew, but I didn't know. I saw
The mountain of information I needed to know again
And felt overwhelmed, discouraged, depressed
 and inadequate.

Then I did not know and knew I did not know
But wanted to know again.
I became determined.

I did not know and knew I needed to relearn
And became surrounded by people who aimed to
 help me know again
And I had hope.

I surmised I did not know,
But felt I was learning how to know again
And felt encouraged.

Then I thought I knew
But did not completely know
And felt embarrassed.

I began to know, but did not know fast enough
And disappointed myself—
And those who thought I already knew.

Then I thought
I might know
But felt tentative.

I was afraid I did not know enough,
And though I was gaining ground to know again,
I felt trepidation.

I began to know again,
But was not sure that I knew
And felt fear of failure.

It was revealed to me
I could know in new ways.
Time passed and I learned to adapt.

I began to know
And felt success
In learning to know again.

I came to know as advocates the teachers around me:
My therapists, patient co-workers, a special
 gracious friend,
My granddaughter—learning to read, too;

And found I could disclose
That I still had difficulty with knowing:
I learned to trust.

When I realized I was learning anew,
I was thrilled by what I knew I knew,
And felt exhilarated!

Sometimes I knew I knew some
But did not believe I truly knew enough
And felt small and defeated,

But
You helped me.
So—

I began to feel sure I could know I *would* know
And I felt safe revealing
What I knew I still needed to know.

When I practiced what I knew and discovered
 dormant skills
Just waiting to be coaxed to life, I was comforted
And learned to smile again.

Then you encouraged me
To exhibit pieces of what I already knew.
I felt reliable, gained assurance,
and felt the sun shine.

But I also began to know which of those pieces
I might *not* be able to pick up again,
To accept my not knowing, and to adjust;

Which, strangely, freed me
To apprehend what I did not know before
And it was enlivening.

I was learning how to know again;
I learned I *could* know and *know* I knew,
And knew now I could know what I had not
yet known.

And if I didn't know,
I could ask for help;
I gained confidence.

I learned there were new ways of knowing
And doing and being and speaking and recalling
And I felt prepared to face the world.

I realized I knew new things
About myself
And it was growth.

Now I know I can know how
To be both independent and interdependent;
Now I know I can cope.

The beginning. Again.



“The more I know, the more I know how little I know.”
–Father Thomas Joseph, paraphrasing Aristotle.



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2

Naiveté
Innocence
Bliss



“I look at my disability as a career move.”

– Mayor of Montreal

“He searches his mind
and does not recognize the view.”

– Danny Scheinmann, author of
Random Acts of Heroic Love.

Chanj is Gud

I,m an all to gather difrent prson
 than i was B weeks ago.
 My frnds and famile may not have note iced
 But I,m all-messed *UnRecogNizAble*
 to myself at teyems
 more **reck-**
 less **-cog.**
 It.s **nize-**
 but Wondering about the **-able** part.
 I,m les **judg-**
 but less **-mental,** to.
 Hav les *unRellistic Xpektasuns:*
 more **-real-**
 les **-list**
 i hope I don't get **-peckt-on**
 Or become an **expekt-**oration
 and end up x'ed at this **-station** in life.¹

¹The author's initial efforts. The rest of the early material is corrected for readability.

Robert Frost with TBI

Stopping by a black and white wood
 On a snowy evening
 Letters, white capped fence posts;
 Yesterday and today
 Mirror images
 On a skating pond,
 Little black words
 Nimbly skittering away
 Beneath the blank.
 Ten dawns and
 The fields of flowers
 Dreamed of under the snow
 Are now wallpaper
 Covering unfamiliar flat,
 Spinning,
 While I wait in the rinse cycle.
 One morning black and white transforms
 Back to living color.
 The living part isn't quite true;
 More of a birthing process, really.
 Flashes of remembrance come washing back,
 Landing silently, tentatively,
 On carefully colorized stills,
 Recollections in memory's hues.

Thinking of "Stopping by Woods on a Snowy Evening" by Robert Frost, 1923.

It's In My Blood

I've been accused—
That's the only way I can put it—
Of being a Type-A personality.
You other A's out there know what I mean
As if we could be anything but
As if
But the gift of the brain injury—
There I've said it—
Is that I have no worries at all
No deadlines, artificial or otherwise;
My brain will take its own sweet time
And leave me mostly with a smile on my face
So now I don't have to do it all,
Even if the accuser is me.

Caregiver or Caretaker?

Some of us are both the patient patient
And the wary advocate,
The one who needs the help
And the one who has to give it,
The cheerleader
And the one requiring a good bolstering.

No Worries, Mate

I find myself content, largely,
With the unexpected pleasure
Of not knowing I should be upset;
Not even longing for the flashes
I once called brilliance;
Content when they just show up—
Or not.



"Light Rings": Kilohana Plantation Luau; Kalamakii, Fire Poi ball Twirler, April 27, 2005.

Incontinence

In the state of matrimony
She shoveled together
His lunch

He was to launch
At 5:30 A.M. on the dot
So she busied herself

With things unknown
And unrelated, blissful,
In a continent nearby.

Warm coursed down her leg.
Fascinated,
She watched a puddle

Form on the kitchen floor.
He did not notice;
She could not bridge the gap.

Salle de bains¹

I'd love to be traveling the world
Flying the skies
Seeing the sights

Skimming the ocean
Learning the language
Nestled in some foreign port

Instead
I'm
Incontinent.

¹ French euphemism for water closet, which is British for bathroom.

Uncertain

I'm not certain who you are
But you sure are beautiful.



Pearl Crescent Butterfly (*Phyciodes tharos*),
North Shore of Lake Superior, MN.

Genius Species

Forgetting so much has given a gift:
There is no longer an urge
To jump up to label
A hapless lepidoptera
When she comes floating by
With her stained-glass wings,

But
With my fall and her landing,
I've stumbled upon the ability
To observe only,
To again label a thing "beautiful"
Just because it is.

It may not be the right¹ word
But right now it is my word
So that makes it the right word right now.

¹ Right: best, proper, perfect, succinct.

Take Me

Take me as I am.
Please, take me.
Take me as I wish to be:
Sound, whole, sentient.
Take me as I was:
Your friend, lover, confidante
Your son, father, brother,
Your aunt, wife, mother.
Take me as I want to be again:
Playful, subtle, complex;
Brilliant, normal, ordinary.
Take me.
Please.

Lodestone¹

My physical therapist says
To keep my eyes off the ground
And focused on a point ahead,
Which is good advice;

But I also make sure
My nose is parallel to the ground
So she can't look up
And see what I am thinking.

My once-perpendicular presence
Wanders around the bend,
A listing aberration² of my former self
Falling off the page.

¹ A lodestone has magnetic properties which can make a compass read off true north.

² Aberration: Point-to-point correspondence between an object and its image; small periodic change of apparent position in celestial bodies due to motion of the observer + light source. Aberrant: a person whose behavior deviates/departs substantially from the standard.

Cohort

Let me hold on to you
With my eyes
So I won't lose your thought
It's worth a lot to me
More than all
Of mine put together
At the moment.
Please
Let me peer.

Thanks to Elizabeth Vincent.

Spirit of Generosity

A wordless one-eyed squirrel
Bargains for position at the feeder
Birds rearrange themselves
Silently
Willingly
To make sure
He gets more than his share.

Speed Bump

We called him Donnie in high school.

Now there isn't one day that goes by
He doesn't ask himself
Why he
Didn't look before he stepped out.

He has no answer.

He's come to a conclusion though:
Things happen
To everyone
And to no one in particular.

God isn't waiting
To break our necks,
But He might like us
To slow down a little.

How much?
Top speed
Of Don's motorized wheelchair
Is 8 mph.

With thanks to Donald Korpi.

Theological Question

Martin Luther¹ gave
All the brain injured of the world
The right to ask a simple question,
Good in any instance:
"What does this mean?"

¹ Martin Luther (1483-1546), German Monk who introduced every religious conundrum with, "What does this mean?" And then he would respond to his question with a statement of faith.

Up the Creek Without a Spoon

Four words are better than three
And three are better than two
But they need to be the right ones. Sort of.

Delighted with the creativity of it,
I search my tipped disheveled mislabeled invisible
File drawers for usable stuff:

I grab *roller skate* for *car* because they both
 have 4 wheels
And who wouldn't be able to decipher the term
To butcher for *to slice* when referring to a sandwich?

I frost a cake with an *oar*,
Ask my son to go out to *Eden* for an onion
Name a *dishtowel* a *flag* as it dries in the breeze.

But my husband, an Asperger literalist,
Because he is so deep in his groove,
Can't even take *talking machine* for *radio*.

Without knowing it
He is willing me
To get my words back.

Thanks, Debrorah Dille, for discussing word substitution.

3

Perplexed Frustrated Lost



“I sensed the empty chair was for me,
and it filled me with an uneasy longing.”

– Nancy E. Turner, author of [Sarah's Quilt](#)

“That's all I can think of right off the top
of my head—except that the top of my head
isn't working very well.”

– James Hunt

Shaken, Not Stirred

Feel? I don't.
Inside.
Right. Entirely.
I've been shaken?
To the core.

Inside
I've been to the core:
Entirely shaken,
I don't feel right.

Right inside
I don't *feel*;
I've been shaken entirely to the core.

I don't feel entirely right;
I've been shaken inside my core.

Eye to Hand, Hand to Mouth

What's the point?
My eyes and my hands
Won't catch the ball
Even though I've got on my lucky underwear.

And I'm afraid now
My eyes and my hands
Can't get to first base with you
Even with my lucky underwear.



Kalamakii Fire Poiball Twirler, "Light Rings":
Kilohana Plantation Luau, April 27, 2005.

Retrospecting

Before I forget to remember
Before I remember to forget:
Ten days back from my trip
And fall
The baggage arrived.
'Til now it seemed the thing
Most broken was my pride
—And it was mending nicely.
My knee cap skin making an effort,
Like continental railroads on a bet,
Seeing which side could reach center first.

That really is my trouble:
Feeling centered.
With dizziness,
I sense a profound loss.
At least I still have my faculties,
But they have opted for a very low curve.
Unsure how to even form the question, "How am I?"
I'm startled to ask, "Where am I?"
And the unnerving, "Who is it I am?"
I barely have the inkling to ask,
"Where will this bring me?"

My self-assessment skills
Were the first to go,
Left on the sidewalk,

Hiding under elbow skin.
My nose:
Crumpled shut,
Stuffed into my skull¹,
Refusing to admit the evidence that
I have changed.

Everything seems so benign
So blank and snow-fresh
Tender as toddler kisses
Covering me
Forgiving me
Leaving me for dead.
Lilting flakes that
Blanketed
Shrouded
Annihilated
Who I was.

¹ Ethmoid sinuses crushed by nose impact.

Home from the Hospital

I feel so alone
Without my thoughts;
Surrounded only by tissues
Strewn about,
Little ghosts of Christmases past.

The Diagnosis: Mild to Mid

After a nap
And before a nap,
I walk into the clinic
And your pleasant smile greets me.
You are acting as though I am normal
Except for my injuries,
Accepting me for who I am today.

All dizziness and jerking gait,
I am examined for range of motion.
My eyes panic when I realize
Words will be required of me.

Thought haltingly expressed
Pain measured
Plan discussed:
It is then you identify
The limits of my abilities:
“Right” and “Left” are mis-reads.
“Stop” and “Go”? Lag time
Creates the opposite response.
My adding is wrong, my subtraction a guess.
I need help counting to 10, so we do it together.
I save face.¹
You save my professional psyche.

¹Closed head injury without so much as a nosebleed, therefore no facial images were taken until a month later with this exam.

Heart to Heart

The neurologist said,
“Give it time and you’ll function again.”
What does that mean?
“You’ll be able to read again.”
How well?
“We’ll make sure you can read the newspaper.
That’s functional literacy. That is our goal.”
*You don’t understand. I am a librarian.
I need to be smarter than a 5th grader!*

Copious hand gestures helped the tangled urgent words: *Anyone in the world could come to my desk asking any kind of question in the world. To do my job, I NEED to know how to narrow all the information in the world to the information THAT person needs—in 5-10 minutes. To do my job, I need to know where to find facts to answer each question.*

“Oh. OH! OK.
That is the executive-thinking part of the brain.
Higher order thinking’s what you need to get back.
We will give you an intensive professional’s
Rehabilitation program. Let’s get started.”

When the clinician speaks,
*You, Patient, take along courage, self-preservation;
Advocate yourself back towards normal.*

Down the Rabbit Hole

For your diagnosis, you ask one last question: "When was Easter?"

In the 12-minute deafening quiet, I wonder if this is a religious question presuming some rote response ("It's always Easter in my heart!" or "The Sunday after Good Friday" or "33 A.D., 3½ days after Pass-over began"); I don't know whether you want the Gregorian Calendar or Roman Calendar answer; then I ponder: do you need it figured for previous years by the Perpetual Calendar? I try, but my math is worthless.

Finally it dawns: you are asking me if I recall when Easter happened THIS YEAR. "Recently," isn't close enough. I poke at every brainy lump for clues. It does no good. It could have been 6 weeks ago, so I mutter that. You keep your pencil poised. I begin to sweat, worried I'll be wrong again. Played out with mental exhaustion, I blurt, "For all I know it could have been yesterday." Bingo.

What a shame I don't recall I sang joyfully in the choir, letter perfect.

A salute to David Quam.

Spuds

The juxtaposition of words on a page
Forming the diagnosis
Pronounced upon my body
Has pried up my emotions
Like a pitchfork in hardpan.
I can't quite put my finger on them yet,
Solid, earthy emotions,
But they are there.
Other things, too.
If I dig,
Perhaps I can pick them up
Like warm brown potatoes
Or leave them awhile
To sprout.



Rows of newly planted sugar cane seed eyes on the last operational Kauai'i sugar plantation, Kaumaka Olokele Sugar Mill, 2005. It ceased production in 2009.

Tools

What good is a vocabulary
When the words won't come out right?
"Advanced Degrees" are just numbers
A little higher on the oven dial,
And "Coping" is just a saw blade
That moves in place a whole lot.
It chews through wood
Slowly
Carefully So dis-joint-ed from my-self
Methodically I a-pol-o-gize sep-ar-ate-ly
On be-half of my brain and me
Gets along fine
'Til it hits a knot
Of one sort or another.
I've hit enough *nots* today.
I feel like going back to bed
'Til words I know like old friends
Can use their electricity to sing me awake.

Boo!

A question smacked me in the face today.
Didn't even see it coming.

Needy

I need to feel
Something
Anything
To have some visceral hormone
Grab me by the throat
And shake me alive
To have tenderness
Sing to my soul
And ruffle my hair with its feathers
To have joy come at me full throttle
Take me along
And lay a patch of rubber the whole way
To have sorrow
Whisper in my ear
And remind me I am not alone.

Perplexed, Meet Frustrated

You said, "Call me later"
And I wondered why
You would ridicule me so;
But how could you know
"Later" might be 5 minutes or 5 weeks from now.
I can't predict when it will come back around.

Would you help me
With my warped sense of time?
This has been a struggle since my stroke,
My brain on daylight saving time;
Now exacerbated by TBI,
A Theory of Relativity uniquely mine.

Here's how I need your help:
Get my attention
Look me in the eye
Say, "It's nearly time to go."
In a little while give me
The 5-minute warning to head for the car.

Then, after *your* 5 minutes,
Help me on with my coat.
This is the only way I will not frustrate you
'Til death us do part.
I want you to be happy, not put out with me,
Your Standard Deviant.

Substitutes

Of course, I couldn't possibly fit it into my schedule
So I said "Sure!"

I meant "bowl"
So I said "cup";

Those things you offered I needed very much
So I said "No", to thank you for your kind generosity.

And it would have been
Unthinkable to spend money on a frivolous trip at
that time
So of course I expressed my interest.

Sadly, I wasn't able to attend,
So naturally I told you "Yes" when you asked if I'd gone,
Then wondered why you looked so puzzled,
Retracing the faces you'd seen in the crowd
Behind your mind's eye.

Under the Pauses; Between the Lines

Thanks for hearing
What I *intended* to say,
And then thanks
For listening
While

I tried to say it.
I'm not so frustrated with you
As I am with my own body
For marginalizing me;
It has placed me

On the sidelines for awhile
And I've been
Darned angry about it.
I wish I could do more.
Life has me tongue-tied.

Thanks, Connie Sylvester.

Table at Hali Lani
Bed & Breakfast,
Kapaa, Kauai'i, HI.



Cooking School I

Water cools
My temper and numbs cut skin;
Mad at myself
Frustrated
My body won't cooperate
To just get the job done.

Sorry I've disappointed you;
I can see it in your eyes, you know.
It is not spoken or even intended, patient as you are,
But it is felt across the room anyway:
"Why can't we have something like you used to cook?
I'm tired of burned macaroni-and-tease."

But you don't know—how could you—
That I can't make sense of recipes,
Can only trace my fingers across
Their stains of use and add
Fresh drops of warm saltwater
For good measure.

How Many Times?

How many times have I already come this way?
But now that I can venture out alone again,
Nothing, absolutely nothing
Has a familiar face.

Buildings I've greeted a thousand times over,
Caressing their railings and doorknobs
In sunlight and shadow,
Hold no meaning for me today.

The street names turn over in my mind,
Common as a penny
But the heft is different.
I'll need you to inch my past forward a little.

Sympatico

If you really love me, listen with more than your ears.
Why do you assume I'm OK
Unless I tell you differently?
Why can't you see between the blank stares
And the angry frustration
To my vulnerability, my need?
Why can't you help me:
Just once wait until I find the right word?
Or, hear my struggle
And realize it won't be coming today,
So you gently start it for me—
Just the hook of a syllable—

And see if I can grab hold and pull it through.
If you really love me,
You will laugh with me as long
As I can laugh at myself—
But no longer.
There is a limit, you know,
To being the brunt of the joke
Even if it is one's own.
Test the wind to determine when
A cloud might suddenly come over me,
Then mingle your tears with mine
Until the storm has passed.

G'Day, Mate

I'm having a good day today
Of course
"Good" is a matter of opinion
On a scale of hopeless to barely manageable

Take a number
1 to 10
Pick one,
Go ahead

Of course
It could be worse:
Knocked out with meds
Or, moaning that low hollow moan that you try to stifle

So you won't wake the spouse
But it escapes through clenched teeth anyway,
So congratulate me
I'm having a good day today.

4

Grief of Loss Helpless



"My brain is sorry. So am I."

– Angela Hunt

"My train of thought
Has been derailed."

– James Hunt

In the Waiting Room I

He told me
With a shrug,
Without eye contact,
Among the untouched magazines
In the waiting room:

“I used to enjoy being behind
The driver’s seat of a nice cold tall one,
White head of foam coursing over my knuckles,
Laughing with the guys.
Now the joke is on me

Tips me all the way back
Like the smooth going down
As it slips past ears
That don’t catch the humor like they used to.
Somehow I’m stuck to the sides of the glass.”



Foamy Beach at Lydgate State Park, Kauai'i.

This is an Emergency

Quick

Get

Me

A

Pen-

Cil

And

Some

Pa-

Per.

Computing

A question is posed:

Brain Stimulated

Loading

Thought Initiated

Loading

Loading

Query: Is movement or speech required?

Processing

Processing

Processing

Long Term Memory Initiated: Social Situations

File

Processing

Processing

Processing

Processing

Speech Toggle Selected

Response Loading

Loading

Loading

Loading

Loading

Query: Have I ever heard this question before?

Long Term Memory Initiated

Recall Pending

Loading

Loading

Recall pending

Loading

Loading

Abort. Battery Low.

Query: How have others around me just responded
to this question?

Short Term Memory Initiated

Activating

Activating

Activating

Activating

Activating

Short Term Memory Accessed

Feedback Response Prepared

Query: Is their response appropriate for me?

Activating

Activating

Activating

Activating

Response: Affirmative

Command: Load response and prepare to deliver

Accessing

Accessing

Accessing

Accessing Time Expired

Access Denied.

Delivery Aborted.

Automatic Shutdown Sequence has been Initiated.

The Wheelbarrow

Do you know

Where I left the wheelbarrow?

A simple question

Desiring a simple answer.

You respond incredulously:

Don't you remember where you left it?!

There is a wide pause.

It's right where you left it!

Another aching pause.

Don't you *know*?!

I was hoping for

Yes, it's under the tarp by the solarium.

Or the generous

No, I've forgotten where I saw it , too.

Or even the marvelous

Let's look for it together.

Instead

I am reminded

Of my flawed brain.

I am trying to save face

Because that *façade* is just about all
I have left of my self.

It would have been such a simple thing

To answer me mano a mano¹

But

You made me feel small.

Flawed.

Worthless.

(I won't ask again.)

¹One-on-one, man-to-man literally hand-to-hand.

Stale Mate

Even with her dragging foot, drooling lip, numb hand,
Confusion, changed personality, ingrandiloquence,¹
And blurted protestation "Something's not right!",
No one admitted to the operating room event.

Because there was no diagnosis,
Husband denied it, too;
Their children tittered and taunted in the back seat
When she invariably got lost in the neighborhood.

Husband's own mother had vehemently backed him up:
"Just wanting attention", and
"No diagnosis, no stroke!"
8 years after Mother-in-Law's death,

And long since the hospital had changed hands
after reams of headlines,
Wife heard, "There's a fresh brain bleed from this fall,
But there's old scar tissue, too. What happened?"
The patient could only pump her fist and say, "Yessss!"

¹ Lack of words

Reality Bites

I apologize
For my arrogance.
The truth is
I am trying to save face.
You, of all people
Should be allowed to see my vulnerability.

I fear that nakedness.
I want to appear
To be competent,
But I became a fool.
I was trying,
By brushing you off,
To cover my own tracks.

A Lighter Load

That's OK.
Let's go back and get it.
I forgot a couple of things there myself.
I just don't know
What they are yet.

No Horse Sense for Pinocchio

I wish I were not made of wood:
My eyes, knots; my nostrils, wormholes;
Unable to nuzzle a sniff of emotion out of the facts:
Unable to breathe feeling into anything.

My dear Susan, an English Dressage rider,
Confides she had to put her marvelous horse
Down, then halts; no more words would come.
But hollow, I cannot see

How the two were made one,
Him bending the fence to reach her,
Blurring the line between animal and human,
Leaning into her soul to say goodbye.

She can't let any more thoughts out to pasture
And I am not able,
With my oak arms,
To swing the gate to invite them in,

So our stilted conversation
Just lopes along
On deadwood
And fodder.

With thanks, Susan, for your patience. Today my jiggly brain remembered, and grieved your great loss. Thanks for waiting four years 'till I came around the bend.

Shorthand for MaryPat

You were fascinated by my shorthand notes¹
As I took down your suggestions
And assignments during therapy sessions.
I'd explained, "The line ' _____ ' means 'm',
and the curve '(' means 'p',
Therefore together, ' _____(' they mean
'Important' — or 'MaryPat'!"

You thought you could certainly use
A skill like that when taking clinical notes.
Enthused about being useful,
I went home to find my old textbook
To ease your load,
For you had helped *me* so much.

Yesterday
I was headed your direction on another errand,
So tucked the book in the car, pleased
I'd remembered to bring it to your receptionist
With a note.
I'd promised, after all.

You called today, confused,
Admitting you'd not asked for it.
I was flummoxed, reciting

The very conversation,
Word for word.
You patiently explained

You use a computer program now,
Typing everything into client records,
So shorthand would no longer be necessary,
Graciously thanked me
And hung up.

It was then I realized
That therapy session was in August 2005.
This is August 2011.

¹ An old skill was easier than spelling because shorthand is based on sound chunks and short pencil movements.

Technologically Challenged

Instead of 911 on speed dial
Brain fumbles for a steady crank
On a sturdy platform,
Labors to be heard
Through a crackling receiver,
Yeans to be understood with the wrong transceiver.¹

Word retrieval employs a leaky wheelbarrow
Vocal delivery rings a broken doorbell
Emotions course through an uncharted sidewalk crack;
Every thought process races with snails.

There stands a patient caregiver
Queuing to help formulate Brain's thought
Making no sigh,
 no rolling eye,
 no tapping toe,
Keeping only a ruminating chair at the ready.

¹ When I was a child, we had an old-fashioned crank telephone and a party line. A transceiver is a device that can both transmit and receive communications. It converts an electric signal to audio.

Tried; Tired

Tired
Of going the distance
Of inching around
One foot at a time
Measuring myself with my club—
And I don't mean golf—
Just the tonnage of life
Injected into muscle
Expecting me to lift it one more day.

Thanks to Barry Dorscher.

5

Paranoid Heartbroken



"I'd rather be a PISTON than a *hubcap*."

– Angela Hunt

"Life is a near-death experience."

– Kevin Young, author of poem "Anthem",
MPR Daily News Poet 3/29/12.

Anxiety,

Thy name is doctor's office
Thy torture chamber,
The therapy bench.

Ether has escaped
Without a tether;
Where has it roamed?

Watching on its haunches,
Not about to lift a paw
Of loyalty to help.

Return Trajectory

Words about this last episode
Are like elastic bands around my heart.
If I stretch them toward you
I'm afraid they'll snap back at me.

In Black and White

Today I am a shell
And a pair of pants.
I'm not sure what is holding
The legs open
So don't look down those culverts
To see my empty shoes.

Today I am a sock, blowing in the wind
A sad sack
With chaff and brush inside
Just a tangle
Of last year's productivity
And not much to show of that, either.

Today I am ether. I'd cry
If there were real tears
But there aren't
So I won't
I'll just try to remember
How good it would feel if I could.

Today I am a feather,
Burley clouds and
A phantom gale
Pummel me

Under these worthless blankets
This broken pillow.

Today, instead of firing blanks, I write,
Shooting out thoughts of loss,
Of pain my face refuses to express.

Gone, Fishing

What have I lost?
My rod to fish for words and reel them in,
Satisfied with the catch; my net
For schools of phrases with commas for scales,
Laid out for market;

My boat to get to ideas
And apprehend them,
Trophies for the taking:
I don't want to be left in the wake
Sputtering.

I work so hard
At walking
Speaking
Thinking one clear thought.

Every time I have a wave of pure delight
At some accomplishment
There are two more whitecaps
To strike me in the face
Pull me down and drag me under

Back where I started
Or worse.
I want to enjoy life again
Not just tread water for all I'm worth.

Pedal to the Mettle¹

Consider the gasoline 4-stroke:

Intake

Compression

Power

Exhaust

Like sex

Like breathing

Each one a lusty stroke of productivity.

Therapy is not a show of weakness,

But only a revelation of need:

Intake

Assessment

Exertion

Release

Merely a vehicle

To get back where I want to be.

After all,

I'd rather be a piston

Than a hubcap.

¹Mettle: quality of temperament; spirit, courage.



Hermit crab, inching away from my cane, at Kikiaola Beach, Lydgate State Park, Kauaïi.

Crabby

Even an old crab

Has to come out of his hole in the sand

Every now and then.

He got old from hiding

But he got large and strong

From the nourishment waiting for him

Above.

6

Overwhelmed
Discouraged
Depressed



“A miasma of melancholy hangs there.”

– Nora Ephron, author of
I Feel Bad About My Neck

“Here’s the ‘patient parking’ lot,
But where’s the ‘impatient parking’ lot?
I’m in a hurry to recover!”

– Jennifer Hemken

The Edge of the Cliff

My eyes may not be saying much
That you can read
But from here they are delicious with fright.
My tongue is more drool than syllable these days
But it wishes it could scream to you
From the edge of this cliff
That I feel exactly 98.6 degrees north of normal.



Anole at Allerton Botanical Garden, National Tropical Botanical Gardens, Kauai'i.

Deference

Decisions don't come easily:
They yank and twist
Then pull their own hair
At my ineptitude.

What if I go, what if I stay?
WHAT? If I go...
What if?
I stay.

It seems
I'm always
Navigating
Stormy whether.

Blot

The dark black ink of mood
Infused onto flat
Stays there
All dried up.

Fly On the Wall

i come to slowly
so slowly
i feel the shadow
in my room
wipe its dirty hand
across my face
my eyes
creak open

but my brain
safe in its chamber
refuses
to clear its cobwebs
come
to attention
or unlock
its door

a fly
stares at me
unafraid
then falls asleep
waiting for change
i roll over gently
careful
not to wake him

Making the Ascent

A stairs
Whose rail has a familiar heft,
Used to be an old comrade;
Both of us stalwart infrastructure.

But will it recognize me now,
With my new cane
And strange grip?
I look up

Exhale
And draw in
A cloud of courage,
Grab hold

Tip forward
Start the first step
And realize,
With this new project,

My morning
Calendar
Has just been
Rearranged.

Checking Out

There was so much
That,
When asked,
“Paper or plastic?”
I wept.

Thanks, JoAnn Alberg, Sharon Willson, and Cathy De Graff.

7

Determined Hopeful Encouraged



“The strongest Norwegian trait that passed through my family is determination—to go forward, without complaint, and to make the very best of what you have.”

– Hubert H. Humphrey III, from the introduction to *A Scandinavian American Family Album*, by Dorothy Thomas Hoobler.

“Those who will be strong decide:
Not out, but through.”

– Angela Hunt

Another Chapter

The fog is lifting
The mist has cleared
The tide is shifting
The shore is near.

Selection from My Father in Verse, by A.H.

Spouting Off I

The joke is on me.
In fact, it has soaked right into my skin,
Curdled my perfectly good hand
Turned my smile into what some
Would label a sneer
But it's not.
It's still a smile,
Stretched by Courage
Propped up by Grit.
A fellow is supposed to take
Pressure
Stuff
Derailings

Just fold them up
And stick 'em under his hat.
Trouble is,
When it finally blows
What a waste of a perfectly good hat.



Geysir (Blow Hole): Spouting Horn, Kauai'i.

I'm hanging on to life
Like a tenacious nose hair;
It's inevitable
The tweezer will come
But
Even if I can't stay forever
I'm gonna see
If I can't at least make Death
Wince.

Cleaning House

What is it
About life
That demands our attention
Keeps us beating our hearts
Even when emergency rooms
Paddles and monitors
Are nowhere in sight?

What is it
About the will to live
That creates order
Prioritizes
Lays the facts in neat, stacked piles
And helps us work through them
One by one,
Until
The crisis has passed?

Note to Self

Reacquaint
Thoughts and Actions

Reword
Success and Failure

Rethink
"Do" and "Be"

Reevaluate
Worry and Ease

Re-accommodate
Work and Leisure

Respond to
Peace and Rest

Readapt to
Joy and Pain

Rebalance
Effort and Relaxation

Re-admit
Hope and Faith

Rearrange
Difficult and Easy

Reinspect
Hard and Soft

Rearrest
Zeal and Meekness

Rejoin
Passion and Purity

Reenlist
Friend and Foe

Retool
Ability and Skill

Rejoice in
Past, Present and Future.

Having Words with You

Words are my life:
I'm a librarian, You know,

An author, speaker,
A radio personality. On one of *Your* stations.

How could You remove
My identity from me
Only because You want me to take on Yours?

What kind of cruel joke is this:
Telling me to dance for joy on one good leg?

I've felt needled about it,
Thinking I deserve all the loose ends tied;

I have lost the thread of my own familiar song
So, finally, I will sing another tune, God. Yours.

Surprising, Isn't It?

You, Reader,
Are here.
In spite of circumstances
Hindrances
In spite of your *self*
You are here.
A strong cord has tethered you
Something of umbilical strength
Defying age
Interest, intention,
Drawing you
Gathering you in
Picking you up
Causing you
Of all people
To have hope again.
Just a shred, a scrap
But enough
To stitch around
To fashion a new garment,
Serviceable
Malleable
Warm;
Go ahead
Try it on for size.



Bald eagle at Birch Lake near Babbitt, MN.

Eagle

Now when I look behind me,
Over my one weak wing,
Rather than get dizzy,
I see how far I've come.

Standing on one wobbly foot in therapy,
Like an awkward flamingo,
I peek out of the nest
And see I could be an eagle again.

Liquid Gratitude

Your pronouncement,
"You'll make a full recovery",
Bulged with hope.
Back in April I did not know that meant
I hadn't yet completed the first bounce
Or that there would be many dribbles
down the court.

Thank you for your validation:

"Full"¹ is

- containing as much of normal as is possible
- complete in detail
- having all distinguishing characteristics
- enjoying all rights and privileges
- not lacking in any essential
- being at maximum
- completely occupied

What a gift you promised,
That I'll get my pieces back.
The ultimate present
Is that 3 months from now
I will look back
And see how much further, still, I've come.

¹Webster's dictionary.

8

Embarrassed Inadequate Disappointed



"Caustic twitches of the tongue
spit acid speech."

– Angela Hunt

"Today is not a day of rest,
It is a day of struggle,
A birthing,
So that the rest will be understood."

– Angela Hunt

"An empathetic tear
Is the milk of human kindness
Concentrated to its essential oil.

– Angela Hunt

Spouting Off II

There is some trouble here,
With nonverbal cues.
What should be a Windsor knot of propriety
Seems more like a henchman's noose.
I blurt interrupt interject
Like a launch of clay pigeons sprayed by
birdshot,
Not sure which is which.

Having a conversation is like playing hide &
seek,
But with me it is boo and ollie-ollie-in-free
Even before ready-or-not-here-I-come.
I see your pink cheeks
And your tight smile
And then realize, too late,
You aren't pleased, but frustrated,
Thinking me rude for speaking
My half a mind on a subject
Considered too um delicate
For the common social dance you had in mind.

Half Cocked and Dangerous

Laughing at myself
Is the cultural expectation
But I try too hard
And it is much too easy
To be the brunt of the joke.
A chuckle on steroids
Is stalking me;
Violent laughter
Has me by the throat.
Deficiency and levity
Are unconditionally incongruous:
Melancholy tears mixed with gruesome guffaws;
Exorbitant equalizing effort
Has been expended
To keep up appearances—
And my name's not even Jones.¹

¹Reference to "keeping up with the Jones".

Breaking the Ice

I was, once, the only mixer people needed,
 A five foot four ice breaker
 Clasping hands, introductions all around
 Towing reticent bergs into the conversation
 With witty questions carefully molded
 To form gracefully crystallized arches
 From hoarfrost buttresses
 To those on the outer banks.

Now small talk
 Is a BIG DEAL.
 My attention span
 For conversation seems
 Strapped to a stove timer:
 When it goes off
 I'm fried.

It's not enough to know again
 That things
 REAL things
 Are going on around me.
 Here I sit in a nervous puddle,
 A brave and stoic ice cube
 Sublimating in the corner.

My stale exchanges stall;
 I can't seem to
 Jar my tongue loose
 From its tightly hinged case
 To add to the mix of pleasantries,
 Ideas clinking together
 Bubbly as party punch.

All I can manage is silently to think:

Help!

A

Conversation Pit

Is

lodged

In my throat.

Nervous Pudding

My tottling brain rattles in its cradle.
 "Will that stocking cap help
 Your jiggly brain, Nana?"

A grandmother, methodically knitting together
 Past and present into a new reality, replies,
 "Gee, I hope it fits."

Making Change

The scars are beginning to fade
The gait is gliding easily
Breakfast phrases smooth out
Like warm peanut butter on toast.
But when you suggest teaching me
To crochet a finishing edge
On my simple, rather ragged knitting project
(That I mostly hide from your view)
It is just too much.

Your eyes hid disappointment well,
Wanting to pass the baton of skill
To another generation before it is too late,
But it's still too early for who I am now:
A bailer with a leaky bucket exerting
Against the tide of brain injury and age,
Deciding what to strive to recapture
And what to let go down the drain.
I still struggle with social currency

And paper security¹
Trying to preserve your great value to me,
So I fumble to make change for a crochet hook:
Feeling like a foreigner
Only two blocks from home,

A former MBA² student
Now sliding coins across a counter,
Hoping it is enough to satisfy. Unfortunately,

Being in a different place than my own living room
PLUS learning a complex skill
Is more than I can take on,
Especially because you are Her Excellency³
When it comes to handiwork.
My nerves short-circuit at my fingertips;
I can't compete,
I can't even meet expectation
As novice yet.

You are a great-grandmother
Who has also survived a stroke.
Why can't I just tell you I've been amped down
To "low voltage",
And am no longer the "brilliant lightbulb"
You thought you had?
Why can't I just admit I need help and time
To get back up?

¹Writing *everything* down to help recall.

²Master of Business Administration.

³With thanks, Mom, who also has been jolted by a stroke.



"Fantasy Island" Cove on the way to National Tropical Botanical Gardens, Kauai'i, HI.

Paradise Lost

Things are calm today
 I hide the effects of my personal hurricane well,
 Don't you think?
 You say you would never have guessed
 About the personal struggle
 Of my last year
 Had you not known;

But you really don't know
 Do you, that
 Under my calm pool
 Are the windswept branches
 Of nurtured intentions
 The scuttled boats of well-provisioned desires—
 Some already set out to sea—

That have sunk
 In this personal storm;
 Well-anchored goals,
 Dashed and waterlogged;
 The windswept fodder of daily life—
 Growth whipped off prematurely
 Or never allowed to sprout.

Under this serene surface
 Are schools of ideas still aimlessly darting about,
 Bottom feeding,
 Skittish about coming to the surface
 Fearful of being caught
 In the huge net of inadequacy
 Or harpooned by a fool who might well be me.

So don't assume that "calm" means
 Paradise,
 Unless "paradise" means:

Regeneration:
 Regrouping energies;
 Compensation for previous skills

Adjustment:
 Redirecting concentration;
 Rearranging priorities

Compromise:
Realigning effort;
Calculation of the adequate course

Recovery:
Recharging enthusiasm;
Collaboration of efforts

Reality:
Substantive¹ focus;
Reconciliation with a changed body

Truth:
A mooring between past and present;
Lashing logic to emotion.

¹Renewed

I Know the Trouble You've Seen... Before Breakfast

I know
The trouble you've seen:

Unscrambling the morning refrigerator
To discover what goes on flakes,
Stumbling over a routine,
The secrets of life spilling onto everyone else but me.

Trying to read an undecipherable window
In order to interpret the closet;
Selecting unpressed vagrities, uncombed cliches
Presenting themselves for hangdog inspection;

Interrogating the calendar for clues
To uncover the chronology of the universe;
Using a hopscotch liturgy to land on the right day;
Skipping things, sometimes IMPORTANT things

Because of a brain that keeps no cadence
With the tick of the clock.
How to cope?
There are BIG questions demanding good answers—
So large, they fill an entire hemisphere
And leak out the eyes as liquid trepidation.

10

Adaptation Success Exhilaration!



“When my vocabulary broke down,
I hitched with smiles,
Nods and gestures going along for the ride.”

– Angela Hunt

“**In’-va-lid** (n.), perhaps;
In-val’-id (adj.), never.”

– Angela Hunt, author
of My Father in Verse

Cooking School II

Mom,
You asked for some favorite recipes
To make a family cookbook.
What a gift you gave
By forcing my fingers to pry open
The hinges of memory!
Fingering stained cards of family favorites
Of forgotten food
 (Both IN the recipe box and ON the stove!)
Assembled, not reconstituted,
Created, not canned.
The *I Who Was* of the culinary world
Suddenly became the *I Who Can Be Again*.

Your gift of clearly typed comfort foods.
Helped my frozen memory thaw.
It reviewed
What my nose should be smelling
It retaught good taste.
So what
If I can't understand the complex timing;
I can make my own. With a nap in the middle.
If I puzzle over too many directions
In one place, I find
Another one with more blank space on the page.
I can do this.

My reviving eyes see life is no longer about lists
Of complex ingredients,
Timed and ordered carefully:
 Chopped into hours
 Minced into minutes;
Rather it is about outcome:
 A sliced apple is as elegant
 As beautiful
 As nourishing
As deep-dish apple pie, don't you think?
Now, if it is not more finely prepared, at least
I am more willing to stop and appreciate it,

To marry simple,
Exquisite flavors,
To meld, like Spock,
One mind's interest
To another mind's palate.
A chance to create.
To re-create.
I stand before my blank canvas
Turn on the heat
And find a spoon.

Road Trip

Success today!

My driver set me up as navigator

But did not set me up to fail.

I remembered highway numbers

With our friendly review review review

And only a prompt here and there.

I said “left” when I meant “left”, mostly.

My friend,

The one whose praise I live for,

Did not lavish it upon me;

That would have made me feel like a child.

Instead,

He chose his timing carefully

To interject into the silence

Of my private invoice of errors,

“You remembered a lot today.”

His careful choice

To identify and negate my fears,

To validate without flattery,

Was the gift I needed

To release the debt I owed.

To be honest,

The short trip exhausted me, but

With so much still to accomplish,

And you, friend, by my side

To celebrate our successes,

Who could possibly consider

Being laid to rest?



On Hulemalu Road near a pond,
southwest of Lihue, Kauai'i.

Thanks to my drivers, Gary White (for appointments) and Jim Hunt (for hauling me around in the rest of our world).

11

Pleasantly Surprised



“Until life hardwires itself
Back into your synapses,
Let your mind’s eye
Snap a photo-finish
Of your own future success.”

– Angela Hunt

“I use the time it takes to re-boot to be pleased I am
thinking faster than the computer.”

– Janiece Aldinger, MD, Minneapolis Clinic of Neurology.

Testing Skills

Doctor Thomson
Tests present logic,
Spatial abilities,
Vocabulary;
Pushes to fatigue—
Which doesn't take long.
Then he encourages my soul
That there is yet hope.¹

A diagnosis "Mild to Mid"—
Brings him to believe
It will all come back:
Access to stuff I've packed away over the years:
Facts, memories, recollections,
Processing time, comprehension,
Cognitive abilities, event-sequencing,
Problem-solving.

"In fact," he says
With the only unworried smile in the room,
"These things are not really *missing* at all,
Just not *found* right now,"
Like an elusive key
In a messy house."

¹ Zechariah 3:16: "Return to the stronghold, ye prisoners of hope."
Job 11:18: "Your life would be brighter than noontday; Darkness would be like the morning. Then you would trust, because there is hope."

At last.
A group of words I can relate to!

One of my favorite tests
Is fitting pegs into holes based on shape.
With full concentration, I get a good score.
I ask to do it left handed, too,
So he humors me and restarts the timer.
Feeling those pegs move through my fingers
Brings out a 33 year-old story
From a college classroom,

A psychological principle
Shown with a can of marbles
Moved one by one to another can.
Each successive candidate
Secretly told "average"
Was a higher score
And each improved
What the previous one had done
Because no one wants to be merely average.

Even though-eth my left hand
Seemeth not to knoweth
What my right hand doeth now,¹
The same thing is going on here:

¹ Matthew 6:3: "Let not thy left hand know what thy right hand doeth."

I need to prove something to both sides of my body;
And after having stumbled
In his office over cognitive cliffs for two hours,
I tell the story of the experiment smoothly,

As if I'm still hearing each marble
Echo into the can,
While pegs drop into place,
Like keys into keyholes, ligands into receptors,
More and more quickly.
It seems easier
To fish for words
While my hands are working with bait.

To Knit or Knot to Knit

Knitting, after a 30-year silence:
The needles are clicking again.
It is an involuntary need to move and create:
But I cannot remember how to cast on
Or read cryptic directions.

Step-by-step sign language does no good:
My mind translates only mirror images of the page
So I devise a simple loop
And from some distant memory-yarn,
Those needles start devouring fiber.

Something comfortingly familiar takes charge,
And though I cannot decipher a pattern
I *can* do the same thing over and over again.
It calms me, orders me,
Makes me think linearly,

Even if only in the epic tales of scarf-language.
Something wonderful occurs:
My own stories begin to have a beginning
And then there is some middle,
Though they might trail off around the bend

Before I get to the end,
Or drag behind me
While I pick up loose threads.
Yet, I'm starting to include a point
And an actual conclusion.

Some comments still sit in a pile in my lap,
Mere thrum.¹ But some of them are tied tidily,
"Yes, Please" or "No, Thank You."
Once in awhile an idea even comes out
With a bound-off edge.

I'll keep telling my tales
Until I run out of yarn.

¹ Thrum: a tuft or short unused piece of fiber.

Rube Goldberg's¹ Linotype

This life,
Another newspaper statistic:
Who, what, where
Neatly folded
Into gray matter
Like notes in a steno pad²,
Dormant as yesterday's rag
Yet alive;

Waiting to notify its reader
When, why, how
There are things
Worth caring about.
Words, chinked into sentence, strung
On a lede bead³ of thought,
Stare at the reader

In black and white,
Lock in clarity;
Ligand to receptor⁴
To secure a mooring which
Completes the circuit, shocks
Its vessel with thought;
A bucket brigade
Transferred cell to cell,

Finally
Smudging on
A smile
A tear
Pure clean rage,
Pulling emotion out of static printer's ink,
Sentimental chemistry
Erasing dead eyes.

¹ Rube Goldberg: (D. 1970), American engineer, author, inventor, famous for cartoons of convoluted contraptions that perform simple tasks indirectly.

² Steno pad: narrow, two-columned spiral bound stenographer's notebook often used by newspaper reporters.

³ Lede bead: the channel in which moveable type is organized.

⁴ The concept of ligands locking into brain receptors was discovered by Candace B. Pert and reported in her book, Molecules of Emotion, 1999. Poem in honor of MaryPat Parker, speech therapist, who made cognitive exercises fashioned from Pert's book, the daily newspaper and chemistry texts to touch my last pre-med student nerve.

Setting Up

Lively creative juices
Jell into jiggling essence;
Gyrating substance:
The jeweled jam of being.

Ekphrastic Art¹

They say
You can't judge a book by its cover
But I pull myself up to the full height of my spine,
Look past inky mascara
Leaf through the pages of my mind
Beyond the disheveled, the dog-eared,
The mended, the sublime;
Select a blank one
Then paint some gilded phrase
All shiny for attention.

¹Art created when one medium engages in conversation with another.

Taxes

SCHEDULE D-1 (Form 1040)

Department of the Treasury
Internal Revenue Service (99)

Name(s) shown on return

Continuation Sheet for S (Form 1040)

▶ See instructions for Schedule D (Form 1040)
▶ Attach to Schedule D to list additional transactions

Part I Short-Term Capital Gains and Losses—Assets Held One Year or Less

(a) Description of property (Example: 100 sh. XYZ Co.)	(b) Date acquired (Mo., day, yr.)	(c) Date sold (Mo., day, yr.)	(d) (see p in
¹ Taxes			
It is so important To keep everything tidy			
During this stage It is less taxing somehow			
To keep note of one's assets And liabilities			
Maintain accounts of progress And withdrawal			
Take stock of previous years Plan the ledger of the future			
All in pencil Eraser in hand			
Because columns And perceptions change.			

At the Rehab Center

Little poinsettia
With two heads broken off
Still smiling at the world
Still able to be a bright spot

Making an effort
To look perky,
Its remainder pumped full of
Rosy optimism

Grounded in a sturdy pot;
Patient in demeanor,
Willing to wait
As long as it takes

To reach
To stretch
To grow
To heal.

Replacements Unlimited

It occurred to me
The reason I drop things
Spill Dump
Break Bang Clang
Is the TBI
Left its stigmata¹ on my grip.
Involuntarily I let loose
But it is only in the physical realm.
I can handle the minor inconvenience
Of saliva fresh in my mouth—
While warm pudding
Languishes on floorboards.
I can take a dropped garden tool
Slicing my foot,
A released balloon
Waving goodbye in the breeze,
A broken dish mocking a piece of my mind,
As long as I know
My grip on reality
Is steady
My self-control
Is intact
My sanity
Is sure.

¹ Stigmata: mark, scar, brand, stain.

Construction Zone: Reduce Speed

Something warm and wonderful
Has settled on my broken parts.
I'm gaining mastery
In more than syntax and pronunciation,
In more than controlling
The fits and starts of a dragging foot.
My quick temper has been placated
By a warm blanket of realization:
Things worth doing take time.
My impatience to get on with life
Has become delight with small successes.
This aside, this inconvenience, has become
A new trail to blaze.

I cannot think yet how to play piano or clarinet;
Too confusing, that chorus of spots
And jumble of fingers.
But strong and wonderful new music
With full, rich chords
And original, beckoning melodies
Comes from my ¹
To my inner ears—like none I've ever heard—
At least none I can recall.
I listen in awe, and sometimes
Capture dots of sound on an envelope

¹ Psyche: (Greek) core; inner life, one's inmost being, seat of the soul.

To tuck away
Until I am fluent in the language again.
Wonderfully, I recognize there not only
Could be an opportunity to revisit them later,
There WILL BE a later.

I sleep, study therapy assignments,
Devise telephone scripts—in case it should ring—
Attend to exercises and efforts,
And sleep some more—18 hours some days—
Imagining little highway workers repairing me,
Needing minimal traffic
To get all the bridges reconstructed.
My new words are signage
To direct not *to* but *through*;
To bring me not just past the tangle of repair,
But to the pristine view beyond,
To see as beautiful
Even my stark cliffs,
Dark caves
And stagnant ponds.

Biped

I deserve
A standing ovation,
Though nobody's clapping.

I'm on my own two legs,
Not three today,
So I've gone ahead

And
Given it to me
Anyway.



My cane, left in the corner.
"How sweet it is."

Words

Another load of words came back today
Drop-shipped at 2 a.m.,
No assembly required.
Brain spoke with wild abandon
Overeager to explain
Where she'd been and what took her s-o l-o-n-g.

It took me by surprise,
But here they were
A confetti of prepackaged syllables.
So I had myself a party, tossing them to the air,
Rolling them around my tongue like lemon drops,
Tart, sweet, clear as crystal, having lollied so long.

It's nice, really nice to have you back—
I'll never say "at my disposal" again.
I'll no longer use you,
I'll *employ* you,
For I've paid dearly for the privilege, trying
To make change with 5-cent thoughts so long.

I ask your permission:
Which one will step forward and volunteer?
Now I am at *your* service,
Grateful you are here again, Words,
Until death do us part and people say,
"What took her?" "So long."

I Get It

Laughing again!
Not blank smiles with no one home
Not a polite grin of propriety
Not nervous titters to cover naked space
But belly laughs of glee.
I'd given up the funny papers after my fall
They seemed confusing—
Not the notes, *per se*, but the score:
The melody line
The rapturous interplay
Of one instrument counterpointing upon another.

But the curtain has been lifted gradually until,
When I heard your joke,
I reacted.
Properly.
This was not, after all, just *any* joke.
Friend, dearest,
You strung together an intricate recipe
Of subtle extracts,
Dainties *à la française*,
Seared on the grille of political innuendo,
Your own private *milieu*.

You don't just "roast", you *flambé*
And I was illuminated.
The reward—for both of us—

Was a great raucous belly laugh.
I laughed a deep, echoing water-well of a laugh—
It felt good to be rinsed of emotional flatline.
So taken with my own hearty melody,
I laughed with scrumptious delight.
I laughed with the spirit
Because the Spirit loves to laugh,
And with the understanding also;¹

And I understand now,
Starved of it for 10 months, how hard-won
Real laughter, deep, cleansing laughter,
Is in this world. Praise the Lord.
Yours was a *Crème de Menthe* fountain special
In a canned-soda world,
The delight frothed-out with a cherry² on top,
Commemorating an emotional *anniversaire*
Called sentience.
You, Dear One, returned me to human being.
I got it.

¹ 1 Corinthians 14:15: "What is it then? I will pray with the spirit, and I will pray with the understanding also: I will sing with the spirit, and I will sing with the understanding also.

² Related French terms:

cher (adj): expensive

chère (f): living well; cheer

chéri (m): dearest

chéri (v): to cherish

xérès (m): cooking sherry

Training the Part

Comb smooth
Verbal directions
Tease apart the process
Section off directives, goals
Ponytail inflection into a hank of non-verbal cues
Catch a twist of uncertainty
Tame panic, untangle urgency.

Projects are no longer a wad of loose ends
To brush aside,
To glare at what is not understood
With lacquered eyes.
Now there's a great sense of accomplishment
In setting it up
And seeing it through.

12

Discover Teachers Helpers Everywhere



"May all your expectations be frustrated. May all your plans be thwarted. May all of your desires be withered into nothingness. That you may experience the powerlessness and poverty of a child and sing and dance in the love of God the Father, the Son, and the Spirit."

– A blessing prayed over Henri Nouwen by a friend

"Say, 'I am easily loveable.' After all, God called Moses—who had a speech impediment—a viable, useful person. Say, 'I am just a little different than when I was created. God still loves me.'"

– MaryPat Parker, Speech Therapist

Dog, Tagged

The dog was all
She got from the split
After her head
Had broken open
But, surprisingly, that was
all she truly needed.



National Tropical Botanical Garden nomenclature plate, a tree's "dog tag".

Tucker taught her to eat:
He would not touch the food set in front of him
Until she had also remembered to fix something
for herself.

Tucker taught her to drink fluids:
When she filled his bowl with fresh water,
She learned to take a glass for herself.

Tucker taught her to take her meds; because
When Tucker got his heartworm pill or a dose of
flea powder,
He wasn't concerned other dogs would judge him for it.

In this way,
Though she thought she was abjectly alone,
This mongrel angel lifted a paw to help.

Thanks to Marie Cooney, author of blog [Tucker Taught Me](#). (See pp. 227-8.)

Meniscal¹ Tear

A couple times a day
The knee would buckle
And I'd catch myself,
So an operation was scheduled.

As I lolloped² post-op into physical therapy
I met a pro-basketball player on the next bench.
Our knees were unwrapped in unison
And we formed a sort of gauze-bond.

I said he gave me courage,
He said I gave him grace!
We'd laugh and count and wince and stretch,
Giving each other grins and grist.³

That young man was all about helping others have
A good time in their gain over pain.
I'd arrive in my Chevy, he in his 'Slade,⁴
The white granite of bone cementing us.

¹ Me-nis'cus: cartilage ring that holds the patella (knee cap) in place.

² Lolloped: to move forward with a bounding, cropping motion.

³ Grist: something turned to advantage, the value forming the basis of a story.

⁴ Slade: Cadillac Escalade.

To a special Timberwolf who allowed me to howl with him.

Primer¹

I'd been reduced
To the verbal monosyllable,
Elemental building blocks of speech
Second grade spelling lists of words, like:

Walk, Sit and Stare.
See, Fear and Beg.
Cry, Hurt and Want.
Work, Long and Hard.

Then I looked into your eyes
That said volumes
Without talking
About the value of advocacy

And about trying again
Even when life becomes really rotten.
You, my teacher, my therapist,
Added words like:

Can, Come and Hope; Speak, Share and Grin.
Good Job and More.
So I added a few more of my own like:
Gain Back and Thanks.

¹ Drafts of this book were copied on the backs of old 2nd grade reading worksheets which helped me learn to read again after my vascular events in 2011.

Tough Love: Parting Words with My Speech Therapist

It's OK.
The reason you are so good
At being you
Is you speak the truth in love,¹
Just like the Father speaks
And clay stands up to listen,²
Like the Son sees hollow eyes³
And breathes⁴ His life back in:
That is the value of your gift to me.

We are in the process of untying our knot:
Teacher encircling pupil.
It's natural that there will be
A few wrinkles
As the bonds loosen
And I take my steps alone.
I am hanging on to letting go
And you are letting go
Of holding me up so long.

So speak the truth in love
In your clear, pure way,

¹ Ephesians 4:15

² John 5:21, Genesis 2:7

³ Luke 7:14-15

⁴ John 20:22

I'll do my best to listen
Without protecting my heart
From your clean, swift blade
Teasing asunder⁵
The "who I was" and "the one I am"
From the "flawed" whom I feared I had become.
Your words must sink through this thick skull

In order to nourish my bones.⁶
And they will,
Like a balm,
If I let them.
Just give me a minute
To drape the fragile skin of humility
Over the bruised pride
Of realizing how transparent I am
Before your trained eye.

These changes you propose
Are a much better fit, anyway.
"When Jupiter aligns with Mars,"⁷
The old song goes,
There is space for change.

⁵ Hebrews 4:12

⁶ Proverbs 3:3-8

⁷ "Age of Aquarius" by Andrew Bird/5th Dimension, 1972.

When brain injury dip
Aligns with estrogen deprivation,
Tears come
To soften the soil⁸

So your carefully sprinkled seed
Can take root⁹
And bear fruit worthy of the struggle
You have graciously shared with me.
So keep telling me the truth
As long as I'm here to hear.
I need you
To honor me that way.
Don't let up.

As your stumbling pupil
Tries to become a peer again,
May your own clear-eyed pupil
Peer into this heart,
See what I am
And share with me
As much as you dare
To bring me
To the truth in love.¹⁰

⁸ Ezekiel 17:8,14

⁹ Mark 4:20

¹⁰ 1 John 1:8, 2 John 1:2,3

Mentor, Friend

Everyone needs a great, good friend¹
One loyal and true sample
Of humanity,
A familiar.

Each of us deserves
One bright shining example
Of surety,
An upright.

Humanity should require
One benevolent companion
Of good,
An intimate.

I needed someone,
One who has shot ahead¹
And pointed the way to where I should aim:
An arrow.

You are that person: responsive, gentle
One who has breathed life back into me
For a better cause than just my own;
A noble.

¹ Samuel 20:32-42.

You are a delight, a benefit, a guiding light
One who has made time for me.
Each of us should have one *you*:
A compass.

Typeset

You were right.
I see it now.
I was centered too far in,
A bookmark,
Too close to the security of
A nice firm binding;
Tucked into the ditch so I wouldn't risk falling
out.
I *wanted* to feel comfortable,
Right,
Having anonymity among measured and
trimmed equals.
But what I *needed*
Was a jog¹ to feel approved.
I was afraid to expose
The fact that all I had to stand on
Was white space.

¹ To tap papers together on their edge to realign.

With appreciation to Physical Therapist, Patti.

Leaving

Everyone falls to the ground eventually
It's inevitable
But for some reason
Of all of us crumpled on the earth
You noticed *me*
And picked me up.
Not only did you assign me value,
You made me worth something again.
Thank you
For pressing me into new service.



Red Maple leaf, North Shore of Lake Superior, MN.

Thank You, Therapist

You've carefully straightened my bent feathers
Fed me easily digested worms
And tough beetles.

You've encouraged me right up to the twiggy edge,
Caused me to look out at the wide,
Wide world again,
The one without your caring safety net.

The future will come,
Day by measured day,
Just as God intends it.

So I give a chirp of thanks as the wind offers to
lift me;
I leap off the edge of your warm thatch
And soar to the cathedral of your hopes and
prayers for me.

This embryo grown,
Its mute mouth wide with hunger,
Has finally found its sweet, trilled song.

Patch, Work, Quilt

This recovery process
This work of improvement
Has been a quilt of therapy sessions
Lined up in rows of solid clear colors;
Assignments with straight edges
Clear expectations
Soft correction,
A pattern for success.

But Life happens, too, Hap-
Hazard pieces
P atch ed in hereAndthere
U n e v e n
Fra Y e d around the edges
Placed by proxy
When nothing else showed up.

The delightful shock of patterns
Given by friends
Mélange overlayed,
Hiding holes
That therapy didn't quite cover;
The gift of stitches made by two needles
Meeting just in time
To make a patch secure.

13

Trust Adjustment Assurance



“I forgot—
So be it.”

– Marie Cooney

“All courage is a form of constancy. It is always himself that the coward abandons first. After this all other betrayals come easily. Those who have endured some misfortune will always be set apart, so one may as well be set apart for valor as for bitterness.”

– Cormac McCarthy, author of All the Pretty Horses

The Gift

A gift (I'll generously call it that)
Was found under the Christmas tree.
It was a gizmo called GPS (Global Positioning
System).

It's true
It was practical. Thoughtful. Needful.
I could, after all, drive to a place
A dozen times,
Each trip, shall we say, a fresh adventure.
I needed help to find my way.
But it took me aback.
I felt transparent,
Like my secrets
Had told on me.
I had a choice to make:
I could feel old
And insufficient
Broken and embarrassed,
Or I could accept this tool
In the spirit it was given
By a daughter
Who is worried when I cannot find her house.

So I opted to be grateful.

I felt overwhelmed at the 96-page instruction manual
The programmable display
And entourage of options.
It had a cord attached,
Which is a sure sign I'm going to feel intimidated.

So I opted to ask for help.

My husband input my regular haunts
Friend's addresses
Family locations
He likes to do that sort of thing
And frankly, he knows the gaping shortcomings
In my orienteering and programming skills.

I opted to say OK to a technology that
Scares me to death,
And bravely sat while he gave me the ultra-short course
And follow-up review.

How will I attend
To a screen
To the road and
To 4 rather large, and up to now, pristine fenders
All at the same time
When drivers are zooming around me
With iphones in one hand

And a smoothie in the other,
While I feel sandwiched in?
I hate to seem incompetent.
But I hate to be isolated even more (what a pickle!),

So I opted to say I will try it out and see if it will help.

The maiden voyage
Was with an 88-year old copilot:
My mother, with the razor-sharp memory
Patient wit and wise calm.
Destination: my sister's house.
I packed Sister's freshly reiterated instructions
Chocked with detail,
Just the way I need them,
In my lap.

Three crutches:

Map
Word's-eye view
And Mom— who is

My “Hot Chicken Soup” in the passenger seat—
Ready to set me back on the straight and narrow
In case the new machinery won't work for me.

But it does,
And I see the benefit
Of the thing adjusting the scope of my journey
If—when¹—I make a wrong turn or miss an exit.

So I opted to let it do some of the decision-making
for me.

I finally felt able,
After the glow of a successful trip,
To write a proper thank you note
To a darling daughter
For giving me wings again
And a safety net all in one.

I had a good visit with my *sisster*.
I had *misssed* her.

I think I'll opt to go see her again.

¹ I Corinthians 15:10: “But by the grace of God I am what I am, and His grace toward me has not been in vain.”

Note from Home

Will I give You permission
To change me, God,
As deeply as You want?

The reason You have told me
To count it all joy
Is not for the lesson's sake,

But because of the result You intend:
That I may be complete,
Entire, lacking nothing.¹

So do with me as You will,
That I may count with my flawed mind joy,
While the internal clock is being repaired.

¹James 1:2-4: "My brethren, count it all joy when ye fall into divers temptations; Knowing this, that the trying of your faith worketh patience. But let patience have her perfect work, that ye may be perfect and entire, wanting nothing."

Reservoir

"I used to be ____"
"I used to do ____"
"I used to ____"
Fill in the blank
There are plenty to choose from.

Part of learning to speak again
Is discovering
What to pack in there
Mastering
What to let come out.

"Here's how I do it now."
"This is my best today."
"It's good enough."
"I'll give it a try."
"When I need it, I'll ask for help."

When there is a blank—
And there are plenty—
I fill it with a smile
There are plenty of those now
To choose from.

With thanks to MaryPat Parker.

I Feel a Draft

I cannot do it all.¹
Yet, leaving things to the winds of chance
Could scatter the results of a lifetime of effort
irretrievably.

Then again
It seems as likely
That all will be devastatingly swept clean

As that a vortex will find me,
Pull me in
And tidy up all my loose ends:

Either way,
Entropy² or enthalpy,³
Freeing me for new adventure.

¹Prayer is a request to the God of Order, an opportunity to override the Law of Entropy.

²Entropy: A Law of Physics that states that everything tends to disorder.

³Enthalpy: the sum of the internal energy of a body and the product of its volume multiplied by the pressure applied.

In the Waiting Room II

It took a while
To become *me*
This one I thought I finally was;
So if it takes a while to find her again,
It's worth the struggle.
Perhaps I can send out scouts
Or a flare
To help her on her way,
Then I'll quietly
Get to know
This one
While I'm in the waiting room.

Re-becoming

Today I stepped on the very brick
Where I fell.
It was re-set,

And I stood amazed
At how much like myself I, too, have re-become.
I'd avoided that brick 'til now that I know

At least *some* of the end from the beginning.
Can you see I'm still me,
Even when I've grown so much?

I Am Still Me

Look past the slight limp on cold days
Ignore my
Pauses when I am fatigued
For I am still me, my friend.

See beyond my indecision
When there are too many choices on the shelf;
Know I may have to make a U-turn up ahead,
Gracious stranger, for I am still me!

Remember, I must have a patient explanation,
And time to write it down. Noisy chatter
Derails me. I need a clean landscape to chug ahead
So I can still be me.

14

Reclamation
Preparation
Confidence
Comfort



God recycles;
He made *you* out of dust.

“Bold Scripture & Truth” Sunday, August 7, 2011.

Fresh Fruit

Life in orderly rows,
A packed calendar
Full and heavy
As a rotund watermelon
Huge
Significant
Resonant
Complete

Falling to the ground meant
Smashing into
Several rather large homely pieces¹
The same parts as the whole
But more accessible
Raw
Exposed
Unknown
Unexpected
Surprisingly. . . sweet.

Delicious words spilled out, trickling away,
but also
Juicy thoughts gushed forth,
Carried the whole time,
Just unable to escape my tough rind.
Directions to places,
Destinations, important or not,

The sense of time and place,
Are still fractured;
But the succulent flesh of life
Can now run down my chin
To tips of elbows
And be truly enjoyed.

¹Figuratively speaking. Mine was a closed head injury.

Weeding the Collection

At first it seemed more like a yank
Meant to tear me right out of the book,
Which would have rendered me useless,
Relegated to Withdrawal from the Collection.

But who is to say that this bone-jarring event
Reinventing my existence was not
Orchestrated from the foundations of the world
And laid to rest as a pixel on my page?

As I heal, I discover it is more than just a dot,
This period,
Placed to prompt me to quit running long
And start fresh.

This wrinkle in the time that is my existence
Is mendable.
Even if it takes more than a little Scotch Tape[®],
I am useable again

Although I am not as pristine as I once was,
I am patched up
Both more wholly vulnerable
And more durable.

Dead or Alive

Some say
The only difference between
Being dead or alive
Like the poster says
Is that to be dead would mean
No more head-banging pain,
No more embarrassed looks from friends
Or pity that passes for love.

But I see that to be alive
Means the chance to write one more sentence,
To bring someone else,
Weak from pressing against

His own threshold of pain
To where we both are at this moment,
Grasping at love that comes by,
Passing the test for endurance,
Remembering pangs of hope
Gathered up from friends
Like a bouquet at the Olympic finish line.

So I offer this small sentence
As if it were a carefully woven laurel wreath:
With great pomp I place it on your head
And say, "Well done."
If that's what I'd be missing if I chose today to die,
Then I guess I'll stay awhile.

... .. *you* run on by,
And fall as well,
Then finally crawl to the finish line
With bloodied knees
And eyes that see what others miss
Down here where the playing field is level;
With cinders under fingernails
And swollen hearts that cry,
Let it be said we cheered each other on
And said, "Well done."

Philippians 3:13b-14: "Forgetting those things which are behind, and reaching forth unto those things which are before, I press toward the mark for the prize of the high calling of God in Christ Jesus."

15

Growth Acceptance



“‘Why?’ Indeed¹.”

¹ Without any question, truly, used to express irony. [It is important to examine everything that has happened to us, and use it for our growth.]

– Angela Hunt

“It is never too late
To be what you might have been.”

– George Eliot

“She came to at that narrow moment where leaving the past as far behind as it already was seemed the only appropriate course of action, where only peace could make more peace, which was exactly the kind of peace she needed.”

– Angela Hunt

The Road Not Taken¹

At 9:43 a.m. on the route from car to work
A still small voice mentioned, "Step over here."
I couldn't imagine how 2 steps in a wider arc
 would benefit me,
So I chose my original trajectory, stepped in a
 hollow of swirling snow
And caught my hurrying toe on a raised brick.

Come to think of it,
I've never blamed myself for a 20-minute con-
 sciousness gap,
Whiplash or cracked sternum cartilage,
So why would I blame God, Who, instead of saying,
 "Told ya so,"
Made something unexpectedly good out of the pieces?

And I didn't expect, just now,
Knowing what this experience has done to me,
That I would wonder so hard,
Given the choice again,
Would I willingly take that other path?

¹With thanks to Robert Frost.

Falling, Finally

The end of the world
Did not come with an earthquake,
Or cataclysmic upheaval
But only with the thud
Of a single person falling in slow motion
On a soft blanket of falling snow.

It was the subtle end
Of a very small world
Anticlimactic
Compared to the apocalyptic version
Of lava floes overturning the traffic flow,
A riot of screaming people on the silver screen.

Some of us have a stroke
And lose what we are sure is everything
In a moment;
Others of us have to let go gradually
On our grip
Of whom we have been.

Gracefully giving up or giving in
Does not seem to be the American Way.
We hear inspirational stories
About "fighting cancer"
"Refusing infirmity"
And "cheating old age" in a culture perennially young.

Yet, gracefully yielding way allows us
To continue to thrive,
Keeps us the teacher, not the victim
(From whom we desperately
Want to keep our distance,
And everyone else does, too. Except Jesus.)

His disciples admired a body of human work:
"What a beautiful temple," they said,
Referring to a structure, a design money bought
And commerce was capable of producing;
An orientation engineers reckoned
For sunlight to blaze on its Western Wall.

But Jesus pointed out,
*What are the stones you have piled around you?
What will you do when they all tumble over?
What if you come back,
And they are no longer
In the neat stacks where you put them?*

And then He revealed,
*The Father is concerned more about
What is nestled below the gold
Hidden under the make-up
Residing beneath the flesh and blood
Than the fortresses humans build of themselves.*

His intent is to undo us,
To show us, when all our achievements
And degrees are no longer meaningful,
That what is left of us is still worth keeping.
God looks
At those broken

Haphazard plain brown blocks
And rejoices—
Not at our undoing,
But that we are finally ready
For His building process
To begin.

Loader at Commercial & Hawaiian Sugar Company (C&H Sugar) processing plant.



Dumped On: A Heavy Load

Probably the biggest word in all the world
Certainly the one
That carries the most weight
Has the heaviest baggage
The grandest entourage of
Excuses reasons accusations
Is one of the littlest, mightiest words:
“Why?”

Not, of course, when it’s used,
“Why dear, you’ll catch your death”
Or “Why do steam engines need railroad tracks?”
Not those kinds of why,
But the sick-feeling “Why-didn’t-I _____?”
Or “Why-did-I _____?”
Fill-in-the-blank kind of Why,
And the “Why did this have to happen,”
Especially when followed
By the participial phrase
“To me?”

Which is to suggest,
“Why am I, of all people,
Suffering?”
Or “Why is he or she?
They are my loved ones, you know.”

In case we’ve forgotten
Jesus reminds us
We’re all in this together:
“In this world
Ye shall have tribulation”
(That’s thee and thee and me)
“But be of good cheer,¹
For I have overcome the world.”

God,
You are not
A wasteful God,
So the excruciating effort
You went through
To get me here,
At Your mercy,
Must be for Your glory.

With thanks to Ellis Noone

¹ John 16:33: “be of good cheer” is perhaps better translated from the Greek (Thars-é-o) as “you must take along courage.”

16

Comments and Thoughts for Discussion



“Still writing, after all these tears.”

– Angela Hunt

“We don’t know what we don’t know.
We must learn from those it’s happened to.”

– Physician for Arizona Representative Gabby Gifford who was shot in the head. From ABC-TV special 11/18/11 with Bob Woodruff, who also had a brain injury, so he delays, too.

“Brain Injury can be harder on families than on the patient, because they have to pick up the injured person’s duties, and help with recovery, too. Families need good resources.”

– David A. Santella, M.S., L.M.F.T.,
Marriage and Family Therapist and Brain Tumor Survivor.

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Disclaimer

This discussion section is not meant to be diagnostic or a substitute for care by a health professional. These are laymen's thoughts and observations from recovering people's own experience to create awareness and open a forum on brain injury. Personal experience may vary widely among individuals who have suffered traumatic brain injury or stroke. No promise or cure is implied or legal advice is intended, but is informational only. For help with personal questions, consult a health care provider, legal professional, social services worker or other resources noted.

Coming to Terms

Abbreviations used in the Comments & Thoughts for Discussion and Appendix sections:

ABI = Acquired Brain Injury
ADA = Americans With Disabilities Act
BI = Brain Injury, concussion or brain trauma
CRP = Community Reintegration Paraprofessional
EMDR = Eye Movement Desensitization Reprocessing
IC = Insurance Company
ILS = Independent Living Services
PCA = Personal Care Attendant
S = Stroke
SNT = Special Needs Trust
TBI = Traumatic Brain Injury
TIA = Transient Ischemic Attack ("mini-stroke")
WC = Workman's Compensation

Comments & Thoughts for Discussion

Author's notes to the reader are in *italics*. Remarks by other contributors are in quotation marks (“ ”) with attribution.

Section 2: Naiveté, Innocence, Bliss

..... page 11

Chanj is Gud (p. 12): After injury, there may be a sudden or over-days change in communication skills, including spelling, decoding, typing skills, syntax, pronunciation, word substitution.

Caregiver: Watch for unusual word choices, garbled speech, slow processing time, and report any oddities to a health care professional. Provide to the patient a method to communicate, whether it is with pencil and paper, flashcards, extra uninterrupted time, or a familiar word processor. The practice of texting has removed spelling rules in favor of phonetics as an option for those who have speech or writing deficit. Be on the alert for unconventional messages, and enjoy the unexpected humor that can bubble out.

“Interact with children: ‘Can you spell words? Then you help me when I ask, OK?’ To an adult: ‘Eunice, I’ll need help with the spelling of your name.’” —Deborah & Marie

Robert Frost With TBI (p.13): New experiences lend a

twist to long-remembered snippets of information. Employ these artifacts of memory to help the patient describe present circumstances and feelings.

Caregiver: It is a challenge to ID vision changes, but the presence of headaches may be a clue there have been changes. Faded, blurred vision, perception problems, and focus issues may present themselves. Keep walkways clear and mark step edges. If the person processes something different from what is actually there, help him make sense of visual and verbal stimuli by describing a setting for his comparison, or offering writing rather than speech.

Librarian’s Pick: Blink: The Power of Thinking Without Thinking, by Malcolm Gladwell.

“A traffic accident gave our adult son a year in a coma. For coma patients, passive-exercise *everything*. Flick lights on and off to get eyelids to exercise. A doorbell can get the head to turn. Just like babies, as patients progress, crawling can help the speech center as well as the process of learning balance and eye-hand coordination. Stick with it and give people hope. He’s got his sense of humor back and is walking with a walker down the block now.” —Eunice

It’s In My Blood (p. 14), **No Worries, Mate** (p. 15): After a latency stage, learning to embrace the BI or S personality changes and gifts from the “new” person can be both a challenge and a blessing; BI persons might shift from left-brain to right-brain dominance, or extrovert to introvert. It is possible that great maturity and grace could result from the recovery

process even if anger, rage, belligerence, depression, quick frustration, or being weepy, bewildered, or overwhelmed are exhibited in the process of getting there.

“For a week I was in the balance. No one was sure I would live. No one told me what to expect with a brain injury. When I got home, I thought, ‘I’m fine; everything else is the problem.’ I wanted to feel like myself again, but didn’t know who I was. A person tries to be who they were, but that is not easy work. ‘High-functioning’ is not who you were the day before the accident; ‘competent’ was.” —Cathy

Caregiver or Caretaker? (p.14): Even a “bump on the head” can bring deficits in memory, verbal fluency, naming and reasoning. These symptoms may improve over time, but long-term accommodations may be needed.

“The wife and sole caregiver of a S patient was hospitalized herself, for exhaustion. While she was recuperating, a long-distance daughter who didn’t even like her father very well—and her stepmother less—was granted power of attorney at the hospital, no questions asked. It took a lot of legal work for the wife to get power of attorney back to do the best possible things for her husband.”—Betty

Consider getting legal advice for a SNT if a family member is unable to support himself physically/financially or for a child with long-term disability. Ask about the nuances of Durable or Non-Durable Power of Attorney.

See also **Heart to Heart** (p. 31). S or TBI can be an elusive

diagnosis in that sometimes people aren’t even aware they have had one, and sometimes the medical community doesn’t think to look for it even if the patient presents himself.

“Find a good health care professional. Recognize with ‘concussion’, you are in a new brain now. Differences may or may not happen, but you need to know the information about what symptoms could appear. It’s like a prescription: all the side effects are listed even though the patient may not experience any of them, so why not express as many of the possibilities about BI to patients as we now know?

People aren’t going to *try* to have debilitating symptoms that carry the stigma of brain injury. Different levels of injury have different experiences, rates of recovery and outcomes; medical professionals need to listen to patients and work as a team.” —Charity

Librarian’s Pick: How to Speak and Listen Effectively, by Harvey A. Robbins.

Caregiver: Keeping appointments, identifying what’s wrong, managing the advised care, filling out forms, can seem insurmountable. (See Appendix for help.)

“Advocate for the patient when a WC or IC is assigned to ‘help with paperwork’ at the one-year mark after the accident. Ask yourself, ‘Where was that person when the patient had trouble remembering his own name and address for hospital forms?’ Evaluate: Is IC’s sole motive to make sure the patient has the extended care needed, or has he been directed to shrewdly sign off and close the case? The patient has the right to patient-doctor confidentiality: is the WC or IC inappropriately

wedging his way into doctor visits? Massaging statements made by the clinician? Be alert, because the BI person's thought processes at this stage are no match for *anyone's* legal savvy.

For impartial help, ask your doctor to refer to County Social Services for ILS to help with paperwork and bill management; an occupational therapist to reteach functionality or to assess for assistive devices; a skills worker to reteach tasks, manage cleaning, develop plans to function in the existing living space; a PCA to assist with dressing and grooming." —Charity & Marie

Librarian's Pick: Windows with Birds, by Karen Ritz, for addressing relocation/changed living accommodations.

"Moving is cognitive chaos. Balance time in the mess with time in nature." —Marie

No Worries, Mate (p. 15): ..."Flashes of brilliance..." Sluggish thought processes may limit contributor or problem-solver roles. But TBI/TIA sufferers may also close their eyes and see flashing lights, brilliant fractals, tessellations, interesting patterns, perhaps even mathematical equations becoming solutions as interrupted sunlight hits closed eyelids on a drive through trees, for example. These may start out as frightening episodes something like a *petit mal* seizure, but their sheer beauty and speed make them fascinating, and the anomaly might be missed as the person recovers.

Incontinence (p. 16): Embarrassing symptoms may not be

identified to a doctor—until a medical question is specifically asked. The patient may only mention symptoms after they begin to improve—because it is a *change* afterwards that gets Patient's attention.

Try drinking more water; a result of reduced output is bladder infection. Try Kegel exercises that help firm up the perineal area. Try not to lift heavy objects for a while to reduce strain in the brain as well as upon the bladder. For help with swallow reflex, make thickened drinks with yogurt/protein powder & a juicer; gelatin or psyllium-thickened liquids.

Family: How to recognize there might be a BI? Consider new behaviors/conditions that surface: missing behaviors, changes in perception; financial life: uncharacteristic or impulsive decisions, trouble remembering money issues, disorganization, lack of functional daily systems.

If you think you may have an undiagnosed BI, ask your friends and family:

- Do you see a difference in me since (date)?
- What specifically are you noticing?
- Do you see _____ in me (specific attribute: forgetfulness, clumsiness, lack of attending; change in penmanship, spaciness, poor personal hygiene; dressing inappropriately or without much care)?

Bring these findings to a neurologist. Note changes in yourself. Be specific: "I got lost going home from work twice last week. When I found my street, I parked in my neighbor's driveway."

"Creditors can be told of the TBI, and the need for leeway on payment deadlines as part of the permanent record of account in the spirit of good customer service, businesses can waive

late fees. There is a court precedent for ‘No late fees’ for one memory loss patient.” —Marie

Salle de bains (p. 17): Besides personality traits, basic abilities like swallowing or holding urine can be affected, depending upon seriousness of the injury, affected location in the brain, previous health of the patient. If swallow reflex is delayed drink more liquid before meals to improve esophagus function. For coughs during meals, try reducing sugar intake and adding acidophilus to the diet.

Uncertain (p. 18): Are you forgetting things, faces or objects?

Caregiver: If “This is not normal!” comes to mind, seek medical help. Re-introduce yourself to the patient. Don’t say, “You remember me, don’t you?”, which causes stress by putting the patient on the spot. Rather, enter the room with, “It’s your daughter, Elaine, bringing you lunch.”

There is a kind of beauty in forgetfulness, according to **Genius Species** (p. 18): grudges and slights are not remembered along with forgotten vocabulary; what was planned to do stays guiltlessly silent in a file drawer. There is a strange but remarkable opportunity for metamorphosis when both cultural expectations and perceived failures are erased.

Librarian’s Pick: The Magic of Groundhog Day, by Paul Hannam.

“(Enthusiastically) “I’m not ‘all there’, but I’m totally ‘here’ [present in the moment]!” —Sanh

Take Me (p. 19): A patient may fear loss of social status and inclusion.

Caregiver: Reassure the patient he is still a viable part of the family. If he has been active in a group, keep him involved. Even someone recovering might help fold newsletters and seal envelopes. See also p. 95.

Librarian’s Pick: The Genius in All of Us, by David Shank.

Dizziness discussed in **Lodestone** (p. 20) can be a common problem after TBI. A neurologist might discover the hairs in the middle ear responsible for balance have been disturbed by the force of a fall; if this is true, one remedy is for the doctor to reposition them with a tiny “vacuum cleaner”, and most of the vertigo abates. Physical therapy provides coping and retraining for the rest.

Cohort (p. 21) and **Spirit of Generosity** (p. 21) speak to the need for peer unselfishness and adjustment in the workplace, especially during the patient’s hyper-recovery phase after an injury. Assign low-stress and repetitive tasks with limited exposure to the public, yet allow possibilities to relearn the former job, with hope functionality will be regained. The person may help update the personnel manual, for example, to relearn policy and procedure.

It worked for me, with thanks to Carver County Library System. Give the time needed to be able to return to being a fully functioning team member. After the “new-normal” skillset is assessed, a new permanent job can be provided, if necessary. Two years is a common benchmark.

A one-eyed squirrel would have a lack of depth perception and a poor sense of balance. Paranoia can prevent a BI survivor from being as willing to pitch in as before. Supervisors can set the tone by personally inviting the employee to fully participate.

“Everyone was watching me when I returned to work. I felt sure they were looking for mistakes or a reason to fire me. I felt like I was in a fishbowl.” —Jean

“Co-workers ‘walking on eggshells’ when you return to work is common, but holding a BI worker to a different standard of proficiency or scrutiny after ability has returned is another matter. If a different job becomes a necessity, Workforce Center: Disability Rehabilitation Office will help evaluate, retrain, partner for job searches, coach interviewing techniques, help overcome stigma attached to BI, address employer relations, identify limitations through the ADA context, and develop reasonable accommodation.

The WFC works on answers to the question: ‘What resources would make this person successful on a job?’ Get advice: ‘Do I disclose I’ve been BI’ed to a perspective employer who might not understand what that means and assume I am not functional, when I am highly functional, but have some flukes when tired?’

Befriender Volunteer Program/Brain Injury Association is for people who go back to work, and continues for 2 years post-injury. 1-800-669-6442.

I went back to work too soon. I required 14 hours of sleep to recover from a 1-hour meeting.” —Marie

“Ask your current employer for ‘reasonable accommodations’ through the ADA office. It is a struggle to stay working but an even harder job to try to get disability once you are fired. I’d like to work, and think I have something to offer, but do you know how hard it is to get another job with a history of brain injury?” —Patty

The Department of Human Services/Public Health could be an advocate. Pamphlet: “Head Injury: Information & Answers to Commonly Asked Questions” by Center for Disease Control; “Understanding Brain Injury: A Guide for Employers” by Mayo Clinic.

“For more difficult cases, besides ‘reasonable accommodations’, a WC lawsuit will be litigating over ‘compensatory strategies’, ‘reasonable accommodation’ and ‘facilitation’. Get a referral from a satisfied BI person before signing on with an attorney. Choose a law firm who knows disability law and understands BI—not just disability in general—and is willing to do the work of representing you.” —Marie

Speed Bump (p. 22) and **Theological Question** (page 23) shows that not just you, but everyone who has a life-altering injury asks herself the same soul-searching questions. You are not alone in wondering why your event happened, and where you will go from this point. Be encouraged that some sense will eventually come from a senseless act. Wisdom can come from BI; meaning can return to your life. Watch for fear of failure.

“Being around others with TBI gave permission to admit what was already happening to me. It is the first time I’ve talked about my BI—there, I’ve said it—to anyone. I didn’t want it to define who I am.” —Cathy

- Who are your role models now?
- What are your concerns about _____(current needs)?
- What fears do you have about your future? If you are considering setting up a foundation to address long-term needs, research tools are available at a county courthouse Law Library.

“Learn all you can before hosting a fundraiser for hospital expenses or a specialty van, for example. If a fundraiser is publicly advertised, ‘accountants’ may show up at the benefit, and if checks happen to be made out to a family member instead of to a foundation, the family has 10 days to turn in these ‘inappropriate funds’ or risk a hefty penalty. The assumption is the family will ‘forget’ to pay tax on the donations.” —Eunice

Get advice on SNT and naming a trustee. Anticipate how insurance needs will change. Do you qualify for long-term care insurance? SSDI (Social Security Disability Insurance) may deny a rightful request on the first round, even when your application seems comprehensive to you. Appeal a denied request, adding more documentation as it becomes available. Some patients have had claims denied up to 4 times, and then been accepted on perhaps the fifth try.

Librarian’s Pick: God Isn’t in a Hurry: Learning to Slow Down and Live, by Warren Wiersbe.

Theological Question (p. 23) is meant to reveal that asking basic but profound questions will help to teach professionals and caregivers what is needed to work towards regaining patient skills. Limited communication ability can also help distill information into urgent requests or bedrock statements. What is the question you have been burning to ask God? (I’ve *heard* He doesn’t mind some honest anger.)

*My husband unknowingly made me become a proficient, accurate speaker again after S, because he could not decipher my “creative” use of the language, in **Up the Creek Without a Spoon** (p. 24). At the time I thought he was obtuse. But 20 years after S, with my TBI, I realized he is on the Asperger’s Spectrum and also needs understanding. He truly wants to be compassionate, he just couldn’t decipher my aphasia/Semantic Word Substitution. (See **Substitutes** on p. 37).*

For cognitive task help, try Independent Learning Services through Courage Center which helps people with life issues, and has an advocacy component. Recognize all resources are finite with any sort of assistance, so reapply at a different time of year if a program is not currently available.

Ask, “How’s my relationship?” You’re doing occupational therapy and cognitive therapy for yourself, so don’t be too proud to get help for your marriage, too. A reality:

“Most marriages end 3 years post-injury, when the patient’s improvement begins to level off. With ABI, some people may lose knowledge base, confidence, status, career AND 25 years of invested emotional existence. That’s a lot to fight back from.

It's a good thing anger can be a powerfully motivating force [to get back on one's feet]." —Marie.

Linguistic competence can break down even with mild injuries. Realize that when a significant other lives by logic and has no clear diagnosis for you from a respected health care professional, he may try to deny ideation, make an effort to force the patient back into the previous state of being, or try to belittle descriptions of change from the patient.

"70% of marriages fail after a brain injury because the spouse cannot understand or bear the changes manifesting in the patient." —Charity. See also **Stale Mate**, p. 50.

Make an effort not to be a statistic. For self-help with marriage issues: <http://www.serverfirefighter.org/catalog/2009/index.htm>, feature film "Fireproof" (Kirk Cameron), with accompanying book Love Dare by Stephen Kendrick.

Be gracious to each other. It may require learning a new language from Patient as well as seeing Caregiver more generously.

"We're still married (45 years), and after TIA, appreciate each other now more than ever." —The author. Transient ischemic attacks can occur in TBI patients after significant progress has been made, and can be temporary.

Librarian's Pick: Asperger Syndrome and Long-term Relationships, by Ashley Stanford, gives insight about the TBI patient as well.

"Kids with their limited vocabulary get it. But sometimes I just don't say anything around adults, especially when what comes out is, 'That dog is in the front yard of that car.'" —Deborah

Section 3: Perplexed, Frustrated, Lost

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Shaken, Not Stirred (p.26) and **Retrospecting** (p. 28) are attempts to show both the fractured thinking of a brain injury, and the difficulty figuring out how to put the observance into words. Having no awareness of *any* pain at the time of a serious event could be a tip the brain has been injured.

I initially did not feel pain from my injuries but put a simple bandage over an exposed patella (kneecap) and didn't recognize seeing bone might be something requiring more attention. There was initially no complaint of headache. However, four months later I was able to express—haltingly—that behind a fractured ocular (skull bone below/around eye socket), beneath the tenderness of a crushed nose, under the pain of my torn shoulder and below the complaints of my patella, there was dull and abiding headache pain. Had my neurologist used the single symptom of headache to identify presence of concussion, I could have been sent home without the proper diagnosis.

Don't minimize the injury because pain is not present: see a doctor who will look for BI. See also **The Diagnosis: Mild to Mid** (p. 30) for additional possible indicators.

Caregiver: Ask careful and specific questions. A BI initially can continue to worsen over a week or month. The patient might present at the time of initial diagnosis appearing externally unharmed, but the injury can advance beyond patient coping skills over time, or may be more apparent to others than to the patient. Direct to the

emergency room or doctor to see if there is closed head injury. *Tell your story to help caregivers understand, and to help others get a diagnosis when they need it.*

“Because TBI is difficult to diagnose, too often it is misdiagnosed as an ‘emotional problem.’” —Cathy

Eye to Hand, Hand to Mouth (p. 27) Eye-to-hand coordination can be a major problem after BI. The poem tries to express libido and spatial changes due to TBI. Be aware of the possibility of additional injury due to distance-gauging difficulties: *I poked myself in the eye with the vacuum cleaner hose getting it out of the closet because I couldn't tell how close it was to my face, resulting in a scratched cornea.*

Libido, like sense of smell, may be absent during recovery, especially until emotional sentience returns. The fear of not being able to catch or give appealing cues, or of sending mixed messages, can add to the concern that they are now sexually unattractive.

“The herb black cohosh is offered as a nutritional supplement to help women's libido return.” —Richard Froehly, DDC

“B-12 for men.” —Byron Richards, CCN (Certified Clinical Nutritionist). See also **Pedal to the Mettle** (p. 62).

Librarian's Pick: Waiting: A Memoir of Trauma and Transcendence, for a discussion of impotence and sexuality after BI.

“BI makes it difficult to gauge traffic flow while driving, causing you to cruise too close to a bumper, letting the car drift across lanes or lagging behind the prevailing speed.” —Tammy

Courage Center 763-520-0312 offers unofficial driving tests on an off-road course to help determine if you are fit to be behind the wheel. Local Driver Evaluation for people with disabilities: <<http://www.adaptiveexpert.com>> 651-501-5680.

“EMDR (see p. 248) exercises developed by Francine Shapiro helped me to calm myself when I thought about the trauma of my accident. It brings in both parts of the brain to deal with the trauma through specific strategies without the problem of having to relive the experience. This has been of help to people in combat, and to first responders, too, needing help with Post Traumatic Stress Disorder (PTSD).” —Barbara

“When noticing where you are parked in an unfamiliar place, move your eyes side-to-side every ½ second for 3 seconds while standing in place. ‘Besides noticing details about the surroundings, the simple eye movement may increase your long-term memory by up to 10%,’ say researchers at Manchester Metropolitan University in England. ‘That little extra boost might be just what's needed to help you recall an important piece of information,’ says Andrew Parker, PhD, the study's lead author. (From “7-Step Solution”; “Health Magazine”, May, 2011.)” —Connie

Retrospecting (p. 28): “Rhythm and music are located on the right side of the brain; speech and language are located on the left side of the brain. This was why I was able to still sing [after my left-quadrant stroke], even though I didn't remember my own name.” —David, Opera Singer.

“Bring a person with you to appointments as a second set of ears.” —Betty

The message of **Retrospecting** (p. 28), **Home from the Hospital** (p.29), and **The Diagnosis: Mild to Mid** (p. 30): Don't assume just because external injuries are healing that the brain has also repaired. Once bones are set, the patient may finally have the opportunity to assess that something else is "just not right". Remove the notion that if there is no blood, the person must not have suffered injury. Closed head trauma is rampant in our society due to falls, traffic accidents and sports injuries.

Home from the Hospital (p. 29): Seven guidelines when visiting stroke overcomers or those convalescing:

1. Listen attentively to each word. 90% of good conversation is listening.
2. You aid recovery by visiting.
3. Keep your visit short. People tire easily.
4. Make sure that the patient can see your eyes and mouth for help with non-verbal communication cues..
5. Follow hospital instructions. Cooperate with hospital staff chores.
6. Bring flowers, a gift or a card if you wish, but your visit is enough.
7. Don't try to give medical advice, just encouragement.

—With thanks to Pastor David Quam, author of Wipeout: Memories of a Stroke Overcomer.

Additional thoughts:

8. Consider bringing a simple guest book so the patient can be reminded who has come to see him.
9. Introduce yourself ("It's Linda, your eldest daughter.")—even if you are a family member—to alleviate confusion. Don't make the patient guess or search for clues.

Ask for a social worker before you leave the hospital to direct

you to appropriate out-patient services and assistance. Realize the hospital social worker will only be available to you as long as you are in the hospital, so have a plan of care set up before discharge.

The same is true for the hospital chaplain: ask for a referral to a caring community that could offer a support system during recovery.

Ask at the Patient Information Center of the hospital for printed material about your condition to hand to friends and family. Coming home without a safety net of trained staff can feel unnerving.

"Before sending a patient home, someone should assess the capabilities of the potential caregiver." —Barbara

"'Caring about' is different from being good at 'caring for'." —Marie

"The hospital transferred my husband to a nursing home for rehabilitation. It wasn't a good fit—and he fell twice. Once discharged, his entire care fell to me, and the hospital wouldn't accept him back except for a 72-hour hold for time to find another facility with one-on-one care." —Betty.

Pamphlet: "Where Do I Go From Here—Besides Home?" from Paper Crane Mentor Volunteers Association 1-800-669-6442. What is necessary for my particular needs and situation?

Get a case manager from your county social services office. Categories of resources:

- support groups for specific issues,
- socialization needs,
- consumer guides,
- durable equipment advice,

- re-entry services.

Ask a social worker about waiver programs called ILS, TBI Waiver, CADI Waiver for a range of services.

“With each encounter ask, ‘What do I want the outcome to be?’”—Cathy.

It’s OK to take part in the services offered. “If there’s no advantage to being disadvantaged, what’s the point?” — Anonymous

“A future doctor should be told about Patient’s history of TBI before any further surgeries: patients may have a greater incidence of CODE BLUE events, take longer to come out of anesthesia—up to 6 hours or more—and be more combative in recovery.” —Charity. 1-800-HELP-TBI for more information.

Heart to Heart (p.31): “I’m a former teacher. It took me 10 years to feel ready to tackle relearning to read, but I’m reading again—and training and mentoring others.” —Barbara.

Don’t be afraid to advocate for yourself. Unless given cause to do otherwise, the IC and WC systems will opt for an acceptability standard of 5th grade literacy and math skills. If you have a job or avocation requiring specialized abilities or higher skill levels, a neurologist has the right to include those disciplines in remedial therapy orders.

Caregiver: Patient frustration with communication may make a sense of urgency or concern about being believed look more like aggression. Stand *with* the patient rather than making him feel he has an adversarial role.

Watch for an inability to gain clues from context, poor processing skills, fear of being “discovered”, rapid fatigue and amnesia; all are displayed in **Down the Rabbit Hole** (p. 32).

“Emerging awareness battles with cluelessness, panicked thoughts loop, and swearing can surface. You know it is ineffective, but can’t stop. When there is a renewed awareness of affect, one is able to change behavior with persistence.” — Marie. (See also comments about **Retrospecting** on p. 173).

Spuds (p. 33) and **Needy** (p. 35) indicate awareness that something that had changed was starting to come back into focus, but emotions were only beginning to regroup: Do you have a concern about a TBI diagnosis and what that might mean to you professionally? Do you feel worried about the future? Are you concerned about whether losses can be regained?

Caregivers: Be alert to a patient’s nonchalance about urgent needs, faulty choices, over-arching dread, or paralyzing fears.

Note: *Had I not had a diagnosis—and a prognosis of improvement—I would have quit my job because I couldn’t perform it at that moment; my employer would not have had any reason to change that choice or become educated about BI, and I would have felt completely confused and demoralized about what was happening to me. After the accident, I became fearful of returning to work because what seemed easy before was impossible at the time, and I couldn’t imagine ever regaining all the skills required to be productive.*

As it was, my neurologist urged me to “get back in the saddle” by working very limited hours, and being fully engaged in re-

gaining skills, which was the optimum course for me. My employer graciously agreed and made every possible accommodation for my success. Don't assume every employer will do that.

Librarian's Pick: A Funny Thing Happened on the Way to the Future: Twists & Turns & Lessons Learned, by Michael J. Fox.

"Crying releases healing endorphins to the brain." —Marie

There were plenty of opportunities to feel inadequate, used up, or separate of time and place: **Tools** (p.34), **Boo!** (p. 34). Learn to gauge how long you will have energy to work/pay attention/stay awake." Patient may feel keenly inadequate to the task.

Caregiver: Get the person's attention before conversing. Provide technical information in very small bursts. Allow for lots of rest breaks.

"I'm a teacher who had TBI. July is for *me*. Teachers know it takes June to recover from school, and August to build up to going back. For me it is building up courage: I can't read aloud and eavesdrop on whispering anymore. One student can help me, but not all 32 at a time. I can only deal with so much, so I talked with my second grade school kids: 'This is the way my brain works now.'

Kids understand everyone has different abilities so they are OK with it. One kid counseled earnestly, 'You need an IEP (Individualized Educational Plan).' They realize not being able to spell shouldn't be used against me. Another one said, 'Are you having fun?' because he thought a 'creative' answer to a problem was

sometimes better than the 'real' one. For this reason, I don't correct spelling in my music class. Wrekuns= raccoons: if the thought gets across, it has to be OK right now." —Deborah

Tools (p. 34): "Patient and Doctor can unfortunately become adversaries. Ego plus money can equal a lack of cooperation from either party. Keep the goal of working together to improve patient outcome the number one objective. A patient, even one who can't articulate, or becomes belligerent, has a right to question everything that is happening to him." —Charity

"BI is like having a funeral. Once you are in recovery mode the assumption is you are progressing nicely. But lack of communication skills causes problems making or keeping friends, even causes isolation. Physical Therapy is a bright spot because it provides interaction." —Marie

Needy (p. 35) laments the inability to access and enjoy a full spectrum of emotion. Flat affect (failure to register emotion in facial features) might or might not be accompanied by an inability to register internal emotion.

Perplexed, Meet Frustrated (p. 36): *Unfortunately, it took years after my stroke at age 29 to come to the realization that my tardiness was due to brain malfunction, and not just a character flaw. Throughout high school, college and early career, I'd been involved in so many activities I kept a very tight calendar, so if I'd been able to step back and identify it, I could have realized this new tendency wasn't "me".*

Learn to be honest enough with your mate to allow these things to be pointed out before they become sources of deep irritation. See also **Shorthand for MaryPat** (p. 53), **I Know the Trouble You've Seen...Before Breakfast** (p. 93).

Librarian's Pick: Managing Personal Change: A Primer for Today's World: Handling Change in a Positive and Productive Way, by Cynthia D. Scott, Ph.D., M.P.H.; and Dennis T. Jaffe, Ph.D.

1. "Repairing" the clock: Practice counting with a chiming clock and then check the result. Practice telling time with Roman numerals, digital display, and numbered dial/sweep second hand.

2. Internal clock: Set a timer and guess how much time has elapsed. Add activities and items needing concentration to make the exercise more realistic.

3. As the nights get longer toward winter, check in, especially after a nap: "Which 6:00 is this—a.m. or p.m.?"

4. The moon cycle may have more effect on you now. Be aware of mood swings or insomnia. The supplement Pantothenine might be helpful.

5. Circadian rhythm may have been reset with TBI. Become aware of sleep pattern changes and work back to a more normal schedule by gradually adding or subtracting sleep time: try to stay awake longer in the evening hours and shorten naps so you will be able to sleep at night. If you are awake at night, do some exercises to fatigue the body. Try middle of the night Bible study, prayer, or meditation which calms the spirit.

"Consider Melatonin supplement taken by 6:00 PM. If afternoon dose keeps you awake at night, try taking it in the morning." —

Byron J. Richards, CCN <<http://www.wellnessresources.com>>

6. "Tell the story of the last hour in as much detail as possible. Build items in the sequence until you have 40 or more.

7. Estimate time elapsed since you've visited on the phone, driven to a location, gone on an errand, and then learn to mentally string those times together." —MaryPat Parker, Cognitive Therapist

Substitutes (p. 37), See also **Up the Creek Without a Spoon** (p. 24): The patient may not even know misspeech is happening. Listeners can recheck facts by restating intent.

Awareness to the problem does help, but things can sneak out. Listen carefully and nonjudgmentally to the patient. Try to glean facts from context.

Librarian's Pick: Reflections on Christian Caring: A Listening Ear, by Paul Tournier.

Under the Pauses, Between the Lines (p. 38) is a word of gratitude to caregivers who use intuition, interpolation, patience and creativity to discern what the patient is saying. Try not to let Patient's frustration about communication or circumstance seem like a reflection on your care.

Librarian's Pick: Self-Care for Caregivers: A 12-Step Approach, by Pat Samples.

"I was called 'Patient Patty' until my car accident. There was no blood, so TBI wasn't diagnosed right away; instead they sent me

to a psychiatrist for profound personality changes. We decided ‘what’s up there’ had been bounced around: I wasn’t crazy, but I *thought* I was! Don’t be afraid to get a 2nd, 3rd, or 4th opinion: find a doctor who both cares and has the expertise, or wisdom, to refer.” —Patty

Cooking School I (p. 39): Take performance pressure off. Try already prepared food, delivery services and take-out while you attempt to relearn preparation skills. Start with 3 once-familiar tasks: open a can, heat and serve.

For healthier alternatives at the grocery store, see picture-based **Eat This Not That** series by David Zinczenko/Matt Goulding. Right now, just tend to an “on” burner or oven, and stir.

Later try **A Man, a Can, A Plan** picture-based cookbook series by David Joachim for recipes using 3–4 ingredients. Then have family members cook with you to relearn the secret to family favorites.

Librarian’s Pick: Spoon, by Amy Krouse Rosenthal.

For laundry, paperwork, and other household tasks: hire temporary help that may be covered by injury/disability insurance, or enlist friends and family to help until improvement shows up. Apply for a county caseworker for short- or long-term disability help, which could include: LTC (Long Term Consultation Service); PCA for help with dressing, bathing, etc.; ILS allowance for help managing bills, relearning checkbook skills, insurance paperwork; or possibly Consumer-Directed Home Care (a hybrid model for Patients either at home or in a living situation to prepare for independence).

Check with your local county Social Services Department at the County Government Center to discover eligibility:

- PACER Center 952-838-9000,
- Metropolitan Center for Independent Living 651-603-2038,
- Mains’l Services, Inc., 763-494-4553, or
- Courage Center <http://www.couragecenter.org>, <http://couragecenter.us> can direct to or provide specific services.

How Many Times? (p. 40) speaks about being travel-challenged, even in previously familiar surroundings.

1. Set up a buddy system and keep a cell phone you are comfortable with. See **Road Trip** (p. 98) and **The Gift** (p. 132).
2. Keep a notebook of directions using landmarks in addition to street names; sometimes street signs are confusing or too small.
3. Try to park on the same face of a building every time.
4. Ask a companion to drive to make it on time to important appointments.

“I have an invisible disability: no one can take a picture of it.” —Deborah

Unfortunately the caregiver just can’t win some days. **Sympatico** (p. 41), **G’Day, Mate** (p. 42) and **Tried, Tired** (p. 56) relay the effort it takes the patient to communicate, the need for autonomy and to be treated like an adult,

and the frustration when communication or locomotion is stalemated.

Sympatico (p. 41): “How can people act so insensitively to another person’s disabilities? He has TBI, I have a hearing loss, and we have to have compassion with each other, call upon our past skills, and learn to work together, that’s all.” — Mary

G’Day Mate (p. 42): “Give me some air. I needed to be protected at first, but now I need to have some independence even if life is difficult. It is especially hard for parents to grow with the patient and be willing to release them again.”—Brian

Recovering patients will tell you when “hovering” is a problem for them. Both family and Patient should agree to:

- touch base about it from time to time.
- overcome severe emotional distance.
- mend fences.

Librarian’s Pick: Daily Comforts for Caregivers, by Pat Samples.

Use kind hearted humor when possible; take the pressure off by providing a tablet, erasable board, Magic Slate, or electronic assistive device. Be careful of overloading the patient with technology; but seeing the benefit of the device may motivate the patient to use it with carefully repeated instruction as necessary. Sign up for free low-stress technology classes at

stores, libraries, workforce centers and community education venues.

Section 4: Grief of Loss, Helpless, Ashamed page 43

In the Waiting Room I (p. 44): Set aside alcohol since it reacts poorly with anti-seizure and other prescribed medications and impedes brain repair. “When I fell off the stage during set preparation I felt like I fell off the earth. Watch out for impulse behavior after injury: casinos, drinking, drugs, addiction to pain meds.” —Marie. For AA Chapters: <http://www.aa.org>

Humor is confusing for those with S or BI, because it often uses sarcasm, which might not be understood correctly by the patient due to impaired brain function. Not “getting” jokes casts a person to the sidelines in social situations. Instead of Saturday nightlife in an overwhelming noisy boisterous atmosphere, try one-on-one relationships, small groups like book clubs or Bible studies, support groups, or new immigrant groups like English as a Second Language classes where people tend to speak slowly and distinctly and the laughter is related to the context. However, since humor is an extensively used coping mechanism that aids recovery immeasurably, find opportunities to both employ it and receive its benefits.

For ways to use humor without sarcasm, try the advice in House Calls: How We Can All Heal the World One Visit at a Time, by Patch Adams, M.D.

One benefit of BI can be less solitary pursuit of success and

more interpersonal interaction. Because reading can be very difficult at this time, recounting verbal stories becomes a pastime. There may be trouble gauging intimate space, wanting to provide too-personal stories, but there is also the desire to share learned wisdom. Check in with your host:

“Have I told you this before?” “Do I know You?”

“Have we met?” “Would you like to talk?”

“Have I told you this before?”

“Could you stop me when you have to leave?”

See also **Gone Fishing** (p. 61).

“Post-injury relationships are better for me because no one asks me, ‘Why can’t you be more like yourself?’” —Marie

“I wish doctors had visited more with us and had educated our entire family immediately about the condition, and what we could expect, as soon as there was a diagnosis. This wasn’t done for us, so my husband’s adult children thought I was fabricating his condition. Because they are not frequent visitors, they didn’t notice changes in him like I did.” —Betty

This is an Emergency (p. 45): Heavy effort is sometimes required to react to a crisis, regardless how small, but words and concepts are formed and transmitted slowly for the BI’ed. It is easy to panic or explode if one cannot be understood. Paper and pencil could help if speech fails. The practice of hearing information, producing tactile output, seeing visual cues on paper, hearing activity on the page corresponding to produced letter strokes, all help restore language through multiple learning styles, to attach and retain ideas, synthesize thought—and help

communicate.

Computing (p. 46): Providing simple instructions/uncluttered information to refer to—often—even if it is only a rough sketch or a word or two, helps recall details. A picture-based message notebook can help the patient refer to symbols for FAQs (Frequently Asked Questions). See <http://www.thejointlibrary.org/autism>, click: “Use These Resources”, then “Library Special Needs Communication Guide” to print out a point-to book.

Get a canvas for yourself, be it lined paper, a prepared easel, or a computer screen, and get down something of what you are experiencing. Expose yourself to sensation: it could be a meaningful movie, a swatch of fabric, or a delicious texture of sweet and salty that helps you define and express your world to yourself and those around you.

Librarian’s Pick: Attention Deficit Disorder in Adults: A Different Way of Thinking, by Lynn Weis.

The Wheelbarrow (p.48): “Anxiety [over a medical event] turns to relief, and then families don’t know how to feel after the medically critical phase has passed. It’s quickly on to business as usual if there are no broken bones with casts to remind them. Then there’s the relationally critical phase!”
☺ —Marie

“I vicariously teach 800 kids a year about coping with BI, that is my advocacy.” —Deborah, music teacher

The person you love is both fundamentally the same and fundamentally different after BI. Patient: upon whom do you depend? Whom do you avoid? Why? Ask your general practitioner for a neuropsychological evaluation to find what parts of the brain are working well, and what needs to be “carried along” with help. Having a professional corroborate your symptoms usually helps others accept your needs. Or, the incredulous person might be the patient:

“Frustration with trying to convince my husband and his grown children his personality had changed after S was almost insurmountable until he got a diagnosis from a geriatric neurologist. Now hopefully he will be open to getting some help.”—Betty

“Find ways to defend a partner’s thinking: say, ‘That sounds like it would work.’ Verbalizing a positive response activates the brain to justify the response toward agreement.” —Stevie Ray, in his Fall, 2008, e-newsletter.

Caregiver. Help the patient save face whenever possible: there are already plenty of opportunities for her to feel inadequate.

Librarian’s Pick: All Cats Have Asperger Syndrome, by Kathy Hoopmann, works for brain injury survivors, too.

Stale Mate (p. 50), see also **Anxiety** (p. 58) and **Return Trajectory** (p. 58): *I learned to forgive my mother-in-law for her 20 year-old refusal to believe I’d had a stroke. It helped to read Ethnicity & Family Therapy, Third Edition, which describes particular difficulties mixing quite compatible cultures in marriage, even to the 3rd and 4th generation. The research showed me the British, after all, need a darned good reason not to buck up and sally forth. A stroke, apparently,*

isn’t it. With my stroke 30 years ago, I felt totally alone because no one believed me. With this new ABI, because the medical community took it seriously, so did my family. I get help around the house. Same family, different outcome, because they accepted it this time.

“For patients not to understand BI is not unusual; after all, the medical community is only beginning to understand. Tell yourself, ‘I’m here to change that.’” —Marie

Reality Bites (p. 51) and **No Horse Sense for Pinocchio** (p. 52): It might seem counter-intuitive, but the sooner you are able to admit and describe cognitive shortcomings to close friends and even to strangers, the more latitude you will be given to relearn those skills—and often, the more help you could receive from others wanting to help you be successful again.

Librarian’s Pick: It’s So Much Work to be Your Friend: Helping the Child with Learning Disabilities (LD) Find Social Success, by Richard La Voie. Information adapts to adults with LD, too.

A Lighter Load (p. 51): Short-term memory loss creates plenty of opportunity to revisit familiar haunts—sometimes 2–3 times in the same day as forgotten items are retrieved. Make friends with the keepers of Lost and Found boxes. Pass out business-size cards to personnel introducing yourself and asking for help remembering to collect all personal valuables (providing a phone number and chocolates to them ahead of time helps a lot).

Get help at home marking items clearly with an identifying code, and keep an example of it on that card or on a pendant around your neck. Use colored tape or spray paint to ID small items like flash drives. Wear cell phone on a lanyard so it is attached to your person whenever possible. Use mitten clips, and attached hoods rather than hats. Always bring home 3 books, for example, so you know how many to look for when returning to the library.

Shorthand for MaryPat (p. 53): *Who knew it would take 5 years to recall a conversation and fill the “need”?* For the brain injured, time can stand still even while the clock is ticking to get to an appointment, or great chunks of it can slip away like pieces dropping from an iceberg.

Use a portable stove timer to help get ready for work, but realize the minutes between the timer sounding off and actually leaving the house can still be a black hole.

“The Law of Relativity was created for my friend—she leaves home the instant she is to be arriving somewhere else.” —Gary

Ask friends (see **Perplexed. Meet Frustrated** on p. 36) to call half an hour before you are to meet them for lunch, use the reminder function in Outlook email, set a watch or iPad to alert for a meeting. Notify your boss of your time warp, and offer to stay half an hour after your normal quitting time every day you are a few minutes late to start.

For long durations, keep a notebook record listing items you need to do (and have crossed off and dated when completed) so there is no panic about whether you thanked Aunt Alice for

that Christmas present—and then actually got the appreciation note in the mail.

Technologically Challenged (p. 55): Provide plenty of time to “explain the explanation”, and for the patient to process information. Go back to familiar childhood skills and simpler technology whenever possible; gain mastery, then bring technology forward gradually to present day. Provide visual as well as auditory cues to prompt the desired response: gloves on signal, “It is time to go”; a bowl on the table says, “Soup will be served”.

“Apraxia: I have the physical ability to talk using my tongue, jaw, larynx, and soft palate. However, due to my stroke, the transmitters in my brain do not function properly and I literally know what I want to say but I cannot say it. Apraxia causes the stroke overcomer to change the word ‘screwdriver’, for example, perhaps to something like ‘drewwriter’. Severity of a person’s communication problems depend on the area of the injury and the extent to which the brain has been damaged.” —David.

Caregiver: Listen carefully and learn the new language.

“For what I would like to do, I do not; but what I don’t want, that I do.” —Paul, Romans 7:15 (Angela’s version).

“After being struck with an airbag, my brain fails to decode sounds of speech properly. Volume is not the problem, understanding the sounds my brain substitutes is.” —Elaine

Tried, Tired (p.56), also **G’Day, Mate** (p. 42), **Paradise**

Lost (p. 90): Realize part of rapid mental fatigue is that a patient now has to consider which foot to start with at the top of the stairs, which hand to use to open a door: *all* decisions require evaluation and processing effort.

When discouragement mounts, give persons good reasons to keep trying: visit a favorite museum or animal shelter, bring home an unabridged audio CD copy along with the book of a good story to assist reading and comprehension skills, visit parks, converse with others who are learning to talk or read, too, including young children.

There is hope: Much of the healing occurs within 18 months of the incident, yet even six years later, I notice skills and memories returning to me. Redirect energy instead of beating yourself up.

Librarian's Pick: Those Who Save Us, by Jenna Blum.

Money worries can also create weariness. See Social Services or SSDI for possible aid. If your [father] was a [specific war] vet, you or your [mother] may be eligible for Aid & Attendance: <http://www.medsupport.org>

Section 5: Paranoid, Heartbroken

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Facing pain *and* the fear of having to express oneself to an authority figure like a doctor or boss can be very difficult for one who has compromised communication skills. During the recov-

ery-of-emotions phase, expect tears to express whatever is urgent, important, or needful.

Anxiety (p. 58) and **Return Trajectory** (p. 58) discuss the need for perceptive and patient caregivers and professionals: patients can feel very alone in their experience. They may react with paranoia to peripheral laughter, not want to try due to fear of saying or doing something inappropriate, and are especially concerned about not being believed. "You're just pretending", or "It's all in your head," can even come from the closest comrades.

In Black and White (p. 59) shares that in the midst of one's own suffering, ABI survivors still have the business of life move in, just like everyone else. They need to process difficult news, without the benefit of a full range of emotions, or a full spectrum of coping skills. See also **Needy** (p. 35), **Fly on the Wall** (p. 68).

What are your goals for today? This week? Do your plans include interacting with others? Ask questions and let them talk.

"I cried a lot. I cried over the accident even though I'd survived it. I've survived survival, but the challenge is to keep on surviving." — Cathy

"Coming to terms with BI is like mourning at your own funeral." — Brian

Caregiver: It may be difficult for Patient to process grief or other emotions. To help him express sentiments, assist in nar-

rowing down appropriate greeting card selections in lieu of phone conversations. Attending to other's needs can help the S survivor relieve depression.

Librarian's Pick: Chemistry of Joy: A Three-Step Program for Overcoming Depression Through Western Science and Eastern Wisdom, by Henry Emmons.

Gone, Fishing (p. 61) discusses how stifled communication can become.

"What might be missing is one's battery of thoughts, or a passion for each thought that moves through, or knowing how to inspire others with words, or to motivate someone to follow-through on what you intended [authority of thought, mustering referent power]." —Cathy

"I lost my gestalt, the ability to see the whole picture." —Marie

Take a lesson from the Greeks: start by using the most important word that will convey your intention. The first word to come out tends to be the strongest and clearest in tone. That way if you are unable to form additional words, or have trouble composing a sentence, your intention will still be present and others can ask questions surrounding that word.

Syllables are often slurred or misplaced after TBI; work on forming your words so they sound like they used to. To avoid slurring, use proper pronouns: "I will" rather than "I'll" can help develop crispness throughout the thought. Then join a pronoun to a verb. Work on adverbs later, adding more life to action and intention. When those feel comfortable, practice adding adjectives

tives to sentences: colors, feeling words, descriptors for nouns that will help convey meaning.

Librarian's Pick: A thesaurus (New American Roget's College Thesaurus in Dictionary Form) helps broaden a vocabulary by providing synonyms for unpronounceable words.

Write letters by hand to practice small motor skills, or use email for important sentiments, rather than using the phone and suddenly being at a loss for words.

Test some devices at PACER Center Library, 8161 Normandale Boulevard, Minneapolis, MN 55327, 952-838-9000. There are assistive devices for many of the skills we have lost. Trouble with concentration? Try earplugs.

"Headaches from sunlight? Ask a neurophthalmologist to have you try amber surround sunglasses, or a special type of bifocal for double vision. These may be reimbursable through a 'durable medical equipment' clause if conditions or resulting medication reduces your quality of life." —Marie.

Concentration can also be affected by dwelling on perceived losses.

Librarian's Pick: Ambiguous Loss: Learning to Live with Unresolved Grief, by Pauline Boss.

Pedal to the Mettle (p. 62): Therapy sessions or helps like Webster's New World Pocket Misspeller's Dictionary (ISBN 978-0-02-861720-6) should not be looked upon as a crutch for weakness; rather they are just vehicles to regain mobility and

life skills. We'd all prefer to be productive rather than decorative. *Thanks to Dr. Sarah, my neurologist, who kept working with me until I was firing on all cylinders.*

Crabby (p. 63) includes the possibility that a faith life can play an important part in recovery. How are you feeling on a scale of 1-10? What would take it up a number?

Librarian's Pick: Thank You Power: Making the Science of Gratitude Work for You, by Deborah Norville.

Section 6: Overwhelmed, Discouraged, Depressed page 65

The Edge of the Cliff (p. 66): Changes in ability can be disturbing, especially if some former attribute the person relied on in the past (a sharp memory, a quick wit, the ability to rapidly figure math problems) is suddenly no longer available.

Caregiver: Assure the person he is still valuable, worthy, loveable without promising everything will return to "normal", or overly-minimizing perceived losses.

Librarian's Pick: Grammar for the Soul: Using Language for Personal Change, by Lawrence A. Weinstein.

ing, even when the patient previously was a self-assured person. S survivors can feel that they no longer have enough information at their disposal to make a wise decision. A person with a BI might wonder if she has already made a different decision about the same facts, or worry the time limit has expired to act on something—not recalling it is already done (or not!).

"Be aware of potentially invading the privacy of a vulnerable adult. Fear heightens emotion, blocks productivity: fear of failure, easy intimidation, and subtle feelings of harassment can backfire on the caregiver." —Marie.

Caregiver: Encourage the person to create two columns for decision making: one Pro, one Con. Weigh the arguments for each side, come to a conclusion, and stick to the choice (unless new facts persuade). Keep the sheet handy to review reasons why the person decided upon the good course she did.

Librarian's Pick: Inner Simplicity: 100 Ways to Regain Peace and Nourish Your Soul, by Elaine St. James.

Blot (p. 67) shows how quickly and seemingly permanently a bad mood can show up and stick to a person.

Caregiver: Jog her by redirecting attention, sharing a new opportunity, or providing a success. Interaction with plants or animals often lifts mood.

"Even providing a bucket of warm soil for her to crumble or smell can be very therapeutic." —Lois.

Librarian's Pick: Writing Through the Darkness: Easing Your

Depression with Paper & Pen, by Elizabeth Maynard Schaefer.

Fly On the Wall (p. 68) reveals how completely depression can permeate a life, but it also reveals how close to coma deep restorative sleep is, even negating the need to eat. Watch for weight loss or gain and keep hydrated. The body is trying to regain equilibrium, both physically and emotionally.

Caregiver: Don't be afraid to broach the topic of suicide when depression is suspected, and encourage the patient to talk to you and a professional about it. A trusted source about the continuum of depression, interest in suicide and helpful dialogue is <http://www.SAVE.org> Suicide Awareness Voices of Education, Daniel J. Reidenberg, Psy. D.

Librarian's Pick: Crucial Conversations: Tools for Talking When Stakes are High, by Kerry Patterson.

Making the Ascent (p. 69): Limited access to former employment, or added difficulty due to brain and other injuries can add to depression. Every movement takes more effort just when processing takes more energy, and can make both seem overwhelming. Remove barriers wherever possible:

1. Try using rhythms to smooth the walking process and coordinate the muscles.

"I feel like my left side is my right side now." —Sanh

2. Ask your doctor for a temporary handicap sticker: the car is easier to find if it is in a predictable spot.

"I fell down a stairs and ended up changing from Law School to Courage Center to learn to walk and speak again. Practice co-advocacy with friends. We can do for others and with others what we can't do or face ourselves." —Brian

3. Add a temporary cane especially if dizziness or gait is a problem. It will also clue in others that you need extra time.
4. If you frequently go to a building, take the time to orient yourself to the layout:
 - Draw a map showing where your car is in relation to the office you visit to reinforce recall and avoid getting lost;
 - Find a stairs with the best railing and stair height;
 - Choose an alternate door to avoid an uneven brick sidewalk;
 - Use the side entrance to avoid getting jostled or remove the need to address heavy or revolving doors;
 - Select a quieter restroom;
 - Ask someone to help you figure out the elevator;
 - Learn the building: it could prevent you from becoming easy prey.

Librarian's Pick: Crime Signals: How to Spot a Criminal Before You Become a Victim, by David Givens, help with relearning to read body language.

Checking Out (p. 70): "I would scream and cry in the grocery store because there was just too much stimulation. We are not crazy, just brain-injured. We need to know what's wrong. And we need to know strategies to fix it." —Cathy

“Dr. Cathleen Reike, St. Cloud, helpfully answered my ‘Is this normal?’ questions.” —Jean

“I don’t decorate or shop. I’m overwhelmed by it.” —Barbara

Sensory overload is possible anywhere there are bright colors, bright lights, and decisions to make. If being overcome in the grocery store seems like a possibility, what can reduce the anxiety?

- Prepare a list ahead. Organize the list by location in the store if possible (at least group all dairy items together, for example).
- Go to a store whose layout you were familiar with before your injury.
- Shop for only two day’s needs at a time to avoid fatigue.
- Stay with the cart along the perimeter and have a friend help locate items in the interior of the store to limit over exposure—and have more fun:
- Make it a hide-and-seek cognitive game instead of stressful chore, with a reward of a favorite treat if all items are found, or if a time limit is observed.
- Call a friend to check in with you while you are in the store: Train them to ask: “Where are you now?” “Did you find what you need?” “Are you concerned?” “What are some options?” “Take 3 deep breaths with me,” to avert panic.
- Go on a weekday morning if possible, when traffic is light, or call and have groceries delivered.

“I planned a trip to take our adult children to Las Vegas for a winter break, and immediately realized the flaw in my plan: all those flashing lights, milling people and random sounds would exacerbate my son’s TBI issues. We chose a calm location instead.” —Mary.

Ask the right questions when trying to help: *When Social Services called to see if I had food in the house, I said yes. I failed to say all I had was 52 jars of dill pickles from the garden.*

Section 7: Determined, Hopeful,

Encouraged

.....page 71

Section Quotation: “...Not out, but through.”:

Avoiding the heartbreak of identifying losses and evading the stress of effort to regain skills is not worth nearly as much as facing the difficult challenges and exhausting endeavor of recovery—then seeing successes at the end of the gauntlet.

“Just because a person is 85 and has had a stroke does not make him mentally incompetent. Include the patient in decisions. And be realistic with him about the situation.” —Betty. See also **Construction Zone** (p. 112).

Librarian’s Pick: What are Old People For? How Elders Will Save the World, by William H. Thomas.

Another Chapter (p. 72): A condition often affectionately called “brain fog” by concussion and TBI patients can clear for

moments, days, then weeks. Get enough sleep, drink enough water (9-13 cups per day), keep blood sugar properly regulated, consider adding acidophilus to the diet; making sure the body has enough fluids to function and that food is properly digested can help keep the mind clear.

Ask: Do I see and note the improvements I am making? Am I keeping a hopeful attitude concerning my recovery?

Librarian's Pick: Improve Your Memory, by Robert Allen.

Spouting Off I (p. 72): Positive and Negative changes can occur to the TBI or S personality. Psychologically speaking, positive aspects could include anger, swearing (even when those words weren't part of the person's speech before), bouts of frustration, obstinance; negative aspects could include depression, introversion, trepidation, reluctance.

"PseudoBulbar Affect (PBA): When there is damage to the emotional center, the result can be sudden, unpredictable crying, laughing or other emotional episodes. It can be disruptive and embarrassing." —ad for Avanir Pharmaceuticals.

"Procedural (learned skills) memory which has been practiced over time is typically preserved, even with TBI or S." (Clinical Neurology of the Older Adult by Joseph I. Sirven and Barbara L. Malamut, Chap. 20: "Cognitive Effects of Head Trauma in the Older Adult" p. 287.)

"Do I misappropriate inferences, misread body language and social cues?" Ask a friend or caregiver for non-emotionally charged, accurate feedback from social situations. Don't give

up. Try a book to train social skills, like Reading People: How to Understand People and Predict Their Behavior—Anytime, Anyplace, by Jo-Ellan Dimitrius, PhD, and Mark Mazarella. Learn the art of apology, and use learned tenacity to keep trying.

A patient may be brusque because of desperation, trying to hold on to the few things that seem not to have changed.

Caregiver: Acknowledge perceived and real losses and help the patient form new focus and skills. Allowing Patient to select and play music may cue listeners to Patient's emotional needs. *When I am feeling powerless, I play Wagner.*

"I have a BI. My filter vanished. I blurt what I think. So? (Other people make social gaffes, too.)" —Barbara

Cleaning House (p. 74): Priorities can change in an instant— from picking up the dry cleaning to determining how to remain alive. After a life-altering event, priorities are re-evaluated and clarified. What are your priorities now? How did they change? Did events change them, or did you, or both? How might you congratulate yourself right now? Are you able to give thanks to God? Or, discuss the present results frankly with Him?

Librarian's Pick: Last Day of My Life, by Jim Moret.

Note to Self (p. 75): Which tasks actually *need* to be accomplished? Have you given thought to reworking your life list to make sure things important to you get the time they deserve?

Librarian's Pick: Don't Sweat the Small Stuff and It's All Small Stuff Unabridged: Simple Things to Keep the Little Things from Taking Over Your Life, by Richard Carlson.

Having Words with You (page 77): Have you confronted God about what has happened to you? A conversation like this often helps to move forward from injury.

Another perspective is **Surprising, Isn't It?** (p. 78). Realistically assessing the situation and taking inventory of remaining assets are part of the difficult work of recovery.

Librarian's Pick: Moments of Grace: When God Touches Our Lives Unexpectedly, by Neale Donald Walsch.

"There are physical, emotional, cognitive, spiritual changes due to injury, but that does not make you mentally disabled. Recovery includes addressing mental health issues." —Patricia

The ability to note improvement provides its own hope, as in **Eagle** (p. 79). Part of a clinician's job, **Liquid Gratitude** (p. 80), is to provide hope. However, patients have their own list of what amounts to "Full Recovery".

"A BI-ed artist might still produce a technically accurate drawing, for example, but it may show a lack of depth of field or evocative emotion, which is needed to make a painting come alive." —Tammy

Clinician: Ask for examples of what Patient's skills were "before", so there is a better awareness of what level of skill

might be worked toward. Individual gifts and talents should be assessed to provide the type of therapy that matches the true need.

Librarian's Pick: Success is the Quality of Your Journey, by Jennifer James, PhD.

A patient may still be experiencing "scrambled" (not aware of things still missing); so only pronounce a patient "fully recovered" if he also thinks "I'm satisfied. My progress is Good Enough to function now".

Clinician: "Be sure to ask, 'Before I release you, what did you used to do that you can't do yet?'" —Tammy.

And, **Patient:** Reality is that the injury might reward you with "differently-abled" not necessarily "the same as pre-injury".

Librarian's Pick: Getting the Job You Really Want: A Step-by-Step Guide, by J. Michael Farr, to discover strengths and passions in case another field needs to be explored.

"A TBI occurs every 18 seconds in the U.S." —Helen Mathison, MA, CCC-SLP, from the BI of MN Professionals Conference Workshop "Treatment of Mild Traumatic Brain Injury (TBI) Using an Interdisciplinary Approach", 3/30/12. With that amount of patients needing treatment, how much help can each person realistically receive?

Discuss: Should Workman's Compensation or insurance companies limit the amount of therapy each patient receives to keep costs down and allow every patient some services? Is formal therapy always necessary? Should there be a standard protocol for services, and therapy guidelines for triaged concus-

sions? How might a standard protocol be followed if every injured brain is unique? How serious does an injury need to be to receive services? How important is terminology: concussion vs. traumatic brain injury? Mini-stroke vs. TIA? Is injury taken seriously enough in the U.S.? Patients interviewed felt they could have used more therapy and services. How can this be accomplished?

It has been said that professional athlete's high salaries are hazard pay. Why are we comfortable with a gladiator culture? How can our society convince a sports culture not to let—or subtly demand—amateur athletes play hurt? How will discouraging children from crying after injury play out as they grow?

Thesis statements for discussion:

- WC begins a good strategy to get the worker to be productive again, but misunderstands the process of BI improvement by imposing an unrealistic time limit for recovery.
- WC/Insurance enforces a benefits cutoff, but in its zeal to save money and close the case, can short the patient important time for recovery that would ultimately benefit the employer.
- Patients should wait to sign-off WC/Insurance paperwork prepared by enthusiastic adjusters until the therapists and clinicians *also* believe patient has reached his new normal, remaining deficiencies are adequately assessed, and coping strategies taught.
- “Rather than being intimidated by a possible court case, look forward to it to tell your story.” —Marie

Clinician: “Don’t ever pronounce a ‘You’ll never ____ [walk

again] “ or ‘You’re as good as you’re gonna get.’ It is debilitating and cruel. How does one person know what another is capable of fighting for?” —Debra & Brian.

Patient: “Fight an ‘independent medical exam’ because it is legally adversarial. Ask for a WC mediator that understands BI. Ask for an independent QRC (Qualified Rehabilitation Consultant) who would work for your attorney, rather than for you OR for your employer or insurance company for a more equitable result. If there is a question about impartiality, ask, ‘Who is paying the QRC?’” —Marie

“Belligerence or advocacy? Belligerence or advocacy? Each side views assertiveness differently. Start a BI support group for WC issues.” —Marie

Section 8: Embarrassed, Inadequate, Disappointed page 81

“As far as I’m concerned, **Spouting Off II** (p. 82) asks advocates and family members to come out of hiding and advocate for the patient.” —Marie.

Half Cocked and Dangerous (p. 83), and **Breaking the Ice** (p. 84): Social interactions can be stilted or inappropriate as patients try to manage re-emerging emotions and interpersonal communications skills. Ask a partner to help you work on:

1. Conversational turn-taking
2. Grandness of gestures
3. Loudness of speech
4. Matching verbal and facial appropriateness
5. Understanding humor

Try a community college small group communications course for relearning unspoken social rules, or check the self-help or relationships sections at the library.

Librarian's Pick: All Dogs Have ADHD, by Kathy Hoopmann.

“Paranoia is only half the problem. The mistake I made was thinking what everyone *said about me* was the truth. BI people might also be considered vulnerable adults because the B.S. Meter is out of order. Think about getting a trusted person to filter info.” —Patricia

“The stigma of ‘being crazy’ made me very vulnerable to scrutiny. The System didn’t help 25 years ago. In fact, [due to TBI] I was a vulnerable adult, expected to care for vulnerable children. What, really, did they expect the result to be? Mental health changes are part of [the continuum of] BI. Nothing written before 1997 deals with this fact.” —Patricia.

“Eventually you can learn to laugh again. I had a BI. What’s your excuse?” —Jeffrey Hatcher, Playwright, “What’s the Word For...?”, World Premier at Illusion Theater, Minneapolis, MN, April 2012.

See also Sympatico (p. 41), G’Day. Mate (p. 42), Anxiety (p. 58), In Black and White (p. 59), Gone. Fishing (p. 61), Edge of the Cliff (p. 66), Spouting Off I (p. 72), Surprising. Isn’t It? (p. 78).

Senior Linkage Line (clearinghouse for services and housing) may be of help to older BI clients; they even consider a long-ago injury as qualifying for services.

For dual diagnosis, try First Street Center, Waconia, MN. 952-442-4437, Crisis Line: 952-442-7601.

Breaking the Ice (p. 84): “BI survivors may stay away from social situations due to embarrassment with cognitive or speech deficit, or fear of being cognitively found out.”—Cathy

See list of **Games** in **Appendix** (p. 250-251, notation on xiv) for regaining cognitive and social success. Also see games listed on pages 223-225 under comments for **Setting Up, Taxes**, and **Replacements Unlimited**.

Caregiver: Help the patient prepare ahead of time for conversation.

Patient: Ask others about family, job, hobbies and interests, neighborhood activities or sports, and let the other person do the talking. People will think you are the best conversationalist they have ever met.

Librarian's Pick: How to Work a Room: The Ultimate Guide to Savvy Socializing In-person and On-line, by Susan RoAne.

“As people move from crisis to maintenance mode and conversation becomes more natural or better understood, have a frank talk with Patient to see how much Caregiver fill-in speech

is appreciated. Allow me to chat with new acquaintances without prefacing the encounter with my medical history. ‘Let it go’ that I am disabled.” —Brian

Nervous Pudding (p. 85): The title is a reference to gelatin dessert, the way a newly-injured brain feels. Wearing a hat like a newborn or schizophrenic seems to help. Keeping the head and shoulders warm lessens headaches.

Using skills learned in childhood can provide self-confidence, but even long-term memory and muscle/motor skills could need coaxing after S or BI adjusts dexterity. Have you identified a compassionate teacher who could help you rebuild skills for personal relaxation and enjoyment like playing the piano, fly-tying, carving, photography—one building block at a time? Vocation and avocation should both be addressed in a recovery program.

Making Change (p. 86): Be honest with the teacher. Learning to admit disability can be very difficult.

Everyone prefers to present an air of competence to the world. Defer the lesson if it seems overwhelming, or take the information in very short spurts on familiar territory.

“It’s hard to find a poster child for brain injury.” —Charity.

Librarian’s Pick: Sensory Integration: A Guide for Preschool Teachers, by Christy Isbill.

Start interacting with money by using a debit card, if you trust

your spending patterns, or with whole bills of currency and let the cashier make the change. If you get too much pocket change, trade it in at the bank for more bills. When it’s gone, you quit spending. Practice counting change at home; count out, starting with largest coins to smallest. Keep a log of cash transactions to start relearning the checkbook.

Librarian’s Pick: Left Brain Finance for Right-Brain People: A Money Guide for the Creatively Inclined by Paula Ann Monroe.

Black and White Noise (p. 88): Hypersensitivity to background noise limits concentration and makes it difficult to focus. Family members should be alerted: constant radio or TV chatter—even a subliminal hum—could make it impossible for Patient to successfully attend to even simple chores.

Caregiver: Keep the environment as free from distraction (clutter, too many things to do; rapidly switching from one conversation topic to another; stacks of paperwork) as possible.

Weariness affects the ability to retain info. Fatigue adds to processing time. Noises seem sharper than pre-BI: songs with cymbals grate on nerves.

“If the TV is on, use it as cognitive therapy: take notes on the plot and subplots. Use detective show clues to retrain memory and use deductive reasoning. If short-term memory is a problem, load it to long-term by testing yourself: How much of each plot or documentary can you recall a day later? Two days later?” —Marie

Section 9: Tentative, Trepidatious, Arfraid of Failure page 89

Section Quotation: “...acts like a duck...”, Paradise Lost (p. 90), **Half Cocked and Dangerous** (p. 83):

Caregiver: Never overestimate the person’s returning skill set or underestimate compensatory skills: incredible effort goes into veneering appearances. Have you grieved with the person for lost skills? Have you helped the patient practice latent, rusty, or difficult skills? Have you encouraged the patient to regain deferred goals, and offered help and compensatory skills so those goals might still happen? Skills so those goals might still happen? (If finishing college is one of them, check with admissions to learn about free tutors, accommodations for disabilities, and extra helps. Consider auditing classes; interacting on campus may be more valuable than a letter grade or being able to hold a job in the chosen field later.)

Librarian’s Pick: Fooling Some of the People All of the Time: A Long Short (and Now Complete) Story, by David Einhorn. (This is actually a book on the stock market, but it is amazing how traits in economics can mirror human flaws; and when the economy struggles, so do human beings.)

“Take it for a day, then go home and pay. (Keeping a ‘normal’ stressful American schedule for a day needs several days for the Bl’ed to recover.)” —Cathy

Paradise Lost (p. 90) includes the reality that chunks of

the patient’s life might never be retrieved due to amnesia, coma, or hyper-focus on the work of regaining self. “What were my kids doing then?” could be helped by bringing out a family scrapbook. “Why am I in this photo?” can be responded to by sometimes we must rely upon the kindness of friends who overlook supposed insults, acquaintances too gracious to comment on a gaffe, strangers willing to ignore social foibles, and family to pick up the pieces we can’t hold.

Librarian’s Picks: Forgiveness: How to Make Peace with Your Past and Get on with Your Life, by Sidney B. Simon, and Stop Walking on Eggshells, by Paul T. Mason. Questions like, “Why did my fiancée leave me?” will ultimately take time and compassion to comprehend.

Librarian’s Pick: When to Forgive, by Mona Gustafson Affinito.

The weather might be beautiful, but barometric pressure changes can make the head want to explode. Visit a headache specialist for new options. Some advice from Dr. Frederick R. Taylor, Neurologist–Headache Specialist, Park Nicollet, SLP:

- “Daily drink 80 oz. unchilled water,
- Use up to 4000 iu/week Vitamin D3 derived from sheep.
- Some people are helped by cutting out caffeine, wheat, chocolate, milk.”

In **I Know the Trouble You’ve Seen...Before Breakfast** (p. 93), an average day can present a need for

thousands of previously undetected discernments, decisions, decoded environmental cues:

- “What do these boxes, jugs, and containers in the kitchen have to do with my hunger?”
- “How should I dress?”
- “What do I need to do next/tomorrow and how should I prepare for it?”

Things might change, but always go to bed with a basic plan for the following day. Make a wipeable checklist or keep a notebook to help assemble things the night before: stage items to go to the car in the order of their need, so the first thing needed is easiest to get to, lay out your outfit ahead, charge the cell phone overnight. Count backwards from your departure time and note by what time each item on the list has to be accomplished so you can be on time for each event. See **Perplexed. Meet Frustrated** (p. 36).

“Marco has high expectations for himself and he gets frustrated. I just say, “Do what you can when you can. Take small steps [toward your goal].” —Eunice

Keep a dialogue with yourself: “Where am I going right now?” “Am I driving on the correct side of the street?” “Am I on my way to, or on my way back from_____?” Day/night changes perception of distance and road surface.

A calendar is truly only a help when there are appointments on it to anchor context. Ask the BI’ed person specifically what kind of prompts are most appreciated: reminder calls the night before? Or an hour ahead, to help S or BI employees until a

routine is re-established? Lead toward reliability by providing reorientation info to help the employee feel competent and productive again. Schedule retraining to refamiliarize him; include computer training. Don’t assume material recently learned will be retained after S or BI.

Employee: Ask for a refresher from a family member about the alarm clock, and put a note on the mirror why it was scheduled to ring.

And who shares... **Before Breakfast** (p. 93) with us but our families and companions? That can be stressful, too: “Solve your inner, then you can do your outer.” —Patricia

“When Marco suffered a severe accident, I let his adult sibling’s jealousy [over redirected attention] float [not take it personally]. Parents might find themselves in the role of family mediator. They eventually got over it; after all, Marco is the baby of the family and his sense of humor won them over.” —Eunice

“What happens if you have your own crisis while you are dealing with someone else’s?” —Marie

“Caregivers need to make final plans for themselves, for the patient, and for what should happen if the patient survives the caregivers—or doesn’t.” —Eunice

“I’m convinced [helicopter] parents are born beside a hospital bed. Let’s face it: parents have to protect themselves from being hurt again, so mine [after an adult child’s accident] don’t want me to drive again. In an effort to help my short-term memory, Dad constantly reminds me, ‘write it down’ or ‘take

your pill' so he doesn't have to pick up the dropped pieces later. But I am an adult and might decide I don't need to recall that fact, or take that med today." —Brian

"Mom, you saw me at my worst, so it is hard to let me grow back to a separate, viable person. You invested an incredible amount of time and love in me. I'm very grateful, but in that regard, the caregiver role can be addictive. Be on the watch for that in yourself." —Brian

"Dad telling me, 'You're not who you were before the accident and it's OK... You'll never be a lawyer again and it's OK', while it might be true, actually lowers my expectations and reduces hope that I might try something in that field again. It is a fine line, but don't make assumptions or decisions about what Patient wants to struggle to regain, and what he is willing to leave in the past." —Brian. (See **Making Change** on p. 86.)

- If you need to change jobs or retrain for a different career due to disability acquired as an adult, contact Vocational Rehabilitation Center (Carver County 952-368-7007, or Minnesota 1-888-GET-JOBS).

- Positively Minnesota Rehabilitation Services assigns a caseworker for retraining, preparation to re-enter the workforce, and facilitation at the new job: 952-402-9808.

- MRCI WorkSource gives an evaluation for types of work (if injured as an adult) you can still physically/mentally tolerate (regional offices in: Chaska, MN 952-448-2234).

Section 10: Adaptation, Success, Exhilaration! page 95

Section Quotation: In'valid/Inval'id: Being drafted into the TBI army is hard work. Don't minimize the self-discipline required to work at regaining skills. Realize the patient is much more than the sum of his injuries or requirements for care.

Cooking School II (p. 96):

A gift of clearly typed family favorites
Helps a frozen memory thaw.
It reviews what a nose should be smelling and
Taste buds should be recording:

"If I follow the recipe for an expected outcome (delicious comfort food), and the result is bland and tasteless, maybe it is not the ingredients, but the sense of smell or taste that needs attention. It takes time to figure things like that out. It took me +30# to realize I was going through the cupboards trying to find things that tasted like they used to." —Cathy.

Librarian's Pick: What Are You Hungry For?: Feed Your Tummy and Your Heart, by Emme Aronson.

Caregiver: Be aware food might not even taste identifiable to Patient. When the taste sensation is muted or gone Patient might lose interest in food and need to be coaxed with good quiet company around the table. Relearning old favorites can provide a predictable outcome for the family, even if Cook can't smell the results.

Librarian's pick: I'll Carry the Fork, by Kara Swanson.

"Raid the spice cupboard for practice identifying smells and flavors. Try just a couple a day. Remind yourself, 'This is cinnamon.' Cedar wood & frankincense essential oils are helpful fragrances for TBI sufferers." —Eunice.

Zinc is a necessary mineral for taste and smell." — Dr. Byron Richards, CCN

"Hypersensitivity to chemicals was new for me after TBI. If there are bleach fumes, I need to go NOW." —Marie & Angela

Many daily events, like **Road Trip** (p. 98), can become opportunities for basic skills review and practice. *Before I dared get behind the wheel of the car again (it seemed like—and was!—a massive problem to keep track of all four fenders besides running the thing—and finding a destination). I was asked to become navigator for my friend who was driving me to appointments. He had already studied the route to reduce event stress.*

Librarian's Pick: Brag! The Art of Tooting Your Own Horn Without Blowing It, by Peggy Klaus.

For the best success in the car:

- Keep the cell phone off. Use separate GPS that is programmed before leaving the driveway.
- No radio or language-learning on CD—it adds confusion and draws attention away.
- Be aware that riding with children is immensely distracting.

Provide them a quiet activity or give them earbuds for their own music.

- People with BI fatigue faster, so stop for breaks.
- Practice gratitude for each car horn: other drivers are assisting you.
- Be vigilant, and forgive poor drivers: they may be fellow BI survivors.

S and BI people might think it all adds up: "Stuff I misjudge or can't do now' + fatigue + lack of confidence = 'mistakes made by a flawed person', but fail to realize those without BI might make the same errors and still consider themselves to be acceptable people." —MaryPat

Librarian's Pick: The Myth of Self-Esteem: How Rational Emotive Behavior Therapy Can Change Your Life Forever, by Albert Ellis.

"Be forthright when somebody else is counting on you to hold up your end. Try something like, 'I know this is [a competitive situation], but I have a BI; please allow for my injury.'" —Marie. See **Cohort** (p. 21), **Spirit of Generosity** (p. 21).

"If you lose your license due to TBI seizures, don't give up the car. Keep it in the garage, because more than any artifact, it is a symbol of your independence, which is huge. Who knows, a new medication and time might allow a new driver's license. It then becomes a great motivating force, sitting there." —Marie.

Section 11: Pleasantly Surprised

Testing Skills (p. 102): “The best neurosurgeon I could find told me he knows 20, maybe 30% of what there is to know about the brain. That’s why it’s so hard—no one knows yet.” —Cathy

Find someone who can give hope and offer encouragement.

Clinician: Be sure encouragement doesn’t negate Patient’s concerns. (Example: “You are still functioning better than 80%, so don’t worry about it.”)

Testing Skills (p. 102) and **To Knit or Knot to Knit** (p. 104): Tap into long-term memories for problem-solving strategies. See if:

1. moving in a rocking chair, clicking knitting needles together (kinesthetic), or slow dancing could help conversation flow;
2. words set to a familiar tune (tonal) could help phrases come out;
3. touching objects like a filament of yarn through fingers or rubbing a ruminating stone in your pocket (tactile) could help with recall, especially if you have done the same activity while the memory was formed (that’s why going back to the initial room after you forgot what you were going to get helps);
4. spoken tapes or directions to yourself on your cell phone voice-mail (auditory) can reinforce written directions or jog memory;
5. family video (visual) helps name faces and recall events.

Long-term memory can be willfully employed if short term memory is problematic. *I tell myself to listen carefully, (add a visual or auditory context record), and instruct myself to add [something] into long term memory if I think I’ll forget it in short-term memory.*

“ALC (acetyl L carnitine) or Pantethine is a good supplement for memory...” —Byron Richards, CCN, Wellness Resources.

To Knit or Knot to Knit (p. 104): There are Charity Projects through “YarnPlayers” e-newsletter, offering free and \$ knitting and crochet patterns from very simple to very complex. There is a needlework coach to answer questions. <http://cache.lionbrand.com>

Knitting gave me the confidence I could do something meaningful and valuable again. Interestingly, it also helped me weave together my sentences, assisted me with the woof and warp of multitasking, and added heft to my vocabulary.

Rube Goldberg’s Linotype (p. 106): As rewiring occurs during the healing process, new cognitive, spatial and personality attributes can surface. For example: *Before my stroke on the operating table at age 29, I was National Mathematics Association Award winner in high school, earned a merchandising degree, and became a businesswoman in a fast-paced environment. After my stroke, I lost much of that capacity, but could write monologues for radio. After my TBI 25 years later, I didn’t understand the nuances of humor in order to perform witty skits, but I could put together free verse, which required only silence between phrases. After*

recovery over the last 6 years, I couldn't tell some days that I'd had brain trouble, until August 2011 when a series of vascular events showed up. Even forming questions to interview writing group guest speakers seemed stilted. A few weeks later, when I knew what I wanted to say, my fingers still produced keyboard garble. So there had been both speech and small motor skill temporary damage again. I was confused enough that I knew I shouldn't drive more than the mile to work. For about 12 weeks during the editing process for this book things were difficult, so pardon if it is a little rough around the edges. I've just had a refresher course on the topic of stroke!

Now tell your own 150-word story. It will help you succinctly share what has happened to you and might even become a good advocacy sound-bite!

Setting Up (p. 108): Have fun with words. *Speaking of agar-agar petri dishes from days in the lab identifying fantastic landscapes within the morphology of multicellular fungi, be aware that Aspergillus mold exposure (and some others) can also muddle cognitive ability and create headache, exacerbating or mimicking S or BI symptoms.*

Setting Up (p. 108) and **Ekphrastic Art** (p. 108): "It can be tough to find adult things to do with others." —Brian

Ask to start a game night at your local library. For info how: <http://www.thejointlibrary.org/autism/> Ask a social worker about getting a Life Skills Trainer. They are not limited to occupational retraining, but can also address avocations and hobbies.

"Learn to enjoy the sound and texture of words, whether the thought they produce together makes much sense or not: it will take the fear out of the power elusive words have when they are used for creative play. Try some word games for practice: forget to keep score, make up house rules for happier outcomes. (See more games on 250-251.)

- **BananaGrams** is better for patients than adult **Scrabble** because everyone gets to make her own game board and change the words at will;

- **Upwords** scores little words as well as big ones, and it has a tray game board for travel.

- **Scattergories** is good for groups.

- Try using **Shakespeare Magnetic Poetry Kit** or any magnetic word strips in a cookie tin—start a poem inside the metal lid; it can be put away to finish later if the person tires."

—Barbara

Taxes (p.109): **Librarian's Pick:** Master Your Money video and workbook, by Ron Blue to relearn how to make budgeting decisions.

"Learn through games with numbers if mathematics is a challenge now."

- Try **Sudoku** (logic) or **Sets** (logic/attributes)

- **Tangoes** (match the picture by manipulating shapes)

- **Rummikub, Yahtzee** (addition/multiplication/variables)
- **Racko** (addition/multiples)
- **Cribbage** (attributes/counting/recall)

—Marie & Barbara. See **Appendix** for more games (pp. 250-251).

“I lost my parents’ health insurance benefits because being hospitalized with multiple injuries stopped my veterinary-medical-student status. My body is now worth \$4 million; still, I only got a \$15,000 legal award from the accident.” —Charity.

Legal Defense Fund, Pro Bono legal advice (subject to available volunteers): contact state Attorney General’s office.

Perceptions of what is “Perfect” and what constitutes a “Disaster” can change over time, per **Taxes** (p.209). Realize these two points form a continuum that allows for an amalgam of many positive outcomes throughout life. Also see **Training the Part** (p. 118) and **I Feel a Draft** (p. 138).

Inspiration and encouragement can come from the most unlikely places, even from a bumped plant on a busy reception desk **At the Rehab Center** (p. 110). Look for motivators cheering on your recovery, and you are apt to find them almost everywhere.

Replacements Unlimited (p. 111): To replace broken dishes in your pattern, contact Replacements Unlimited, 1089

Knox Road, Box 26029, Greensboro, NC 27420, <http://www.replacements.com> 1-800-270-3708.

“For improved dexterity and hand strength try polishing an agate smooth with your fingers, squeezing a tennis ball, manipulating 1, 2, or 3 small balls or shooter-size marbles in one hand, then 1, 2, or 3 in both hands, then add balls, then rotate them clockwise in your palm, then counterclockwise. Practice moving a penny and a washer inside one hand at a time. Try working **Tangle Therapy** (crafted mobius circle), and **Cats-in-the-Cradle** games with a partner.”—Marie; Barbara; & Karla Businaro, Carver County Librarian.

“While I was in the hospital, someone must have changed my entire filing system—I can’t find a thing! Short term memory challenges cause misplaced stuff, but disorganization/confusion presents the opportunity to pair ideas in a new way.” —Deborah (See **I Feel a Draft**, p. 138, and **Up the Creek**, p. 24.)

Construction Zone (p. 112): Have I learned patience with myself and with the process of recovery? Can I see change as something positive; my “dark side” as something worth understanding?

Biped (p. 114): In what ways am I my own best cheering section? Do I devise rewards for myself when I have reached a milestone (chocolate, lunch with a friend, a foot massage)?

“Anyone with a medical disability can enter Burnsville Golf League for the Brain Injured/Profoundly Disabled. Contact

Courage Center 1-888-846-8253.” —Brian (See Bibliography for exercise DVDs.)

“Physical exercise increases the volume of gray matter in the brain and the activation and connections among different parts of the brain.” —Embody Health, February 2012, p.1, Mayo Clinic.

Words (p. 115): Do I commemorate and allow myself to truly appreciate returned skills, or only think about what is different about me now?

I Get It (p. 116): Since laughter is healing, plan for ways to giggle again: attend a child’s birthday party and play pin the tail on the donkey, check out a corny joke book, read humorists, invite a cheerful friend to help you grocery shop, ask family members to send their favorite comic strips. Find humor in your situation and laugh *with* yourself often.

Training the Part (p. 118): If a person can’t smell food, he won’t be able to smell stale clothing, either. If forgetfulness is a problem, set up a formal plan for bathing, changing sheets and washing clothes. After learning how to complete grooming and hair care tasks again, use that spiffy new look: cut notices of events from the newspaper, tape them on that date in your day-planner and entice a friend to join you. (You will have all the details to share about the event, be able to locate the information when it’s time to go, and also have a record where you have been.) When you attend, ask for clarification on points unsure, take down notes—everywhere you are. Keep

a 3-ring binder of visits, meetings, class syllabi (note date, who attended with you, what you ate, and what you wore that day for better recall of the information.) At the end of the year, you will have a summary of your productivity and a record of your accomplishments.

Librarian’s Pick: The Disciplined Life-style, by Richard S. Taylor. Devise ways to make projects and duties manageable for you; then transfer those skills to larger personal life management. See also **Taxes** (p. 109).

Section 12: Discover: Teachers, Helpers Everywhere page 119

Dog Tagged (p. 120): “A dog can medically be considered a companion animal for ABI overcomers. To register your pet at the Service Animal Registry of America (SARA). A doctor must indicate your pet is “for medical, therapeutic benefit” and “necessary companionship.” Registry can include deductible pet food and vet visits. HOD Fair Housing/Mpls (Ask for Peter Vost) helps advocate for service dog admittance into an apartment.

“Service dogs can’t be kicked out or charged an extra deposit.” SARA pets might have special accommodations on airlines. There may be trained animals available for adoption through SARA. ADA may also be of help for adaptive living issues.” — Barbara & Charity

Librarian's Picks: What Shamu Taught Me About Life, Love & Marriage: Lessons for People from Animals and Their Trainers, by Amy Sutherland; "Teamwork II: Dog Training for People with Disabilities" (service exercises) DVD.

Meniscal Tear (p. 121): Find encouragers everywhere by being an encourager to others. Realize it is hard to focus on both physical improvement and mental mending. Take turns on the focus of recovery if you have multiple injuries. It is frustrating, but be gentle with yourself. See also **Making the Ascent** (p. 69), **Biped** (p.114), **Leaving** (p. 128), **Thank You, Therapist** (p. 129). Once some body parts are working again, return to the business of cognitive reclamation.

"My husband was an academic before his stroke and refuses to read anything picture-based, so now he doesn't read at all. He seems angry at the world, and directs it toward me." — Betty

See pamphlet: "Coping with Depression After Brain Injury" by MN Brain Injury Alliance.

After a BI, don't try to start where you were academically, build up to previous proficiency gradually. After all, athletes gently exercise the muscle that was injured in order to gradually restore function. Repetition helps. Read to children, select picture books with adult themes or with an adult as the main character, realistic watercolor renditions or photo-illustrated stories. Read your own stories aloud. Graduate to newsprint (meatiest info is at the top of the article to accommodate rapid fatigue), magazines (short articles designed for a short attention span), next Adult ESL materials, then juvenile chapter books with adult themes (less complex plot lines, vocabulary), teen materials

(tight plot, high-interest, shorter page count than adult; some adult authors also write for young adults). Then choose adult fiction (more complex plot line, higher vocabulary). Try a movie and book by the same title to help explain non-verbal cues in the movie. Or use an unabridged audio book and follow along with the print edition to relearn reading cadence and pronunciation. Then advance to nonfiction, and academic (technical vocabulary). Go ahead and argue with (or at least question) the writer in each situation to exercise higher order thinking. See bibliography for a list of sample titles about functional brain injury.

"The Reading Institute in Rochester, MN might be of help." — Barbara

Gratitude expressed to various therapists: **Primer** (p.122); **Tough Love: Parting Words to My Speech Therapist** (p. 123); **Leaving** (p. 128); **Thank you, Therapist** (p. 129). Permission granted for you to base your own thanks on some of these sentiments.

Don't forget to say thank you in special ways to those who did not get paid to stick with you. Thank even those who used "sandpaper" rather than "silk" to get desired results: **Mentor, Friend** (p. 126).

"Congratulate your own 'guerrillence': anger converted to inner courage, strength of conviction for self-advocacy." —Marie

Typeset (p. 127): The brain's most efficient activity is pattern

(routine) recognition. The least efficient is info retention.

“We naturally resist new ideas. Rather than correct pattern thinking, say, ‘You’re on the track’, gently direct, and let their patterns define the new idea instead of explaining yours.”
—Barbara.

Patch, Work, Quilt (p. 130): “Assignment: read aloud into a recorder and then play it back, taking down the information as dictation. As you learn to speak faster, writing speed will also be improving.” —MaryPat Parker, Speech Therapist.

Librarian’s Pick: Favorite Counseling and Therapy Techniques: 51 Therapists Share Their Most Creative Strategies, by Rosenthal.

Tough Love... (p. 123): “I was labeled ‘unreliable’ because I would forget, and ‘combative’ because I would do stuff in spite of myself and because I questioned [my professional caregivers about my care]: ‘What are you going to help me do about it?’ Nobody appreciates an aggressive person, but to put on someone’s chart, ‘Watch out! This person is combative’ is not a good message for staff, because assertive people are the only ones who come back [from injuries as severe as mine were]. They should be encouraged to use that strength, redirected—not avoided at all costs.” —Barbara

Section 13: Trust: Adapt, Adjust, Ask, Be Assured page 131

The Gift (p.132): Ask: “Do I accept help in the spirit it was intended?” “Pride goeth before a detour and a haughty spirit before an empty tank.”—the Gospel according to Angela. (See Psalm 16:18)

Explain why Angela may have written “Pride goeth...”.

Note from Home (p. 136): Humans don’t generally enjoy change. Becoming willing to embrace change regardless of the form it takes could ultimately produce a more meaningful result out of life.

Librarian’s Pick: The Purpose-Driven Life, by Rick Warren.

Reservoir (p. 137): Make some decisions about how you intend to use your recovered vocabulary on yourself.

Librarian’s Pick: Telling Yourself the Truth: Find Your Way Out of Depression, Anxiety, Anger and Other Common Problems by Applying the Principles of Misbelief Therapy, by William D. Backus and Marie Chapman.

I Feel a Draft (p. 138): Keep an open mind about how the tremendous upheaval in your life will work itself out. There is as much chance there will be a happy ending as a tragic one.

Some patients experience more pain and headaches when weather turns cold. To sleep better, wear a turtleneck and stocking cap to keep neck and head warm. See also **Taxes** (page 109): Creativity is using more than one way to look at a circumstance or event.

Librarian's Pick: Grace: An Invitation to a way of Life, by John Ortberg, Laurie Pederson, Judson Poling.

In the Waiting Room II (p. 139): Don't neglect who you really are in the midst of all the therapy appointments, or through the long night of a court case. I might surprise you to see how wonderful that person is—even without all the previously acquired skills.

"Admitting changes is like 'coming out' about my invisible disability." —Cathy & Marie.

Librarian's Pick: The God of Second Chances: the Remaking of Moses, by Don Baker.

Re-Becoming (p. 139): Though difficult, be sure to document as many details of the accident as possible, including detailed photos, which will be needed for auto insurance, Workman's Comp/OSHA, legal briefs—or for the maintenance department to know what to repair at the accident site so someone else doesn't get injured. At some point going back to the spot may help with closure for the event that changed your life so much.

Librarian's Pick: Embracing the Wounds of Post-Traumatic Stress Disorder: An Invitation to Heal, by Bernadette Cioch.

"I wanted more information about S, but all the doctor said was, 'It's your cross to bear,' and left the room. Professionals need to realize that the patient values information as much as doctors do." —Betty

I Am Still Me (p. 140): Choose a classic TV series or old movie if there is interest in watching again: there are less layered plots and flashy scene changes. Shut it off during manic commercials to avoid being catatonically engrossed or overwhelmed by stimulation. Choose something other than "high-def" news programs with moving subliminal backgrounds which can trigger vertigo.

Even without competing noise, sometimes I still forget social currency—like saying hello out loud even if I am thinking it, or asking how you are after you ask me—but it does not mean I care less about you than I did yesterday.

Section 14: Reclamation: Preparation, Confidence, Comfort page 141

Fresh Fruit (p. 142): Everyone has formidable coping skills that can mask a brain injury, either for reducing emphasis on the injury, for denying it exists, or for hiding it to refuse timely help. One coping skill is to try to cover up the fact that things aren't running smoothly. A novel thought is to let the fallen away "pieces" lie there. *Enjoy* what has newly opened up for inspection. One woman went to a restaurant with her friend, and as many BI or S people do, had difficulty making decisions—and recalling them. When the waitress asked for her order, the woman said cheerfully, "Surprise me! It will be a surprise when you bring the plate, anyway."

Most of those interviewed for this book (5+ years post-injury) reported feeling greater compassion, humor, and graciousness for themselves and others, and having better stress management than pre-injury.

Weeding the Collection (p. 143) and **Reservoir** (p.137): Self-talk can be very comforting and it may help to hear spoken encouragement from your own recorded voice, or a loved one's. Call voice mail and leave yourself an upbeat message that can be played back on a tough day. After all, "Faith cometh by hearing." (Romans 10:17) Some BI and S survivors say self-talk is best done out loud. What messages are you telling yourself? How often?

"My husband has denied any handicap since his brain aneurysm, and therefore won't cooperate with help anyone offers him. A person needs acceptance of the situation in order to get 'different'." —Bett

Dead or Alive (p. 144): What opportunities do you have today in which to cheer others on who are also struggling?

Having a clear vision to serve plus commitment to do it changes both the race and the outcome. In When the Game is Over, It All Goes Back in the Box, John Ortberg posits that every encounter is an opportunity to impact lives. Johnny, a grocery bagger with Down Syndrome, decided to receive motivational speaker Barbara Glance's challenge to take moments of opportunity to impact lives. From that day on, he has selected a thought for the day, has his dad run 43 copies, 7 to the page. He cuts them out, laboriously signs each one, and attaches them to the last grocery

bag in each order, making sure each customer understands he has selected it with the purpose of making their day brighter. By the second week people were lining up back to the milk aisle for his checkout lane. Testimonials abounded. Grocery sales rose 30%. Johnny doesn't fill grocery bags. He fills lives. People need a genuine blessing. —With thanks to Pastor Paul Biebighauser in his sermon, "Hold Up My Arms", Ex. 17:8-13, 1 Pet.4:1-2, from Christ Victorious Lutheran Church, Victoria, MN. 2/26/2012.

Section 15: Growth, Acceptance

.....page 147

The Road Not Taken (p. 148): Release others and yourself from blame. Even though a bone-jarring accident can remake lives so fundamentally, there can still be ambivalence about whether people are better or worse off with the addition of adversity. 32 (80%) of the 40 people interviewed for this book readily admitted there were benefits from the tremendous changes in their lives after injury, so much so, 12 (30%) were actually glad, on some level, the accident happened. (Those interviewed had TBI from 1 to 31 years ago.) Appreciation for the event to the point the person was willing to have it happen all over again was expressed only in those at least 3 years past the date of their incident.

"I had a one-month coma, it took intense persistence to walk again; I have double vision despite eye surgeries. I'm not wishing for anything different. It is not what I had planned for

my life, but I wouldn't change it." —Sanh.

Librarian's Pick: When Bad Things Happen to Good People, by Rabbi Kushner.

Falling, Finally (p. 149): The people who were somehow involved concerning your injury are tucked between the lines, along with their sense of irresponsibility about it, and whether you are able to come to some sort of peace or resolution about their part in it. Inattentive drivers were mentioned as the cause of accident with injury in many of the 40 stories gathered.

Explore the possibility of forgiveness toward each one involved, for many experts talk about the exercise of forgiveness helping the patient. Forgiveness doesn't have to release the person from culpability of a crime, but it does include release from a sin of omission or commission against you. Honesty about our own part in the accident can reveal a difficulty forgiving ourselves, so that must be addressed as well, and is sometimes the harder part.

Given that:

1. 1.7 million new brain injuries are reported every year,
2. residual effects of BI can last for years, and that
3. not only cell phone users, but also BI drivers can be inattentive.

There is therefore a chance that a driver causing an accident which results in a BI, might be a BI survivor, himself, struggling to maintain independence. How does the possibility of forgiveness look now?

Dumped On: A Heavy Load (p. 152): "Misfortune comes in Pandora's Box: it is a lavish treasure that spills over onto the rest of your life. Misfortune given carefully in the form of the lessons it provides is a particular gift. Try to put into perspective: Angels might look like drunk drivers, come to help you to more self-awareness. Don't reject their help.

When Pandora's Box is opened, we think only horrible stuff can come out, but hope and change and new gifts come out, too. If the lid is slammed down, all opportunities as well as all tragedy stay buried inside. The real Pandora story is also a hope chest waiting to be opened by each BI person in our own way." —Barbara & Patricia (+30 year BI survivors.)

BI people need perspective. It is not the end of the world. Just the beginning of a new one. My blessings are there for a reason, and so are my troubles." —Charity (15 surgeries), graduate from Health Resilience Training, Health Leadership Training.

Keep revisiting the "Why?" question until you are settled enough about the answer that you can put it to rest.

Librarian's Pick: The Search For Significance Book and Workbook, by Robert S. McGee.

17

Appendix



“Wisdom is the principal thing; Get wisdom: and with all thy getting, get understanding.”

– King Solomon, Proverbs 4:7 KJV

“Axioms in philosophy are not axioms until they are proved upon our pulses: we read fine things but never feel them to the full until we have gone the same steps as the author.”

– John Keats (1795-1821) to J.H. Reynolds, 5/3/1818

What Was the Same About My Stroke and Brain Injury:

- It took a while to realize I wasn't cognitively functioning as I had been, perhaps up to a month in both cases.

- I had right side weakness. For the brain injury, whether it was due to injuring my shoulder, face and knee, or strictly the second time the brain was compromised, my right fingers were weak and the right side of my mouth drooped and drooled. I had trouble forming words. My right foot dragged and the toe caught as I walked.

- I had aphasia, a difficulty accessing words.

- I had delayed speech.

- I worked as hard as I knew how to regain skills.

What Was Different:

Stroke¹ vs. Brain Injury:

- I didn't know who I was anymore and knew early on something wasn't right.

- I knew who everyone in my family was.

- I didn't think anything was wrong with me.

- I didn't recognize family members or know their names. I didn't know their relationship to me and would not have known I had a family if I hadn't been living with them.

Stroke vs. Brain Injury:

- I couldn't get my family to realize or admit anything had changed about me.

- I wanted to find answers.

- I had fits of anger, flash rage and depression.

- Since no one identified the problem, supported, or encouraged me, I was confused and frustrated with myself for a long time. I felt like I wasn't worth the time for anyone to help me recover, and became depressed.

- My family and co-workers knew something was wrong; I didn't, or at least didn't admit it until I had exhausted all my coping skills.

- I didn't want doctors nosing around to discover something.

- I was blissfully ignorant until I had a crisis that brought me to the emergency room, and a diagnosis. Once I was aware of deficits, even though I lacked reasoning skills, I grieved the loss.

- Encouragement I could regain at least some skills gave me hope.

¹ In 1985 there was no cognitive, occupational or executive-thinking therapy. Brain injury recovery was just starting to be addressed.

Additional Resources

About Brain Injury <http://www.aboutbraininjury.org.uk> "nurse anna" especially for kids and teens.

Advocacy Board for Independent Living: see Brain Injury Association of Minnesota.

Asperger Syndrome/Autism Spectrum, Adult Dyslexia Test, Leibowitz Social Anxiety Scale (LSAS), Schizotypal Personality Questionnaire (SPQ-A), Dr. Amen's ADD test, Dyspraxia Foundation, others: <http://rdos.net/eng/Aspie-quiz.php>

Brain Center. <http://www.braincenter.org> 1-800-592-1117. (Search any of 48 states for resources nearby.) Info about living with BI.

Brain Injury Association, Inc (BIA), 1776 Massachusetts Ave. NW, Suite 100, Washington, DC 20036-1904, 202-296-6443. Fax: 202-296-8850, Family Helpline: 1-800-444-6443. <http://www.biausa.org> for support and advocacy.

Brain Injury Recovery Network <http://www.tbirecovery.org> 1-877-810-2100 provides practical, actionable advice for BI victims and families; alternative therapies, assistive aids, computer tools, home modifications. Crisis phase to long-term phase.

Brain Trauma Foundation (BTF), 523 East 72nd St, 8th Floor, New York, NY 10021, 212-722-0608. <http://www.braintrauma.org> devoted to improving the outcome of TBI patients during the acute phase. Videos, participate in research.

Buckbee, JeanMarie, Coma/Recovery and morphine-damage, Electroconvulsive therapy (ECT) with memory loss and brain damage. iamjmb@centurylink.net

Catholic Charities HOPE Community for people with chronic conditions and disabilities including BI. Contact Sue Dale. 911 18th Street N., St. Cloud, MN 1-320-650-1550.

Courage Center. <http://couragecenter.org> 1-888-846-8253.

Danger Committee, as seen at Dudley Riggs Theater, Minneapolis, MN. (Well-crafted live context-rich family humor; barrier-free intimate seating, gentle crowd atmosphere, visual aids, Q&A following.) <http://www.thedangercommittee.com>

Dyslexia Institute of Minnesota at The Reading Center, 847 Fifth Street W, Rochester, MN 55901 for acquired dyslexia issues. <http://www.theReadingCenter.org> for children or adults with acquired dyslexia. \$ to go through course yourself, then mentor someone else.

ECHO-TV(Emergency and Community Health Outreach), c/o Association of Minnesota Counties, 125 Charles Ave, St. Paul, MN 55103, 651-789-4342. (Info produced in 8+ languages.) <http://www.echominnesota.org/tools/echo-tv>. (Helpful segments made available in cd format to consumers because brain injury is not just a Caucasian experience.)

Electroshock Convulsive Therapy (ECT) and head injury. <http://www.ect.org/effects/headinjury.html>

First Call for Help (dial 411) for ideas about additional services available in your community.

Head Injury Symptoms, treatment, recovery. <http://www.aftertheinjury.org>

Head Injury Hotline, 212 Pioneer Building, Seattle, WA 98104-2221. 206-612-8558. <http://www.headinjury.com> promotes self-advocacy, education, information on self care, denial, anger, loss of self; memory strategies.

HCMC (Hennepin County Medical Center), Park Avenue, Minneapolis, MN 55415. <http://www.HCMC.org/braininjury.org>

International Brain Injury Association (IBIA), 1776 Massachusetts Ave, NW, Suite 105, Washington, DC 20036-1904. 202-835-0580. <http://www.internationalbrain.org> for positive interactions among diverse cultures and nations. International leadership for brain injury issues and solutions, programs and conferences.

Jean's Journey: jean@jeans-journey.com speaker on dangers of Distracting/Distracted Driving. Working with Sheriff's Initiative Toward Zero Deaths.

Knapp Rehab = Miland E. Knapp Rehabilitation Center, HCMC (Hennepin County Medical Center), 701 Park Avenue (MC-B3), Minneapolis, MN 55415.

Lash & Associates Publishing, 100 Boardwalk Dr, Suite 150, Youngsville, NC 27596. 1-919-556-0300. <http://www.lapublishing.com/contact.php> (publishes unbiased/non-commercial information for ABI for adults, children, family, friends and professionals, and posts blogs of personal accounts and BI training. "Blog writing gives meaning to my life." —Marie Cooney, author of blog "Tucker Taught Me")

Search "Legal Defense Fund" +[medical condition] for pro-bono or \$ counsel.

Mayo Brain Rehabilitation Clinic, Rochester, MN, 1-507-266-6442. "When I was there, they couldn't seem to get beyond the professional level of info to the family level of info. Otherwise a good experience. Must apply and be accepted into the program. They will only take individuals who can comprehend and have the motor skills to actually do the tasks to be worked on at the time of acceptance. The candidate must be able to communicate in some way, pronounce sounds, recognize written words, and be able to

move. The program works on clarity of letter sounds that are already being produced, on rebuilding synapse detours to reteach reading skills. I applied 4x and finally got in."—Barbara. (Offers the option of previous patients as volunteer mentors for TBI in-takes.) <http://www.mayoclinic.com> (Search for "stroke" or "brain injury": signs and symptoms, when to seek medical advice, coping skills. Request a list of free mailable pamphlets and materials, like "Returning to Work: Specialized Approaches for Individuals with Brain Injury.")

MetroMobility, DART and VA Services vans are opportunities for transportation (contact through County Social Services), but may be driven by volunteers and might not offer as reliable transportation as you need for job or therapy appointments.

(Minneapolis) Metropolitan Area Eldercare Development Partnership: a clearinghouse of information pertaining to Seniors. 651-917-4632

MN Brain Injury Alliance 612-378-2742, 1-800-669-6442. <http://www.braininjurymn.org/education/BIBasics.php> lots of classes and workshops offered. (MBIA offers a \$ Professional Conference in the spring, and a free Consumer & Family Conference in the fall.)

Minnesota Speech, Language, and Hearing Association. <http://www.ASHA.org> Cognitive, communication, swallowing disorders.

Minnesota Stroke Association, 34 13th Avenue NE, #B001, Mpls, MN 55413. <http://www.strokemn.org> (Has aphasia support groups, now partners with MN Brain Injury Alliance.)

National Alliance on Mental Illness (NAMI), <http://www.nami.org> TBI, veteran's resource center, BI and MI.

National Rehabilitation Information Center (NARIC) 4200 Forbes Blvd, Suite 202, Lanham, MD 20706-4829, 1-800-346-2742. <http://www.naric.com> quick reference and referral to nearby rehabili-

tation facilities and support groups. Spinal cord injuries, publications.

“Neurology Now” magazine. Box 1908, Lowell, MA 01853-9967

No Wrong Door. <http://www.ucnowrongdoor.com/mentalhealthrecovery.html/counseling&support> (This website entry is for mental health issues, but there is a metasearch “No Wrong Door” in many states and other countries to address a variety of conditions. No Wrong Door Initiative begins in 2014.

Optimist Clubs may offer grants for assistive devices or a Walk For Thought. Contact local club for direct assistance. For a club list: Optimist International, 4494 Lindell Boulevard, St. Louis, MO 63108. 314-371-6000.

P.W. Healthy Living. pwhealthyliving@gmail.com for natural food liquid supplements. Patricia Warren, distributor.

Save This Brain <http://www.savethisbrain.org> Sports Related BI.

Sister Kenny Rehabilitation Institute for therapy and assistive devices. 333 Smith Ave N, St Paul, MN 55103. 651-241-8290.

Special Olympics International <http://www.specialolympics.org> is for acquired-disability athletes as well as Down Syndrome competitors.

Speech therapy in languages other than English: Brain Injury of Minnesota. Beatriz Martinez batrizm@braininjurymn.org 612-378-2742, 1-800-669-6442.

St. Francis Regional Medical Center, 1455 St. Francis Ave, Shakopee, MN 55379. 952-403-3000. Physical & Occupational Therapy, 1661 Park Ridge Drive, Chaska, MN 55318. 952-448-5077. (Including certified swallow therapy/MaryPat Parker.)

United States Department of Veterans Affairs. <http://www.va.gov/bin21/Benefits/exams/disexm58.htm>: Traumatic Brain Injury. (Note: “Service people have to ask Veterans Administration for help with PTSD or blast-induced BI—it is not to be automatically assumed that this benefit will accompany a soldier’s combat experience.) One treatment for PTSD is EMDR. (See EMDR on page 248) Branches of service may intimate that asking for recovery help is a sign of weakness—it’s not.” —Charity. (See **Sympatico**, p. 41)

United Way: First Call for Help United Way, call 211 or 952-746-5551

Additional Bibliography

Adams, Patch: author of humor titles for recovery (Librarian’s Pick on page 181) Livetulaff@aol.com

Brain Fitness Kits, 4 games per checkout unit, Carver County Library System. <http://www.carverlib.org>

Brain Lash, by Gail L. Denton. 2002.

Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science, by Norman Doidge, M.D.

CareNotes, Abbey Press, St. Meinrad, IN 47577. 1-800-325-2511.
“Finding the Courage to Face a Serious Illness” by Jim Auer,
“First Weeks After a Stroke—A Guide” by Rev. Michael D. Moore

Consumer Guide (annual), Brain Injury Association of Minnesota. <http://www.braininjurymn.org> 1-800-669-6442.

“Coping with Depression After Brain Injury”, Brain Injury Association.

“Dear Brain”, Minnesota Brain Injury Association.

“EMDR (Eye Movement Desensitization & Reprocessing) Heals the Wounded Soul, Part 1: What is it and can it help you?” by Nancy Schimelpfening. <<http://www.depression.about.com/library/weekly/aa11400a.htm>> (See page 172.)

Exercise DVDs”

“Back to Fitness” <<http://www.mdfitness.biz>>

“Cane-fu: Moving Beyond Disabilities”.

“Chair & Standing Routines: Ageless Yoga”.

Finding Water by Julia Cameron.

Five Dysfunctions of a Team, by Patrick Lencioni. Adaptable to a therapy team.

From My Brain to Myself, Minnesota Brain Injury Association.

Hopes and Dreams series by Tana Reiff. (Easy adult-themed chapter books with comprehension questions.)

“If You Want Me To”, Song by Ginny Owens. <webmaster@christianryiconline.com> or <<http://www.Youtube.com>>

I'll Carry the Fork by Kara Swanson <<http://www.amazon.com/Coma-Recovering-After-Brain-Injury/dpl0933670044>> (Poignant humor about short-term memory loss.)

Mayo Clinic Pamphlets series:

Functional Electrical Stimulation (FES) for Neurological Conditions.

How to Help Someone Who Has Brain Injury: Patient Edition

Perceptual Changes After Acquired Brain Disorders

Understanding Brain Injury

Understanding Brain Injury: A Guide for Employers

Understanding Pediatric Brain Injury: Guide for Parents & Teachers

“New Game Plan for Concussion” (Sports Injury). “Neurology Now Magazine”, Feb/Mar 2011. pp. 28-35.

“Newsweek”, Series on the Brain, Nov 2011.

Self-Care for Caregivers by Pat Samples (Provides good suggestions to keep from being swallowed whole by caregiver duties.)

Smile on My Forehead by Jennifer Mosher, Lulu Press.

Stroke Recovery Book: A Guide for Patients and Families by Kip Burkman.

“Substance Abuse Issues: After Traumatic Brain Injury” by Brain Injury Association.

In an Instant: A Family's Journey of Love and Healing by Lee Woodruff and Bob Woodruff. (Award winner, National Academy of Neuropsychology.)

Who Switched Off My Brain? Controlling Toxic Thoughts and Emotions, by Caroline Leaf.

Wounded Warrior by Don Philpott, Veterans Rehabilitation Services ISBN: 1605902713 for veterans with brain and other injuries.

“You Look Great Inside a TBI”, <<http://www.Youtube.com>>

Games

Attn = Attention
AudComp = Auditory Comprehension
Mem = Memory
Plan/Seq = Planning/Sequencing
PrbSol/Reas = Problem Solving/
Reasoning

PrSpeed = Processing Speed
Reas = Reasoning
ThotOrg = Thought Organization
VisSpac = Visuospatial Skills
WdRet = Word Retrieval

Game/Activity	Skills Addressed
1. 30 second mysteries, by Moog/Pinsker (Games by James)	PrbSol/Reas, AudComp, Attn
2. Bop-It (Toys R Us)	AudComp, PrSpeed, Mem, Attn
3. Simon (Target)	AudComp, Mem, Attn
4. Blink (Target)	PrbSol/Reas, PrSpeed, Attn, Plan/Seq
5. Qwitch (Target)	PrbSol/Reas, PrSpeed, Attn
6. Card games Pyramid King's Corner Golf	Mem, PrbSol/Reas, Attn, Plan/Seq
7. Cribbage	Mem, PrbSol/Reas, Attn, Plan/Seq
8. UNO	Mem, PrbSol/Reas, Attn, Plan/Seq
9. Logic Puzzles Sudoku Crosswords Word Searches	Mem, PrbSol/Reas, Attn

Game/Activity	Skills Addressed
10. Nintendo DS, including: Big Brain Academy Brain Age 1 & 2 Flash Focus	Mem, PrbSol/Reas, VisSpac, Attn
11. Online games (www.msn.com) Text Twist Alchemy Bejeweled	PrbSol/Reas, Mem, VisSpac, WrdRtr, Attn
12. Outburst	WdRet, Attn, ThotOrg
13. Taboo	WdRet, Attn, ThotOrg
14. Scattergories	WdRet, Attn, ThotOrg
15. Boggle	WdRet, PrbSol/Reas, Attn, ThotOrg
16. Mancala	Mem, PrbSol/Reas, Attn, Plan/Seq
17. Blokus	PrbSol/Reas, Attn, Plan/Seq
18. Sequence	PrbSol/Reas, Attn, Plan/Seq
19. Scrabble	PrbSol/Reas, Mem, WrdRet, Attn, Plan/Seq
20. Broccoli for the Brain, book by Michel Noir (Amazon)	Attn, PrbSol/Reas, Mem, ThotOrg, WrdRet, Plan/Seq
21. Rush Hour (Games by James)	Attn, PrbSol/Reas, ThotOrg, Plan/Seq
22. Set, card game (Games by James)	Attn, PrbSol/Reas, Plan/Seq

Postscript

Coma

You touch me
And pain makes me tremble
Along with the delight of interaction.
My eyes are behind the shades
Of sealed lids
But I see shades of light
Surrounding your out-scaled form.

You lovingly say
“Dad, we’re going to move you on ‘three’”
It is not rocket science
And my tired ears
Barely decipher the muffled syllables,
But you count down anyway
Roll me
And love tumbles out
With a bloody bowel movement.

That thing
Which you have greatly feared
Has come upon you¹
But you know it has come upon me, too
So you tenderly
Clean me up
As best you can;
I know you have not been trained
In this line of work
It’s your soothing touch

Your acceptance of
Who I am now
That gives me fresh perspective
Of this new plight,
For I am farther down the road
Than I was yesterday.
As I struggle
Wordless
To bring you
All the stories of my life,
One hopeful fist
Stiffly surrounds your tender fingers
I quake with urgency
For palsy underscores my depth of emotion
At the importance of what I want to convey
Reduced only to love
—And you get it.

¹ Job 3:25: “For the thing which I greatly feared is come upon me, and that which I was afraid of is come unto me.”

Poem reprinted from My Father in Verse by Author.

Inspired by Derry Bresee, Hospice Nurse, Coma Survivor. <http://www.near-death.com/experiences/triggers13.html>

Letter to Leone

Father, God of all comfort, *every* kind:
God of warm blanket, God of fluffed pillow,
God of embrace when we are tired and alone,
God of encouragement when we feel like we have not worked
 “hard enough”,
God of grace when we are full of shame,
God of hot chicken soup after a long, cold day,
God of flannel jammies when we are depressed,
God of tears.

God of “atta boy”s when we have been ridiculed,
God of compliments when we have labored all day and no one
 else noticed;
God of thanks when we give up our children to His service,
God of a Good Book when we don’t know where else to turn,
God of the listening ear when we need to vent,
God of butterflies floating on air when our load is too heavy,
God of funny bunnies and soft kittens and nuzzly puppies
 when we take ourselves too seriously,
God of belly laughter.

God of the good word, the right word, the final word, when
 we have been bawled out by humans,
God of silence when we expect the other shoe to drop,
God of the deluge when we deserve a sprinkle,
God of extravagance when we have given a mere pittance,
God of wisdom when we have acted the fool,
God of mercy when we finally see our sin,
God of help just exactly when and how and where we need it,
God of chocolate.

Thank you for Leone today,
Thank you even for her stroke: so she can quit having to
 explain herself and just listen to You with her inner ear.
Thank you even for her frustration, for that very gnaw reminds
 her she wants to keep living.
Thank you even for her fears: the one about another stroke,
 the one about losing her self, the one about being de-
 pendent upon the very people she has been caregiver
 to, the one about thinking she’ll be forgotten when she
 dies; for in those fears she will be more likely to seek
 Your arms, Your solace, Your care. You respond with
 Your promise of perfect remembrance, Your pledge
 that the Word in us will remain forever and that is
 enough.
Thank you for the chance she has now to acknowledge all
 the abilities You had given her to use over the years
 that she never quite noticed before. So, thank you for
 giving and for taking away. Blessed be Your Name:
 Creator, Abider, Enough, O, God.
Thank you for Leone:
For making her, and then calling her good. For naming her
 Your beloved.
For keeping her. And never saying, “Til death do You part” to her.
For loving her in sickness and in health.
May she recognize today that is exactly Enough,
God of all comfort, every kind.

Based on 2 Thess. 2:16, 17: “Now may our Lord Jesus Christ Himself and God our Father, who has loved us and given us eternal comfort and good hope by grace, comfort and strengthen your hearts in every good work and word.”

For Leone Vogel Jarvis, mother of Fr. Paul Jarvis, who was transparent enough to let me see the gift of his tears.

Benediction

Now may you have freedom to be the lovely person you are.
May you be confident in the insights you have been given.
May you be marinated in grace and covered with favor.
May you be encouraged as you go.
May you encounter those who either need what you have to give
or can supplement and enhance what you already share.
May you have protection from whatever is out there.
May you have security in whatever you do.
May you embrace the Father's strange goodness.
May you rest in the Father's love for you.
May you rejoice in working with the Son.
May you be emboldened with the empowering of the Holy Spirit.
May you know you are entirely loved.

– Connie Sylvester

In His love,

Angela E. Hunt

Photo Credits

All Kauai'i, Hawaii, photos were taken by Jim Hunt,
Photos on pages 18 and 79 by Gary Carlson,
Front cover & page 128 photos by Linda Carlson,
Back cover photo is by Dara Gades.

Thanks

Thanks to Tammy Robinson who believed this
book needed to go beyond my small world.
Special thanks for editing and production
work by Linda and Gary Carlson and Jim Hunt.

Other Books by Angela Hunt:

My Father in Verse: Working Through the End of Life

Understanding, communicating with, and ministering to the terminally ill in the crisis phase.

Am I Still Me? A Group of Words with Fundamental Questions for Those Struggling to Recover Themselves

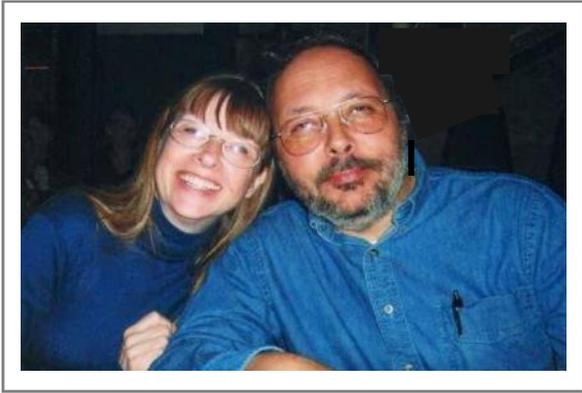
Awareness of and coping with the struggle of brain malfunction.

Way Out on a Limb: One Mother's Journey Through Her Daughter's Rape

Discovering the function of family, the possibility of forgiveness.

To Order: [<http://www.rangeprintworks.com>](http://www.rangeprintworks.com)

or [<http://www.booksbyangelahunt.com>](http://www.booksbyangelahunt.com)



Angela Hunt has a Psychology of Communications Degree from Concordia University, St. Paul, and is a Public Librarian in the Southwest Metro Area. Since her brain injury, she has come to enjoy spelling as an art form.

Jim Hunt contributes a photographer's eye and some tech support to keep things running toward the finish line. This is his second book, but maintains, "I'm just stuck between the covers because I'm married to the author."

I Am Still Me! is about overcoming the angst and frustration of concussion, brain injury or stroke, assessing and naming changes, helping friends, family and caregivers comprehend what is happening inside, as well as coming to terms with new skill levels. It might even be for acceptance of, and adaptation to a new way of life.

"Brain Injury can be harder on families than on the patient, because they have to pick up the injured person's duties, and help with recovery, too. Families need good resources." —David A. Santella, M.S., L.M.F.T., Marriage and Family Therapist and Brain Tumor Survivor.



See also the companion book **Am I Still Me?** by the author for more ideas on managing day-to-day living. Available through RangePrintWorks.com or BooksbyAngelaHunt.com

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