Slowly being robbed of the use of his body, Toronto Sun writer Jerry Gladman and his family come to grips with a frightening diagnosis

Part 2: The struggles of daily life
Part 3: A safe place
Part 4: Acceptance
Part 5: Outpouring of emotion

I have ALS.

There, I said it. I have ALS. God damn it! I have ALS.

Amyotrophic Lateral Sclerosis. Also known as Lou Gehrig's Disease, Charcot's Disease (for French Dr. Jean-Martin Charcot, who first wrote about it in 1874) or Motor Neuron Disease in Europe.

Most of us probably identify it with Lou Gehrig, the all-star New York Yankees slugger whose career was cut short by ALS and who made the famous retirement speech at home plate at Yankee Stadium in which he said: "I consider myself the luckiest man on the face of the Earth."

ALS' CRUEL END

Jerry Gladman and his wife Norma pause at the top of the stairs in their Richmond Hill home after he stumbled while going up to take a shower, only one of many daily activities altered since he was finally diagnosed with ALS last April -- after nearly a year complaining of symptoms. Photos by David Lucas

Many of us also know it from years of watching the Jerry Lewis Muscular Dystrophy telethons during which ALS was a featured component, but took a back seat to the suffering of kids with MD.

Some of us recall it in regards to a British Columbia woman named Sue Rodriguez who challenged the constitutionality of the Criminal Code all the way to the Supreme Court for the right to take her own life rather than await ALS' cruel end. She lost, but later died of an overdose of drugs in the privacy of her home with the assistance of a doctor.

And others yet learned of it from a book called Tuesdays With Morrie, a beautifully inspirational story of a former student's time with his old sociology professor in the latter's last months battling the illness.

But for those who don't know of it, ALS is a disease of the nervous system. It attacks the motor neurons, which convey the brain's messages to the voluntary muscles throughout the body. When the muscles don't get these messages, they cease to function.

Over the course of the disease -- the average life expectancy at the time of diagnosis is only two to five years -- the muscles in the arms, legs, chest and throat weaken and then shut down totally. In the final stages, the body becomes paralyzed, although the mind typically remains active and alert, as do the senses. Some have likened it to being buried alive.

And, unlike Mr. Gehrig, most of us suffering with ALS do not consider ourselves particularly lucky in any way.

The cause is unknown, nor is there a cure. There are relatively few medicinal treatments, although scientists throughout the world race against time to develop those that might be effective. Those that do exist only promise to extend life for some months, which, of course, we will take.

Although my symptoms first began appearing in June 2002, I wasn't officially diagnosed until last April. With the majority of sufferers, the disease first appears in the limbs. Mine started in my throat, which is called Bulbar ALS, affecting my speech, chewing and swallowing. It's now progressed into my arms, hands and legs, limiting a good portion of my normal activities. As well, it's wreaked a fair amount of emotional havoc.

BROKE MY HEART

Because of the nature of my work and my function at The Sun (I do book reviews and write a weekly obit-type column called "One Life"), I am able to continue earning a living. But it's beginning to affect some of that. I can no longer take written notes, talk on the phone or walk very far.
However, the most tragic part for me was having to quit teaching. For the four years prior to my diagnosis, I taught news reporting at Ryerson University. Although I came to it late in my career, I loved teaching beyond compare and my plan was to take early retirement -- I just turned 60 -- and teach full time.

In January, when I realized I could no longer lecture or manage the workload along with my Sun duties, I decided to resign. It saddened my students and broke my heart.

As I write these words, tears freely and frequently spilling onto the keyboard, I know full well this will be the last large story I produce. It signals the beginning of the end of a career that began 44 years ago when I was 16, a Grade 10 dropout who was lucky enough to get into this racket as a copy boy, and who somehow managed to achieve a modest measure of success and write some fairly decent yarns.

But none of this comes remotely close to dealing with the true reality of ALS -- ending my life paralyzed, dependent on others for my every need from eating to personal care to passing the long hours to breathing.

And to the awful realization that I won't be around to see my children marry and shape their lives, my grandchildren flourish, to grow old with my brother and sister (close friends as well as siblings), or spend the next 20 years or so, as planned, enjoying every minute with my life's partner, the incredible woman who has made each day a joy for me for more than a quarter of a century.

I knew even before I was officially diagnosed that I would write this story. What I didn't know was that it would take me so long. I found every form of procrastination -- short of knitting outfits for my computer -- to avoid writing this piece. Deep down I knew it was some element of denial keeping me from it, but then I hadn't yet fully accepted it.

I guess I was thinking that if I went public with it, I would be removing the final barrier. I just wasn't quite ready to tap out that sentence that led off this article, the three little words that would seal my fate for all to see.

And then one afternoon, hard into a peaceful nap, I woke suddenly with an epiphany as clear as a neon marquee. If I don't soon write this story, someone will have to write it for me.

When ALS first stole into my life -- in the form of a periodic nasality in my speech -- it was misdiagnosed as a stroke. Little did I know then I would gladly have accepted that diagnosis along with all it brought to the party, as opposed to what awaits me down the line.

The speech difficulties would crop up more and more, especially when I got angry, excited or emotional. My family doctor, Joel Abrams, a splendid and caring physician, thought, as I did, that it might be something involving my sinus. But never one to let anything slip by, he arranged for appointments with an ear, nose and throat specialist and a neurologist.

The ENT guy went down my nose and throat with a tiny little camera, searching hither and yon, and confirmed it was nothing in his bailiwick. The neurologist, a highly regarded practitioner with whom I was never comfortable, asked my history, gave a quickie exam, and suspected a minor stroke. He then set me up for an MRI (two months down the road).

The stroke made sense. Two years before I had suffered a mild heart attack, and I also had a long tussle with high blood pressure. And even though the MRI was inconclusive, mild stroke seemed like a suitable diagnosis. So they upped my medicine, prescribed diet and exercise and I began taking speech therapy for the nasal problems.

When I resumed teaching that fall, I greeted my new class with the news of my illness and the hope I would be able to work through my speech problems. I got around it by typing out all my lectures and having a student step in and read them when I had difficulties. They seemed to be enjoying the class so we carried on.

When I began to suffer new symptoms -- problems swallowing, sneezing and periodic choking -- my speech therapist, a gifted young woman named Leeanne Rabinowitz, thought there might be something else going on and suggested I revisit the ENT guy. He checked me again and found nothing, but when I told him my new symptoms, he felt it was neurological and sent me back to the neurologist.

"Aha, I know what it is," he postured. "You have myasthenia gravis."

It sounded a little ominous, but it was only a name I recalled from some TV commercials. He explained that it was a chronic auto-immune neuromuscular disease characterized by varying degrees of weakness in muscles, including those that control speech.

"Will it kill me?" I asked half joking.

"Hardly," he said. "It's treated with medication. I am going to book you into the hospital as an outpatient for a tensilon test, inject you with some stuff (edrophonium chloride), have you talk a minute and if it is
myasthenia gravis, your speech should clear up right away."

I did a little checking and learned most MG patients were treated with medicine and went on to lead fairly normal lives. It sounded even better than a stroke so I was ready to become poster boy for myasthenia gravis.

Except my voice didn’t clear up. I talked for a full minute and the nasal problems remained. The frown on the neurologist’s face triggered some sudden and heavy heart pounding. He said they would have to do further testing but he suspected something neuromuscular.

The words fell out of my mouth before I could check them. "Could it be ALS?" That fear had grown inside me ever since neurological was first mentioned by the ENT guy.

"I don't think so," he said. "It usually starts in the arms or legs."

He began testing the strength in my limbs, then stared for a time at my hand. "I thought I saw a twitch." He didn't explain.

I asked him again. "Could it be ALS?"

He paused, looked into my eyes. "It could be," he said softly.

"And if it is? What can you do for me?"

He paused again, shook his head and then said: "Not much."

When he heard the breath go out of me, he added: "But let’s not jump the gun. There are all sorts of treatable neuromuscular conditions. Let's do some more tests and we'll see."

I would await the tests, but from that moment there was a gnawing at my gut I knew wouldn't go away.

And then the twitching started.

I noticed it first in my left arm, one night while watching TV. I could actually see pulsating beneath my skin. I recalled the neurologist staring at my hand and I could clearly see the twitch between my thumb and forefinger that he only thought he saw.

They’re called fasciculations. I know that because I looked up involuntary twitching and neuromuscular on the Internet. A fasciculation is an involuntary, spontaneous contraction of one or several motor units resulting in a muscle "twitch."

Anyone can have this jumping of muscles -- sometimes likened to a bag of worms -- and they are benign and often induced by exercise, lack of sleep or too much caffeine. But in motor neuron diseases, they are a hallmark of motor nerve irritation, particularly in ALS. Their presence may also help in reaching a diagnosis, although they are not specific to any one disease.

Norma leaves the house on an errand while Jerry works at his desk, now set up in the living room. The next day, with both arms jumping and twitching, I raced to my family physician and told him my new symptoms. I was frantic. He examined my arms and then told me to stick out my tongue. The look on his face told me the news wasn’t good.

"You also have them under your tongue," he said, holding up a mirror to the shimmering bag of worms at the centre of my mouth. "I wish I could tell you different, but I think you may have a progressive neurological disorder."

I hit him with my now stock query. "ALS?"

"It could be anything. There are all sorts of treatable neurological diseases that have the twitching. It's just a sign. Let's wait for all the tests and we'll see. It may be something harmless."

But the pounding in my heart as I drove home to delight my bride with the latest somehow said otherwise. It was also accompanied by a feeling of anger. Why did the neurologist not look at my tongue? Why was this left to a general practitioner? And worst of all, why would I now have to wait weeks, maybe months, for testing, as I was earlier told?

All of that became academic that evening when I received a call from my aunt, Dafna. One of the leading specialists in Canada in the fields of rheumatology, arthritis and lupus, she was also an angel to all of our family members in any medical emergency.

Concerned about my situation, she involved her close friend, Peter Carlin, a leading neurologist who had diagnosed my mother with Alzheimer's disease. He asked a bunch of questions related to my symptoms and then he and Dafna decided they would hijack my case and have me treated at their home base at Toronto Western
His concern was the most crucial test, the electromyography (EMG), be done by an actual neurologist as opposed to a technician, who might miss something. In hindsight, as will soon be clear, I would have preferred a plumber.

The EMG is actually part of a three-pronged test consisting of a directed history and neurologic examination, nerve conduction studies (NCS) -- basically shock treatments to test nerve function -- and the EMG, in which small needle electrodes are inserted into muscles in the arms, legs and back to determine muscle function.

The results of these three tests are examined to reach a precise diagnosis. While there is actually no diagnostic test for ALS per se, they can get close enough with the EMG and NCS, as well as ruling out any similar conditions, to determine if it is a progressive neuromuscular illness.

Without going into great detail, let me just say this battery of tests was fairly uncomfortable, particularly the shock treatments and the jabbing of needles into muscles. After the tests were completed, the neurologist -- a woman with genuinely reprehensible bedside manners -- spoke to Norma and me. This was the general thrust of her conversation:

"You have something not very good. It could be ALS, but we want to do further testing to rule out other similar conditions. If it is ALS, you should be aware that in cases where it starts in the throat people generally pass away within two years. There might be some treatment for what you have, but you shouldn't grasp at straws because it would only delay progress for a short term."

**HORROR AND PAIN**

I asked her a question relating to ALS. At this point, her tone sharpened. "You weren't listening. What I said was ..."

It didn't matter what she'd said. What we heard was ALS and two years. I looked at my wife and saw the same agonized expression of horror and pain that I'm sure decorated my face. We both knew at that moment we were beginning a journey into a place called hell.

As for the doctor who gave us the news, we saw her for maybe a total of five minutes. Her manner was cold and hard-edged, there was no compassion, no comforting hand on the shoulder of someone she had basically given a death sentence, and she seemed to be in a hurry.

After she bustled out, leaving us shaken like two shell-shocked infantry soldiers following an enemy bombing, her young associate, who had been in the room and appeared extremely uncomfortable, asked if we would like an ALS pamphlet. We declined politely, but assured him we would get one when we knew for sure it was ALS.

Can you imagine? We had just been given some pretty awful news, news that would change our lives so drastically, and the best they could come up with was a pamphlet. A freaking brochure.

Unfortunately, we weren't done with this particular physician, although we would never see her again in the flesh. The date was Jan. 14. It would be another three full months before I was finally diagnosed, and, thankfully, it wouldn't come from her or from a pamphlet.

**But come it would.**

If I've learned nothing else from my experiences with the medical profession, one expression probably describes it best: Hurry up and wait.

The majority of the three-month period between initial testing and diagnosis was all about waiting. Waiting for people to return from vacation, waiting for tests to be set up, waiting for test results, waiting for doctors to return calls, waiting to find out whether I would live longer or die sooner.

Jerry's son and grandkids play basketball on the driveway while proud papa Jerry watches, right. He is surrounded by family and friends as he fights a deadly battle with ALS.

It was agony, for two main reasons. One is that waiting for results, as we all know, always messes horribly with your mind. It's a roller-coaster ride of emotions from hopeful to fretting to maybe to certainty to positive to dread and back again.

The other reason was I was getting worse. Whatever malady I had was marching onward and it scared the hell out of us.

Initially, it involved primarily my speech, chewing and my partially paralyzed tongue, which made moving food around prior to swallowing an Iditarod-type challenge while, at the same time, contributing to regular, albeit minor, bouts of choking.

Then came breathing difficulties where my throat seemed to close (caused, I later learned, primarily by stress),
buildup of excess saliva at night that could also choke me, sensitivity to strong odours and emotions close enough to the surface to produce periodic crying jags.

Then it invaded my arms and hands, ever so slightly at first (although magnified by stress or tiredness) and then more noticeably. I had trouble holding on to things and lifting objects, my fingers were clumsy at manipulating items like keys and knobs, and the muscles in my arms would get fatigued fairly quickly. Crikey, I couldn’t even pick my nose properly.

At the same time, stress aside, I felt pretty good. My appetite remained solid, I had energy, and my attitude was fairly upbeat. I knew I was treading in dangerous waters, but I was determined to carry on with my life for now.

What kept me up for so long was the support of my family and friends. Norma was a rock, as always, and ran wonderful interference for me. Once the kids -- Lee, from my first marriage and a father of four himself, and Jesse, now 22, and Caitlin, 19 -- accepted the seriousness of the situation, they were there for me every inch of the way. And as for friends, I never realized I had so many and all of them wonderful.

By this time, we had made the decision that I stop teaching so I could concentrate my energies on the job that provided the most finances. The Ryerson people were very supportive, and the genuinely touching e-mails and calls I received daily (and still do on a regular basis) from students stretching back four years were truly humbling.

Over the three-month period, I had a clutch of tests. There were barium swallows for my throat, a genetics blood test, a lumbar puncture (delightful, where they stick a syringe in your spine and withdraw fluid) and the best of all, a nerve biopsy (to determine if it was a nerve disorder rather than muscular), in which they removed a small piece of nerve from my left ankle, rendering the area dead for all time.

The waiting was excruciating. We were told it would take two to six weeks for the results of the nerve biopsy, which in itself seemed like cruel and unusual punishment. You could write a book in six weeks. Meanwhile, our emotions continued their relentless roller-coaster ride.

Several calls were made to the neurologist’s office by ourselves, Joel Abrams and Dafna, but she, personally, never once returned calls to any of us. Can you imagine a professional not giving another physician the courtesy of a return call in such a serious situation?

Then came the final blow. After the six weeks were up, we were told by the neurologist’s secretary that once the results were in, she would need another two months before she could get around to assessing them and providing a diagnosis.

Two months! What part of progressive disease did this individual not understand? Less than two weeks later, I was told my absolute fears were confirmed -- I have ALS.

The news was given to me in a compassionate, straightforward manner by yet another neurologist, Dr. Ralph Kern of Mt. Sinai Hospital, whose wife is a colleague of my aunt. He found out about my case while they were away at a medical convention and said he would see me as soon as he returned.

A few days later, in the midst of the SARS epidemic, Dr. Kern, an amiable, kind and communicative specialist, arranged to see me in a special office set up across from Mt. Sinai. He spent well over an hour examining me and talking to me.

While I still held out a little hope the diagnosis might be less threatening and not so terminal, I felt instantly with Kern I would get the straight skinny and he would answer all my questions. And I was right.

He got all my history right down to the tiniest detail. And then he gave me a thorough physical exam, similar to the one the previous neurologist gave me but quite a bit slower and a little more exacting.

"Look, I don't need to see those test results, although I will arrange to get them today. I have seen enough patients to know with fair certainty that you have ALS. I don't think those tests will tell me any different."

I'm sure I don't have to tell anyone who has ever received bad news what those words did to my heartbeat and blood pressure. Thankfully, I was able to go into shock mode and retain sufficient composure to get the rest of the story. It wasn't pretty, although it was a tad more heartening than the bombshell I'd received three months before.

The first thing he wanted to make certain was that I fully understood the seriousness of the disease and that it was terminal. "You have to start thinking in a different way. You have to get your house in order and there are issues you should deal with along with your family."

As an example, he talked about how I would deal with pneumonia, a common life-ender for people with ALS, and with the possibility of being put on a breathing machine. I told him I was against this type of artificial breathing device and I'd decline.
"All right, that's something you have to make clear in discussing this with your family. When the time comes, you may change your mind -- a lot of people do; I probably would -- and that's your decision. But this is an issue that should be discussed now.

"Meanwhile, the first thing I suggest you do is get a copy of Tuesdays With Morrie and read it. You'll find it very helpful."

I recalled seeing the movie, although that was before I'd become a member of ALS-R-Us. Mostly I remembered Jack Lemmon's sterling performance. (Later that same day I bought a copy, read it, underlined a million lines that now applied to me, and knew it would become a bible of sorts. I also believe everyone should read Tuesdays With Morrie.)

I asked him what I could expect. His eyes were serious (the rest of his face was covered by a SARS protective mask, as was mine). "There will be some bumps in the road, I won't kid you." He knew I knew what he meant and added it was something we could discuss later. I think he wanted me to do my own research, which, of course, I later did.

What I didn't know was just how soon I would be hitting those bumps and what he truly meant by bumps.

I asked him how much time I had left, holding my breath. He said the answer to that is always between two and five years. "That's what we know. What we don't know is why a Stephen Hawking (Nobel Prize-winning physicist) has lived 20 years with it, some have lived 10 years and others five. There is no real way of gauging it other than the averages we have. But everyone is different."

I would find out later just how right he was. All my research, including talking to others who deal with ALS, more or less said the same thing. No one really knows how long anyone with the disease will live.

When I told him what the other neurologist said about two years max because it started in my throat, he shook his head emphatically. "No. It doesn't matter where it started. True, it most often starts in the limbs, but some 25% start in the throat. It doesn't matter."

I asked what was available to treat it and he said not a hell of a lot. I mentioned the AIDS-like cocktail that was being used and getting a lot of attention in the media. He said it was still in the testing stage and there was no hard proof it worked. He also said the side effects were extremely harsh and toxic, often making people worse.

I mentioned some other promising treatments I'd read about. He said that's just what they were -- promising -- but there was no hard evidence yet. He gave some examples complete with facts and figures to show he was up on every aspect of ALS.

He said there was one drug that has proven successful in slowing down the disease -- Rilutek -- with minimal risk and side effects. He said he wanted to get me into the Sunnybrook clinic where he would arrange for me to get the medicine.

"Look, I'm under no delusion about a miracle cure," I said. "But if there is a drug that will slow down the disease for any time at all, I want that drug. The more time I have the more chance there is that something will come along and change everything. All I want is a shot."

He looked at me and nodded. "I absolutely agree. I always believe in erring on the side of the patient if there is even the tiniest chance something will help."

On the way home, my brother, Mike -- he'd sat in on the session because Norma was away -- and I rehashed everything that was said. We agreed it was pretty well the same news I received in January only now it had a name, I would soon be treated for it and my demise wasn't quite so absolutely pencilled in on the calendar.

But as the conversation withered and we drew closer to my home, tears started to trickle down my cheeks.

This soon turned into a torrent as the tension of the past months came crashing down on me along with the reminder that I had yet to share this official news with my family.

I have ALS and no matter how positive a spin we applied to it, chances were pretty high that I wouldn't be with them too much longer.

ALS VICTIMS

- Charles Mingus: Jazz pianist
- Cyril Cussak: Irish actor
AN ALS PRIMER
Amyotrophic Lateral Sclerosis:

A = absence of myo = muscle trophic = nourishment

Lateral = side (of spine)

Sclerosis = hardening

Dr. Jean-Martin Charcot, a French neurologist, published the first full account of this disease in 1874. ALS, also known as Charcot's Disease, Lou Gehrig's Disease and Motor Neuron Disease, is a major neurological disorder. In Canada, it is the most common cause of neurological death on an annual basis.

ALS destroys motor neurons that are an important link in the nervous system, and through which the brain controls the voluntary muscles throughout the body.

Leg and foot muscles are controlled by motor neurons in the lower spinal cord. Arm, hand and finger muscles are controlled by motor neurons in the upper spinal cord. Speaking, swallowing and chewing are controlled by motor neurons in the brain stem.

ALS does not affect the five senses -- sight, hearing, taste, smell and touch -- nor does it normally affect the mind, eye muscles, heart, bladder, bowel, or sexual muscles. There is no possibility that ALS is contagious.

RARELY IN TEENS

ALS strikes about six people per 100,000 per year. Between 1,500 and 2,000 people in Canada currently have ALS. Although it most commonly occurs between the ages of 40 and 70, it can also occur in older people, and rarely in teenagers.

The most common form of ALS is called Sporadic ALS. In addition, about 5% of patients have an inherited variety called Familial ALS.

Symptoms are what you experience, while signs are what your doctor can see. The early symptoms of ALS may seem rather vague. They can include tripping, dropping things, slurred or "thick" speech, and muscle cramping, weakening and twitching. Some people with these early symptoms may assume that they are normal signs of aging. As the disease progresses, the muscles of the trunk of the body are affected. Weakness of the breathing muscles develops slowly over months or years.

For some people, the muscles for speaking, swallowing or breathing are the first to be affected. This is known as Bulbar ALS. The term "bulbar" refers to the motor neurons located in the bulb region of the brain stem, which control the muscles used for chewing, swallowing and speaking. ALS symptoms, and the order in which they occur, vary from one person to another.

The rate of muscle loss can vary significantly from person to person, with some patients having long periods with very slow degeneration. Although the average life expectancy of newly diagnosed people is between three and five years, 20% live more than five years, and 10% live more than 10 years. Being a progressive disease, ALS
may spread throughout the body over time, and at some point in this process, may involve the muscles required for breathing.

ALS can be difficult to diagnose in the early stages, when symptoms may mimic other conditions. However, there are clinical signs that can be indicative of a wasting of motor neurons in either the upper or lower portion of the spine.

**CLINICAL SIGNS**

As such, clinicians familiar with ALS usually see the following signs of lower and upper motor neuron degeneration:

**LOWER MOTOR NEURON DEGENERATION**
- muscle weakness and atrophy
- involuntary contraction of muscle fibres
- muscle cramps
- flaccidity (decreased muscle tone)
- weakened reflexes
- muscle cramps
- disordered articulation
- difficulty swallowing
- shortness of breath at rest

**UPPER MOTOR NEURON DEGENERATION**
- muscle stiffness or rigidity
- emotional lability (decreased ability to control emotions)
- Some may assume these are signs of normal aging.

Over time, as muscles continue to weaken, and the weakening spreads throughout the body, it becomes more apparent that the cause is ALS.

In addition to a physical examination, people are often given an EMG, blood tests, an MRI (Magnetic Resonance Imaging), and other tests to search for the presence of other diseases that can look like ALS.

Doctors who do not usually see people with ALS may be reluctant to suggest it as a possible diagnosis. They normally refer the person to a neurologist.

Telling someone and his or her family that the person may have ALS requires a sensitive, understanding and compassionate manner.

People should also be told about the disease, current research and drug trials, as well as about support services and the ALS Society in their province.

Copy write: JERRY GLADMAN -- Toronto Sun

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**No I can't ...yes I can**

Sun writer Jerry Gladman calls the effects of Lou Gehrig's Disease 'bumps in the road.' In Part 2 of his series, he describes the struggles of daily life

Original http://www.canoe.ca/Columnists/gladman_nov3.html

Part 1: Living and dying with ALS
Part 3: A safe place
Part 4: Acceptance
Part 5: Outpouring of emotion

Copy write: JERRY GLADMAN -- Toronto Sun

I stood at the sliding door leading out onto the deck from my kitchen, watching the downpour bounce off the glass tabletop. Norma quietly slipped in behind me and wrapped her arms around my waist.

"Wishing you could run barefoot through the rain?" she asked.
Although I couldn't really reply, I nodded. That was, in fact, exactly what I was thinking. Along with the reality that I really can't run anywhere any more, rain or shine, and wondering how many more summer rainfalls I will see before I become another ALS fatality statistic.

I turned away, stumbled into the family room and began weeping -- something I seem to do a lot more of now, although it's most often a side-effect of the disease rather than an emotional outpouring over my tough luck (more on that later). This time, however, it was pure sadness.

Not being able to run through the rain, or anywhere, is only one of the multitude of things I can no longer do. The list is frustratingly endless and yet seems to grow longer with each passing day. Most of those things are normal, everyday activities we all take for granted, while others are treasured acts, the loss of which is heart-achingly sad.

Tender loving care keeps Jerry going as wife Norma dries his hair and helps him shave after his shower.

For instance, I can no longer kiss my wife with anything resembling passion, which is a tragedy because she always said I was a great kisser. (Our goodnight kiss on our first date -- a blind one -- magically transformed a relatively crummy evening into a wonderfully enduring love affair.) But the disease has affected my tongue, jaws, throat, nasal passage and lips.

I can't kiss, I can't whistle, I can't blow my nose, I can't suck on a straw and I can't blow up a balloon for one of my grandchildren. I can't sing, I can't speak with any clarity, I can't yell, I can't argue, I can't answer the phone and I can no longer rail at the TV or newspapers, which was also one of my passions.

I can't eat a meal without choking at least once (more on eating later, as well). There are many things I can no longer eat or drink or chew (like gum and candy). I can't eat a steak or any tough meat. I can't eat a salad, a staple at most dinners (too many slipperies I can't manoeuvre into chewing position). And I can no longer go out for lunch with pals (takes me too long to eat and then there are the choking issues).

There are many other things I can't do. I can no longer take a shower on my own. The movement required for washing and drying whacks me out and my unsteadiness on my feet makes it dangerous. However, we have found a way around that -- Norma gets in the shower with me and does all the heavy work (need I say showers have never been this much fun?).

I can't cut my food with a knife and fork and must use special utensils to accommodate weakened muscles in my wrists, hands and fingers. Can't cut my own nails or shave. Can't manipulate the buttons on my pants or tie laces on shoes. Turning keys and door handles is a challenge. Same with lamp switches and TV knobs.

A toddler probably has more strength when it comes to lifting things. Books, magazines, coffee cups, all sorts of everyday items you wouldn't think twice about. However, I overcome this with various strategies I've been forced to develop. Some parts of my hands and arms still work, so I adjust accordingly, if clumsily. But it's a royal pain in the ass.

And speaking of that area, so far I am able to fend for myself, albeit with the occasional acrobatics. The big fear, of course, is the day when I have to ask for help with bathroom duties. But my mentor, Morrie Schwartz (remember Tuesdays with Morrie?) convinced me that isn't as bad as I think. Sit back and enjoy it, laddy (see showering).

I used to be one of the faster typists in the game (two fingers, so I didn't have that far to fall). No longer. I've not only slowed down considerably, I now have to use aids attached to my desk that do all the work for my arms. I'm writing this, so obviously they work. But slow.

What else can't I do? Can't walk very far without the aid of a walker. Can't cook or prepare much in the kitchen. I can still drive without any problems, but I don't because it makes me nervous and it's dangerous. Can't do household chores or fix stuff. Can't shovel the snow, take out the garbage or mow the lawn (I didn't say it was all bad).

There are a million and one other things -- I'll save them for the movie. But it gives you an idea how this disease permeates your every movement. There are certainly times when it makes you want to give up -- this week it took me 10 minutes to remove a pair of tight-fitting socks -- but we ALSers are a more hardy bunch. We find ways around.

Actually, that's one of the key elements to surviving with this illness. You develop strategies to enable you to do many of the things you did before. The first strategy, of course, is asking for help. Can't do it, ask someone to do it for you. Sure, it's hard in the beginning, but not as hard as when you have to pee something awful and can't get your pants open.

(Timely example: As I was writing these words, I tried to be bold and take a drink at the same time. Naturally, I
dropped the glass and spilled pop everywhere. No sooner had I growled -- I do a lot of that -- son Jesse, 22, was walking by, saw what happened and quickly cleaned it up.)

Another strategy is trying different approaches. Can't do this, do that. Remember the socks? My fingers weren't strong enough to slide them down, nor could I step on the toes and pull them off that way. So I got a wooden spoon and used it as a shoehorn. Success.

It's amazing how inventive the human mind can be when necessary. I was trying to light a match the other day. Couldn't do it no way no how. Couldn't even tear it from the package. (I still have a pretty solid grip, but can't work the fingers.) First I got scissors and cut the match off. Then I turned on the burner on the stove, touched the match to it and, voila, fire.

The switch on our bedroom lamp is too stiff. I use pliers I keep by the bed. Works on the TV, too. Can't easily swallow the 20 pills I take each day; I put them in apple sauce. Can't open the pill bottles; I now use a pill dispenser that Norma loads each week. Can't manoeuvre a straight razor -- use an electric one (I hate it). Can't easily navigate the stairs; I hold on to the railing. Can't do buttons -- wear sweatshirts and pants with a stretchy waist. Can't drink from a can or bottle -- use a glass. I read three papers a day and my arms get tired holding them. So I sometimes sit at a table and let it do all the holding.

Pretty smart feller, eh? Nah. Folks have been finding ways around since the very first caveman figured out that the cute ones with the curves were ladies (okay, I like Mel Brooks). But it's true and amazing what you can get done if you have to.

Now if I can only figure out how to shuffle a deck of cards with my elbows.

Here's what I can do:

I can't speak clearly but I can make myself understood in a pinch with a series of mutterings and charades. But mostly I use a laptop talking computer, a wonderful device that speaks for me -- I type, it talks. I tried to get a Mel Brooks' old Jewish man voice for some character, but wound up with somewhat of a Swedish accent named Harry.

Swallowing is a slow, even dangerous process, so Jerry has his food cut in small pieces and medicines are taken with a spoonful of apple sauce.

I take Harry everywhere with me -- including interviews -- and it works out fine. I also use him for phone calls occasionally, although I often have to repeat a sentence. Harry doesn't mind. But the person at the other end has to allow for typing time.

I can also communicate through e-mail, which has been my saviour. I get probably 30 e-mails on an average day (aside from those promising me larger body parts or cheap Viagra), both personal and business-related. My problem is I am as long-winded in e-mail as I am in regular conversation, so I whack myself out responding.

Eventually, I won't be able to use the computer so somebody will have to respond for me. And then, I fear, this machine will go quiet. But I hope that's still a ways off.

They still publish my work every week in The Sun so I am able to do my job. But not without the aid of my new executive assistant, Norma. She sets up all my interviews, accompanies me and takes notes (I also tape). The people seem to adore her because she's so open and fresh. It makes my job so much easier. (If I could only teach her to write, I'd be set.)

I may no longer go out for long lunches, but I can receive visitors. I have a wide range of wonderful friends and relatives who drop by, some of whom also take me on outings, although I can't walk too far. A couple of close buddies come by every week, imbued with the spirit displayed by writer Mitch Albom in his Tuesdays With Morrie. We (meaning me, them and Harry) have wide-ranging and enjoyable chats.

I go once a week to watch my two sons play baseball (although 20 years apart, they patrol the outfield side by each) and they provide me with a multitude of thrills. Harry is one of the louder cheerleaders.

I have my family close by and they look after my every need, which is pampering, in a way, but I enjoy (and appreciate) it to my very core. I am also seldom alone and they are as splendid company as one could have. (And I love them so dearly I can barely say it without tears forming.)

As I said, I can't walk very far, but we can now park close, thanks to the new handicapped decal on our dashboard.
I can still read my books, papers and magazines without enormous difficulty. I watch TV. And during the summer I could lie out on our deck -- with Dave the dog, who seldom leaves my side, as company -- and enjoy the fresh air.

And, of course, I have my mind, which is untouched by ALS' long reach and will apparently remain so for the remainder of this journey. There is certainly plenty of time for reflection, and lately I have begun rummaging about in my past.

Once you come to terms with the idea your time here has been shortened, looking back over your life is a normal and rewarding reflex. Did I live well, did I treat others properly, could I have accomplished more, did I give my close ones the love and support they deserved? Is there still time to do more, to fill in the blanks, to right the wrongs?

So you can see, despite the avalanche of restrictions, my days are quite busy and my life full of riches.

And besides, what I often tell people is that I am not sick. I have a pretty serious disease that makes my muscles useless and will one day kill me. But I feel fine. I have no pain. And my mind works as well as, if not better than, it always did. So I'm raring to go.

Oh yes, there is one other thing I can do. I can hang on to a small sliver of hope, leave open a tiny crack in the door, that things may turn out differently from the way they now appear to be scripted. A cure, more effective treatment, a remission for a spell. Who knows?

But yes, along with all else I can do, I can still hope.

Remember those bumps in the road I mentioned?

I guess if they were restricted to the above-mentioned weaknesses and difficulties, life would be uncomfortable and trying but reasonably bearable. We're humans. We're built to adjust.

But alas, there are unfortunately a few bumps that extend a little further along the path, rise a bit higher and inflict a touch more damage to both body and soul. More than a touch -- a lot.

The least of them, albeit potentially most dangerous, are the falls. Once the disease penetrates your legs, walking becomes a tricky proposition. Some liken it to a Frankenstein Stroll. The danger is you're unsteady and if you're not careful, you can take a nasty fall.

I have already had my share of tumbles. The main problem is my arms are weak so I can't naturally break my fall. They tell you to try to fall straight down, but you don't always have time. I've had an assortment of head knocks, bumps and bruises and even a black eye. So I have to make a conscious point of being ultra careful.

Getting up from a fall can also be an adventure, but that's another story. Let's just say it's ideal if someone is nearby to help you upright.

Choking. That's a delightful bump and it comes in two forms.

First is your everyday choking and it relates to problems with swallowing. Most ALS folks don't get that until the final phases of their disease. But to those with Bulbar ALS, it comes early and often.

At least once every meal, a little something gets caught mid-journey and causes coughing, throat clearing, gagging and repeated swallowing until the little beggar finally goes down. It also happens with liquids.

(As I was reading this section over, I was eating a tuna sandwich. Tuna can be dry and often little shreds get stuck in my throat. I started coughing and clearing my throat, then took a quick drink and it cleared. My ever-vigilant better half ran up the stairs for nothing.)

After a while, you become accustomed to this little feature and develop strategies to combat it. It's annoying and uncomfortable, but also manageable. It just means you eat a lot slower and more carefully.

Then there's Choking. Real Choking. This comes about in the old-fashioned way, when a piece of food gets caught in your throat and blocks the airway. Because of weakened muscles, you aren't able to cough it up as easily as a well person might and you require assistance.

All my family has CPR training and can perform the Heimlich manoeuvre. Norma had to use it on me twice and both times I was sure I was a goner. To safeguard against choking in this manner you make sure every morsel that passes your lips is cut into small, manageable portions.
Alas, the result of all this safeguarding is never-ending meals. Think about it. Not only does it take forever to chew something and then somehow manipulate it into position for swallowing, but then you have to make sure it doesn't stop midway or lodge further down in your throat.

I'd say each meal takes me a good 90 minutes to get down. The danger here is you get so bored reheating your food and sticking with it, you tend to want to give up. But you can't. If you don't eat enough, you lose weight. Lose enough weight and they have to surgically insert a feeding tube opening in your stomach. Although I know I will eventually require one, I'd like to avoid it as long as possible.

(The good news is at my last checkup, the scales showed I've only lost seven pounds since May, which is excellent and due to my perseverance and willingness to down cold meals.)

Because of certain things you can't manage to get down, you are forced to give up many favourite foods and seek others to supplement them. It's an ongoing battle and many of us dread mealtimes. Believe me, it's terribly frustrating and requires some serious adjusting, especially when your appetite is as solid as mine.

But all of the above are pikers compared to my "favourite" bump.

One afternoon, in the midst of an interview with a voice therapist at the Sunnybrook clinic, I started to giggle for no reason. Then I began to laugh, uncontrollable laughter that brought tears to my eyes. I was embarrassed, tried to explain, but could not stop. I laughed like a loon, literally.

The therapist ignored it because she had seen it many times with other ALS patients. It's called emotional lability and it's a son of a bitch.

The condition, which involves both laughing and crying, generally affects people who have diseases or injuries of the brain and nervous system (ALS, multiple sclerosis, Alzheimer's, severe head trauma or stroke). Although there are still many unknown factors, some researchers believe it may result from disruptions in certain pathways in the brain that are important in expressing and controlling emotions.

While many are tearful and sad as a natural reaction to living with ALS, it's most often a side-effect of the disease and about 50% of ALS sufferers experience it to one degree or another. It may be triggered by something funny or sad, but the reaction is way out of proportion to the event. And very often, laughter can turn to tears in a flash.

In some people, it's controlled by medication. So far, I haven't been too successful in that regard.

I first noticed it while watching TV and laughing at something that was only marginally funny or tearing up at the merest suggestion of something sad. Other times, I'd start laughing for absolutely no reason. Or crying.

(I really knew I was in trouble when I was laughing louder than the laugh machine used in the premiere of the Whoopi Goldberg TV show when there was absolutely nothing to laugh about. Hey, maybe I should hire myself out to Hollywood.)

It's much worse now and it's caused me some truly embarrassing and uncomfortable moments, although most people are wonderfully accepting and understanding once they know what it is. However, my tendency is to stay away from a lot of social situations where I know it's bound to happen.

The worst time for me was at my grandson's bar mitzvah. Soon after I arrived I began laughing in a high pitch and couldn't stop. Norma and I left the main room in the synagogue and scurried upstairs to the balcony. When it continued, we left rather than disrupt Jordan's special day.

As soon as I got into the car, the laughter became uncontrollable weeping, but at least I now had a legitimate reason.

It's happened several times since -- at my sons' baseball games, in interviews and at family functions. There are also periods at home -- which is still my safest haven -- when it happens repeatedly. Often, too, it's triggered by my feelings over my condition and how it affects my family and the fact I likely won't be with them for too much longer.

For me it's a royal pain in the butt, mostly just embarrassing, but it's something I have to get over. Or stay home.

Meanwhile, all of these bumps in the road, big and small -- and I know there are even more trying ones down the highway -- have taught me stuff I know other ALSers have learned before me.

The main thing, of course, is to not let them defeat you. Don't fear them. Accept that they are part of something beyond your control. Embrace them, learn how to cope with them, and then shove them aside. They're bumps.

Let others help you. This is not a disease for heroes so there is no sense in trying to go it alone. Let others in,
especially those who love you, be they family or friends. Let them help you, comfort you and love you. And love them back.

Don't dwell on what you can't do. That's done and no wallowing or whining will change that. Focus instead on what you can do -- and do it -- so you can live as productive a life as possible.

That means trying to maintain as much of a normal lifestyle as you did in the past. Sure it's hard, but it's also doable. You're still in control of you, no matter how much of an ass-kicking you're taking.

And guys, keep smiling. There's nothing like a healthy sense of humour to beat back the demons.

The best way to accomplish all of this? Adopt the ALS motto.

Live life one day at a time.

**A safe place**

Sun writer Jerry Gladman got more done in one visit to Sunnybrook than in 11 months waiting for a diagnosis. In Part 3 of his series, he tells why

**Part 1: Living and dying with ALS**
**Part 2: The struggles of daily life**
**Part 4: Acceptance**
**Part 5: Outpouring of emotion**

**JERRY GLADMAN -- Toronto Sun**

Way back in the early shuffle steps of my dance with ALS, I asked the first neurologist if it turned out to be this awful disease what he could do for me. His response was chilling: "Not much."

Well maybe he couldn't do much, but as I eventually found out -- and am still finding out -- there are a whole bunch of people who can do a whole lot more than not much.

Not cure it. Not stop it. Not even impede its progress for any great length of time.

But they can now make life a whole lot more bearable -- and productive -- for ALS sufferers than they used to not so very long ago, when things were so bleak you just went home, wasted away and waited for death's mercy.

Myrna Moore, co-ordinator of the ALS Clinic at Sunnybrook Hospital, checks Jerry's weight during his regular visit.

Photos by David Lucas

I began to find out just how much is available a week after I was diagnosed and made my first visit to one of the world's finest and safest havens for ALS folks, the Neuromuscular/ALS Clinic, located in the Centre for Independent Living at Sunnybrook Hospital.

I got more accomplished, more attention and more questions answered in three hours at the clinic than I did in the previous 11 months of just trying to find out what was wrong with me.

**Doubly effective**

First off, the name, Neuromuscular Clinic, is a bit of a misnomer. Most neuromuscular clinics are really dedicated to different muscular diseases such as muscular dystrophy. The Sunnybrook clinic, which opened in 1982, sees primarily ALS patients, which is a motor neuron disease.

"This clinic might see one patient a week with a muscular disease and 20 with ALS," says medical director Dr. Neil Cashman, a soft-spoken man who has been working in this field for 20 years.

"So it's really an accident of history that we're called that. There was a real need to provide comprehensive services for people with ALS."

The clinic was started by neurologist Dr. Marek Gawel and others, whose idea was a multi-disciplinarian setup with all the different experts required to treat ALS on site. All services and equipment -- everything from A to Z -- would be there.

In the beginning there was only a handful of patients, but numbers increased dramatically when others in the field realized the clinic provided co-ordinated services and quick access to specialized treatments. Its comprehensive setup quickly became a model for other similar clinics.
Not only is it the largest of its kind in Canada, but what makes it doubly effective is its close liaison with the Assistive Technology Clinic (funded by both the ALS Society and the provincial government), which provides a wide array of special technical aids for ALS use. (The talking computer and arm aids I use initiated with them.)

Clinic co-ordinator Myrna Moore, who has been involved with ALS patients for more than 13 years, says it’s amazing the rate of speed and effectiveness at which ATC deals and accesses aids for patients.

"I always say where there is a twitch they will make or find a switch in order to access a computer, electric wheelchair or any kind of assistive device. These devices and equipment were not available years ago. People would become locked in."

She adds that technology plays a crucial role in the lives of ALS patients and has opened the world to them. "ALS people like to be in control and take charge of their lives and technology certainly enables them to do so."

Another huge plus for the clinic is getting early dibs on new medicines, which is why I was able to go on a new cocktail of drugs which only a few months ago was approved for patients.

The clinic is also known as a community outreach operation because of Myrna’s unique position. She is able to interact with the person in the hospital as well as make home visits.

"I also liaise with the community agencies and act as a resource to them," she adds.

And she does a whole heck of a lot more.

My introductory session at the clinic was like being scooped up in a whirlwind. I didn’t know what hit me.

See this nurse, then this doctor, then this therapist, then this doctor, get weighed, do this, try this.

Jerry "talks" to Dr. Anthony Newall using his laptop computer.

Whew.

Mind you, that’s only what it seemed like compared to the old hurry-up-and-wait regimen. There was very little waiting, but in truth each specialist gave me an inordinate amount of time. They all did thorough checkups, got my history down, explained everything in plain language and answered all my queries.

One of the very first things I learned was Drs. Gawel and Cashman don’t run the clinic. They only think they do. The real big chiefs are secretary Olive Grozelle, who keeps all the balls in the air, and Myrna, the sergeant-major from heaven.

Just about every organization in the world has a Myrna. They come in different sizes and shapes and answer to different names. But they have one job -- keep everything running smoothly. They know where everything is, who should be where, who is where and who is who.

And if they don’t know the answer to questions they know where to find them. They do it all quickly, efficiently and, hopefully, like Myrna, with a sweet smile.

And every visit she seems to have a special bonbon to hand out in a very quiet way. "Did you know about this program? Have you tried this treatment? I’ve got a great Web site for you. Oh don’t bother with that. Try this. It’s quicker." All of it designed to improve your lot in some small way.

And the best thing is, if you have a problem or a question at home, she’s at the other end of the phone or an e-mail message. She returns calls as soon as possible and ditto with e-mails.

Now who wouldn’t kill for that kind of service?

The first doctor I saw was Gawel, an affable fellow who appears to have little use for wasting time. Direct questions, direct answers and speedy action. It’s a busy clinic and each patient has different needs.

By the time we were done, he handed me a prescription for three drugs -- Rilutek (Riluzole, the traditional ALS drug), Minocycline and Nimodipine. Ironically just that weekend I’d read a news release that this new cocktail -- designed to slow down the progress of the disease -- would be available to patients.

What I didn’t know was its cost -- $1,300 a month (hey, it’s expensive to stay alive.) Myrna asked if our medical plan would cover it? We didn’t know, but she said if not there were certain other avenues we could follow to make sure we got the drugs.

She put us in touch with a service that did all the checking for us and they phoned the next day to tell us Norma’s plan covered it in full. Myrna also called to find out if we were able to get the drugs without problems.
Within one day of getting the prescription, I was taking this precious medicine.

Next up were the team responsible for seeing to my speech difficulties -- Frances Ezerzer, a speech-language pathologist, and Tasneem Dharas, the augmentative aid technician.

They outfitted me with a talking computer and loaned it out to me for a lengthy period. (After that there was an annual fee to lease it.)

Dr. Peter Webster is the clinic’s respirologist, an amazingly caring physician whose easy manner takes a lot of the sting out of the subject matter. Breathing difficulties are generally the final frontier in the disease and Webster wants to make sure you understand all the implications.

The usual cause of death is failure of the diaphragm muscles that control breathing. So specifically Webster talks about making a decision whether you want to be kept alive by a breathing tube, or ventilator, should you get pneumonia and are no longer able to breathe without assistance. My decision now is that I'd prefer not, so he emphasizes the need to make that crystal clear with family members.

"Occasionally we get some ALS people who wake up in hospital with a breathing tube and they get really ticked off," he said. "If you decide against it the hope is you will slip away peacefully in your sleep, as many ALS patients do."

Of course, the other danger is suffocation, which is when family members or patients change their mind. But once 911 is called, they are committed to put you on breathing apparatus. Anyone can change his or her mind, which is why Webster stresses the need for frank discussion.

He also wants patients who have eating issues to start thinking about a feeding tube (surgically implanted in the stomach) sooner rather than later, especially if you are losing weight. You can still eat normal meals, but they are supplemented by tube feeding, thereby minimizing weight loss and maintaining better health.

Before leaving, Myrna gave me a registration form for the ALS Society, and then made sure we visited the huge pharmacy at the entrance to the clinic which carries many supplies ALS patients might need (we bought eating utensils and a gizmo for turning keys), and other facilities which carry larger equipment.

In subsequent visits, I met with occupational therapist Jessica Comay, who arranged for arm devices to assist in typing and showed me some strategies for getting out of bed and low chairs.

The newest member of my team is Dr. Anthony Newall, a specialist in rehab services, who suggested part of my walking difficulties were likely caused by spasms, not just deterioration of muscles, and he prescribed medication that would loosen the muscles and make the Frankenstein Stroll less pronounced.

Few would doubt Dr. Gawel was on the right track when he recognized the need for such a facility way back when. But I can tell you this -- no matter how poorly I feel prior to going to the clinic, I always feel hugely uplifted when I leave.

Shortly after my first clinic visit last May, I received a package from the ALS Society, which contained a bible of sorts put out by the national office -- A Manual for People Living with ALS.

This is pure gold for it addresses every issue imaginable facing ALS patients and their families -- coping with the disease, managing symptoms and treatment, strategies of every nature to meet each problem and difficulty, assistive equipment, support groups, dealing with financial and legal considerations and matters of death and dying.

**Rights and dignity**

It's not an easy read. It deals with aspects of the disease in a very clear and concise manner and pulls no punches. But it is a must read, for once you have there are very few questions left unanswered. It's an essential aid for every ALS family.

The society was formed for three main purposes -- to provide services and equipment for persons living with ALS, to assist them and their families to manage the effects of the disease and to raise funds for research. Those three goals are the society's mission.

And until a cure is found for this disease, the Society strives to help provide a haven where people living with ALS may realize their full potential in a society that respects their rights and dignity.

In addition to the clinic and the Society there are a wide array of other community services available to us, including one of the more valuable -- Community Care Access Program. The desire of anyone with a serious disease is to remain at home as long as possible and it's groups like CCAP that make this possible.
Unfortunately, there just aren't enough services or money available to maintain everyone in their homes around the clock, but our new government could surely make a dent in this area by providing additional funding. How about it, Dalton? We needs ya'.

Actually, I now find myself turning to this service. Norma is an airline attendant and must go away for periods of time. My kids are in school. This means there will be times when I'm alone and get into all sorts of mischief.

Then, of course there other services such as hospice volunteer programs, palliative care settings and probably the most priceless commodity of all -- family/friend caregivers.

"Quite often they are the forgotten ones," says Myrna. "They are such a valuable entity."

**Acceptance**

Sun writer Jerry Gladman admits he's scared but has found a genuine peace after many agonizing moments.  
**In the last part of his ALS series, he tells how he did it**

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Part 1: Living and dying with ALS  
Part 2: The struggles of daily life  
Part 3: A safe place  
Part 5: Outpouring of emotion

By: JERRY GLADMAN -- Toronto Sun

So many people I've communicated with since word spread I have ALS have told me over and over how I'm facing this disease heroically and with great courage, dignity and an array of other admirable qualities.

I find it somewhat amusing because the truth is I am scared shitless.

Without trying to sound humble, I really don't see myself in that light. Certainly not overly courageous nor noble nor a paragon of inspiration, nor any of those other characteristics ascribed to me.

Group hug brings Jerry comfort and joy, with grandchildren (clockwise from bottom left) Jamie, Jordan, Matt and Emma during a Sunday visit.  
Photos by David Lucas

I see a guy who has been dealt a lousy hand and has little choice but to handle it on a daily basis while trying with all his parts to keep from falling to pieces. I see someone who has good days and bad ones and works hard simply trying to make it through the night.

I'm sure I'm no different from the other 3,000 or so unfortunate souls in Canada who pulled the short stick and wound up with ALS on their life resume. Certainly there are those who fit the heroic and noble profile, but most of us are just average folk whose luck ran out and we're doing our best to cope with the fallout.

Like most others handed a premature death sentence, I have gone through a minefield of stages that eventually paves the way for the final journey. They were first given clear focus years back by Swiss psychiatrist Elisabeth Kubler-Ross in her breakthrough book, *On Death and Dying*.

The five stages go in progression through denial, anger, bargaining, depression and acceptance. I think I’ve revisited all of them at varying times -- I'm sure everyone does -- but after a while the first four become somewhat old hat (and a little boring) and you enter a closer relationship with acceptance. Not always fun, but realistic.

No big whoop. It's basically a process dying people have been going through one way or another since the dawn of time. I’m sure a great many don't even bother to identify the stages, but whatever the route you choose, we all inevitably wind up crossing the same finish line.

Actually there is a sixth stage, although it's the first one you confront. Shock. Bang! You have a disease and you're going to die. What? No, can't be. How did this happen? There must be a mistake. Holy crap, I'm gonna
die? This is insane. I can't die. I don't want to die. And so on.

I'M GONNA DIE

For the first little while, you kind of stumble about with this blank expression on your face and a haunted look in your eyes, trying to process this nasty information fate used to conk you over the head. I'm gonna die, I'm gonna die, I'm gonna die. Over and over until it becomes your mantra and loses its meaning like one of those song lyrics that stick in your brain pan.

Once you've actually dealt with the initial blow and huddled with your family, relatives and friends -- in other words, once the shock has warn out its welcome -- things begin to settle down. Then you start to think about how you actually feel. I know they say I'm dying, but you know, it's weird -- I don't feel like a dying guy. Hey, maybe they made a mistake.

You are now entering stage one. Denial.

Looking back, I can actually see myself going through the denial mode and it's almost funny. Almost. You have a couple of good days back-to-back where you feel pretty good and you start to think maybe somebody goofed. How can I feel this well and be dying?

Before long you start fantasizing (usually in the dead of night when sleep is a lost cause and your mind has ample opportunity to roam). Maybe somebody mixed up the test results and some other poor soul has my true diagnosis of mononucleosis (along with my share of the lottery.) Maybe they were simply wrong and this only looks like ALS.

I even have these visions of being called into my doctor's office and being told it was all an error and I am going to live for a long while yet. (Great. Who do I sue first?)

Every day you test your weakening muscles and measure them against your memory of the previous day's testing. It's amazing how often they feel the same (or better) and you convince yourself you're holding the line, maybe even improving, son of a gun.

Or else you figure you're one of those lucky ones who will fool everyone and live 20 years. Maybe it's plateau. Maybe for no explainable reason it's gone into total remission. Maybe this is the year they find the cure.

What's so interesting about this particular disease that often adds to your denial is that you feel perfectly fine most of the time. You have to tell people: "I am not sick. I have a disease that weakens my muscles and will eventually kill me, but I feel pretty good." (While typing these words I swear I feel normal and not sick in any way.)

Eventually, however, you figure out you're messing with your own mind and this is the real McCoy. That, of course, transports you to the next stage. Pissed off (read: Anger.)

Why me? I've never hurt anybody. I've lived a decent life, worked hard, helped others, given to charity. There are guys running around who murder, rape and steal. Some beat their wives and children. Others wouldn't give a drop of water to a dying man. Why not them? Why let Saddam Hussein and Osama bin Laden live and give me this disease?

Why me, you son of a bitch bastard, what did I ever do to you to deserve this?

Jerry gets a kiss from his sister, Judy Orellana. His large family and many friends help see him through his ALS fight. After a lot more cursing and why me's, you figure out whoever you're aiming at either has a thick hide or simply doesn't give a hoot. So you try another tact. Bargaining, deal-making, heartfelt promises.

If only you'll spare me, I'll live the rest of my life as the best human being possible. I'll help others less fortunate, I'll obey the 10 Commandments, I'll treat everyone like gold. Just make me better.

You even might find yourself appealing to the souls of dead relatives, as if they could actually influence some higher power. Mom, Dad, where are you? I need you. You can't let this happen. Talk to the Man. Work something out. I'm not ready.

But, of course, it is happening and it matters not whether you're ready, sport. And when you finally allow that to fully seep into your mind, this pushes you over the edge into Stage Four. Depression. Really dark, agonizing depression, the kind where you want to bury yourself under the blankets until this horrendous pain vanishes.

The effect of it is so rotten I can barely describe it. Think of the worst day in your life and then multiply by 10. You don't just cry, you weep, you sob uncontrollably, and the tears come from some well deep down in your being. I can't go on. It's too hard. Please let me die now.
Your family members, shell-shocked victims themselves as part of this ageless drama, stand by and watch, unable to ease your pain, unable to find the words to comfort you, and it breaks their hearts.

The worst times are the night hours when you are alone with your thoughts. You think such dreadful things.

You see yourself on your deathbed, struggling for breath, desperate to cling to life. Or your funeral service, your casket being lowered into an open grave, the mound of dirt ready to enclose you for eternity.

And always, always, your loved ones, gripped in sorrow, sobbing in each other's arms. It's almost too much to bear and you wonder why you torture yourself so.

But there's more as your mind stretches for the outer reaches. Time has passed and you watch as your wife, now healed, loves another. She's happy again. How can she be happy when I'm in this place? And not just her -- your children as well, going on with their lives.

The Blue Jays winning another World Series and the Maple Leafs, at long last, sipping from the Stanley Cup. Movies you'll miss, your favorite TV shows, Survivor (Year 100.) Special holidays and vacations. And so much more. All of it taking place without you.

RELAPSES

You don't want to go to those dark corners, you shouldn't go there, but your mind answers to no one and goes anyway. And then one fine morning, at long last, you wake up, look yourself in the face, and say: I am going to die and there's not a bloody thing I can do to change it. So maybe it's time I start dealing with it and make my remaining days the best I can.

Acceptance.

Ah, sweet acceptance, the first day of the rest of your life when, finally, you can really start living until you die.

I'm pretty certain that's where I am now, or at least well on my way. I know this is going to end only one way and, aside from that sliver of hope I mentioned earlier and a prayer that it's a painless, peaceful departure, I feel I'm pretty well coming to terms with my lot.

Sure, I have some relapses and bounce through some of the stages again, but I know it won't last. And if things get a little rougher as the road shortens, I may turn to some professional counseling. As well, I also have a huge pile of books on dying well and thoughts on the hereafter I'll eventually get to. I'll probably even give Tuesdays With Morrie another look-see or three before I'm done.

Mostly, though, I plan to spend as much quality time as there is with my gang. I'm lucky to have such a devoted family, pure treasures who watch over me like I'm the Hope Diamond. And so many relatives and good friends, people who seem to care for me as I do them.

But you know what, fellas? I have absolutely no kick coming.

Oh sure, I'd love to spare my family the burden of having to care for me when things turn worse, and whatever pain they experience by my dying and absence from their lives. But I know -- and they know -- this, too, is part of life, and time and memories will heal their hurt.

That aside, I really have nothing to whine about.

I've had 60 spectacular years. I grew up in a loving family atmosphere with two special parents who loved each other madly for 50 years, and a brother and sister I cherish not only as siblings but as lifelong friends.

I've known wonderful women who shared my life at different times, and wound up spending the past 25 years with one of them, a partner who has no equal. In addition to being beautiful and the sexiest broad I've ever known, Norma has an endless capacity for giving and, for some unexplainable reason, seems to love me as much as I love her.

SHARE OF SCOOPS

I've also been blessed with three children who grew to be such splendid and loving adults (not to mention four gorgeous grandchildren who are following nicely in their footsteps.) If there is anything for which I would love to be remembered, my personal legacy, if you will, it's the privilege of being father to Lee, Jesse and Caitlin.

And, of course, Davey the dog, a delightful companion for the past eight years, who shared my space during so many late-night hours (as well as a portion of my meals) and asked for nothing in return aside from a little loving and to be let out for his nightly whiz.

Friends, so many wonderful, interesting and enjoyable friends, many of them stretching back through most of my years. I know it's been said before, but if one's worth can be measured by the quality of one's friends, I am the
richest son of a bitch I know.

I've had a tremendous career with so many exciting and enriching experiences. I've interviewed some of the most fabulous people in the world (famous ones, too), reported on countless big news stories and traveled to so many fascinating places. Even had my share of scoops (I was the first one to get the news they found the Titanic.)

And the best is they paid me for something I would have gladly done for free (most of the time.)

And to top it all, off they allowed me to take what I've learned over the past 44 years and pass a good chunk of it on to so many promising journalists of the future. My four years teaching journalism at Ryerson was easily one of the most rewarding and fulfilling experiences of my life.

But there's one other significant reason I have nothing to really complain about. And that's all the people who have had it so much worse, many of them whose tragic stories were told under my byline.

So, no, I'm not heroic, courageous or special. Nor do I have any real kick coming. And most of the time -- most of the time -- I believe that in my very heart and soul.

In other words, it's been a slice. And you know what else?

Ya never know.

Outpouring of emotion

Living and dying with ALS
Copy write: JERRY GLADMAN -- Toronto Sun

Part 1: Living and dying with ALS
Part 2: The struggles of daily life
Part 3: A safe place
Part 4: Acceptance

When I decided to write about my adventures in the land of ALS, I approached it in the same fashion as any previous personal story.

I thought it through carefully -- composing a good portion of it in my head -- sat down at the computer and let my fingers fly.

Normally I don't fret much over how a piece will be received, but I'd be a stone cold fibber if I said I didn't think of the potential impact of this series. I knew it was an important story that had to be told and that my decision to hold back nothing would make it a most compelling read.

Folks, I had absolutely no clue what a reaction my little essay was about to unleash.

On the first day of publication, the e-mails began to come in waves, first from every corner of the city, then the province, then the rest of the country and into many portions of the U.S.

The onslaught would continue for most of the week and into the next. At one point, Norma and I calculated we were getting one a minute for most of two days straight. Hundreds and hundreds. Six weeks later, I still get a handful each day.

We quickly developed a routine whereby we'd take turns at the computer, have a good cry and then move on to the next batch. Time and again we were so moved by the wonderful and thoughtful responses from so many strangers.

The majority of the letters were from people with ALS, family members and friends or others who had lost someone to this wretched illness, which surprised me. For one thing, the number of sufferers is minute compared to other diseases. In fact, prior to writing the series I never actually knew anyone with ALS, other than through the media.

Then, within a few days, I knew hundreds. I knew their loved ones and their friends. I knew all about their lives. I suddenly became a member of a very exclusive club in which all of us share so much. And it's so gratifying.

I learned that a great many of them followed the same path as me seeking a diagnosis and that they encountered similar roadblocks, some with the very same doctor.
Oh my God, it is all coming back to me. I have just read your first article in the series about ALS and it sent shivers down my spine it is so close to home. You see my brother was diagnosed with ALS in 1997 at the age of 64. Your story is so true in describing the wait for tests and results, the way the diagnosis was given so coldly. It is unbelievable!

My brother received the news himself -- shockingly. His wife had let him off at the door of the medical building as he had difficulty walking. By the time she parked the car and was coming into the building, he was in the lobby waiting for her. He had been in to see the doctor and was ready to go home. He told her in the car what the diagnosis was -- not a good move as she was driving the car.

I’ve also learned so much from so many of them, particularly how to deal with this disease with dignity and on your own terms. Whenever I’m feeling down all I have to do is read a few of the e-mails and I’m quickly reminded that despite being dealt this crummy hand, there is still so much that life offers.

Fully aware of what I was up against, it became clear to me that I had a decision to make, perhaps the most crucial and important one of my life. I had to decide how I was going to live out the years I had left. I could give in to the feelings of anger, impotence, frustration and despair which inevitably would lead me into a general state of depression from which I could hardly escape -- mainly because in a progressive neurodegenerative disorder such as mine every new day comes with bad news: Something you could still do yesterday, is impossible to do today no matter how hard you try. Or I could hold on to my shattered and diminished faith and lean on God’s love and the love of family and friends and live my life intensely, with optimism, happiness and joy.

The first thing I learned was to value and truly appreciate all those things we take for granted: One’s health, being able to walk, one’s wife, one’s children, a new day, a new sunrise, being able to talk, one’s friends and all those precious and wonderful gifts that God gives us every single day.

Some have even become my personal heroes. Their situations are far more dire than mine yet they live each day with such joy, with such determination and with such dignity they will never know defeat.

I was also heartened by the number of folks who were simply touched in some fashion by my words and took the time to sit down and drop me a line. Several admitted they were so affected it inspired them to make changes in their own lives.

Nothing was more rewarding than the people who thanked me for helping them now understand what their loved one went through during the illness but couldn’t express.

I guess I just wanted to write to you to tell you how much your articles have helped me understand. I have read about the disease in so many books but this was the first time I had read something real, someone just pouring their heart out, however tough it may be. It really made me understand what my Opa felt and reassured me that although frustrated, he was not in pain. You are an inspiration to me and to many others that have been affected in some way by ALS.

A close second, of course, were professionals in the field who commended me for not only bringing greater public awareness to ALS, but for doing it in such a competent and professional manner, as well as giving such detailed information on what daily life was like in ALS’ grip.

It is wonderful that you decided to apply your talent and skills as a writer to document your journey as a roadmap for others. I have kept copies of all the articles and I know that I will reread them many times to help me understand the personal experience of ALS better and better as I continue to work with (patients). Your facts and personal insights are better than any textbook for students new to the field of ALS.

Countless times I was stunned and brought to tears by the number of people who were now including me and my family in their daily prayers.

Of course there were a ton of people with medical and nutritional advice, magical potions and ancient remedies -- several worth investigating -- as well as Web sites offering same.

The biggest downside to all of this tremendous response is I couldn't answer them all and I so wanted to. Heaven knows I tried, but I just kept falling more and more behind. So any of you who were awaiting a response, now you know why, and that I shall keep trying.

But most of all, thank you. Thank you for writing and thank you for caring.

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