

1) Introduction

I am the proud father of Carol Skinner (née Sharman). In 2013, at the age of 41, Carol was diagnosed with **ALS** (a.k.a. Amyotrophic Lateral Sclerosis; Lou Gehrig's disease; Motor Neuron Disease or **MND**). Since being diagnosed Carol has been an incredible, outspoken advocate for ALS funding and research, and has been documenting her story via her blog, <http://www.livelovelaughwithcarol.com/>.

What I'd like to share with you is an account of her journey since diagnosis from the perspective of an immediate family member - her devoted, loving father.

Upon hearing about her being diagnosed, I immediately went to the computer and looked up ALS. I wanted to see if all those terrible things I'd heard about it over the years were true. They were. All of them. My dazed reaction was "now what?". I needed to stop running in circles, sit down, organize, and THINK.

I wanted to record my side of the story for a few reasons: to present the experience from a parent's perspective; to continue to raise awareness of this terrible disease; to highlight that government support is absolutely necessary (in Canada there is **absolutely none**); and finally to make a case for increased fundraising to speed up research programs and make ALS treatable at the very least.

Together we can make ALS treatable, not terminal...

2) Our Daughter Carol

Carol was born in Vancouver in 1971. Our family moved to Montreal in 1972 where Carol remained until she graduated from McGill University with an Art History degree in 1995.

Carol very much enjoys working with youth. While attending school, she worked as a camp counsellor for five summers at Camp YMCA Kanawana in Quebec. After graduating from McGill she moved to Cape

Cod and was the Camp Director of YMCA Camp Hayward. After her ALS diagnosis, Carol received the “Giving Tree Award” of Lifetime Achievement for outstanding service to youth from the South Shore YMCA Camps (Camp Hayward). She also received the Pip Award from Camp Kanawana “for her commitment to the values of Non Nobis Solum (Not for Ourselves Alone) in the world beyond camp, shown through her enormous personal strength, determination and dedication to the fight against ALS for herself and others”.

While obtaining her Master’s Degree in Art Therapy in Toronto, Carol worked as a supervisor at the Children’s Museum as well as practicing art therapy for her internship with the Centre for Addiction and Mental Health, with young adults suffering with first episode psychosis.

From the time she was diagnosed, her advocacy and focus has understandably turned to ALS. This disease has taken away my daughter’s ability to work in a field she loved and has also deprived countless young people from having the opportunity to work with such a dedicated, thoughtful and caring Art Therapist. It’s one of the many reasons I wonder why ALS has happened to her. At the same time, ALS advocacy has gained a superstar.

Carol also enjoys spending time abroad. She lived and worked in England for a year (she holds a UK passport as well, since I was born in England). She also spent 5 years in St. Maarten in the Caribbean working as a teacher. Carol married her husband Travis in 2009 after meeting him in St. Maarten years before. They had moved from St. Maarten to Canada two years prior to start another adventure.

Travis has been Carol’s pillar of strength and a fantastic husband in more ways than I could possibly count. I am in awe of the amazing job he is doing balancing his long hours at work as a Cordon Bleu Chef with caring for Carol. It is no small task and requires a vast amount of physical and mental fortitude.



Carol before her wedding, September 29, 2009 in Antigua

Carol and Travis are a truly international couple, both having lived and worked in a number of countries before settling here in Ottawa, Ontario.

For Carol: Canada → USA → Canada → England → Canada → St. Maarten → Canada

For Travis: South Africa → New Zealand → St. Maarten → Canada

For Nemo and Dory (their beloved cats): St. Maarten → Canada

Their adventures took them around the world and looking back it feels inevitable that their paths would eventually cross.

In her time as an Art Therapist, Carol worked for the Canadian Mental Health Association (CMHA) in Ottawa. This comprised of working as a group facilitator for people struggling with mental health and addiction issues. Carol also produced several papers and gave speeches on art therapy at various conferences throughout North America.

We are in this together...

3) ALS and the ALS Society of Canada

To date, this **terrible, terminal** disease (whose cause is unknown) continues to hand it's patients a death sentence of unknown duration. Many who are diagnosed with ALS are told they have 2-5 years to live. However, it is important to understand that many live shorter or longer lives depending on how quickly the disease progresses. Each year in Canada, close to 1,000 people are newly diagnosed. Approximately the same amount of ALS patients will pass away in the same period. For that reason, at any given time there are 3,000-3,500 people living with ALS in Canada.



*Carol and Travis, Andrew Haydon Park, Ottawa
photo courtesy of Vicky Elias, London House Photography*

The ALS Society of Canada provides support in many areas, including the provision of necessary equipment. The Society also coordinates financial and advocacy activities including soliciting personal and corporate donations, support from foundations, coordinating

volunteers, government advocacy, research support and hosting major fundraisers across the country. To paraphrase the words of the ALS Society CEO Tammy Moore, the price of entry to this club is awful (an ALS diagnosis) but the community within is truly special.

To support Canadians living with ALS & invest in research to make ALS a treatable, not terminal, disease...

4) Carol's Diagnosis and How She Is Today

Carol was diagnosed with ALS on September 19, 2013 – ten days before her fourth wedding anniversary. However, as in most cases, she likely had ALS for close to 12 months before that.

Her *early* symptoms before the official diagnosis consisted of:

- Leg weakness/falling
- Leg and hand cramping
- Fatigue

She visited doctors and the hospital a number of times, having two MRIs and an EMG which proved that indeed it was ALS.

At that point Carol and Travis' lives were forever changed. They sold their two-story condo (due to the amount of stairs) and Carol immediately had to give up her job and take long-term disability.

The symptoms she experiences *today* include:

- Muscle weakness
- Muscle cramping and spasms
- Stiff joints
- Poor circulation
- Dropped foot/falling
- Exhaustion/fatigue (more so every day)
- Dizziness
- Early signs of speech problems (slurring of words)

- Emotional vulnerability including stress
- Depression
- Anxiety

It's difficult to see my strong-willed, determined daughter lose her independence, but she did eventually recognize she couldn't fight this battle on her own. Because of her lack of mobility she is no longer capable of looking after herself in many ways - she can no longer drive, walk, and write by hand - this is a small sample of the struggles she faces. We are very thankful that so far she has no swallowing or breathing problems.

One setback Carol can experience has to do with the common cold. If anyone is showing or feeling even the slightest symptoms of a cold or other minor sickness they need to keep their distance in order to make sure there is no chance she'll pick it up. Her disease drastically increases the chances of catching something and any illness takes even more out of her.

Carol embraces these challenges with amazing gravitas (and that aforementioned strong will!). She has a fleet of wheelchairs and walkers, and can do short distances with leg braces. And she always appreciates the "rock star" parking when Travis parks the car!!

What now? It was a day I'll never forget...

5) What I Know but Don't See Daily

Carol has shared her experiences living with ALS pretty openly with the world since being diagnosed. That said, as a father I know that there are many feelings and struggles that she goes through on a daily basis that only she and Travis experience.

Some of what she has shared with me is:

- Being down with the reality of a terminal disease
- Experiencing shock and hopelessness
- Knowing she will lose her family
- Frustration and low tolerance for the small annoyances
- Emotional breakdowns, tears
- Anger and rage
- Self-pity

In short, everything is hard for her to do and it's getting more difficult almost daily. She masks most of these feelings on the days we visit and is very brave to do so; although, of course, we know that the feelings remain with her.

Because of all the support, I have hope where I once had none...

6) My Thoughts After 4 Years Since Diagnosis

Before the diagnosis we were aware that Carol was having difficulties. She struggled getting up her condo stairs – swaying a bit, dizzy and out of breath. And bad migraines run in the family, but Carol was getting them with increased frequency.

The journey for my wife Louise and I started when we got a phone call from Travis while on a cruise in the Black Sea. Fortunately we were travelling with friends who helped us through that terrible first day. We got on a plane immediately and headed home to be close to Carol.

Carol and Travis meet regularly with her ALS team, comprised of:

- Psychiatrist
- Occupational Therapist
- Physiotherapist
- Respiratory Therapist
- Speech/Language Therapist
- Nutritionist, Social Worker



Carol at home with her youngest cat Buddy, 2016.

It hurt immensely when the doctor said that her lifespan would now be two to three years (ten months later they reassessed at three to five years). As previously mentioned, there are several ALS patients that outlive this timeframe.

I met and talked at length with two people who have had ALS for over 9 years and are still doing very well. Then there is Stephen Hawking, who has been living with it for the last 50 years.

A few weeks before Carol's diagnosis, a colleague of mine passed away from ALS. I have since spoken with his wife Leila as well as Catherine, the wife of Michael Soles (ex-Edmonton Eskimo football player) to learn more about living both with the emotional and physical sides of ALS.

Some other well-known people that are living with or have passed away from ALS include David Niven, Sam Shepard, Dennis Day, Jason Becker, "Catfish" Hunter and football players Tony Proudfoot, Steve Gleason, Glenn Montgomery, Kevin Turner, Dwight Clark and O.J. Brigance in addition to Michael Soles.

ALS also affected Canada's House of Commons in 2016 when long time Liberal MP, Mauril Belanger, considered a frontrunner to be Speaker of the House of Commons after his 8th election victory in 2015, was diagnosed with the disease and passed away nine short months later.

Needless to say, our entire family was devastated with Carol's news and processed all of the possible emotions both together and in our own ways. We then needed to send emails to friends and close colleagues.

After that we took care of ourselves by taking the phone off the hook for a while. The diagnosis was one thing, processing it a number of times with family and friends as the news spread was something entirely different.

Upon facing the reality of the situation, I found that depression set in (and it still exists for me today). My desire to take on many normal daily challenges and responsibilities has gone, including event planning, helping out at my local golf club, participating in various charity committees etc. Talking to or seeing Carol helps lift me out of it.

Three years later, we put our Montreal house up for sale and moved to an apartment within a 15 minute drive from Carol's apartment in Ottawa. I was already retired so that was easy, and having "stuff" meant nothing anymore.

My emotions in the early days would change on a dime, from **"WHY NOT ME?"** to anger. The balance between having all these emotions and being a parent is at times very difficult. No matter what I'm doing, it's so hard to get her off my mind, or laugh, or really be happy. I've lost most of my sense of humour.

Other emotions or occurrences that have happened to me over these four years include:

- Disbelief/stunned/shocked
- Lack of concentration/distraction
- Attention deficit
- Acting before thinking

- My patience has diminished to 0% (Carol's is 100%)
- I find myself making more mistakes in general
- More miserable/irritable
- I vent more
- I'm losing my memory, and focus
- I don't dress up as much, I should but don't have the interest (lazier about my appearance)
- I carry a lot of guilt because I have the ability to do things my daughter now cannot
- Carol's motto is "Live, Love and Laugh" but I feel more that I "Live, love and feel lost"
- I cry in private for her and the loss of my eldest son
- Increased bitterness and anger
- Louise and I plan carefully around Carol and Travis' schedules (particularly as Travis' work can include long days and weeks depending on the time of year)

(And yes, I recognize fully that some of these symptoms are due to age!!)

I have to stay positive and don't speak of ALS unless Carol brings it up. She really enjoys catching up on the latest news about friends and family.

Carol also loves hockey (#1 Montreal Canadians and #2 Ottawa Senators). Unfortunately she is now restricted to watching the games on TV. Gone are the days when I can take her to the Bell Centre in Montreal for a game. You start to realize how many accessibility impediments there are around town being with someone who requires additional support. There are all the stairs in locations like that, as well as the thousands of people in a confined area. Regardless, she remains a true fan of the game, and has managed to (mostly) convert her South African husband!!

I've become very aware of wheelchair accessibility now – still too few restaurants or pubs etc. are accessible. Sometimes people stare at her in her wheelchair – that no longer bothers her. Since she wears leg braces, I think most people believe she has two broken legs healing!

Streets have been improving, especially at crosswalks with the serrated concrete - although I heard a woman complain that she got her high heels stuck in one! To make our apartment more comfortable, we have a walker and special toilet seat for when Carol visits.

It's so frustrating to watch her go through all these stages from diagnosis to basically not using her hand and leg muscles, and to know what happens on her bad days that only her husband sees. I can try to make her feel better and happy but I'm not sure who makes who feel better! She worries about my problems so much that I forget that she has a much bigger problem. But that's her – always caring about others first, from her cats on!

She has pointed out that she is “literally” living life every day knowing she has a terminal disease, versus others that wait for retirement to start doing what they want. In too many cases people pass on before they've achieved any of their future plans.

Carol is so positive about life that if you could first meet her sitting in a room of 50 or 100 people not knowing she had ALS, she'd be the happiest and most jovial person in the room and you'd never know she was living with the disease. That's just who she is. It's so heart-warming to see her so bubbly in front of family and friends. She seems to have more fun in life than most! Her public personality is genuine, and at the same time other more difficult emotions are generally only shared with her immediate family and closest friends.

Together, we can break through...

7) Her ALS Society Activity Today

Carol is an Ambassador for the ALS Society of Canada. She has taken a personal tragedy and decided to make a positive impact by advocating for herself and those around her living with ALS.

In her role as Ambassador she has given many speeches at ALS Walks, the Montreal Neurological Hospital, various fundraisers, the recent Ottawa City Hall ALS month flag-raising ceremony. She is also a Society representative at the ALS Parliamentary Caucus. Carol has spoken at the ALS research Forum in Toronto (along with Travis)! She has also been interviewed many times on TV, radio, and in newspapers.

The amount of work Carol undertakes can be exhausting; we definitely see that on her when she is busy with events. She often jokes that she has so many speeches drafted that she just has to pull one out of her files for the next event! These powerful and passionate speeches and interviews give us inspiration to continue to not only fight for her, but along with her.

Being an ALS Ambassador has meant a lot to Carol by providing additional purpose to her life after having to give up her Art Therapy career. It also enables her to give back to her ALS community. Taking this work on also helped Carol address the question of “what can I do with my time now?”.

Her hope, and ours, is that all of the speeches and interviews will bring more ALS awareness to Canada in addition to more donations and funding.

Here are some special responses from Carol’s speech at one of our fundraisers:

- “So inspiring” (from several people)
- “I’ll never be the same again”
- “I’m never going to worry about stupid little things again”
- “She changed my life”
- “I woke up a different person”



Carol speaking at the Ottawa City Hall ALS Month Flag Raising Ceremony, August 2017

I'm still here – I'm not done yet!...

8) Family and Friends

The role of the parents in a situation like this is to give your child strength. Louise and I do what we can do to accomplish that. At the same time, we feel that she gives strength to us and her community.

Carol is so loving, caring, social and fun with all her family and friends. She definitely lives by her motto of **“live, love and laugh”**. Her many friends (along with many of ours) dive in continuously to help Carol out in so many ways, including financially through fundraising events.

Over the years many of our friends have become friends of hers as well, which is a true example of her character. We're lucky to have so many caring and giving friends to be there for all of us in so many ways. Several friends tell me often how much they pray for her and they all keep up to date with her blog.

As a friend whose daughter has MS once told me “Everyone asks us how she’s doing but never how we’re doing”. In some ways, that’s ok - it’s tough to share. We know that everyone in our life quietly feels for us in their own way.

Carol has also expanded her social circle since her diagnosis. In her apartment block she met a lady who she befriended and now they meet for coffee regularly. She is always there for Carol. One day, she let Carol know she was struck with cancer. She is now in remission, which we are grateful to hear, but it leaves me wondering **WHY, WHY, WHY?**

My life will never be like it once was...

9) Fundraising and Government Support

The incredible awareness and funding that came along with the ice bucket challenge has unfortunately all but faded into memory. ALS once again faces the challenge of being seen as a cause as worthy as other charitable causes, which can unfortunately be viewed as funding “competition” - and there are many.

Some include, of course, cancer, MLS, Alzheimer’s, heart disease, the Red Cross, the Salvation Army, Children’s hospitals and internationally-based NGOs. The lack of support to-date seems to be with the same reasoning used by drug companies – that there aren’t enough patients.

Progress has been made when the Parliamentary ALS Caucus met in 2016. The group was a cross-partisan, all-party caucus, including both MPs and Senators. Carol, as an Ambassador, attended the inaugural meeting. Soon after came Motion-105 which was introduced to get funding approved. What that means and how the Motion is progressing is unknown to us.

I can tell you from a first-hand perspective that the ALS Society constantly requires new help and equipment, but has only a limited budget for everything it is trying to accomplish. As a result, they do a number of events and fundraisers throughout the year. The major ones

are the ALS Walks that take place in several cities across Canada. Opening speeches include politicians, members of the ALS Society and a guest speaker with ALS.

The Ottawa 2017 ALS Walk kickoff event was held with two doctors who spoke about the upcoming Centre of Excellence in Ottawa which will perform clinical trials. A neurologist will eventually join the team too, which feels like a breakthrough, no matter how small. Carol will be willing to participate in any available clinical trials.

In her capacity as Ambassador, Carol has been the keynote speaker and she has lead walks here in Ottawa twice (her team kicks off the walk). It was a joy hearing how thrilled she was this year when her team (one of many registered for the Ottawa walk) raised approximately \$8,000! I think that by now her teams alone have raised over \$40,000 in the past 4 years. Louise and I try to attend all fundraisers if possible, in Ottawa and Montreal.

The walks are an important and recognized fundraiser; however many smaller events are also required. Carol's friends have regularly put these on, including an annual curling event (yes, Carol curls from her wheelchair!) and benefits as well as house parties.

In addition to the ALS Society and her friends' fundraisers, I felt that I must do something with my group of friends. One of them came up with the idea of a special event at one of our favourite restaurants. Over 100 people came, including the CEO of the ALS Society of Canada.

Jamal (the owner of Table 9 in Montreal) closed the restaurant for us, gave us 5-star meals at cost, and included a DJ. It was very thoughtful of him, and he benefits from alcohol sales plus the advertising value of the event. Two high value items were auctioned off and there was also a raffle. We raised \$7,500 in addition to all having a great time and feeling that everyone got value for their money. We also held two other events at our local Montreal golf club, one of which was an ice bucket challenge.

Short speeches are held at all events to continue awareness-raising. If anyone says they want to attend but can't, we ask them to make a

donation to the event anyway. We have also continued to ask for donations instead of Christmas cards and gifts etc.

From the many previous charity committees I've been on (my focus has also turned almost exclusively ALS); we found it important to change our list of potential donors by at least 50% per year to bring in new friends and colleagues as donors, as well as to prevent donor fatigue. I no longer solicit friends unless they ask first.

I have also learned that most companies allocate their budgets early in the year, so it's very important to solicit them early. A simple bookmark covering ALS facts is one way to keep the Society and the cause front and centre.

I believe that a major part of fundraising must be the media, i.e. TV, radio, newspapers etc. It can't only be social media or websites. Awareness to the older generation (like me!) will come mostly from traditional rather than social media. A lot of seniors have money – and they now outnumber fifteen-year-olds. I rarely read anything from the computer, like many others, but I do read the newspaper and certain magazines, listen to radio and watch TV.



Carol and Travis, Andrew Haydon Park, Ottawa
photo courtesy of Vicky Elias, London House Photography

Live your passion now – don't wait. Live for the now...

10) Research

Obviously the objective of ALS research is to make the disease treatable - either to cure it or at least extend life, and to participate in new areas of that research. I realize that most new breakthroughs would likely take effect for newly diagnosed patients only, so any new announcements run the risk of generating false hope for our family. This hurts a lot, but knowing that there is a possibility for breakthroughs and important advances also brings comfort.

Unfortunately, I will admit that it does bother me a lot to hear so much about funding for other programs in the news and social media and yet very little about ALS (with the exception of the approximately two years of the ice bucket challenge). I realize this is very selfish of me but it is the honest truth. Virtually all (if not all) TV stations advertise the money required for charities worldwide, especially at Christmas – I personally have never seen one for ALS.

Very few hours go by where we're not thinking, hoping and waiting for some "breaking news" or advance announcement. I get frustrated too when I hear that other parts of the world have approved trials that aren't available in North America. Most of these are at excessive cost. I realize that all new drugs take years for government approval but again, desperation will play all sorts of tricks on your hopes and dreams.

My philosophy now is to just keep doing things until I can't and not wonder about 'what if'...

11) What Can I Do for Her Now?

Obviously I try to be a good father. I can do my best to make her happy, make her laugh, yes, but I am always left feeling that I could and should do more.

Louise and I also do our best to support her husband Travis who works long hours as Executive Sous-Chef at The Brookstreet Hotel in Kanata. We help with things like shopping, taking Carol to doctor/dentist visits

and other appointments such as the spa or getting her nails and hair done which she can no longer do herself. Not being able to drive limits her mobility and independence, although she does drive her “super wheelchair” alone on sunny warm days for walks, for coffee or to the spa.

Now that we’re living in Ottawa it’s much easier to have spontaneous lunches and dinners. Being retired helps as well to have the time to assist Carol with any of her commitments. Even though I cannot lift her anymore, I can at least get the wheelchair or walker in and out of the trunk for her and ensure her appointments are kept.

Carol has travelled extensively in the world. (She loves travel and hockey equally!) Here’s where the cruise ship fits in beautifully: what a perfect vehicle to continue to see new and special parts of the world.

Cruise ships are an ideal form of travel for Carol because once she’s on board, she only needs to unpack once, the accessible rooms are very spacious and there are a number of elevators available to take her straight to the bars or restaurants or shows! When she gets tired, day or night, there’s an elevator close to take her back to her room in minutes. At the same time she can get lots of fresh air and still go ashore on most excursions depending on the itinerary. Carol is in charge of researching and booking any shore excursions that we enjoy.

The major consideration now is keeping the length and connections of flights to a minimum due to her cramps and exhaustion – her body shuts down.

Needless to say cruises are now the best form of travel for her. The recent major cruises Carol and Travis have been on have included Asia, the Mediterranean, the Baltic including Russia and a few in the Caribbean. That said, so far she still manages a yearly visit to Sandals in Antigua where she and Travis got married on the beach.

We really enjoy surprising Carol with trips, and to watch both her and Travis’ excitement when they hear about it. Even though Travis works extensive hours, the hotel has been absolutely incredible in terms of

accommodating his time off. In addition, Travis' team has been supportive by contributing in several ways to ALS funding.



Carol with a friend, Boulders Beach, Cape Town, South Africa
Photo credit: Travis Skinner

Carol said it best – she is now living her retirement days, and we are doing our best to live them right along with her. My worldwide travel for business and pleasure has now paid off because I have the ability to act as her travel location scout!

It was an illness without hope, and now I have hope – I feel blessed...

12) Summary

The lifetime incident rate for an average person to develop ALS is estimated at 1 in 400 people across Canada and the United States. Sometimes when I am down I feel that we rolled the dice and lost. In our case, not only Carol's disease but also our eldest son Don's passing at 52 and my sister-in-law and step brother passing in their 30s/40s...however we have to maintain our strength. I remain frustrated that it wasn't me that was diagnosed. I'd give a lot to take this away from Carol and so often feel regret that it should have been me, because I've lived a fairly long, busy and fulfilling life already.

Don, Carol and my middle son Keith were/are all very close. I have two brothers, then two sons, and one daughter - Carol!! As mentioned earlier, in addition to her close family she has at least ten times the amount of friends that we do – some of whom have also become our friends over the years. Fortunately Don, who lived in St. Maarten, was able to visit with Carol twice in the two years before his passing.

Dealing with this journey, the reality has of course changed my life too. My needs and interests now are totally different and minimal – much less “stuff”! To focus on anything for an extended period is a problem. I don’t feel happiness anymore knowing there is no cure for this disease.

With that said, if I had to look at silver linings, they would be:

- More travel together
- Moving to Ottawa to be closer to Carol
- Seeing Carol and Travis more
- Talking together more
- Helping more in spur-of-the-moment situations
- Appreciating every moment together

I’ve been asked what advice I have to share with anyone who knows someone affected by ALS. I will say that I find it hard to answer the greeting of “how are you?” upon seeing friends and acquaintances. Carol’s diagnosis is always top of mind. As a result I do feel more alone now and that’s ok with me. I’m less interested in socializing, particularly when it involves idle chit chat.

Generally, my advice to others that have just learned that they have a relative or friend diagnosed with ALS would be as follows:

- Offer support and continue to offer this support often.
- Initially, don’t ask how they are - surely that’s obvious.
- Visit with them, walk with them, dine etc. as much as possible.
- Discuss openly the subject with regard to doctors comments etc.
- Offer to help drive them anywhere they need to go.
- Give them space to be alone when they ask - let them make the next contact, whether it be visits, phone calls, emails etc.

- Learn as much as possible about ALS.
- Attend all fundraisers where possible.
- Get all legal paperwork done immediately.
- Be prepared to start wanting to spend more time alone.
- Plan finances in order to be helpful in the short/long term.
- Be flexible with visits and stress that if they must cancel at the last moment that's ok. Never just show up.



Carol and I, 2005

My feelings have progressed as follows since diagnosis (though I've run the whole gambit of thoughts and emotions so this is just a taste):

- Initially, feeling total shock, disbelief and severe pain.
- Realizing that I need to be strong for Carol and Travis.
- Listening to Carol and what she feels, needs, wants – surrounding her with love.
- Working on what we can do to immediately make the next months and hopefully years happy for her.
- Learning as much as possible about ALS.
- Meeting people that already have the disease to hear their thoughts, feelings and suggestions on how to move forward.
- Wondering if Montreal was close enough to Ottawa to really help and be there for Carol when she needs us.

- Feeling terrible for Carol yet seeing her so happy and bubbly, Carol as she's always been, in front of others. Questioning how she can be that way given the disease she has.
- Getting used to her having ALS (in reality, I don't think this will ever happen).
- Realizing how serious it is when she transitioned from walking with braces to needing a walker.
- Feeling the reality sink in when she went to the first of many wheelchairs. It really tore me apart understanding that she'd never walk again.
- Increasing my knowledge led to thinking about the swallowing and breathing problems that are so severe and being thankful that for now those issues are not a problem for Carol.
- Knowing that flying to get to countries for trips would come to an end after the first few trips together, as the deterioration of Carol's body started to show in fatigue and cramps.
- Accepting that the time we had to talk daily is reduced now with Carol sleeping more.
- Hurting after seeing Carol's struggle to lift her glass of wine to "cheers" with me.
- Realizing that if she fell down she would need help to get back up, not being able to do it alone.
- Moving to Ottawa. It has helped calm a lot of the hurt I feel
- Being close and seeing her more than the old days, along with more travel together (daily for a while) has made my life less painful, and hopefully hers too.

My personality went from type A to a type L (for "lost") – I don't feel I'm me anymore. I know others see that and understand a little bit. But pity is the last thing we need. Life has changed forever but we are never giving up hope. We no longer want to own any house or condo in order to be totally flexible and to travel with Carol/Travis and Keith/Tania, mostly to suit their schedules. I now call life 'simple' and 'flexible'.

Non-immediate family and friends have supported me throughout Carol's diagnosis, from the initial "leaving the phone off the hook" to present, by:

- Being there for me/us when needed
- Showing up at fundraisers or organizing them on our behalf
- Visiting with us and Carol and making the event (lunch, dinner etc.) fun
- Asking "what can we do for her?" and delivering on the simple but meaningful requests.

Being on a trip with Carol and Travis is the most fun and is the least painful version of daily life – I guess because I feel safer about the future. Also, to get to spend time with them for two continuous weeks or so makes me as happy as can be. I don't feel the continuous pain. Her appreciation for life is much larger than many others, including my own.

Reading her amazing blog can be both painful and inspiring. Watching her speeches live or the videos just builds up my pride even more. At the same time, I still find myself acting more like "Joe Hero" in front of others and not showing my inner self.

It seems that many of the other major diseases people can be diagnosed with have some avenue of trying to extend life, if not being completely curable. As a result, I feel the need to say as loudly, clearly and often as I can:

**TO GOVERNMENTS AND RESEARCH PROGRAMS: PLEASE HELP
FUNDING TO FIND A BREAKTHROUGH FOR THIS TERMINAL
DISEASE AS SOON AS POSSIBLE.**

(And I will say it loud and often for the people in the back!)

Carol will always be my daughter and inspiration first and foremost; and an ALS patient after that. She has been called “a girl with such dignity and grace”. She is an incredible, BRAVE, amazing, strong person whom I’ve always been close to. She hasn’t lost her sense of humour or her cheekiness which comes out every now and again with her favourite expression, “**Oh dad!!!**”.

Carol is still so positive and as sharp and as quick as ever. Smart too – Veuve champagne is almost always #1 on her needs list!!! She always “lives for the moment”, whereas I’m “always planning”. I now see why she’s right!

Finally, what I can do is be there for her whenever I’m needed and especially to visit and help play with her cats!! All we have for now is hope, love, inspiration and prayers. But travel together helps!!!

Today Better Than Tomorrow... Have No Ego...

THERE’S ALWAYS POUTINE!!!



*Carol and Travis, Andrew Haydon Park, Ottawa
photo courtesy of Vicky Elias, London House Photography*

Acknowledgements

- Quotes for section endnotes are from Carol/her blog and the ALS Society of Canada’s website
 - Chelsea Sharman