The role of a caregiver comes in a variety of forms. It spans across all ages, from children caring for their parents, to parents caring for their children, to a wife or husband caring for their spouse, to a niece caring for an aunt, to a grandparent caring for a grandchild. It touches all races, cultures, religions and walks of life. We will most likely ALL be a caregiver at some level and at some point in our lifetimes.

When a loved one becomes, or is born, chronically ill or disabled it puts an enormous amount of strain on the primary caregivers of that person. Some may require 20 hours of care a week while others may require 40 hours a week or more. It becomes a challenge to the caregiver to balance their own needs with the needs of their loved one.

Professor Diane Kendall, at the University of
Washington Speech and Hearing Sciences department, brought in a panel of caregivers to class one day and had them share their stories. Everyone in the class was so incredibly touched by what they had to say. One of the caregivers that came to class that day, Julie, agreed to meet with me and talk about her story in a bit more detail so I could share it with all of you.

Julie’s husband had a stroke when their baby girl was just a few weeks old. Julie walked in and found him on the bathroom floor. He was 37 years old. I asked her “How has your husband’s stroke affected your life?” She said “In every which way. I don’t think there’s any piece of the pie that’s not affected, friendship with others, work, home life, interactions with him, my family... From psychology I remember there are all these pieces of the pie that you need to fulfill to be a whole person, and there’s not a piece of the pie that it hasn’t affected. Even where he wasn’t involved before, my relationship with my girlfriends, and my relationship with myself, how I view myself, it’s even affected that.”

Their daughter, Morgan, is now two years old, and I asked Julie, “Could you tell me what a typical day is like for you? She said, “I wake up around 7:00am. I’m the only one to get up with my daughter. I get her changed and dressed, fed, I usually plop her down in front of a half hour show like Dora so that I can get dressed and if possible showered, which only happens every three or four days, and then get her to school.

Now I’m laid off. I used to go to work, and while I worked I would be fielding phone calls from doctors’ offices, refilling prescriptions, and the Access bus, but now that I’m not working I come home and get him (Wayne) and drop him off at an appointment, or follow up on referrals, make calls. It’s a full-time job just doing all the fielding of calls and faxing.

I haven’t even filed my taxes yet for this year. I tried but it was when everyone was sick, so I tried for 2 hours, but I was yelling at Morgan, and I was like why am I even trying to do this today. It’s just not going to happen.”

I asked Julie, “How do you feel like you’ve been coping with everything?” She said “It varies. I feel overall I’ve coped very well. I feel like I’m a very strong person. A caregiver counselor told me she hasn’t ever come across anyone with your reservoir of strength. And for me that is just scary, that if I’m somewhat of a rarity then how are the other caregivers doing? That's sad and scary for me because there's definitely times that I don’t do well. Part of me wonders if I’m coping. Because with a new-born you don’t get to just check out and go through your own emotions, you have to be ever present. And I don’t know when Morgan gets to be 4 or 5 if finally I will check out for a few days, so I am trying to see a counselor to make sure I am staying on top of my grieving and mourning. I feel like I need to be taken out of my situation and figure out who am I, how do I define myself, how do I function in stressful situations, and then get put back in.

I don’t know how to deal with what’s been handed to me. In a way, you’re either accountable for his (Wayne’s) actions with the brain injury, or you’re accountable for your own crap. If you (Wayne) skip the Access bus and you can’t find your way home and you’re lost until 8:00pm, I can’t come rescue you every time. I set up the Access bus and this is the plan. But then he’s lost until 8pm, I feel like there’s no middle ground.

I feel like there are no resources to truly train caregivers on this. Maybe for older caregivers it’s not as much of an issue, but when you have a 39 year old who wants to be more independent.

I asked her toward the end of the interview, “What do you need?” Julie replied, “I feel like I need to be checked into some caregiver training for a month. Cause I’m trying to deal with so much. I don’t know how to deal with all this. I don’t know who I am any more. Every piece of my pie is gone. I went back to work 5 months after the stroke, and people were like this will be so good for you. It will
just be you. And it was the first few weeks. I didn't have to do everything for everyone. It was great. But when I left work [when Wayne had his stroke] it was a 3 person department, I was really in control, I had touched all the protocols. I came back and it was a 12 person department and everyone knew more than me. I felt like I didn't know anything from their perspective. I tried to tell them that's not how it's supposed to be, I've been here 5 years and they didn't want anything to do with my knowledge. I felt like it was the one piece of pie that could still be there but had been totally destroyed as well. And all I wanted was just to go somewhere and feel like the old Julie.

So I just feel like I need intense therapy, which scares me because I feel like I'm doing good, compared to some other caregivers I know. One thing for me that I feel like can get me through, but maybe it's because I'm not dealing with anything in my section of the pie, is this idea of the non-profit organization. I feel like a passionate student again with the whole world ahead of me. Let this be the pressure cooker that lets me blossom into who I was supposed to be. I think I'm only coming into my greatness now. Psychology was my passion before when I was in school, but now my passion really is caregivers, and stroke survivors, and families who have kids. How do we get them the help they need? Nothing is easy.

Julie and Professor Diane have started a caregiver’s support group on Saturdays at the University of Washington, and are always in need of volunteers to watch their children and be with their loved ones. As clinicians, students, friends and family members we need to keep in mind the types of challenges caregivers face every day. Lend a shoulder to cry on once in a while, offer to babysit for someone you know in your life that has to care for someone and has children. I’m sure they would greatly appreciate it.

It reminds me of that saying “It takes a village to raise a child.” It is so true. We can’t always do it alone.  

(Continued from page 1)

Very physical?

Yes, snowboarding every weekend, working on the yard, working on the house. Within our relationship, companion wise, (crying) he was a good mirror for me. I got to see myself, he helped me realize a lot.

So, was your interest outdoors, too?

Yeah, common interest in being outdoors, socially, and then he, regarding the good mirror comment, he was able to break apart who I was and why I was certain ways. What was ok and what wasn't.

I think that's very important to your story and for others to try to understand what you're going through. This always is a very stressful situation.

It's okay. It's nice to actually feel all these feelings. I feel it everyday, but when I'm prompted to think about in a concise kind of way, it's like I miss him but what do I miss? I haven't thought about that.

That's not a pleasant situation to be placed in. Please pardon me but to me in my mind, it's very meaningful and helpful to me and I'm convinced that it's meaningful and helpful to other people that have had similar situations.

The other people in our support group are people that each have been affected by strokes very differently. With some people one stroke is all you'll get. So the one stroke that some people have can be so overpowering that everybody else could feel, “Why am I the unlucky one, that guy's had a stroke, and he walks around, and I cannot, he speaks and I cannot, he hears and understands and I cannot.

It's a huge difference, and that is a difficult story to relate and it's even more difficult to understand if a survivor looks the same as before, but doesn't ACT the same. There's this huge chasm and "Why can't I get back what I have lost?"

I grew up in Minnesota, very traditional, like the aunt is the only one who can hold the baby shower. So I moved away. There are
certain things I didn't like about the way I grew up, not only for environment and temperature, but also attitudes. Wayne's position was "Like you don't have to have your sister hold the shower. We're just gonna fight about it." And I'm like "Oh, I never thought about it like that."

Try to compare a day of Wayne 'then' to a day of Wayne 'now'.

Now, after the stroke, it's very hard to interact socially. He can't talk. He's not supposed to drink, and he cannot drive.

And he cannot go to work—he can't be on scaffolding because of seizures. He used to have them every day, every other day. Grand Mal seizures *(abnormal neuron electrical activity over the whole brain –ed.)*.

Now he has a partial everyday, or every other day. He takes a sedative almost everyday to calm his brain and body down.

Seizures started happening 4 months after the stroke, when he had his first Grand Mal then.

He was very articulate, very intelligent.

And now, what communication does he have with you?

He couldn't 'turn on' his voice for two months after the stroke. He was completely silent. So my memories of the hospital are of him just sitting there. There was no sound.

Now, he is nonverbal, so he cannot use words. He only has a syllable or two, like "we", and "no". So when he is trying to say it, I'm like "Can you show it to me, can you bring it to me, can you draw it?" And he doesn't want to draw it. So he's very stubborn.

Did he reflect to you that he was very frustrated and angry about not being able to speak, or was that pretty much completely quieted?

Now that he can 'turn on' his voice and tries to speak and say "Milk" he'd be like "we....we..." and be done.

But the first 2 months when he couldn't 'turn on' his voice he didn't get mad.

But, now, he often is?

Yeah, he gets very frustrated.

How old was your daughter when his stroke happened?

His stroke was April 1st, 2008. That was three weeks after, so my daughter was three weeks old.

How do you see him reacting with Morgan now?

He's a bit more interactive. It's not how it would have been before the stroke. But if I cue him up and get him set up to do something with her, he can sit and play with her, like with building blocks.

Yesterday, we were working in the yard, so she was playing with water and a bucket and she kept asking if he wanted some tea. And he didn't know what to do with it so he just kept hitting his shoulder with it, and she was like "Daddy, no, it's for drinking."

And he just keeps doing weird stuff with it (because of the apraxia *(loss of the ability to make purposeful movements –ed.)*. And I was like "No, you have to pretend to drink it."

And then Morgan was frustrated, "Okay, Dad obviously doesn't know what to do, so I won't go back to him." And that just kills me.

So I changed it to "How about we just come over and splash the water?" I'm like "Wayne, just take a break from the weeding," and he wanted to just keep weeding. And I'm like "No, your daughter needs to play, and you guys need to connect and here's an opportunity." So I made him take off his gloves and come over, and he was not happy about that.

But then they would both splash and laugh, and then he'd splash and she'd laugh. So in that moment I thinks it's normal, but it's a lot of work.

So, they do interact. She'll sit and read books to herself. She remembers the story enough, and then he'll kinda lean in and she'll be like "Daddy, no." And then he'll just sit back and watch her and sometimes she'll engage and try and move his lips and be like "Butterfly, Daddy, butterfly."

But other times she doesn't want anything to do with him. And I don't know if that's just
normal. Since this is our first kid, I don't know what's normal for a daughter and dad relationship.

Because the stroke and the baby happened at the same time, I think I blame a lot of things on the stroke, like: our friends not coming around, I'm losing good girlfriends. I think it's because of the stroke, that they don't know how to relate to me anymore, but it could just be because we have a kid.

But because they happened in such proximity, I think even Wayne feels that way "I deserve to go have a beer," and I'm like "No, you have a daughter now." Because to him he can't go drink with buddies because of the stroke, and it's like "No, our lives would have completely changed anyway."

We just didn't have time, and maybe it's a good thing. If we had had time to get used to the baby with more of a partnership, I would have maybe felt even more of a loss as a single parent, in a way. I don't really feel a loss and know how having a partner would have worked. I could imagine it, imagine what we had talked about and planned. How we would be a team, and how we would go fifty-fifty.

To me there's one loss I don't feel for real. Like it's just a dream that didn't happen.

Morgan goes to daycare everyday, so she goes to school, but we don't really have any neighborhood friends. We'll go to people's houses, some stroke families' houses that we've met. So we'll go to their house and play.

*How does she feel doing that, does she just have fun as you would expect?*

Mmm, yeah, she loves to get together with other friends.

*So she's able to react just like any normal daughter in that way?*

I think so. The only families we hang out with are stroke families. We don't have any families that want to hang out with us, because they don't want to do a dinner date when the husband can't talk. The only time I see a normal family with their kid is at daycare when they're picking up or dropping off their child.

So I try to interact with Morgan, like I worry about her gender typing that men always stay home. So I always say,"Mommies have to go to work and Daddies have to go to work. Mommies have to go home and drive Daddy." So like at school when people talk about "No, my dad's at work," she doesn't feel any different.

But I think she knows something is different. The way she attaches to the other stroke dads is clear, I feel like. Like she loves Monty and she loves Lou. It's weird. And it is what it is. You can't change the relationship she and Wayne will have. I can't take away the stroke. So all I can do is have some goals in mind.

I watched a sitcom where it said,"90 percent of being a dad is showing up, is just being there." That's really stupid and unfair.

So I think it's not about the perfect thing to say nor is it just being present. But being there and interacting is probably the most important thing for her as a daughter. So, we have that.

I'm crying because I'm remembering who Wayne used to be.

*Julie had two interviews. Each time, the meetings included Nancy, Anne, and BobA. with Julie. Anne conducted the first interview, Bob, the second.*

*The second fortunately added so much more emotionally committed conversation over the feelings, sacrifices, and relationships, that a completing article will perhaps be released in the next newsletter. - BobA.*
In Search Of …

Caregivers—and Care Needers

-by Ted

I found an intriguing pair of interlocked articles in “Brain Attack—the Journey Back”, Kope Associates, 2005. (These articles were researched and edited by Liz Pearl, M.Ed., who granted permission to reprint). One focuses on the experience of a young stroke survivor. The other emphasizes the impacts of a stroke on caregivers.

In the first article, a survivor chooses to write about recovery and future opportunities. Overall, the article is positive and optimistic.

The accompanying article describes the stroke as a sudden attack on the family. It is a tribute to the entire family and friends in providing support at a time of crisis. -Ted

The Opportunities Ahead of Me are Endless, by Janel Nadeau (daughter).

I was 19 years old during the summer after my first year of university. I finished the year at Queen’s University in Kingston, Ontario with excellent marks and new friends. Back home in Calgary, Alberta, I was enjoying a fantastic summer job in a cancer research lab. However, the sense of invincibility I had once felt was soon replaced with frustration, fear and utter confusion. I had a stroke.

Even in my state of muddled awareness, I remember thinking that the doctors must be mistaken. How could I, a young person, with no obvious risk factors, have had a stroke? It made absolutely no sense to me. How long would it take for me to recover? Was my intelligence affected? Would I ever be the same? There were so many unanswered questions.

I quickly realized I had no choice but to come to terms with the challenges I suddenly faced, because I desperately wanted to get my life back.

Learning to walk, striving to speak again and trying to arrange my thoughts in my once overly-organized head were frustrating. Every time I made noticeable progress, I felt that I was overcoming these seemingly insurmountable obstacles. Through hard work and persistence the tedious, yet fundamental tasks, were conquered, leading me to set my sights on an even greater challenge – completing my university degree.

I had worked so hard to be accepted to Queen’s University, but not nearly as hard as I worked for five months post-stroke in order to return to Kingston. The challenge of balancing schoolwork with my physical, psychological and intellectual recovery was agonizing. My reading was slower and disjointed; I struggled with my memory. Writing was complicated by difficulties with word-finding. Furthermore, I was feeling constantly drained. Still, I pushed myself; taking courses that I knew would force me to confront my residual impairments and weaknesses.

As part of my emotional recovery, I decided to begin public speaking. This was the area that intimidated me the most, since my speech was far from perfect. However, with the help of the Canadian Heart and Stroke Foundation (www.heartandstroke.ca), I was given the opportunity to visit schools and to speak with students about strokes.

The fact that my primary support network – my family and my friends, whose encouragement I had come to depend on and cherish, was 3000 kilometres away, did not make my recovery process any easier. By breaking tasks down into smaller achievable targets, I was able to accomplish the largest goal of getting myself back into university education mode.

Through this experience I have gained and learned so much.

I have reorganized my priorities for the better and my life is currently on an even better track than pre-Stroke.

I value my family and personal relationships a great deal more.

My new found resiliency has made me a stronger and more confident person.

I recognize the support of loved ones is essential to any meaningful recovery.

I have found that support groups are a
wonderful tool to assist in recovery and to
make me feel like I am contributing to other
people’s recovery.

My life post-stroke is fuller and richer be-
cause of opportunities and focus that I have
found.

I am enriched from having experienced vul-
nerability.

What began on a fateful day in 2001 will
continue to be an ongoing challenge for years
to come. However, I look at the stroke ex-
perience as exactly that – a challenge – and I
have never been one to back down from a
challenge. The opportunities ahead of me are
endless!

Janel Nadeau has graduated with a BS in
Biochemistry. She has belonged to the Stroke
Recovery Association of Calgary and is the
founding member of the Young Survivors sup-
port group
www.geocities.com/youngsurvivors. Her
future career plans include attending medical
school and continuing on with clinical re-
search.

What Doesn’t Kill You Makes You
Stronger by Roxanne Nadeau (mother).

Like many parents’ worst nightmare the
story began with police officers standing at
our door. Thus began our long journey.

My daughter suffered a hemorrhagic stroke
at the age of 19, with no warning signs,
symptoms or family history. Our experience
was a sudden attack on our family. Our learn-
ing curve was high and we became educated
quickly – stroke is not restricted to the eld-
erly.

We lived in the bewildering fog in the days
and months following the stroke. In hindsight,
I have had a change to reflect on what hap-
pended and how we have been impacted.

Previous to her stroke, I was a passive per-
son content with life and very appreciative of
what had been given to our family. We fought
this stroke on all levels; socially, emotionally,
cognitively, and physically. What the hospital
could not provide, we searched for elsewhere.

I believed it would have been counter-
productive to Janel’s recovery to rail away at
a system and its perceived inadequacies.

Anger and pity were not options for us as
we chose to simply focus on the wellbeing of
Janel. We took strength from one another and
I learned so much from the experience.

I have come to appreciate the great
strength demonstrated by the individuals
most affected by this stroke experience.

I was, and continue to be, in awe of my
daughter’s strength of mind and her perse-
verance as she fought to get her life, as she
knew it, back. She refused to settle for any-
ting less.

I was in awe of the strength of my son, who
stood by our daughter through all aspects of
her stroke recovery. He was with her when
she drooled, when she couldn’t walk or talk.
And he continues to be by her side to this
day.

I was in awe of the strength my husband
demonstrated as he returned to work soon
after Janel’s stroke in order to provide our
family with some semblance of normalcy after
our lives had been turned upside-down.

I now know that my greatest strength is in
providing support. I became an advocate for
my daughter and discovered how best to sup-
port her in a time of crisis. I possess a
greater belief that everything will turn out
well; we’ve been to the bottom and know how
to find our way back.

I learned several important lessons from
this experience.

I learned that we are not alone. We re-
ceived enormous support and prayers from
our family and friends.

I learned that we took strength from one
another, we pulled together and we got
through it.

I learned that there is enormous potential
for recovery and that the human spirit cannot
be measured.

I learned that one’s options are not mini-
mized by stroke – they are simply changed.

Roxanne Nadeau is a long-time resident of
Alberta, Canada, married and with two grown chil-
dren. She works as a middle school secretary. <<
Caregivers are not an unknown quantity; we’ve all dealt with them (at least I know that I have had a mother). Yet the impact that a panel of caregivers had on a capable, smart, quite-well experienced large group of people was a definite, resounding discovery.

Julie’s tales are inspiring—they are unique in that a two-year old girl is also exposed to the now sadly common effects of a disability—a brain attack, a stroke. This led to the caregivers as the theme for this newsletter.

And, Ted’s book review includes articles by a stroke survivor and her caregiver mother.

There have been other articles submitted by caregivers: Bob Hay’s two daughters, in N/L #18; by Jerry of his spouse, in #21; about Penny’s spouse, in #22; Sharon’s partner—#23; Lesley’s daughter—#25; Kay’s daughter—#26; and, now Julie—this issue. Caregivers is a major part of our stories.

Caregivers definition and purpose.

Caregivers are people who take care of other adults, often parents or spouses, or children with special medical needs. Some caregivers are family members; others are paid. -National Institutes of Health

This may be the official meaning of the word, but it is far short of recognition of the impact upon the caregiver.

For more complete listing of help and information available, consult:
www.thefamilycaregiver.org/
www.caregiver.com/
www.caregiver.org/caregiver/jsp/home.jsp

There is a National Family Caregivers Month, this coming November (each November). This is a time for special recognition and support for those that give or have given.

Retreat on June 05, was led and coordinated by Nancy Alarcon and with many volunteers. It was attended, with thanks, by ~60. Half care-needs and half caregivers.

Breakout sessions for stroke survivors and for caregivers were set up to address their specific needs and potentials.

Keynote presentations were made by Sara Schepp, MD, on “Staying Healthy Post Stroke”, and by Diane Kendall, PhD, on “Brain Plasticity”.

Booth exhibits included examples of art by stroke survivors and informational references about aphasia and strokes.

More Retreat details or references will be collected and posted later.

May was this year’s Better Hearing and Speech Month. Lack in speech and hearing breaks the human connection with other people. These special ‘Months’ serve to raise general awareness and understanding. So, it’s a special opportunity to expand our knowledge.

And, June is an Aphasia Month. This is the best time to learn more about Aphasia and to share it with friends—and those who should know more about it.

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http://depts.washington.edu/sphsc/clinic

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"In Search Of …"