



Long-Term Care News

ISSUE 25 MAY 2010

1 Alzheimer's Disease—Will It Become An Epidemic?
By Karen Henderson

2 The Fight for Bettering Long-Term Care
By Brad S. Linder

3 Our Journey Forward
By Mark Costello

7 No Class
By Ronald R. Hagelman, Jr.

10 The Missing 1 Percent
By Jim Del Vecchio

13 Mental Health Issues of Particular Groups: (1) The Dichotomies of Caregiving: Mental Health Challenges of Informal Caregivers
By Karen Henderson

Alzheimer's Disease—Will It Become An Epidemic?

by Karen Henderson

From the deeply forgetful we learn that love—not cognitive capacity—is the deepest human need and reality. In our aging society, an attitude of gratitude for those who have lost in large measure the very story of their lives is a necessity.

— Stephen G. Post, president of The Institute for Research on Unlimited Love at Case Western Reserve University in Cleveland

January was Alzheimer's Awareness Month in Canada and consequently, the media has been filled with articles, stories and research about this frightening condition. As the result of being the principal caregiver for a father with mixed dementia: vascular dementia and probable Alzheimer's Disease, I have always been aware of and concerned about dementia. If you have attended any of my presentations, been

a student in my classes or follow the content of this newsletter, you know that the subject of dementia is invariably present.

The Alzheimer Society of Canada is warning that the number of Canadians living with Alzheimer's Disease or dementia is expected to swell to epidemic proportions within a generation. About half a million Canadians—119,700 of them Quebecers—are affected. But based on a new study made public on Jan. 5, 2010, the association predicts that within 25 years, the number of cases of Alzheimer's or a related dementia will more than double, ranging between one million and 1.3 million people. It is seen in all cultures, but affects more women. **Women account for 72 percent of Canadians with Alzheimer's Disease.**

The Fight for Bettering Long-Term Care

by Brad S. Linder



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Quitting members of Congress highlight the current news as I write this particular op-editorial. According to these same members, they are called a symptom of the current state of mind over legislative battles, political game playing and simple gridlock. Call it frustration, but this will have the effect of killing off health care reforms until another solution is found. Hopefully, better solutions will be found with a lot less pork tied to the final legislation(s). That members of Congress can't even get a copy of the legislation for evaluation prior to a vote is a surprising news disclosure. Perhaps sunshine laws should apply to everything that Congress does to prevent secret meetings and secret dealings? It appears that these "porkers" are too hard to catch. Pundits joke about the effect of the record-breaking snowfall in Washington D.C. (e.g., would that record snowfall be the largest snow job that we've seen in D.C. in quite a while?) Interestingly, pundit humor has been a traditional symptom of the national mood. Don't they know the fight for bettering long-term care is serious?

To contrast, you don't see many examples of the Winter Olympians quitting. They train; they keep on going. If they stop, they are injured significantly. Those that "retire" often give advice or coach others coming along in the sport. Their spirit, their passion, is wonderful to see. I would not be surprised if everyone decides to turn off the news during the Winter Olympics (except for the weather reports, of course!) The Olympians know what they are fighting for.

As this column simmers on George Washington's birthday, I cannot help imagine where we would all be right now if Washington decided to quit as general, or quit as our first president. Despite notable bickering and sour moods of his fellow Americans, very heavy frustrations and setbacks, he kept on going. He kept participating; he looked for solutions. Washington knew what he was fighting for. I was very glad when I learned that the story about Washington chopping down the cherry tree was false. How horrible, to be wrongly blamed. Talk about a really bad hatchet job! The truth helps the cause of what you are fighting for.

We have an LTC Section full of spirited members. I cannot thank you **each** enough. We know what we are fighting for. Without spilling the beans, this issue explores that fight with some spirited articles. We have our Chairperson's Corner written by Mark Costello. Two articles are from the Canadian perception, each written by Karen Henderson. One article is from the claims perspective written by Jim Del Vecchio. Another article, written by Ron Hagelman, challenges the CLASS Act. I feel that I should have some sort of surgeon general's health warning label on this issue. There may be some acidic humor hidden among the articles. Then again, humor does relieve frustration.

Many thanks go to each of our esteemed authors. ■

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Our Journey Forward

by Mark Costello

Yesterday, in the midst of e-mail exchanges on a variety of topics, Brad Linder mentioned that he needed me to write a column ... in six days.

How many words, Brad? *As many as you want.*

Any thoughts on topics? *You have carte blanche.*

Thanks Brad.

I put together a list of things that needed to be covered:

- Excitement about being your chair/gratitude for work of outgoing chair
- Upcoming ILTCI and Think Tank
- Involvement of Track Chairs on the Council
- CLASS Act
- New research
- Changes to the newsletter

But, there it stayed ... a list of bullet points and not an article. I just couldn't come up with a way to tie everything together. So, I went back and reread Brad's e-mail for direction. Then I noticed his parting words. "Just have fun with it. Let the readers feel your passion."

Passion. Let the readers feel my passion. I could share with you the passion for my family or for teaching the kids in my Sunday school class or an Eli's cheesecake. I could write a whole column about the emotions I feel here in mid-February as players from the sure-to-be 2010 World Series champions report to Jupiter, Florida.

But, let me tell you about a different kind of passion. Steve Schoonveld just completed his term as chair of this council. You could see his passion for the industry as he worked tirelessly to get affiliated members added to the council and as he spearheaded the industry response to the CLASS Act. I want to make sure section members appreciate the job he did representing you. (We won't talk about his misguided passion for the sure-to-be 2010 cellar-dwellers now reporting in Mesa, Arizona.) But, he is so committed to Long-Term Care (LTC) that he is now working with the SOA in setting up the LTC Think Tank that will take place in New Orleans on March 17. These organizers are committed to a structure that will maximize participation and result in specific, actionable measures. And, here is more passion: over 60 individuals, an LTC "who's who" representing carriers, producers, regulators, reinsurers, staying an extra day in New Orleans to discuss and address the issues and concerns that are confronting the industry that they are so committed to—passionate about. This is an exciting event that could help shape the industry over the next few years.

Let me also tell you about the passion of the council that you elected. Dave Benz is nominally your vice chair and treasurer. In reality, he is so much more. He has been part of every discussion and project that we have undertaken this year. He is always prepared and always provides insightful comments and recommendations. I have leaned on him heavily and he has been awesome. The council is in great hands for next year. Meanwhile, for 2010, the council has significantly expanded with the addition of three affiliate members—Ron Hagelman, Denise Liston and Winona Berdine—as well as the chairs of each of the newly created Tracks—Steve Pike (marketing); Mark Whitford (actuarial); Jim Smith (operations); both Denise Liston and Winona Berdine (underwriting and



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CONTINUED ON PAGE 4

claims); and Ali Zaker Shahrak (compliance). I am truly privileged to work with this entire group. In our first call this year, I set aside the majority of the call to go through the process of filling the different council roles. I shouldn't have worried as each position was quickly filled.

Dave Kerr took on the critical role of liaison with the track chairs. Given that the track chair concept is new, this role is critical; and, Dave has taken it on with his usual zeal. He and the track chairs are excited about finding opportunities to create track-centered communities within the overall SOA LTC Section.

The council feels that research is one of the most important benefits we can provide to our members. As such, we have allocated a significant portion of our budget this year to research projects. Roger Gagne will continue to have responsibility for our research projects. You will soon be seeing the results of a morbidity improvement project that has begun. In addition, by time of publication, we should be well on our way to selecting additional projects culled from a formal RFP process.

The council knows that we need to capitalize on the Internet more and we are moving in that direction. Laurel Kastrup has stepped in to take on responsibility for our Web site. She is working closely with the SOA to make sure the content is up-to-date; as well as to find ways to increase traffic. She is working with the track chairs to meet their needs and provide track-specific content. Meanwhile, piggybacking on the success of our first webcast last year, Mark Whitford has jumped in to oversee more webcasts for 2010. The first webcast—on ALM and ERM—is right around the corner on May 26. We would certainly welcome any member feedback on potential future subjects.

Along with research, we feel that education is another very visible benefit that we can provide our members. For continuing education programs, we have several people that have stepped up. Jay Bushey and Amy Pahl are working on the SOA Annual Meeting while Al Schmitz is working on the LIMRA/LOMA meeting. Meanwhile, Roger Loomis is working with the SOA on providing new LTC content for the exams.

One very tangible benefit members receive is this newsletter. Brad Linder and Bruce Stahl continue to put in countless hours producing this publication. They are not sitting on their laurels either. We have begun discussions about how to transform the way you receive newsletter content. We are going to be capitalizing on Web technology and networking groups to provide fresh content more regularly and allow the ability to comment and provide feedback on that content.

Too many times, these types of columns come off as just a laundry list. That is not the message I want to get across. You are members of this section and I want you to know that you have chosen representatives that are passionate about LTC. This is more than a laundry list because of the commitment of these people to make things happen. Let us be honest ... things need to happen and things need to be done differently. LTCI is in the midst of some very trying times. For LTCI to face and conquer these challenges, it is going to take the dedication, commitment and passion of all of its stakeholders—not just the council. As a reader of this newsletter, you have a stake in what happens to LTCI. Many of you are just as passionate about this industry as your section council or the Think Tank participants. I grew up in Missouri and I challenge you to show me. Of course, we always need speakers or volunteers and even council members. But, there's so much more. Participate in track events. Answer surveys. Tell us your ideas. What can the council be doing that we're not doing now? What research would you like to see? What webinars or SOA sessions would you attend? Show us what you think. Show us your passion. ■

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Called *Rising Tide: The Impact of Dementia on Canadian Society*, the initial findings report the first new prevalence data since the 1991 Canadian Study on Health and Aging.

“These new data only reinforce the fact that Alzheimer’s Disease and related dementias are a rising concern in this country, an epidemic that has the potential to overwhelm the Canadian health care system,” Ray Congdon of the Alzheimer Society said in a statement.

DEMENTIA IS STRIKING A GROWING NUMBER OF BOOMERS

The report also states that of the half-million Canadians affected by various forms of dementia, about 71,000—or almost 15 percent—are under 65. Of those, 50,000 are 59 or younger.

“We know that we’re finding far more individuals in their 50s and 60s who have dementia,” said society CEO Scott Dudgeon. “We’re talking about dementia generally, including Alzheimer’s Disease.”

WHAT ARE THE DIAGNOSTIC TESTS USED FOR ALZHEIMER’S DISEASE?

According to medical experts, there are no specific laboratory tests that can tell unequivocally that one has Alzheimer’s Disease. Brain imaging can detect lesions that can suggest a possible Alzheimer’s case. A number of tests need to be performed to eliminate other possible causes of Alzheimer’s like symptoms. The diagnosis is done by memory and cognition performance evaluation using specific noninvasive tests. These tests assess learning and retention of short-term memory. They are very powerful and can distinguish normal aging-related memory deterioration from Alzheimer’s marked memory and learning deterioration. Together with other indices derived from brain imaging—clinical and personal history as well as family observations—a physician is able to conclude whether or not an individual may be suffering from Alzheimer’s symptoms.

CAN THE RISK OF DEVELOPING ALZHEIMER’S BE DRAMATICALLY REDUCED?

What can individual Canadians do immediately to protect themselves? We have heard it before:

- Eat healthy and nutritious food—pass the fish please—and avoid common hazards in the typical modern diet.
- Control your blood pressure and cholesterol.
- Stay active physically and mentally.
- Avoid harmful toxicants and pollutants.
- Be socially engaged with family, friends and community.
- Surf the Web.



WHAT IS RESEARCH TELLING US?

Extensive research has been going on around the world for many years. According to a report by Dr. Jack Diamond, scientific director, Alzheimer Society of Canada: “Almost invariably when Alzheimer’s Disease is mentioned, be it in the media or in medical reports, the words “for which there is no cure” appear with depressing regularity. The Conference on Clinical Trials on Alzheimer’s Disease (CTAD), the first of its kind, held in September 2008 in the historic School of Medicine in Montpellier, France, marked a significant change in the attitude implied by these words. As this conference made clear, within five to seven years we may well have treatments for Alzheimer’s Disease that could halt, or certainly significantly slow down its progression, a position justifying the

CONTINUED ON PAGE 6



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active search for treatments that could go further, and reverse the effects of the disease. Whatever the answer, another stumbling block is emerging in the search for a cure. But hopes remain high, and rightly so. The future is still more promising now in regard to a cure for Alzheimer's Disease than at any other time in our history."

DEMENTIA AFFECTS THE WHOLE FAMILY

"At first we fought back. We fought the disease, we fought her, we fought the system, we fought ourselves. But then something began to sneak up on us. Slowly, we learned that Alzheimer's is not the end of a life. And that it need not be the end of a relationship. Alzheimer's, we found, is pretty much like anything else life brings one's way. It is change, and change brings with it opportunity. In this case, the opportunity to develop new, even deeper connections than we had had before. This is not to say that the experience was not difficult. It was almost always profoundly difficult, and by turns saddening, frightening, exhausting and infuriating. But it proved also to be enlivening and enriching, and at times even hilarious. Ours was a broader, more complex, and far more richly rewarding experience than we had anticipated, or been led to believe awaited us." — A caregiver

WHAT CAN YOU DO NOW FOR YOURSELVES AND YOUR FAMILIES?

Become aware and become educated. Dementia is not going to disappear any time soon. It is up to all of us to be proactive and take the necessary steps to protect our loved ones and ourselves.

I have been there. My 14-year dementia care journey changed me forever. It was the toughest thing I ever did. But I would do it all over again because it enabled my father and me to journey from rage, hopelessness and despair to understanding, acceptance and forgiveness—from darkness to light. It allowed me to make a truly profound difference in the life of another. It taught me what unconditional love really is. ■

Additional Educational Resources by the Author:

- Long Term Care: A Practical Planning Guide For Canadians
- The Long Term Care Resource CD – Everything you need to know to locate long term care information and resources across Canada
- It's never too early to start the care conversation ... A Guide For Adult Children & Their Parents
- The Long Term Care Readiness Questionnaire/User Guide
- The Critical Illness/Long Term Care Planner

Visit www.ltpcplanningnetwork.com for more information.

MORE ABOUT THE AUTHOR

*Karen Henderson is founder of the Caregiver Network (Howtocare.com). Moved by her personal experience of caregiving, she started the Caregiver Network on the Internet in 1996 and *How to Care* in 2000. She also launched *The Caregiver*, a quarterly newsletter and the *Personal Care Binder*. She cocreated and produced the TV/video series *Caregiving with June Callwood* and *The Complete Aging and Caregiving Resource Guide*. Henderson sits on provincial committees for elder abuse and dementia and is also a founding member of two national coalitions to improve the lives of caregivers and end-of-life care for all Canadians. She can be reached at karenh@ltpcplanningnetwork.com.*

No Class

by Ronald R. Hagelman, Jr.

[Editor's Note: The following is reprinted with permission of the author, Ronald R. Hagelman, Jr. and Broker World magazine. The article first appeared in the February 2010 issue of Broker World. While we try to present a balanced set of opinions along with the facts on issues important to LTC, we have this additional opinion which continues the discussion started in our December 2009 newsletter. Of course, all of these opinions appearing are the authors' own opinions and should not be considered the opinion of the Society of Actuaries.]

The Community Living Assistance Services and Supports (CLASS) Act floating around Washington since 2005 has been cut and pasted into both the House and Senate versions of pending health care reform legislation. Although it is still unknown what, if anything, will be forced upon us, it is safe to suggest something will change.

A generation of legislation has attempted to provide incentives to American consumers to buy (HIPAA, DRA 2005 and the PPA). However, ownership of long-term care insurance remains somewhere south of 10 percent. We have not succeeded, and it appears that impatience, partisan politics and bad math are conspiring to create yet another social entitlement program to overburden future generations.

Why is this happening? There is a long list of false assumptions. It begins with a belief that the insurance option has not worked. Even if true, the critical concern must be to ascertain the cause. Begin with the notion that an insufficient number of agents sell or have sold the product. Those who do sell it recognize that it remains a difficult sale, and they understand that LTC insurance must be sold each and every time. In addition, a philosophical prejudice is embedded in the legislation that paying claims at home is inherently cheaper than in an institutional setting. With current home care costs running as high as \$25 per hour, I am at a loss to understand this line of reasoning.

Yes, something must be done. However, this new entitlement monstrosity is not the answer. There



are affiliated health care industries that are probably almost giddy at the prospect of open, easy cash flow such as home care or assisted living corporations. There are also voices within our own ranks that suggest that increased awareness of long-term care needs caused by this bill is a good thing. This is not about good or bad anything. This is wrong. *Wrong will always be wrong until it becomes law, then we will adapt and continue to do everything possible to protect our clients.*

There are several structural issues and concerns that require careful consideration. The new trust fund created will book premiums for years before substantial benefits are paid. This creates an artificial credit against the cost of the health reform legislation and reduces the perceived cost of the legislation, creating a direct catalyst for its inclusion. The Society of Actuaries has concluded that the programs would be insolvent in 11 years. In addition, a nonbinding Senate vote mandates that the new trust funds can be used for this program only. No matter how you look at what some have called a "Ponzi scheme," we are all being asked to simply have faith in yet another social welfare program.

The voluntary "opt out" enrollment provisions, making this a guarantee issue opportunity with a



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CONTINUED ON PAGE 8

liberal definition of actively at work, will contaminate rather than encourage sales at the worksite. If you completely ignore adverse selection, you are no longer marketing insurance—you are simply prefunding a known risk. More confusion will be brought to the worksite in terms of what is being accomplished, what is actually covered and how much is enough. There is virtually no commission available from this program, which dooms any real enrollment success. Premium for long-term care insurance will not sell itself. The size of the benefit of \$50-\$75 per day is insufficient on any level, unless perhaps it is being added to a Social Security check, to provide universal assisted-living admissions.

The proposed cash advance will coordinate with all reimbursement policies creating more confusion. Do you keep current coverage? Do you reduce coverage or only buy alternative supplemental insurance? The answer is leave realistically priced benefits in place and frankly, don't change anything. We have always sold "supplemental" coverage. The numbers and thresholds may move, but the nature of the sale itself will not change.

The CLASS Act panders to the lies that have plagued us for too long: *Insurance underwriting practices based on avoiding adverse selection are somehow undemocratic.* Conversely, egalitarian offerings of

universal coverage must therefore be inherently good. Besides, everyone knows Americans will always eagerly line up to protect themselves and their families.

The CLASS Act has no class. It is built from a solid foundation of hollow misrepresentations. It represents a wind tunnel of philosophical fantasies, false assumptions, monumental adverse selection, faulty pricing assumptions and a complete disregard for human nature. Other than that I have no opinion on the subject. ■

More About the Author

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The Missing 1 Percent

by Jim Del Vecchio



Jim Del Vecchio is CEO and founder of Asset Protection Unit Inc. He can be reached at jdelvecchio@apuinc.com.

I have wandered the insurance claims landscape --- for lo --- many years now. I have litigated, negotiated, adjusted and adjudicated in some form or another in every branch of the insurance claims tree. During my oversight of various claims operations, I never ceased to be amazed when a processor or adjuster would walk into my office carrying a check that a provider or a policyholder had returned, claiming that they had already been paid. My jaw would always drop, my mouth hanging open, agog with skeptical wonder, sometimes with worse!

In one memorable instance, after picking myself up off the floor (the check was particularly large), I started asking the obvious question, “How can this be?” After all, we had system edits, process audits, supervisory controls, repricing software (in the case of medical claims) all of whose function was to prevent the very thing that happened from happening.

These events launched me on a quest, a sojourn, a lifelong journey to understand the source, the nature and the degree of payment error that seems to inhere in insurance claims payments—Long-Term Care (LTC) claims in particular. And, I wanted to find the Holy Grail of claims processing: The Perfect System. My quest has become even more urgent as my business has taken me into the world of LTC Insurance. For me, this was undiscovered country where my impression was that nothing is solidified, codified or routinized ... very little of it anyway.

Unfortunately, I have yet to find the Grail. In fact, my never-ending quest, a byproduct of which has been a detailed exploration of claim payment error, has compelled me to certain conclusions, most of which an LTC claims person is likely to find disheartening. (Fear not, however.) I want to describe my journey to these conclusions so that you will see I am not pulling rabbits out of hats. And hopefully, these conclusions will resonate with you and perhaps cause you to do something about it.

Conclusion Number One: It’s all about the data. Consider that when an LTC adjuster or processor sits down to resolve a claim, its resolution depends

on correctly answering several questions: Is there an insuring obligation of some sort in force? Is there a person who is entitled to a benefit pursuant to its terms? Who is it? What is the nature of the service or loss being paid for (put differently, what is the benefit)? Who is the person or entity entitled to the actual payment? Why? How much? When and how must the payment be paid? What is the immediate effect of the payment on the insuring contract? What is the future effect?

At the most basic level, the answers to all of the foregoing are data driven. Sometimes the data is written down on paper; more commonly it is stored in a machine. Sometimes data must be calculated or derived, but it’s all data one in the same. Let’s recap a few of the foregoing questions but note the common data processing systems associated with them to make the point more meaningful:

Is there an insuring obligation and is it in force?
.... policy and/or underwriting.

Who is entitled to the benefit?
.... enrollment/eligibility.

Who is entitled to the payment?
.... provider/payee file.

How much should be paid?
... claims/adjudication.

So here’s an LTC adjuster looking at a claim or a bill calculating its ultimate resolution. All he or she has to go on is the information that exists at that moment and all that information is driven by the accumulation of data. It’s all about the data. Q.E.D.

Conclusion Number Two: The data will not be perfect; no way, no how. Why? Because the data originates out there in the real world and the real world is driven by people, and people simply cannot sit still. They are born, they die, they get hired, they quit, they marry, they divorce, they buy a policy, they cancel a policy, they change their coverage,

they forget to pay their premium, they get promoted, they join a network, they change doctors, doctors change labs, and on and on and on. The insurance claims data universe is, in short, chronically dynamic. It simply never comes to rest. Ever. Period.

Even more so in the world of LTC insurance—where new insuring products are constantly emerging—claims forms are not standardized, nor are treatment procedures, networks, billing practices and on and on and on. So when the LTC adjuster hits “enter” and the claims processing system starts ... well ... processing, the data universe that existed when the bill was submitted is not the same one that existed at the moment the electrons whirl.

Another element of the constant state of change engendered by us mortals is that the raw data that finds its way into a machine at some point or another had to be entered by a human, and therefore will never be perfect. I know of one Being that could do it perfectly, but as far as I know that Being is not working in data entry.

Lastly, recall from above that data originates in various IT systems. Here’s the point: none of these systems were ever designed to articulate with each other in real time. The correct data that an LTC adjuster needs may in fact be loaded up somewhere; it’s just that it’s not always available in the claims system at the precise moment that it’s needed.

Based upon the foregoing, I assert that the data will never be perfect because it *cannot* be. Q.E.D.

And that gets us to **Conclusion Number Three:** Claims processing exhibits sensitive dependence on initial conditions, LTC claims processing in particular. Sensitive dependence is a concept that arose during the development of chaos theory. At a very high level, sensitive dependence simply means that if things aren’t just so at the beginning, the deviation from the path a system is designed to follow grows greater over time. A classic example comes from the putting greens of golf. The farther away the ball is from the hole, the more accurate the stroke must be. A millimeter’s deviation from the correct stroke produces a huge deviation near the hole (in my case, *really* huge). Putting is a process that exhibits sensitive dependence on initial conditions. So does claims processing. Consider all the things we talked about that virtually by themselves deviate from their intended path. Any, and sometimes

all of these things, bear upon a correct resolution of a claim. If there is the slightest deviation from correctness, the likelihood of complete accuracy in the outcome decreases over time. Insurance claims processing exhibits sensitive dependence on initial conditions. Q.E.D.

The inescapable **Conclusion Number Four:** LTC claims processing is going to contain some degree of payment error. (I hear the gnashing of teeth already). Fear not, however. The same chaos theory that compels the existence of payment error also prescribes its limits. Without boring you with the math (most of which I don’t understand, and I have tried, *really* I tried) the mathematical margin for error hovers at about 1.5 percent. That’s not bad. Flipped around, the claims process is correct 98.5 percent of the time. Let’s keep the math simple and say the error rate is 1 percent. After all, there is a margin for error in our margin for error, so call it 1 percent. That means that for every \$100 million in paid claims annually (peanuts in the world of LTC), someone is leaving over a million dollars lying around out there and I don’t know anyone who can knowingly walk away from that kind of money in this day and age.

My personal opinion is that the percentage of error in the world of LTC claims is higher. So what’s a claims processor to do? Find it, of course! There are lots of ways and means. Manual audits, software products, and so forth, but consider the following: The same chaos that generated the error still exists in the search for it. Therefore, the search must account for the chaos. If so, a proper search must feature certain things:

Retrospectivity: What happened in the past is going to happen in the future unless some force causes events to change. Therefore, the biggest clue to identifying sources of error lies in the errors that a claims operation has already encountered. There are many sources of such information. The audit function and the customer service function are frequently very good places to start.

Comprehensiveness Number One: A search must account for all the originating data sources. After all, that is where the deviations from the correct path originate. I’ll put it this way: claims systems issues are the tip of the iceberg; the troubles lay in the ice below the surface.

Sensitive dependence is a concept that arose during the development of chaos theory. At a very high level, sensitive dependence simply means that if things aren’t just so at the beginning, the deviation from the path a system is designed to follow grows greater over time.

CONTINUED ON PAGE 12

Comprehensiveness Number Two: A search must examine *all* claims and their related calculations. I have personally written analytics that excluded claims payments of zero only to have the results turn out that elements of the calculation that led to that amount were themselves incorrect and the erosion of a policy maximum was missed.

Automation Number One: Humans will never operate as rapidly and efficiently as computers when it comes to the millions of records that need to be examined. Let the computers do the work.

Automation Number Two: Claims data universes are like fingerprints and snowflakes—no two are alike. The automation must be designed to fit the claims universe, not the other way around.

Validation: Humans are much better judges of right and wrong than computers. Validate the output.

Claim payment errors fall into two classes: underpayments and overpayments. Acknowledge and fix the former. Do not be afraid to pursue the latter.

I am coming to the conclusion that the Holy Grail of claims processing does not exist. Well, let me say I'm 99 percent certain. If you agree, then some form of retrospective data analysis is the only avenue available to find and account for the missing 1 percent. One last point of science: the principle of entropy holds that the universe moves from a state of order to a state of chaos as time goes on. Delay therefore suggests to me that the missing 1 percent will not shrink but rather will grow. You'd better get after it! ■

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Mental Health Issues of Particular Groups: (1) The Dichotomies of Caregiving: Mental Health Challenges of Informal Caregivers

by Karen Henderson



[Editor's Note: This article is reprinted with the permission of both the author and the Division of Aging and Seniors, Health Canada. The author prepared the article under a contract with the Division of Aging and Seniors, Health Canada (now the Public Health Agency of Canada) in October 2002 and which was published in Writings in Gerontology, a publication of the National Advisory Council on Aging].

LIFE AS A CAREGIVER

When I developed the outline for this article, I thought the hardest part was over. After all, I had been a caregiver for my father for 14 years—a man who suffered from mixed dementia, crippling arthritis, incontinence, aphasia and dysphasia, a man who ended a proud, accomplished long life in a faceless long-term care facility. I had been through it all and believed I understood caregiver emotions and what

it's like to have one's mental health and well-being compromised because of love for another.

But as I began to unravel my thoughts and memories, I realized that it's as difficult for me today as it was then to understand what went on in my mind and how these thoughts and emotions changed my life completely. Logic tells us that caregiving today should be easier than ever. Yes, our health care system is under huge stress; yes, our population is aging rapidly; and yes, we live in an age where there is too little time to think about life and our obligations to others and ourselves. But what about the never-ending advances in medical technology, miracle drugs and aids and equipment that allow seniors to live healthier, more independent lives? Don't these realities make up for all caregiving difficulties we face in today's world?

CONTINUED ON PAGE 14



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On a good day we feel useful, even capable, and positive to the point of believing our expert care may in fact influence the course of the illness. We revel in our accomplishments.

The answer is definitely no. My caregiving experience taught me that because of the long list of physical and cognitive deficits endured by my father, I ended up adding spouse, parent, personal care aide, friend, chauffeur, decision-maker, advocate, personnel manager, financial manager and funeral planner to my role as daughter. How could anyone fill all these roles and emerge unscathed?

There are 4.5 million caregivers in Canada today who are sacrificing all or part of their lives to care for chronically or terminally ill loved ones. No matter where care is provided—in the home or in an institution—caregivers invariably end up paying for products and services out of their own pockets. In fact, informal caregivers' financial contribution—in the form of subsidizing the cost of services delivered to the home, and in casual expenditures (food, laundry, gas, parking, etc.)—totals about \$100 million a week or more, suggesting that caregivers spend at least \$5 billion a year. Many caregivers report they have had to cut back on their personal budgets, use up their savings or borrow money to meet their caregiving financial obligations (Berger Monitor Special Report 1999).

The economic value provided by family caregivers is enormous. It is estimated that help given to seniors alone saves the public system over \$5 billion per year (Fast, Forbes & Keating, 1999) and is equivalent to the work of 276,509 full-time employees. (Keating, Fast, Frederick, Cranswick, 1999).

Yet there are no formal, customizable and accessible training programs for caregivers, no 24-hour help lines, no national policies for financial support or job protection and certainly no formal recognition or thanks for putting our lives on hold.

Of course there is help available to caregivers. But what and how much often depends on what province you live in, or whether you live in the city or the country. Getting help also depends on our connection to our community, on knowing the questions we need to ask as well as on our awareness of what we are owed by society and governments. But getting depends mostly on our ability to ask for it.

I have heard professionals say over and over: "Why don't caregivers ask for help?" "Why do they tell us in surveys what they need and then ignore the services that we develop?" I believe the answer is this: being a caregiver is like walking a tightrope. As long as you hold on to your pole—your sup-

port—and maintain your concentration, you may wobble but you will keep your balance and remain upright, physically and emotionally. You don't feel you need help. But as soon as something begins to shift and your pole becomes unbalanced you start to lose control; you lose your balance and you fall. You still don't ask for help because you now think it's too late to fix the impossible. There is no escaping this reality where there are problems that can't be solved, questions that can't be answered and complexities that can't be understood—where the only relief comes in someone's death.

When I read Webster's definition of dichotomy—a separation into two parts that differ widely from, or contradict each other—I knew I was seeing the essence of caregiving. When you look at most caregivers, you can almost see two people precariously existing within the body of one. You experience a person wrestling with contradictions that sometimes even she does not see or accept, a person struggling to rationalize extreme polarities.

What are some of these caregiving dichotomies that demand such a delicate balancing act?

SENSE OF ACCOMPLISHMENT VS. HOPELESSNESS AND DESPAIR

Caregiving is a task-oriented and emotional minefield. Most of us can do the physical job. We even take pride in learning how to assist another with dressing, eating or transferring. On a good day we feel useful, even capable, and positive to the point of believing our expert care may in fact influence the course of the illness. We revel in our accomplishments.

But then a fall happens in the home that we so carefully modified to prevent just such a catastrophe. Our euphoria turns in an instant to despair. We admit the unthinkable: Who am I trying to kid? I can't change things at all; in fact I barely cope from day to day.

Our fatigue permits us to surrender to the emotional turmoil that is always just beneath the surface. We are torn between knowing we can do the job better than anyone else and admitting that we lack the tools—knowledge about the diseases we face, treatment options, appropriate medications and, more importantly, the experience to make the right decisions when the times inevitably come to make them. We feel helpless; we become hopeless.

RELIEF VS. GUILT

When I made the decision to place my father in a long-term care facility, I was emotionally burned out. I could see no other alternative for either of us. Intellectually I knew my father needed what I could not give him—24-hour, two-person skilled care in a safe environment. But I was still overwhelmed with remorse.

I had to admit I felt relieved that someone else would now take over the minute-to-minute care and watch over my father's well-being. The other side of me raged at my selfishness. How could I do this to my own father, who was so fiercely independent and had instilled this quality in me? How could I put my needs before those of my father, a helpless, frail shell of a human being? The guilt was inescapable and filled me with a profound sorrow that still lives in me today.

Fortunately, time and a wise fellow caregiver taught me a valuable lesson. Placing my father allowed me to concentrate on loving him and not on worrying about him. I was released from the constant tension of doing, so I could now just be with my father, to sit quietly beside him, hold his hand and comfort him with my presence. I had time to quietly care.

THE NEED TO CONTROL VS. THE ABILITY TO ACCEPT HELP

Caregivers are renowned for saying: No one knows my loved one better than I do. I can do the job better than anyone else; it's easier if I just do it. Some of us refuse help because we are perfectionists who don't want others to know that we need any help; others come to fear that the caregiving may be taken away from them, robbing them of their reason for living.

I believe what caregivers are really doing is trying to preserve some degree of control over a situation that has spiraled out of control. We need to do it all, yet we also resent being left totally responsible for the life of another. Whatever goes wrong is our fault because we are not working hard enough.

But something else is also going on here. In today's world we are considered successful if we are capable and independent. As we grow up, we learn to regard the need to lean on others as a sign of weakness or as an indication of decline.

Suddenly we become caregivers who are supposed to ask for help, to depend on others. How can we

reverse years and years of learned independence virtually overnight without feeling anxiety, confusion and fear—of losing what we have been taught is a requirement for a successful life? Caregivers have lost the war before the first battle is fought. We need to change the rules of the game so that we grow up understanding that we all need others for varying reasons throughout our lives; it's normal and essential.

We must learn to heed the words of one wise old woman who said: "If you accept help you teach the next generation how to give help." (Lustbader 2001).

ANGER VS. ACCEPTANCE

When someone we love falls ill and we know things will only get worse, we get angry. The more we care, the angrier we get because it's all about someone else and not us. Why my father, my mother, wife or husband? We rail against fate, seeing only the injustice of it all, particularly when we must watch a loved one lose his mind to dementia.

Anger is a healthy part of an emotional life. It allows us to admit to and put words to pain so deep it seems unbearable. But when anger consumes, it burns like a raw flame. There is no room for anything positive as everything that we have always cherished starts to die.

Over time, my anger started to give way to acceptance. I learned that I could not change or control what was happening to my father's mind and body; what I could control was the life I learned to build for my father, one in which he felt safe, loved and protected. There were setbacks but I accepted each new challenge, each change in his capabilities and occasionally felt triumph in my own small way over the seemingly impossible, because I finally accepted the fact that my anger was justified.

LOSS VS. GAIN

How we view our caregiving experience can colour our mental well-being for the rest of our lives. Some look back on their caregiving journey and see only pain and suffering; they see themselves and others as failures because no one was capable of changing the course of events. They continue to experience unending loss—lost companionship, lost time, lost opportunities, loss of self.

CONTINUED ON PAGE 16

In the few quiet times we allow ourselves for contemplation, we have the unhealthy habit of repeating over and over: I should have done more; I should have been there more. Caregivers need help understanding that in giving everything they have to another they end up finding themselves. They need help in rejoicing in their huge capacity for love and forgiveness—expressed through the selfless act of caring for another. Without this awareness, they may never recover their initial spirit and zest for life. They risk remaining bitter and inconsolable, unable to ever recognize caregiving for what it can be—an incredible opportunity to give the best of yourself to another and realize that you have made a unique difference in someone else's life, a difference no one else could ever have made.



SELF SACRIFICE VS. SELF PRESERVATION

Although many men provide care for others, most caregiving is still performed by women. We learn to associate caregiving with family, duty and commitment because we learn caregiving from our mothers who held these values that they absorbed from their mothers.

Most women never entertain the idea of saying no to caregiving. Society expects women to sacrifice themselves for others and so we respond to the call. But the call in today's world is not one that lasts for a few weeks or months but one that can last for 20

years. We struggle to be the accomplished wives, mothers and professionals that society expects us to be while seeing our souls and our spirits slowly being extinguished because we cannot be all things to all people, even ourselves. We rage silently at our self-sacrifice because we are powerless to stop it.

I was once told that depression equals swallowed rage and I now realize how true those words are. I swallowed my rage so many times caring for my father that I was no longer aware I was doing it. I thought I was functioning, managing my life and my father's; I kept telling myself I was OK. Suddenly one summer morning I could no longer function. In the blink of an eye I felt absolutely incapable. I was diagnosed with depression. I had succumbed to the pressure and the worry and the self neglect even though I believed I could rise above them. I became skilled at meeting my father's needs while becoming totally unable to meet my own. Self sacrifice had won once again.

GRIEF VS. FULFILLMENT

Grief is a caregiver's constant companion, from the day of diagnosis until after the day of death. It starts with the little things—the inability to go out for dinner or the loss of a weekend trip. But the grief continues to grow as the losses reveal themselves to the caregiver in crisis after crisis. We know death is coming but we are denied the small joys that can keep us going because we will not allow ourselves to grieve for that moment and then continue on. Small sorrows collect and sneak up on us, preventing us from feeling that we are decent human beings doing the best we can.

When our caregiving days have passed most of us feel too little satisfaction at what we have accomplished. How many of us say to ourselves after the death of a loved one for whom we cared: "I am satisfied with what I did." As my friend Sandy admitted after her mother's death: "I think I played the game well but I didn't win the prize." I believe very few caregivers allow themselves the peace that comes from knowing that they did everything humanly possible for the sake of another and that it was enough.

CAREGIVING AND DEMENTIA

Caregiving until the end of life leaves few untouched. In most cases the death of a loved one allows caregivers to heal and move forward, wiser in the knowledge that the circle of life continues as it always has. Dementia, however, imposes its

own set of unique sorrows upon caregivers because when the dementia journey is supposed to be over, it's not over. After this unspeakable injustice has robbed us—the daughters and sons—of those we love, after we manage to shake off the shock, the fatigue and the disbelief over what we have managed to live through, what remains is the dark terror that we will follow in our parents' genetic footsteps.

If a little knowledge is a dangerous thing, what will too much knowledge do to us who are left behind, year, after year, after year?

Caregivers spend their days walking a fine line between success and failure, joy and grief—between life and death. There is no tougher task in life. We must encourage caregivers to feel and express the dizzying range of emotions that influence their mental health from day to day. By helping caregivers to openly accept their strengths and weaknesses, their own needs and biases, health care professionals can then normalize these feelings and reactions and allow caregivers to better bear the incredible demands made upon their bodies and souls. ■

MORE ABOUT THE AUTHOR

Karen Henderson is founder of the Caregiver Network (Howtocare.com). Moved by her personal experience of caregiving, she started the Caregiver Network on the Internet in 1996 and How to Care in 2000. She also launched The Caregiver, a quarterly newsletter and the Personal Care Binder. She cocreated and produced the TV/video series Caregiving with June Callwood and The Complete Aging and Caregiving Resource Guide. Henderson sits on provincial committees for elder abuse and dementia and is also a founding member of two national coalitions to improve the lives of caregivers and end-of-life care for all Canadians. She can be reached at karenh@ltcplanningnetwork.com.

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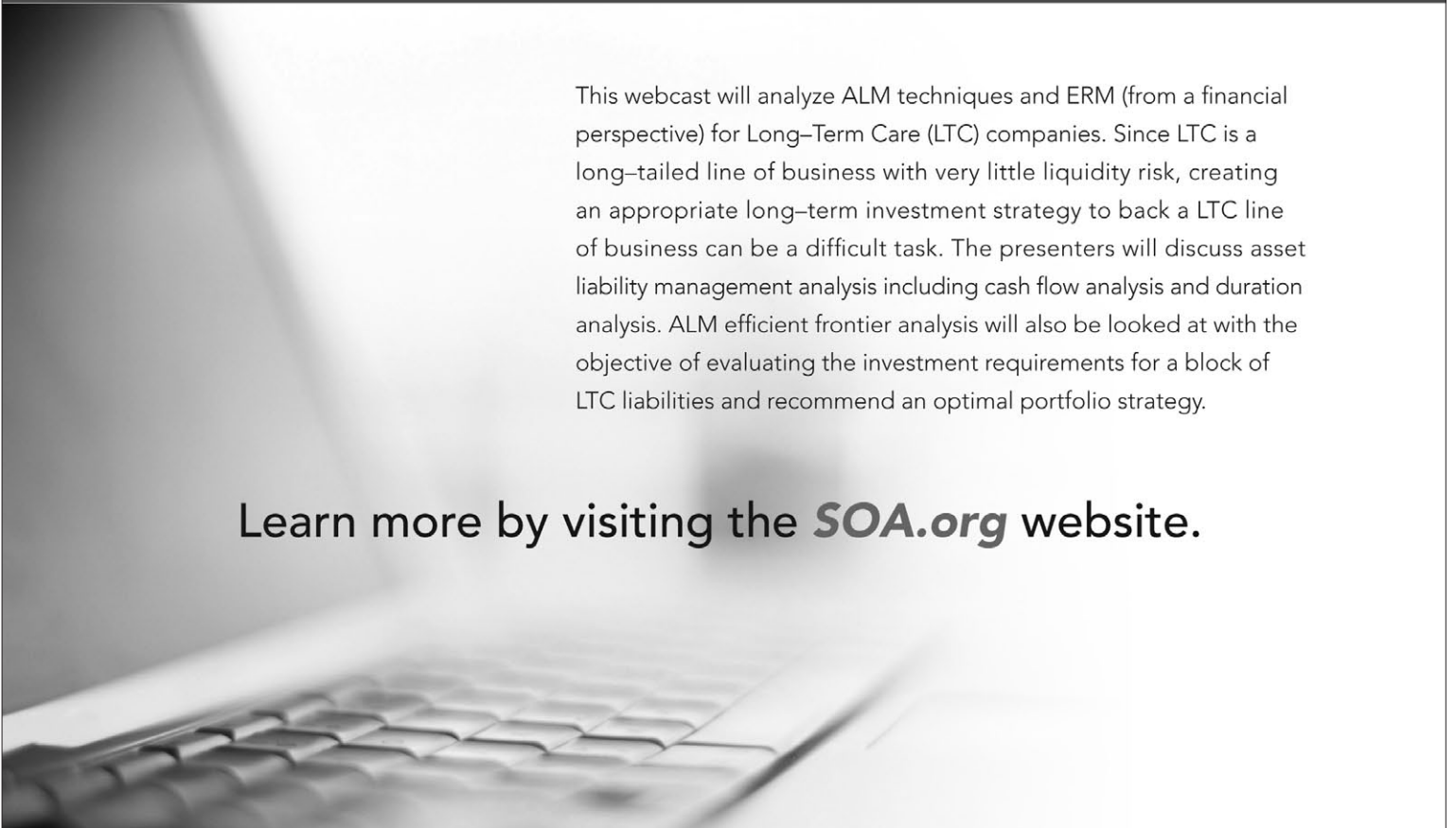
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