

NeuroMatters

Connecting You to the Research

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Welcome to ONF's World

It's your world, too

The word "research" conjures up images of scientists, white lab coats, beakers, and books. Most of us are so removed from the formal research process that we may find it hard to see its relevance to our daily lives. But the reality is that we research all the time. For example, we research the best movies to see by asking friends, reading reviews and making comparisons. That's research! And you know what? Only you really know what kind of movie you want to see. Obviously, your opinion counts!

Similarly, the Ontario Neurotrauma Foundation (ONF) believes that people with acquired brain injuries and spinal cord injuries may have something important to say about research being undertaken into brain and spinal cord injuries.

The ONF is an organization that is supported by the Ontario Ministry of Health and Long-Term Care, and that funds neurotrauma research. The research falls into one of the following areas:

- prevention of neurotrauma
- quality of life for people with acquired brain injuries
- quality of life for people with spinal cord injuries

The ONF is committed to working with people with neurotrauma, also known as consumers, to ensure that its research priorities and activities are consistent with their needs. ONF also wants to ensure that the results of its work are communicated to consumers. This newsletter is a first step.

Shauna Petrie, the Chair of ONF's Consumer Outreach Committee, says: "It is so important for people to have their own say; an opportunity to make sure

the research and the process is relevant. I think this is crucial." Shauna encourages people to find out how they can be informed and involved.

So how do you find out what is going on in neurotrauma research? Well, if you haven't already done so, you can subscribe to *NeuroMatters* by linking to <http://www.onf.org/newsletter/> or calling 416-422-2228. This free newsletter will keep you informed about the latest research initiatives.

So how can you get involved? *NeuroMatters* will advertise upcoming opportunities to participate in studies, sit on committees, attend conferences, or have a say in other ways. By taking a first step and signing up, you'll find out what's new in neurotrauma research and you'll probably meet people, feel good about getting involved, and who knows what else! Most importantly, you can make your opinion count!



Thanks to support from the Ontario Neurotrauma Foundation, ten people from across Ontario were able to participate in the National Spinal Cord Conference. They can now share the information and resources they obtained with others in their communities.

According to the Rick Hansen Institute, 90% of what we know about spinal cord injury has been discovered in the last 20 years.

According to the Ontario Brain Injury Association, the annual cost of traumatic brain injury has been estimated at \$3 billion in Canada (\$1 billion in Ontario).

According to the ThinkFirst Foundation of Canada, accidents involving brain and spinal cord injuries involve alcohol almost 1/3 of the time.

NeuroMatters
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is
brought
to
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by



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A Chance to Contribute

Consumer Outreach Committee seeking new member

The Ontario Neurotrauma Foundation (ONF) is seeking qualified consumers who have an acquired brain injury (ABI) or family members or caregivers to serve on the Consumer Outreach Committee.

Role:

The Consumer Outreach Committee is responsible for the development of plans and actions that will ensure that consumers have direct and expanded input into the activities of the foundation and that the activities of the foundation are communicated to consumers. The member will ensure that consumer perspectives, rather than simply individual perspectives, are reflected, and that final decisions take into account issues of concern to consumers overall. The member will not serve as representatives of a particular organization or association.

Commitment:

The committee meets at the ONF's office in Toronto approximately four to five times per year, although the frequency of meetings depends on the committee's current workload. Members will be expected to attend at least 75% of meetings, as well as give additional time for meeting preparation and possibly other tasks. Materials on the issues to be considered will be provided prior to the meeting. Members are asked to make a minimum commitment of two years. The term may be extended for up to four years.

Selection Criteria:

The foundation is looking for residents of Ontario with a strong knowledge of ABI, consumer issues, experiences and perspectives, and who will be objective, prepare fully, and actively engage in the process. They will be expected to represent consumer issues *in a broad sense* and seek the views of a range of consumers. The member must have the ability to focus on achieving outcomes and tasks, propose solutions, take responsibility and follow through on a given assignment. Strong knowledge of current consumer communication networks, commitment to the goals and values of the Ontario Neurotrauma Foundation, excellent verbal communication skills, and the ability to work cooperatively are also essential attributes for committee members. Complete selection criteria are contained in the information package found on our website.

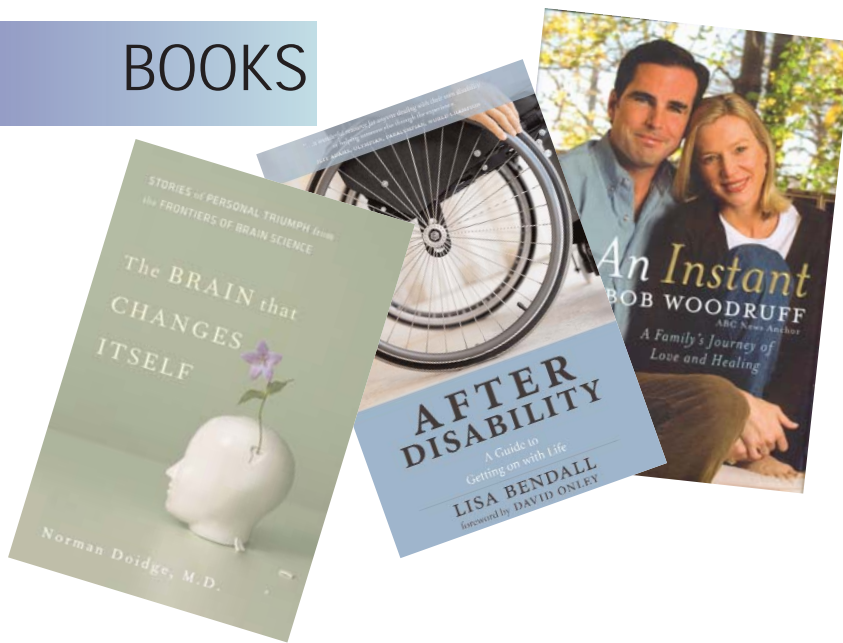
Remuneration:

Service on the committee is voluntary. Travel and other expenses will be reimbursed according to ONF guidelines.

How to Apply:

If you are interested in serving on the committee, you can download an information package from our website at: http://www.onf.org/knowledge/consumer_outreach_committee.htm or call 416-422-2228 to receive a copy by email or mail. The closing date for expressions of interest is November 1, 2007.

BOOKS



The Brain That Changes Itself -
by Norman Doidge MD

This book looks at a new type of science called neuroplasticity, that focuses on the brain's ability to create new nerve connections and reorganize itself to re-learn. Dr. Norman Doidge, a psychiatrist and psychoanalyst, writes about the doctors who are involved in this brain science and those who are benefiting from their research findings. Readers are introduced to people whose disabilities change and even disappear over time.
 ISBN 9780670038305

After Disability: A Guide to
Getting on with Life - by Lisa Bendall

An all-inclusive, easy-to-follow guide for people learning to live a quality life with a sudden disability like spinal cord injury, brain injury or stroke. It's also a useful resource for loved ones. The book covers self-advocacy, assistive devices and technology, accessible housing, financial matters, health care, employ-

ment and education, relationships, transportation, recreation, and travel. It includes tips, resources and contact information, as well as experiences of other Canadians living well with disabilities. "After Disability" has been endorsed by June Callwood, Patrick Watson, and has a foreword by CityTV's David Onley.

ISBN 1-55263-747-6

In an Instant: A Family's
Journey of Love and Healing -
by Bob and Lee Woodruff

In January 2006, ABC news anchor Bob Woodruff was injured while reporting in Iraq. An explosion left him with a brain injury. He was placed in an induced medical coma to help him with his recovery. The doctors removed part of his skull to reduce brain swelling. This book details Bob's journey and the effect his injury has had on him and his family. A percentage of the proceeds are donated to the Bob Woodruff Family Fund for Traumatic Brain Injury.
 ISBN 1400066670

UPCOMING
EVENTS

September 27, 2007: 12 p.m. - 1:30 p.m.

Peer Connections: Bladder Matters - The Canadian Paraplegic Association of Ontario brings together healthcare experts and product manufacturers in a learning and sharing environment at Chedoke Rehab, Hamilton, Ont. More info: Ron Rattie at ron.rattie@cpaont.org

October 25-26, 2007: Coming Together: Quilting the Pieces After Brain Injury - The Brain Injury Association of Waterloo Wellington (BIAWW), in conjunction with the Ontario Brain Injury Association (OBIA) is hosting the Provincial Acquired Brain Injury Conference in Kitchener, Ont. More info: <http://www.obia.on.ca/2007conference/> or 905-641-8877

October 25-27, 2007: 15th Spinal Cord Injury Interurban Conference - Following this Conference's theme of Research to Reality, topics covered include: living with chronic health issues, neurological repair and recovery, motivating clients, complementary health modalities, and independent living. Hamilton, Ont. More info: <http://spinalcordinterurban.org> or mjkorec@mcmaster.ca

April 9-12, 2008 - Seventh World Congress on Brain Injury at Pestana Palace Hotel, Lisbon, Portugal. Call for Abstracts: The deadline for submitting a paper for the Congress is November 16, 2007. More info: <http://www.internationalbrain.org>

If you have events you would like included in this newsletter, please send them to info@onf.org for consideration. Unfortunately, not all events will be able to be published.

The Up Side of Down

Research to help people with depression

Depression is unfortunately all too common for people with traumatic brain injuries.

As Melissa Felteau, a board member of the Ontario Neurotrauma Foundation (ONF) and a person living with a traumatic brain injury, points out: "Loss of cognitive abilities, psychological changes, physical

pain, loss of independence, and loss of social interactions all substantially influence a person's quality of life. These physical and psychological changes may result in limitations in daily activities, putting one at further risk of developing depression."

The ONF is committed to improving the quality of life for people with neurotrauma. To this end, it is funding three research projects relating to those people with traumatic brain injuries who experience depression. The first project is on Internet-based intervention, the second one is

on antidepressant maintenance, and the third is on mindfulness-based cognitive therapy.

INTERNET-BASED INTERVENTION

There are several reasons why the Internet has the potential to offer people with traumatic brain injuries a way to get help and support for depression:

- People with traumatic brain injuries tend to be young, and young people are often familiar with computers and online environments.
- Since many people with traumatic brain injuries also have

What to Do When You Feel Blue

Ever hear people say that you'll feel better about yourself if you **EXERCISE**? It may be hard to exercise when you don't even feel like leaving the house, but it is true that you will feel better. When you get active, your body releases endorphins, chemicals in your brain that make you feel good. So, take small steps.

- Start by finding out what is going on in your community that you could take part in and that you would enjoy.
- Take a walk around the block and see what is going on.
- A great resource is Get Active Now - a website managed by the Active Living Resource Centre for Ontarians with a Disability providing information and practical tools on healthy living, with particular focus on recreation, sports, and physical fitness: <http://www.getactivenow.ca>. They also have an e-newsletter: Just send a message to info@getactivenow.ca and type "Subscribe to eNews" in the subject line.

When you're at home, **OPEN YOUR CURTAINS AND WINDOWS**. Make sure you are getting enough light and fresh air.

People who do not have enough exposure to natural light can feel emotionally down, lethargic, irritable, hungry, and sleepy. Sunlight will make you feel good, and morning sunlight will help to reset your internal clock and make you sleep well. You will find it easier to get to sleep at night if you reduce the light levels that make the brain active, so experiment with dimmer switches, night lights and heavy curtains. For more information on interesting lighting products, check out the website of Northern Light Technologies at: http://www.northernlighttechnologies.com/NLT_Canada.pdf.

Even if you are not up to going out with friends, **TALK TO PEOPLE** on the phone, join chat groups, start a blog - do whatever you can to stay in contact with others. You can talk about your feelings, or not - perhaps you want to put all the stuff inside aside for awhile. Check out online communities like <http://tbihome.org/boards2.htm> or <http://www.healingwell.com/community/default.aspx?f=19>.

Try to **TAKE ONE DAY AT A TIME**.

- mobility issues, getting out side-the-home help for depression may be a challenge.
- Getting online help is inexpensive and private.

Therefore, the ONF is funding a study - conducted by the Head Injury Clinic at St. Michael's Hospital in Toronto - that explores the potential of Internet-based therapy for those people with traumatic brain injuries who experience depression. The project will use a free, interactive website tool designed to help people with depression. This tool consists of a series of interactive modules. In each module, participants answer questions and complete exercises that help them to learn and understand more about themselves, and teach them how to feel less stressed, less depressed and less anxious. The modules will provide participants with information, animated demonstrations, quizzes, and 'home-work' exercises. Participants record their answers to the exercises in their own personal workbook, which helps them track their progress through the modules. Clinic staff will monitor participants through weekly telephone calls, and there will be follow-up assessments at the clinic.

If this pilot study suggests that Internet-based therapy can help those people with mild to moderate traumatic brain injuries who experience depression, there may be a more ambitious study in the future.

ANTIDEPRESSANT MAINTENANCE

There is increasing evidence that the continued use of antidepressants after a depression goes away prevents the recurrence of depression. However, there are no studies on whether such an approach would prevent the recurrence of depression in peo-

ple with traumatic brain injuries.

The ONF is therefore funding such a study, which is being conducted at the Sunnybrook Health Sciences Centre. The participants are people who are experiencing a major depression following a traumatic brain injury. Initially, all participants will receive medication. For the next fifty weeks, clinic staff will monitor both groups by telephone every two weeks, and

Loss of cognitive abilities, psychological changes, physical pain, loss of independence, and loss of social interactions all substantially influence a person's quality of life.

in the clinic every four weeks.

The results of this study could set the standard of care for the treatment of those people with traumatic brain injuries who experience depression. If the group that continued taking the antidepressants doesn't become depressed and the group who stopped taking them do, then this would tend to indicate that people with traumatic brain injuries who experience depression should continue taking antidepressants for some time after their depression recedes. If there is no difference in relapse rates between the two groups, then this would tend to indicate that antidepressants do not prevent the recurrence of depression in people with traumatic brain injuries.

MINDFULNESS-BASED COGNITIVE THERAPY

After experiencing a brain injury, ONF board member Melissa Felteau enrolled in a course on mindfulness. The course changed Melissa's life:

- It taught her how to keep her thoughts in the present and

live moment to moment.

- It helped her to learn to accept who she was.
- It gave her some perspective on living with a brain injury.
- It enabled her to concentrate and focus.

Melissa thought that what she learned in the course could help others with brain injuries, and so she undertook more training in mindfulness-based stress reduction and mindfulness-based cog-

nitive therapy with a view to teaching others how to use these same skills.

In 1999 she initiated a pilot study in Thunder Bay with people who had brain injuries and who felt they were depressed, but who did not want to take antidepressants. They received mindfulness-based and psycho-based therapy, which included meditation, breathing exercises, guided visualization, yoga, and group discussions. In short, Melissa taught participants how to cope with highs and lows of daily living.

At the end of the study, 50% of the participants were no longer depressed; one year later, they continued to not be depressed. The success of this first study led to a second study which transferred the approach to people with other neurological disabilities (e.g. stroke); the result was the same recovery pattern. A third study involving people who were clinically depressed resulted in 59% of the participants no longer being depressed by the end of the study.

Because of the results of these

studies, ONF is planning to sponsor a larger study into mindfulness-based cognitive therapy. Research teams from the University of Toronto, University of Ottawa and Lakehead University will conduct the study, whose participants will be recruited from brain injury associations and treatment programmes in 2008.

Through these various studies, the Ontario Neurotrauma Foundation is supporting people with traumatic brain injuries who experience depression.

MBSR Clinic at St. Joseph's Hospital, TO

There is a Mindfulness Based Stress Reduction Clinic at St. Joseph's Hospital in Toronto and it is the largest hospital-run programme of its kind in Canada. It follows the principles of the first clinic developed by Jon Kabat-Zinn at the University of Massachusetts Medical Center. Participants in the programme attend ten weeks of classes. Each class is three hours long and there is one hour of homework per day. Taught by doctors, the classes focus on the causes of stress, how mindfulness impacts stress and how to apply strategies learned into real life.

The programme costs \$225 (financial assistance is available for qualified applicants) and \$73 for course materials (4 CDs).

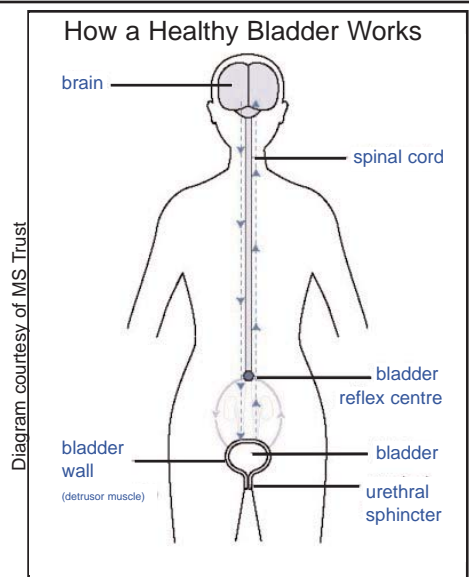
The clinic's brochure describes the programme as "suited to those individuals who are willing to become actively involved in their own care".

The clinic is located on the ground floor of St. Joseph's Hospital in the Sunnyside

Building, 30 Sunnyside Avenue.

If you are interested in attending an information session for the course, call: 416-530-6620.

For those wanting to continue with their mindfulness studies consider joining the Northwoods Mindfulness Community. Also run from St. Joe's, this group meets every Wednesday at 6:15 p.m. On the first Wednesday of every month they offer an orientation for new members. For more information, call 416-927-8072.



Research Priorities for Urological Care

A successful urination is tricky business because it requires several things to happen. First, the sphincter - the muscle that holds urine in the bladder - has to relax. Then the muscles in the bladder wall have to contract so that urine is forced out. Since an extensive network of nerves coordinates this process, it is not surprising that many people with spinal cord injuries experience or risk:

- difficulty emptying their bladder
- difficulty keeping urine in their bladder
- recurring urinary tract infections (especially if they use a catheter or other external device)
- kidney or bladder stones

In light of these difficulties and the effect they can have on someone's quality of life, the Ontario Neurotrauma Foundation (ONF) is funding research into improved management of urological care for people with spinal cord injuries. In order to help it determine what studies it should fund, the ONF asked an International panel of

experts to suggest promising areas of research.

The following outlines the panel's recommendations.

Overactive Bladder

An overactive bladder is caused by the nerves telling the muscle in the bladder wall to push the urine out even when the bladder may not be full, or it may not be at a convenient time.

Many people with overactive bladders use antimuscarinic medicines to "block" the nerve signals that cause over-frequent bladder contractions. Unfortunately, these medications can cause side-effects, such as dry mouth, vision problems and constipation. To cut down on the discomfort, the drugs need to be improved and different approaches need to be taken when creating new ones.

Drug development presently is looking more closely at the role of "receptors" in the bladder wall muscle, specifically one known as the M3 receptor. A receptor is like a listening device in a cell. If it is blocked by a drug, it fails to

detect incoming signals that it is responsible for, and so the cell function changes. Some medications have been developed already that suggest that M3 receptor-specific blockers hold promise for fewer side effects. The panel recommended further examination into the safety and effectiveness of these drugs and clinical trials using these new medications for people with spinal cord injuries.

Genital nerve stimulation on its own has been investigated by several research groups as a way to prevent the bladder from releasing urine. The panel also felt it was a good idea to look into this area further.

Emptying the Bladder

Some people with spinal cord injuries have difficulty completely emptying their bladder either because there is not enough strength in the bladder wall muscle to push all of the urine out; or because the sphincter will not relax to let the urine out, or because the nerves that coordinate these two actions are not working properly.

Electro-stimulation can substitute for absent or abnormal nerve messaging caused by a spinal cord injury. In one study, people with spinal cord injuries received sacral electrical stimulation and had a section of the sacral nerve removed, resulting in better bladder management. The panel recommended further research into:

(a) selectively activating the bladder muscle without removing any part of the nerve, and

(b) sacral nerve electro-stimulation coupled with stimulation to block the pudendal nerve. (The pudendal nerve is responsible for urination, defecation and orgasm in both males and females.)

Catheters/External Collection Devices

Many people with spinal cord injuries use catheters and other devices to empty their bladder. The comfort and effectiveness of these products impacts the quality of people's lives. The panel noted that researchers have been examining different ways to improve the actual components of these devices and they recommended encouragement and support for the design and construction.

The panel also recommended:

- clinical studies of ways to improve intra-urethral valve catheters, including the design and insertion sites, and possible partnerships with industry
- further testing, studies, and product development of external collection devices - especially those for women.

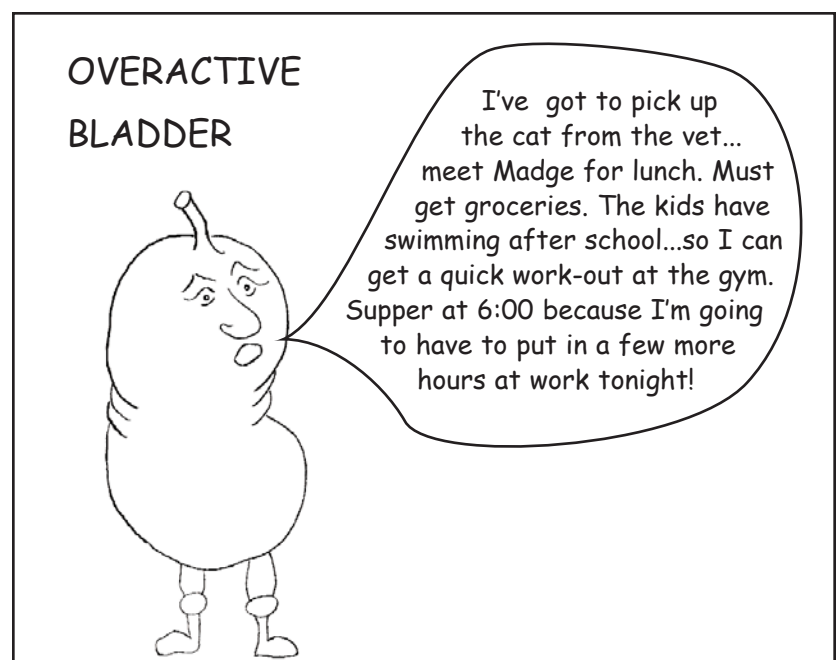
Urinary Tract Infections

Resistance to antibiotics can be an ongoing problem in the management of urinary tract infections. However, there is promising research into probiotics,

“harmless” bacteria that can prevent infection and disease in the bladder. The research indicates that E coli strains can protect against persistent infection by creating safe competition for disease-causing microbes, and that lactobacillus, a friendly bacteria found in the gastrointestinal tract, may assist antibiotics in the treatment of infection. The panel recommended further clinical trials of these new approaches.

Stone Disease

Stones in the bladder or the kidney develop because particles of waste material do not dissolve into the urine and get eliminated out of the body. Instead, they grow over time, developing into a mass or “stone”. Catheters increase the risk for stones because the catheter can have deposits develop on it, known as encrustation and, again, this build-up does not easily dissolve into the urine. The stone and the catheter encrustation can be difficult to get out of the bladder, having the potential to cause great pain.



The panel recommended further research into:

- the cause of bladder stones
- how the disease changes the function of the bladder
- catheter encrustation
- clinical trials of innovative approaches to preventing or medically/surgically managing stone disease

All of the recommendations made by the panel give the Ontario Neurotrauma Foundation a direction to focus its research funding. Future articles in *NeuroMatters* will discuss these studies and the findings. Stay tuned!

We Want to Hear From You

Do you have a funny story relating to SCI or ABI?
Do you have a question or comment for the *NeuroMatters* team?
If so, we want to hear from you!
Contact us today.

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What in the World Wide Web is Going On

<http://www.spinalcord.uab.edu/show.asp?durki=21484>

Bladder Care and Management - SCI InfoSheet #11 - Compiled at the University of Alabama, this resource offers a brief overview of the urinary system and its functions, potential medical issues, and preventative measures that can be taken to optimize health. It covers topics such as the effect of the level of injury on the bladder management programme and offers tips on prevention of UTIs. It has a great resource section and a request for evaluation of the information for continued improvement.

<http://www.csro.com/spinalInfo-2-online.htm>

The After and Beyond Spinal Cord Injury Online Resource Manual - Everything you'd want to know about spinal cord injury. Brought to you by the Canadian & American Spinal Research Organization.

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research news, book reviews, upcoming events, consumer items for people with a spinal cord injury and an acquired brain injury as well as family and caregivers


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