AlzheimerSociety

Dementia Care & Brain Health



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The Importance of Self Care **Don't Forget to Put on Your Oxygen Mask**

n an airplane emergency, you are expected to put on your own oxygen mask first before tending to the person beside you. It's like that when you are a caregiver to someone living with dementia.

"Self-care is important. Unless you take care of yourself put on your own oxygen mask first - you're not going to be able to keep up the pace," says Dr. Janice Keefe, one of Canada's leading experts on aging and caregiving policy. "I think it's incredibly important to recognize the need to take care of yourself."

Dr. Keefe is the keynote speaker at this year's Care4u Family Conference, a day-long event for family and friends caring for a person living with dementia. It's set for October 27 at the Canadian Mennonite University.

She is Director of the Nova Scotia Centre on Aging, the Chair/Professor in the **Department of Family Studies** and Gerontology, and the Lena Isabel Jordry Chair in Gerontology at Mount Saint Vincent University in Halifax.

See "Self Care" inside...





Jessica Harper talks to a client.

The Society's Client Support Coordinators Help is Just a Phone Call Away

he Alzheimer Society of Manitoba is here to walk with you through your journey, whether you are someone with dementia or are caring for a person with the disease.

The staff who do the "walking" are four client support coordinators in the Society's Winnipeg office, as well as coordinators in each of six regional offices. These dedicated individuals are always just a phone call away to offer information and support.

People can connect with these staff members by calling the Society themselves to ask for information and support. Alternatively, people can be referred by health care providers in the community through the Society's First Link® program. When this happens, the coordinators will initiate calls to the referred individuals.

"Phone Call" continued from page 1...

"When we contact people through First Link®, we find out what they need and how we can assist - whether it be providing information about our services or talking about the progression of dementia," explains Jessica Harper, Client Support Coordinator at the Winnipeg office. "We also provide caregiver tips and have conversations about strategies that will help them to care for the emotional and physical needs of a person with dementia."

Another key part in the work of the coordinators involves providing information about community resources and in-home supports. Being knowledgeable about these resources can help those diagnosed with dementia to live in the community for as long as it is safely possible. "And when it's no longer safe, we are here to provide guidance for the transition to long-term care," says Jessica.

As well as communicating with people via phone and mailing or emailing material to clients, the coordinators can be found hosting family education sessions on a variety of topics. Weekend seminars and evening meetings offered

in person or by Telehealth on a topic relevant to caring for a person with dementia let care partners delve into areas of interest more deeply.

Norld Alzheimer's Month Everv 3 Seconds someone in the world develops dementia #WAM2018 #Every3seconds Find out how you can participate at alzheimer.mb.ca

LIVE WELL WITH **PHARMASAVE**°

All through the month of September, Pharmasave will hold an in-store campaign on behalf of the Alzheimer Society. Please add \$2 to your purchase to help people living with dementia.

THANK YOU!





Minds in Motion[®] is a two-hour weekly program running for eight weeks. It is designed for people living with early to moderate symptoms of dementia to attend with a family member or community friend.

Fall Minds in Motion[®] sessions will run at six Winnipeg locations and in Gimli, Portage la Prairie, Altona, Morden, Selkirk and Steinbach. For times and locations, visit: alzheimer.mb.ca.



Jessica sums up the work she and her colleagues do this way: "We want to empower people with dementia and their family members to be leaders in their own care. We do this by providing them with the resources and tools they need."

You can reach a client services coordinator by calling your local Alzheimer Society of Manitoba office.

COMING UP!

Living with Dementia: First Steps

Saturdays, Sept. 22, Nov. 17 & Dec. 1, 9 am to 12 pm Windsor Park United Church, 1062 Autumnwood Dr., Winnipeg

Family Education: Next Steps

Concerned about Signs of Possible Dementia Thursday, Sept. 13, 7 to 8:30 pm River Ridge II Retirement Residence, 2701 Scotia St., Winnipeg

Strategies for Assisting with Activities of Daily Living Thursday, Oct. 11, 7 to 8:30 pm Riverwood Square, 1778 Pembina Hwy., Winnipeg

Moving to Long Term Care Thursday, Nov. 22, 7 to 8:30 pm Sturgeon Creek I Retirement Residence, 10 Hallonguist Dr., Winnipeg

Telehealth Sessions (for regional communities only)

- Join us from 6:30 to 8 pm on the following dates:
- Tuesday Oct. 16: Communication
- Tuesday, Nov. 20: De-stressing Over Bathing, Dressing and Personal Hygiene

To register online, visit alzheimer.mb.ca <u>or call 204-943-6622 or 1-800-378-6699</u> for more information.



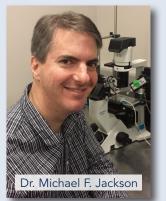
Two Dementia Researchers in Manitoba Get Financial Boost

Two University of Manitoba-based researchers have received funding from the Alzheimer Society Research Program to further their work into discovering how to slow or even stop the progression of Alzheimer's disease.

Dr. Michael F. Jackson and **Dr. Jun-Feng Wang** received \$150,000 and \$149,000 respectively to continue their neuroscience research at the Kleysen Institute for Advanced Medicine at the U of M's College of Medicine.

"Dementia is one of the most complex diseases of our time, and only through research will we be able to find the breakthroughs we need," says Nalini Sen, Director of the Research Program at the Alzheimer Society of Canada. "Fortunately, Canada has some of the best and brightest minds working in this field who are already making significant contributions, so we're proud to support them."

Dr. Jackson and his research partner, Dr. Tiina M. Kauppinen, are researching how brain immune cells, called microglia,



contribute to memory loss in Alzheimer's disease. By identifying potential approaches for harnessing the beneficial functions of microglia while preventing their detrimental actions, the researchers' work provides hope that new therapies can be developed that are able to halt, or altogether prevent, Alzheimer's disease progression.

Driven by "the riddles of how the brain works," Dr. Jackson is also

motivated to research Alzheimer's disease because his own father was diagnosed with it. "It drove home to me how devastating the disease can be."

Meanwhile, Dr. Wang is focusing on a protein called Txnip, which contributes to inflammation and brain damage in Alzheimer's disease. If it can be established as a promising site for early treatment, then the next step will be to explore a variety of drugs and treatment options. Some of these could be effective in slowing the progress of Alzheimer's and/or alleviating the symptoms for those living with the disease.



Dr. Jun-Feng Wang

Dr. Wang, who graduated from medical school in China and came to Canada in 1995, has spent many years studying depression and bipolar disease. There are lots of biomedical connections between those illnesses and Alzheimer's disease, and so it was a natural progression to gradually expand his research into the field, he says.

"With an aging population and an increasing number of cases, this work is becoming urgent."

Alzheimer Society Research Program (ASRP)

Alzheimer Societies across Canada and their generous donors support the ASRP, which funds emerging and established investigators working in the biomedical and quality-of-life fields. Twenty-nine researchers shared \$2.9 million awarded in 2018.

"Self Care" continued from page 1...

Dr. Keefe's knowledge isn't just academic: for several years she was a home care worker before going back to university to work on her PhD. Later, around the time she was named her university's first Canada Research Chair in Aging and Caregiving Policy, she and her eight siblings began caring for their mother, who had dementia. She tries to weave her own experience into her presentations.

Supporting the Backbone

Family caregivers are the backbone of the system because they enable the person living with dementia to stay at home. But, Dr. Keefe says, the system needs to recognize that caregivers have their own needs – sometimes it's the system that must provide them with their much needed oxygen masks.

The "masks" may take many forms, including: respite care; financial assistance to help make changes to the care provided at home; support from their employer in terms of special accommodations for absences; and employee assistance programs to provide information or personal counselling – and eventually help from the system – to navigate admission to long-term care.

"At Care4u I will be recognizing the value of the work caregivers do." – Dr. Janice Keefe

While caregivers can experience a sense of satisfaction when caring for a person with dementia, without the proper supports they may experience social isolation, struggle with their own mental and physical health challenges, and become overwhelmed by a task that is only going to get more demanding as time goes on.

"At Care4u I will be recognizing the value of the work caregivers do," says Dr. Keefe.



QUESTION:

I'm searching for helpful tips about selecting clothing for my father, who has dementia. Can you help

me?

To answer this reader's question we turned to Royce Nowatzki, who gained first-hand experience in selecting clothing that suited her husband Floyd's needs during his dementia journey.

The first step, explains Royce, is choosing comfortable and familiar clothing. Her husband preferred jeans with a belt, which he wore for as long as possible. When getting jeans up and down and manipulating a belt became difficult for Floyd, Royce moved to denim pants with a partial elastic waist and later to a fully elasticized rugby pant. "It was only much later that we went to sweats and light weight pull-up pants like scrubs," she says.

Stretchy or roomy clothing makes the task of dressing easier whether cuing a person to dress or assisting them. Buttons can be frustrating for someone who is trying to dress independently, so Royce chose v-neck t-shirts. Tagless tees and absorbent, comfortable clothing made from natural fibres are good options because a person with dementia may be more sensitive to texture.

When shopping, take along a shirt that you know fits, Royce recommends. That way, you can compare garment size in the store and avoid the time-consuming task of returning items later.

When considering footwear, some care partners recommend shoes with elastic laces or hook and loop closures. "These didn't work for us," says Royce. "Floyd liked tied runners, so I chose to tie his shoes for him." Another practical choice is diabetic socks, which fit more loosely and do not restrict circulation.

Staying active by walking meant finding easy ways to dress for the changing seasons. They opted for mitts instead of gloves and used layers instead of heavy jackets and snow pants. Royce avoided long johns for Floyd and instead used a wind pant over daily wear. This allowed a quick return to "home" clothes after a walk. Vests were also a practical way to add warmth both at home and outdoors.

Ask an Expert



Adapted clothing can be purchased, but Royce altered clothing herself – she added zippers to pant cuffs, created clothing protectors for meal time and sewed pant pockets closed so they wouldn't catch on Floyd's wheel chair when he lived in long term care. "Adapting or purchasing is a personal choice that depends on your skills and what is available in your community," commented Royce.

"Comfort, ease of dressing and providing clothing that the person enjoys wearing are the most important pointers I can give," she concludes.

Monthly Donations: It's the Way to Go!

Ray Bisson will stop giving money to the Alzheimer Society of Manitoba under one condition only: when a cure for Alzheimer's disease has been found.

"Wouldn't that be a wonderful story?" he says, a smile coming through in his voice.

In the meantime, he's happy to be a monthly donor – a method of giving to the Society that, in his words, "is simple, gets the job done and makes you feel good!"

Ray is Vice President of the FWS Group of Companies in Winnipeg. He is a member of the Society's Board of Directors and chairs the committee that plans the annual fundraising gala.

His company has been a long-time supporter of Manitoba charitable organizations and encourages its employees to give generously to their causes. In fact, FWS Group of Companies matches every dollar donated by its

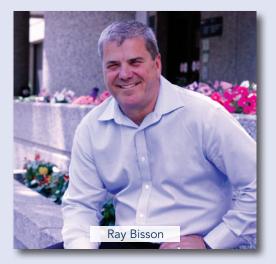
For more information about making monthly donations or about other ways to give, call Lorraine at 204-943-6622. employees. But, says Ray, he'd give to the Alzheimer Society even if his employer didn't match his donations.

"I'd encourage anyone looking for a good place to contribute their charitable giving to consider the Alzheimer Society of Manitoba. It's a great organization full of caring and compassionate people. And with the disease so predominant out there, it's more necessary than ever."

Lorraine Decock, the Society's Director of Development, agrees. "We rely on donors to make up 85% of our budget, and most of this is used to fund client services, community development and education," she explains.

Lorraine points out that choosing to be a monthly donor makes everyone's job easier.

Donors can sign up to make automatic gifts from a bank account or credit card. This makes it easier for them to be strategic about their giving. It also allows for convenient tracking, and it's easier on their budget.



For the Society, receiving monthly donations has several advantages: a stable base of monthly revenue is generated; less time and cost are required for donor solicitation; more money for programs and services is available to benefit those with dementia and their caregivers.

"If you know you want to support us, please sign up for monthly giving. It is a thoughtful and meaningful way to make a gift to help people affected by dementia," says Lorraine.

CEO Message: Getting Help for the Helper

Caregiving is hard. Caregiving for someone with dementia can be harder.

That, in a nutshell, is one of the key findings of a new report published earlier this year by the Canadian Institute for Health Information (CIHI). While caregiving can be personally rewarding in many ways, there is no denying the report's findings: unpaid caregivers of seniors with dementia are more likely to experience distress (45%) than caregivers of other seniors (26%).

This report not only echoes my own caregiving experience, but it will be no surprise to the thousands of others who have contacted the Alzheimer Society for education and support.

Yes, caring for someone with dementia is hard. I firmly believe that it is incumbent on us, as a caring community, to help all families get the support they need. We must find ways to ease their burden, which – for some, at times – can seem insurmountable. For example, the CIHI report found that 21% of caregivers of someone with dementia are so taxed by their responsibilities that they feel unable to continue their caring activities.

No one should have to feel like this, and there are ways each one of us can help.

As a caregiver, say "yes" when someone calls to offer help. Don't be shy about asking family and friends to take on some tasks. Reach out to the Alzheimer Society for support and information.

As a family member, friend or neighbour, check in on the caregiver. Listen to what they need, and do what you can to help – whether it be dropping in to visit or taking the person with dementia for a walk or to an appointment. Be supportive.

As a community, be dementia friendly! Make caregivers and the person with dementia feel welcome when they visit your business or organization. Learn more about what you can do



to be dementia friendly by calling the Society.

As leaders in the health care system,

work towards providing effective supports that are flexible, timely and appropriate for people with dementia and their caregivers.

At the Alzheimer Society, we are working hard to do our part. We're here to assist people on their journey. Please call or email us to learn more about our programs and services.

Check out the article on the front page to learn about one of the ways we can help.

Decisions in Palliative Care

magine knowing you have only a few months to live due to a life-limiting illness. What measures would you take to treat an unexpected acute health problem, such as a serious infection?

What if it's not you in this circumstance but a family member with dementia?

"The key to making a decision regarding medical treatment for an acute issue is the same whether the person has dementia or not," explains Beth Helliar, Client Support Coordinator at the Alzheimer Society of Manitoba. "It's about what that person wants or would want if they could make the decision themselves."

Beth, who has experience in palliative care, points out that knowing what someone would want is a lot tougher when the



person has dementia – even if you are very familiar with their views.

And if you're not, it's important to find out those views as soon as you can. Having a conversation with the person early after the dementia diagnosis can provide insight into their wishes.

In the best case scenario, the person with dementia has designated a health care proxy: usually a close family member or friend who knows the person well and can make decisions on their behalf.

For example, let's say an acute illness requires that an intravenous be inserted for a week, but this upsets the person with dementia. They don't understand that this is a temporary situation, and they constantly try to pull it out.

> The proxy would consider the whole picture. Has their family member's quality of life been deteriorating to the point where the person, if able, would choose to let nature take its course? In that case, the decision may be to forego treatment because it's causing so much distress.

On the other hand, the proxy may have noticed

that the person seemed content and happy before the current health episode emerged. Persevering with treatment for the short term may be called for, especially if it is likely that the acute health issue will be resolved and the person can resume a life of reasonable quality.

How Invasive is the Solution?

In the above example, and in many other scenarios, the proxy has to think about the anticipated invasiveness of the treatment and how it will affect the quality of life of the person. This is done in consultation with the health care team, whose members can advise on the expected outcomes.

Situations that may arise include choosing between administering antibiotics orally or by the more invasive intravenous method, which could be painful and disconcerting to a person with dementia.

What if an operation is suggested as treatment? "Surgery is a big decision to make," explains Beth. "Someone with dementia is at high risk for delirium caused by the anesthetic, and delirium is a very serious condition."

It's evident that pieces of the health care puzzle are many and varied for those in palliative care, but a proxy can rest a little easier in the decision-making process knowing they are acting with the values of the person with dementia at the forefront.





Over

\$333,000 was raised at

50 Walks

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JOIN US!! Awards and Appreciation Evening Thursday, September 27, 7 pm Investors Group Cafeteria 447 Portage Avenue, Winnipeg **RSVP by September 24** to awoodward@alzheimer.mb.ca

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