



A BY US FOR US GUIDE

Living and Celebrating Life through Leisure

An inspirational guide
for people living with dementia

SERIES 1

Introduction

The purpose of this sixth guide is to share with you some thoughts on living and celebrating life through leisure. Meaningful leisure can be a wide range of activities from enjoying coffee on your deck first thing in the morning to being involved with other people in a more structured and challenging venue. Activities that leave us feeling good are so important in contributing to a quality of life that everyone strives for.

Keep yourself open to experiencing and enjoying new people and activities. Being able to express yourself to family, friends and others who are willing assist you is so important in being able to achieve successful and meaningful experiences.

We can help work towards raising awareness and making changes by raising our voices so that we can be heard. Look for those people who seem to understand what our voices are saying and are willing to work with us in a true partnership. We need your valued support in order to be the best we can be.

– Brenda Hounam
Person living with dementia
Advocate and Spokesperson

“[During leisure] my heart is at ease and happy when my mind is calm, when my soul feels like singing.”

(Person living with dementia)

Meaningful leisure experiences

Leisure experiences that are personally meaningful fulfill a need in all of us, yet leisure means different things to different people. When we asked people living with dementia what leisure means to them, what brings meaning to their lives, they identified a number of things. Each of the experiences identified reflects what it means to be fully alive and live life to the fullest by:

- ✓ Allowing us to express ourselves and be ourselves;
- ✓ Helping us find balance in our lives;
- ✓ Providing an opportunity to have fun, laugh and enjoy life;
- ✓ Contributing to our community in meaningful ways;
- ✓ Providing a sense of freedom from the stresses in life;
- ✓ Connecting us with our friends and family; and
- ✓ Offering opportunities to feel challenged, grow and develop.

Being me

Our experiences during leisure mean something important to each of us. Leisure allows us to continue to express who we are and what we value about ourselves by using our unique skills and abilities gained over our lifetimes. Leisure is about doing our own thing – whether that's listening to music, going for a walk or meditating.

Meaningful leisure experiences continued

Ideas to consider

- ✓ You still have skills and abilities but activities may need to be adapted over time.
- ✓ Keep the qualities that make activities an important part of who we are.
- ✓ Ask yourself: What activities are most important to me? What activities reflect best who I am as a person?

Finding balance

It is important for each of us to find a balance between “relaxation” and “keeping busy”. Too much activity could cause stress and too little could cause boredom. Sometimes, structuring the day too much is not a good idea either. Remember to balance structure with free time.

Ideas to consider

- ✓ Know and appreciate your body and what it can do.
- ✓ Accept that whatever you do is the best that you can do today. If you are planning a big event, allow time to rest before and after the event.
- ✓ Take breaks when you become overstimulated.

Meaningful leisure experiences continued

Having fun

Leisure is about feelings of pleasure, enjoyment, and happiness. Sometimes, it's about being mischievous and remembering that laughter really is the best medicine. Having fun can also give us a fresh perspective on our day and help us stay positive.

Ideas to consider

- ✓ See the world through the eyes of your grandchildren and the young people in your life as they have unconditional acceptance.
 - Get down on the floor and play blocks, sing, and dance or have a picnic.
 - Help them play their musical instruments.
 - Play ball with them or attend their games.
- ✓ Engage in activities that bring out the fun such as video games.
- ✓ Remember to laugh a lot – it puts you and others at ease.

Meaningful leisure experiences continued

Making a difference

Leisure experiences are meaningful when we feel a sense of purpose, have opportunities to contribute, feel valued, and make a difference to those around us. Too often, people contribute in multiple ways, but they don't realize the significance of their contributions. Don't overlook the little things – we are all unique individuals; we all have something to contribute.

Ideas to consider

- ✓ Watch for events designed by and for people living with dementia such as a Changing Melody forum where people living with dementia can support each other. Visit the Schlegel-UW Research Institute for Aging website (www.the-ria.ca) to learn more.
- ✓ Keep yourself open to the potential of volunteering.
- ✓ By advocating for yourself, you automatically advocate for every other person living with dementia.
- ✓ Time with grandchildren and young people can involve moments of teaching and sharing.

“I have given up being all things to everyone. I need to pace myself and do what is good for me. Sometimes saying no to someone is better for me.”

(Person living with dementia)

Meaningful leisure experiences continued

Seeking freedom

Leisure activities can help us to take a “time out” and escape the stress of daily tasks and responsibilities by getting out of environments that are overwhelming.

Ideas to consider

- ✓ Practice meditation or breathing exercises.
- ✓ Put on your favourite music and lay back and listen.
- ✓ Get outdoors. Walking in your neighbourhood can provide you with an opportunity to meet new people and experience a change of scenery.

Being with

Leisure experiences that are social help us to connect with our friends, family and neighbours. Being surrounded by friends and family who support you and share a common bond can help you from feeling isolated.

Ideas to consider

- ✓ Spend time with people you trust, people who don't over-help or patronize you.
- ✓ Join in a variety of social groups – like card groups, and mall-walking.

Meaningful leisure experiences continued

Growing and developing

Leisure provides an opportunity for us to continue to grow and develop by learning new skills and abilities; challenging ourselves in new ways. It also provides a space to explore our spirituality.

Ideas to consider

- ✓ Don't be afraid to try something new.
- ✓ Learn a musical instrument, experiment with a xylophone or a drum as a great first step.
- ✓ Consider having a friend or family member help you to learn how to use the computer or other device.
- ✓ Spend time enjoying the beauty of nature

“No, I haven’t lost golf. I’m out there playing and I lose a few more balls, but it’s still fun, and I still enjoy it.”

(Carl Wilson, Person living with dementia)

Challenges we may experience when participating in valued activities

Over the course of our journey, there may be some obstacles we face in engaging in meaningful leisure experiences. Here, we identify and describe three common sets of challenges – personal, social and system challenges.

Personal challenges

Changes associated with dementia are a challenge to participation in meaningful leisure. Based on our experience, some personal challenges are related to cognitive changes, physical changes, motivational levels, and emotional responses we may be experiencing.

Cognitive changes

From our experience, there are cognitive changes related to the dementia process. These can include: changes in memory and concentration, difficulty planning activities, understanding instructions, and perceptual difficulties.

“I paint with a friend sometimes. She can share her expertise with me and that helps keep me motivated to paint more.”

(Carl Wilson, Person living with dementia)

Challenges we may experience when participating in valued activities

continued

Ideas to consider

- ✓ Repetition and routine are very important.
- ✓ Consider recording your favourite shows or the news. You can watch them several times to follow the storyline.
- ✓ You never know when you might want to make a note of something, so keep a pad and pencil close by - even on your outings.



For ways to exercise your brain, refer to the By Us For Us guide: **Memory Work Out**.

Physical changes

It is frustrating when fatigue and declining energy levels stop us from engaging in our most valued leisure activities. Overcoming fatigue and foggy times can be a challenge.

Ideas to consider

- ✓ Balance your sleep and awake time. What part of the day is most important to you?
- ✓ Maintain a healthy diet and good hydration.

Challenges we may experience when participating in valued activities continued

Motivation

A lack of motivation to participate in valued activities can be an overwhelming challenge. Trying to remain optimistic and positive each day can be difficult.

Ideas to consider

- ✓ Negative self-talk can threaten motivation. Take it one step and one day at a time and practice, reinforcing self-talk.
- ✓ Find something you like to do and stick with it.
- ✓ Continuing to be active is extremely important for brain health.

Emotional responses

A lack of confidence, a fear of being judged, anxiety, difficulty controlling emotions and frustration with not being able to keep up with others present challenges to maintaining involvement in leisure activities.

“I still want to learn new ways to do things. I might have to practice a lot and write down simple instructions but I am not going to stop trying.”

(Person living with dementia)

Challenges we may experience when participating in valued activities

continued

Ideas to consider

- ✓ Use leisure as a way to express feelings and emotions through story writing, poetry and art, etc.
- ✓ Focus on what you can do now, in the moment, and try not to worry what others think.
- ✓ Believe in yourself – each person is unique and can continue to contribute.

Social challenges

Some of the challenges we face are socially imposed, sometimes due to stigma or misunderstanding. Based on our experience, some social challenges include isolation, changes in relationships and loss of independence.

Isolation

Big crowds can be overwhelming. Recognize the fact that multiple conversations, loud music, and excessive noises can set our mind spinning. Sometimes friends withdraw because they do not understand or do not know what to say or do. This can lead to isolation as well.

“I am more than my mistakes and I have learned. And I am forever changing - I’m changing in different ways now and I have more to give now.”

(“CJ” McCaffrey, Person living with dementia)

Challenges we may experience when participating in valued activities

continued

Ideas to consider

- ✓ In a large gathering, try to stay to the exterior or position yourself near an exit.
- ✓ If you turn down invitations too frequently, it could result in friends withdrawing.
- ✓ Instead of relying on friends to call you, call them.

Lack of support

The need for support can be a challenge to participating in valued activities. Sometimes it is difficult to find those people who are able to support you in the way that you need. It is also difficult to be willing to accept help and not feel like a burden on others.

Ideas to consider

- ✓ Contact a support group through the Alzheimer Society.
- ✓ Be open to friendships formed at these support groups and get together over coffee or tea.
- ✓ Don't be too quick to say no, people will stop offering.

Challenges we may experience when participating in valued activities

continued

Changes in relationships

Our relationships shift over time yet their impact can have a significant influence on our well-being. As we age, we adapt, but after a diagnosis of dementia, we are full of panic and anxiety. This leads us to make drastic changes in relationships before we have time to work on them together.

Ideas to consider

- ✓ For as long as possible, make decisions together.
- ✓ Over-nurturing is instinctive, but it's damaging to our self-esteem. Talk to people about how you are feeling.
- ✓ When you have a partnership – you still feel valued. You play off of each other's strengths and weaknesses.
- ✓ Relationships should involve people who are comfortable with your ups and downs, wants and needs.



For more tips on how to deal with social challenges, refer to the By Us For Us guide: **Isolation and Enhancing Social Connections**.

System and society challenges

There are also broader system and society factors that limit our ability to participate in meaningful leisure.

Lack of accessible and affordable transportation

Many people live in areas that don't have access to public transportation. Accessible transportation is difficult and can be expensive.

Ideas to consider

- ✓ Budget money by setting aside dollars that were previously spent on maintaining a car for future trips out.
- ✓ Explore options for public transportation.
- ✓ Prioritize trips in order of importance to make them cost effective. If you have a doctor's appointment, consider taking a taxi.
- ✓ Look to see if there are any volunteer driver options in your community for necessities, like doctor's appointments and groceries.
- ✓ Ask friends or family for help. Make an offer to pay for gas or take them out for lunch in appreciation of their kindness. When you are still able to contribute, it makes it easier to ask the next time.

System and society challenges continued

Stigma and misunderstanding

Assumptions about your abilities can be devastating. We are all unique individuals who enjoy and are able to do different things. Mix it up to accommodate this uniqueness. This has to be one of our biggest frustrations – denial of the contributions we can make to society and of our continued abilities. In turn, this leads to being underestimated and being silenced. It's not us personally; it is the dementia that is causing us to forget.

Ideas to consider

- ✓ Keep yourself open to the potential of volunteering. Our past and current life experiences are of great value to others.
- ✓ There is an assumption that with a diagnosis of dementia, you are incapable of contributing to your community. Remind others that they may be overlooking a strong volunteer segment.
- ✓ You personally have to take the steps to work through loss and grief in order to get to the point of acceptance. Once you are in a place of positivity, you can then project that to others.

System and society challenges continued

Being silenced

Along with feeling underestimated, being silenced can be frustrating and, over time, leads to feelings of helplessness.

Ideas to consider

- ✓ Speak up and get your point across - without that there's nothing.
- ✓ Take some time to put your thoughts together before you have conversations with others about your concerns.
- ✓ By people trying to silence you, they are robbing you of your power.

“My challenges at this point in my journey are with trying to do activities that involve people that don't really understand and continue to think that they know best what is good for us.”

(Person living with dementia)

System and society challenges continued

Lack of meaningful opportunities

We've heard from people who attend programs that do not interest or challenge them, but they continue to participate because something is better than nothing.

Ideas to consider

- ✓ Here is a statement that you might find helpful to start a conversation: "I'd like to give you some personal thoughts and feelings on how this can be more meaningful for me."
- ✓ Be willing to accept variety so everyone in a group experiences something they like.

"It's a challenge to find leisure activities that are meaningful, yet not demeaning."

(Person living with dementia)

How we can support each other in enhancing meaningful experiences

This section highlights tips and strategies that we can do to help ourselves in participating in meaningful experiences. It also has some tips and strategies outlining what others can do to better support us.

What you can do

Be intentional

- ✓ Be honest with yourself and others about your physical and emotional health each day.
- ✓ Take stock of what works for you, simplify tasks and prioritize commitments.
- ✓ Don't judge yourself; just accept what you've achieved today.

Surround yourself with positive and supportive companions

- ✓ Seek out people who don't 'overhelp' or try to take over.
- ✓ Spend time talking with friends and family about what you need in your relationships and what is most meaningful to you.
- ✓ Choose people who help you feel positive and good about yourself. Avoid people who judge, irritate or annoy you.

How we can support each other in enhancing meaningful experiences continued

Recognize the need for support (and ask for it)

- ✓ People want to help but sometimes don't know how and need direction on what we need. By not asking for support, you are stopping people from feeling helpful.
- ✓ Asking for help gets easier to say with time.
- ✓ If you're open about your diagnosis in public, people are more accommodating and willing to be helpful.
- ✓ Let others know the value of their support.
- ✓ Seek advice from support group members on things you are struggling with.

Be open to new experiences

- ✓ Keep yourself open to trying new things.
- ✓ Investigate alternatives to your valued activities. If you enjoy cycling, consider buying a tandem bike.

“I adapt to change. I am challenged 24/7 to adapt. I hate to use the word disease, I use journey – it is optimistic, positive. We have nothing to fear.”

(Person living with dementia)

How we can support each other in enhancing meaningful experiences continued

Be an advocate

- ✓ You have a right to ask for the things that you deserve. Don't feel apprehensive about saying things that need to be said.
- ✓ Each person's feelings **must** be respected. You are worthy of respect and dignity.
- ✓ Don't underestimate the contribution you can make to the dementia cause. Offer to speak about your experience so others can learn from you.
- ✓ An advocate is someone who says one thing to one person that defends themselves or others.

"I have adapted all my activities to fit my lifestyle. For instance, I used to have a large garden, now I have a small flower bed and a few tomato plants. That is all I can care for and I am happy to see my progress."

(Person living with dementia)

How we can support each other in enhancing meaningful experiences continued

Keep up-to-date with supportive technology

- ✓ Computers and other devices can help you stay up-to-date and allow you to connect with a lot of reputable websites.
- ✓ Websites or applications that provide games can help you stretch and challenge your brain on a daily basis.
- ✓ Talk with family and friends about some of the newer technological aids available. The choice to use/purchase technological aids needs to be an individual or family decision.
- ✓ Consider using computer programs to assist you in continuing with valued activities (e.g., meal planner program if you enjoy cooking).
- ✓ Meeting new friends via online communities can help you stay engaged with others on the same journey.

How we can support each other in enhancing meaningful experiences continued

Celebrate your accomplishments

By reflecting and celebrating your past and present accomplishments, you can learn to appreciate your journeys and our contributions.

- ✓ “I was approached and asked if I would like to work with a group of young boys from a different culture, teaching them their school curriculum.” (Gail Robinet, B.A., M.Div.)

- ✓ “The journey with memory loss continues to invade my space.

I am alone but I envision you there.

I love you with all my essence and spirit.

I am comfortable and secure knowing you are beside me.”

Excerpt from poem ‘Broken’ by Elaine Smith

Published by Poetry Institute of Canada

- ✓ “I never thought that when you gave me a set of [By Us For Us] guides, at the learning series that I would be working on the new one.” (Lereine Milton)

“Many assume that due to the diagnosis that I’m unable to do anything constructive or creative as if in the end stage of the disease. I feel like, ‘I’ll show you what I can still do!’ Consequently, I advocate strongly for all of us to teach anyone who will listen that we deserve respect & dignity.”

(Person living with dementia)

How we can support each other in enhancing meaningful experiences continued

What others can do to support you

Be knowledgeable and think broadly

- ✓ Become “in tune”, not “in the dark” about my condition.
- ✓ Be open minded to new concepts and don’t doubt my diagnosis.

Listen to me and ask me

- ✓ Ask **me** what is meaningful to me.
- ✓ Learn to become observant, and truly listen and see how various activities make me feel.
- ✓ Listen to what I express about my personal journey and to my ideas for coping, learning and adapting to the challenges of the dementia process.
- ✓ Listen without verbal conversation. You don’t have to agree or disagree, just be there.

Know me

- ✓ Understand my individual preferences for activity and involvement.
- ✓ Find out what I am interested in doing and how I would like to be supported.

How we can support each other in enhancing meaningful experiences continued

Know me

- ✓ Validate my feelings and emotions. The phrase 'it's going to be alright' doesn't validate my experiences. Instead, ask: "Tell me what you are feeling? How can I help?"

Believe in me and my potential

- ✓ Find out about my abilities and interests and use those to help me thrive.
- ✓ Encourage me and find ways to support my abilities.

Enable me

- ✓ Assist me in finding new ways to maintain my current leisure activities.
- ✓ Provide opportunities for activities that enhance my self-confidence.
- ✓ Limit the use of forms (e.g., registration and assessment forms) and other things that make my participation more confusing.

"I use a GPS every time, even if I know where I am going. This is to ensure that I have put this practice into my daily life."

(Person living with dementia)

How we can support each other in enhancing meaningful experiences continued

Enable me

- ✓ Support me in whatever way you can, such as offering to participate with me, driving me, and accepting me for who I am.

Partner with me

- ✓ Include me in decision-making and in the planning and design of programs meant for me.
- ✓ As a professional, explain why things are the way they are and help me to understand if certain things are not possible.
- ✓ Be open and honest with me.
- ✓ Develop a relationship by sharing in activities with me.



For ways to enhance your communication strategies, refer to the By Us For Us guide: **Enhancing Communication.**

“Wow I can still have a lot to do with having input in the way my life is going to go and I think that is important.”

(Jane Mederak, Person living with dementia)

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Resources

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

Volunteer Canada

Website: volunteer.ca

World Health Organization

Website: www.who.int

We also suggest that you check for other local, national and international resources.

Endorsements

As a researcher, I have had the privilege of talking to many people who are living with dementia. A persistent theme in these conversations has been the significance of meaningful activity in people's lives. They talk about how it is not always easy, but doing these kinds of activities remains most important. This new "By Us For Us" guide fills a very real need. It is full of creative and practical ideas to help people feel connected and involved, having fun and continuing to grow and learn new things. Written with sensitivity and compassion, it will go a long way toward helping people who are living with dementia to take part in the kind of activities "that leave us feeling good". What a great contribution!

Alison Phinney, Ph.D, RN

Associate Professor

University of British Columbia School of Nursing

How wonderful to see that this “By Us For Us” Guide is about meaningful activities; promoting living and celebrating life through leisure. The joy I have in both my personal and professional lives are dependent upon my ability to maintain friendships and relationships, to enjoy my leisure interests and most importantly - to bring humour to my life each and every day. The people with dementia and their families and friends I have met through my work with MAREP and the Alzheimer Society of Ontario have inspired me to see my life through another set of glasses. I have learned so much from these connections.

This is the 6th booklet in the series and I am thrilled to say - great job! I hope it provides all readers with a sense of accomplishment in continuing to lead meaningful lives but more importantly it inspires all of us to think about our life-long leisure pursuits and challenges us to find humour and joy even in the simplest of things.

Cathy Conway

Director of Quality Management & Education
Alzheimer Society of Ontario

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Front cover concept

The cover sketch depicts the experience of being diagnosed with dementia as the 'eye of the storm'. At the time of diagnosis, the world is spinning around, seemingly out of control. Over time, our experience grows to reveal a rich tapestry of meaningful experiences and personal understandings.

About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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