A BY US FOR US GUIDE

Managing Triggers

An inspirational guide for people living with dementia

SERIES 1

Introduction

Before our first ‘memory workout’ guide was completed, we in the By Us For Us group knew our second booklet would be on ‘triggers’ (stressors). Triggers are so often discussed in our support group sessions. They are the episodes where we have our buttons pushed and our emotions are triggered in a ‘knee jerk’ reaction. They are those things that cause us to become agitated and experience increased stress. Or, they are those situations that cause us to have MORE difficulty thinking and perceiving, when in the past we may not have been bothered or affected in the same way. Previous to our diagnosis of dementia, we were able to control our emotions in different types of settings. But now, we quite often react before we have a chance to think about it. As if that is not enough of a challenge, new triggers often emerge as dementia progresses.

Understanding our triggers and the causes of them can be very difficult, but is so important if we hope to be able to reduce the incidence of them or learn how to respond to them more effectively when they happen. First though, you have to acknowledge that triggers do happen and reach beyond the embarrassment in order to ask for help in identifying what your individual triggers are. Once you have become agitated, it is difficult to process your thoughts on what has caused you to become upset, but trusted family and friends can assist you with this. When a trigger occurs, write down everything that occurred, as sometimes you may not be readily able to identify what may have caused the reaction. Reflection, when your head is clearer, will bring some clarity.

Introduction continued

Accepting that this is part of the process and identifying your individual triggers are important, as these steps allow you to improve your own personal control capabilities and help your care partners better understand your experience with memory changes and better support you throughout the process. This is the time to be open and honest with yourself and with your loved ones. Don't be embarrassed to communicate what your triggers are, as nothing that you experience is insignificant. Think about what some of your triggers might be, write them down, and share them with all those around you! The purpose of this By Us For Us guide is to help you get started with this.

Dealing with triggers is also a great time to draw on your sense of humour. Laughing at a situation first puts you in command and makes those around you feel more relaxed.

Understanding and accepting what happens empowers you to take control of your life. It will give you back those quality days that are so cherished and will take some of the stress out of your tomorrows.

Humour is a great tool! Remember, **CRY FIRST, LAUGH LAST!**

– Brenda Hounam,
Retired Industrial Accountant, Paris, ON

"I don't know what I'm saying sometimes, but I know what I WANT to say."

(Gordon Sinclair, Brantford, ON)

Tips for managing triggers

I have found that the more open I am about those things that cause me to become stressed, and communicate this with my children, family, and close friends, the more that the stress in our lives is reduced.

What can you do to help gain back control after you become stressed?

- ✓ Practice deep breathing. This is very important to do, especially if you are not physically active, because it allows oxygen to go to your brain.
- ✓ Enter a quiet place with softer lighting, or close your eyes.
- ✓ Meditate.
- ✓ Listen to soothing/calming or favourite music depending on your mood and personality.
- ✓ Participate in something that will distract you.
- ✓ Try to step back, and take a breath of fresh air and calm down. (Count to 10!)
- ✓ Share your feelings with others.

We also ask that others help us in minimizing triggers and stressors. This can be done by listening to us about what we need and by providing gentle assistance.

Social situations

Crowds and loud noise

Many public areas, such as restaurants or shopping malls, are filled with large crowds, lots of noise, including loud music, and there are multiple conversations happening at once, which is very overbearing for us. Family outings can also be tiring and frustrating because of the noise and crowds.

Personal solutions:

- ✓ Remove yourself from crowds when triggered.
- ✓ Go to malls, restaurants, and other public places at less busy times.
- ✓ Ask the establishment to turn down the music volume.
- ✓ Ask those you meet to move to a quieter spot for a conversation.

What others can do:

- ✓ It’s nice to feel included, but allow me to leave when I start to get stressed. Ask me if I would like to go home. That lets me feel I have enjoyed it, too.
- ✓ Keep it as quiet and calm as possible and give me space.
- ✓ Remind me to use earplugs.
- ✓ Search out quiet spaces I might escape to if needed.

Being rushed and not included in plans

Many of us do not like sudden plans or when we are not given enough time to get ready. We do not like to feel pressured or when people rush us and say “get on with it” when we are completing a task.

Personal solutions:

- ✓ Prepare a calendar or daily schedule to keep track of events. Plan ahead.
- ✓ Give yourself plenty of time to get ready.

What others can do:

- ✓ Allow me enough time to prepare.
- ✓ Involve me in decision making and keep me up to date if we are going out or doing something.
- ✓ Take my schedule into account when making plans.
- ✓ Make sure all events are added to my calendar and remind me of them on the day of the event.
- ✓ Be patient and allow me to complete a task at my own pace.

Shopping and restaurants

It can be frustrating when you get to a store or restaurant and you cannot express what you want or what you are looking for. In a restaurant, it is difficult when there are too many items on a menu because you forget what you just read by the time you're through reading the menu. It is also difficult to remember when the server reads the specials or wine/beer list. Making change and figuring out tips is even more challenging now.

Personal solutions:

- ✓ Write down what you want to buy at a store before you go, or take a picture of it with you, so you can show the staff members exactly what you need.
- ✓ Show the staff a card saying you have memory changes or tell the person serving you – they will likely be more patient.
- ✓ When going to a restaurant, write down a list of your favourite foods and drinks so you remember what you like, or so you can show the wait staff.
- ✓ Go to restaurants where you already know the menu.
- ✓ Ask the wait staff for a written copy of the specials.

Social situations continued

Personal solutions:

- Ask the wait staff what they have on special or on tap that suits your preferences, instead of having them list the specials or wine/beer list.
- Ask a trusted friend/family member for help with ordering, tipping, or making change.

What others can do:

- Restaurants can offer quiet areas (such as booths) that will allow us to eat out in a quiet space or call ahead to arrange this.
- Allow us to keep a tab, so we can dine regularly but not have to pay immediately.

For more tips on enjoying meals at restaurants refer to the By Us For Us guide: **Food and Mealtime.**

Notes

Being tested, quizzed, or pushed for answers

People test, quiz, or push us for answers. They may think that this is helpful in making us think, but it is not.

What others can do:

- ✓ Remind me who you are; don’t keep me guessing.
- ✓ Don’t quiz me or test me unnecessarily.
- ✓ If you do ask a question, give me time to think and respond.
- ✓ When talking with me, give me as much information as possible in the conversation.
- ✓ I will let you know if I don’t know something or can’t remember something.

Notes

Verbal communication

Difficulty finding words

When having difficulty communicating, it is upsetting when people respond, “I forget all the time, too” or “We’re all getting older”. They will also jump in too quickly with what they think we are trying to say or they’ll change the subject instead of allowing us time to retrieve our thoughts. They may also show physically how uncomfortable **they** are with our inability to converse at the same level as them.

Personal solutions:

- ✓ Tell others how you feel and how you would like them to assist you.
- ✓ Allow yourself the time to pull your thoughts together.

“I GOT IT! I don’ t need to be hit over the head with it.”

(Janet Dupuis, X-Ray Technologist, St. George, ON)

What others can do:

- ✓ Remember, sometimes things said with the best of intentions have the opposite effect.
- ✓ Ask when or if you can offer me a word or suggestion, or fill in words in a gentle, non-threatening way.
- ✓ Don't **patronize** or **test** me, but encourage me.
- ✓ Be patient and relax in my presence; I can still read your body language.
- ✓ Hints can go over our heads, so please be clearer in what you are asking.
- ✓ Don't say, "I've already told you twice."

Communicating with others and expressing myself

Sometimes, we are expected to make small talk, which makes us uncomfortable. People talk too quickly, too long, they are too loud, or they talk at the same time, making it difficult for us to verbally communicate. It is also hard to be involved in long conversations or be asked for lots of information.

Verbal communication continued

Personal solutions:

✓ Participate in one-on-one conversations or small groups.

✓ Learn to ask others to slow down their speech.

✓ Feel free to leave a conversation.

✓ Keep social events or conversations short.

✓ Reduce distractions and feel comfortable asking others to move with you to a less distracting space.

What others can do:

✓ Don’t interrupt when I am speaking, as I will lose my train of thought.

✓ Talk about my needs with others to reduce my stress.

✓ Don’t make me feel guilty or anti-social. Gently suggest I sit in another room to regroup, and then I might be able to return to the gathering.

✓ Give me time to put my thoughts together and respond.

For more tips on communicating with others, refer to the By Us For Us guide: **Enhancing Communication.**

Your environment

Room temperature and weather conditions

A room's temperature is often a problem for us, be it too hot or too cold. No matter what the condition, when uncomfortable, we become stressed. Bad weather or dressing inappropriately for weather can be triggers.

Personal solutions:

- ✓ If hot, step outside, have a cold shower, use ice in a cloth, or use a fan.
- ✓ Cooking over a stove might be a trigger. In this case, cook with others or have someone else cook when it involves the stove or burner.
- ✓ Anticipate changes in weather – bring a sweater/hat or wear layered clothing.

What others can do:

- ✓ Take notice of how temperature affects me.
- ✓ Control the environment around me as best as possible.
- ✓ If I'm taking off my clothes or putting on extra layers, realize I am just really hot or cold and uncomfortable.

What others can do:

- ✓ Discuss weather conditions with me and respectfully suggest appropriate clothing.

Being in a car as a passenger

Even as a passenger, we feel the pressures of the road. We may have driven in the past, and so we still drive every part of the route in our mind. Bad weather or traffic can stress us out very quickly.

Personal solutions:

- ✓ **Learn how to be a passenger** when others are good enough to drive us.
- ✓ Try to avoid being in a car during bad weather conditions.
- ✓ Think about how you're feeling that day, and recognize when you are having an off day, then decide whether you can go for a ride.
- ✓ Try relaxing techniques (e.g., closing your eyes).

What others can do:

- ✓ Recognize that passengers still drive the distance.
- ✓ Drive with caution and don’t get offended if I am anxious or fearful.
- ✓ Pull over and take a 10-minute break for me to regroup.
- ✓ Lower the music volume.

Notes

Change of memory and abilities

Getting lost or losing things

It is frustrating and frightening to get lost or misplace articles. It is very upsetting when people respond in a way that does not validate our feelings.

Personal solutions:

- ✓ Go on walks with trusted friends and family members.
- ✓ Get to know staff at stores so they can assist you.
- ✓ Constantly use the same stores to help familiarize yourself with surroundings.
- ✓ Organize your time and your belongings.
- ✓ Try to have a place for things and try to remember to put them there.
- ✓ Establish a routine
- ✓ Do only one thing at a time.
- ✓ Write down what you have been asked to do, or what you are planning to do.
- ✓ Use labels on cupboards and closets.
- ✓ Write out directions before you leave the house and reverse them to get home.

Change of memory and abilities continued

What others can do:

- ✓ Don’t say, “I lose things all the time, too”, or “Why didn’t you put it where it belongs?”
- ✓ Don’t say, “It’s not important anyway”, or “You don’t need it right now.”
- ✓ Realize that it is important to me or I wouldn’t be looking for it.
- ✓ Offer to help look for items or help with reminders and establish a routine.
- ✓ Say, “We don’t have a lot of time now, but I can help later.”
- ✓ Help us label cupboards and closets.

For more tips on staying safe in the community refer to the By Us For Us guide: **Safety When Out and About.**

Change of abilities

It is a trigger when we can’t do something we used to do really well, like tie a tie or make change at the store, and now someone has to do it for us.

Change of memory and abilities
continued

Personal solutions:

- ✓ Slow down and have realistic expectations of yourself.
- ✓ Focus on one thing at a time.
- ✓ Try to be as kind to yourself as you are to others.
- ✓ Have patience with yourself.
- ✓ Get enough sleep – it is very important.
- ✓ Leave the task for a bit and try again later.
- ✓ Be comfortable asking for assistance.
- ✓ Try not to let small problems upset you.

What others can do:

- ✓ Allow me to try and endorse the effort.
- ✓ If I become frustrated, gently ask to help.
- ✓ Allow me to cry – it is therapy to me!
- ✓ Don’t protect me or be my gatekeeper.
- ✓ Be patient with me.

Negative emotions

Being degraded and judged

It is hurtful when someone judges us or provides us with comments that degrade our self-worth.

What others can do:

- ✓ Show me affection. Hold my hand or give me a hug – it helps.
- ✓ Just accept me the way I am.
- ✓ Do not yell or shout at me.
- ✓ Don’t assume we are incapable of making decisions.
- ✓ We are still sexual people who enjoy intimacy. We can still have discussions on this topic.

Notes

Negative emotions continued

Not being listened to or included

We feel a negative emotion when people don’t listen or ask us what we want or need. We also get frustrated when we have not been fully included in what others are doing or going to do.

What others can do:

- ✓ Do not assume you know what I need or want.
- ✓ Keep me involved and aware of plans. I do not need to have the first or last comment on a situation, just involve me.

Notes

Stress, frustration, pain or fatigue

Stress, frustration, pain and fatigue can all be triggers.

Personal solutions:

- ✓ Avoid situations and things that trigger a negative response.
- ✓ Try to remove yourself from stressful situations.
- ✓ Try to decrease the number of triggers by controlling your environment as best you can.
- ✓ Get plenty of rest to avoid fatigue.
- ✓ Pet therapy – There's a calming effect when caring for a pet because they give you comfort and love. Talking to your pet might help with easing your frustrations.
- ✓ Relaxation techniques – Music, exercise, reading, deep breathing and meditation can all help reduce anxiety.
- ✓ **Share** your feelings with others. It helps to talk to a willing listener.

Negative emotions continued

What others can do:

- ✓ **Listen** to what I need. Sometimes, just listening is all you need to do.
- ✓ Provide me with soft music or my favourite tunes.
- ✓ Take me home when I am tired.
- ✓ Try to understand my point of view.
- ✓ Do not make requests of me when I am tired.
- ✓ Realize that activities can tire us very easily and we can be over-stimulated.
- ✓ Try to reduce the amount of stress around me.
- ✓ Realize that I am entitled to CHOOSE MY PAIN. There are things we choose to do, such as attend a special event, where we know we are entering an uncontrolled environment with many triggers. We make a conscious decision to do this even though it will cause us to experience a trigger. Allow me to choose and decide to go anyway.

“Keep this in mind that we ourselves do not always have control over what is happening and things can change quickly.”

(Gail Robinet, B.A., M.Div., Burford, ON)

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

To learn more about dementia visit:

Alzheimer Society of Canada
Toll-free telephone: 1-800-616-8816
Email: info@alzheimer.ca
Website: www.alzheimer.ca

World Health Organization
Website: www.who.int

Endorsements

As Chief Executive Officer of the Alzheimer Society of Canada, I once again would like to congratulate the ‘By Us For Us’ team for the development of a second valuable guide designed to help people with dementia and their families manage the day to day challenges of early stage memory loss.

Recognizing the ‘triggers’ that can aggravate their condition is a big step towards helping people living with dementia to minimize some of the stress and agitation associated with this difficult disease. By using their own personal experiences with triggers and the solutions that have worked for them, the ‘By Us For Us’ team is once again reaching out to support people with dementia in a unique and powerful way.

Scott Dudgeon
CEO, Alzheimer Society of Canada
www.alzheimer.ca

As a clinician, researcher, and educator over the past 20 years working in the field of dementia care, I have always been impressed and thankful for the learning I received from those who have experienced the disease and those who provide support. Their careful, wise, and reflective observations have been the most valuable pieces of information that I have been able to translate from one person to the next. I often reflected how a resource guide that collected these insights and strategies would be helpful to the next person or family I had the privilege to work with. This Guide, therefore, is indeed, a dream come true.

The challenges described are common and relevant. The practical strategies for the person with early dementia and their caregivers are useful. The By Us For Us team who gave of their time, shared their experiences, and informed the development of this Guide should be congratulated.

When one considers that an individual every 7 seconds in the world is diagnosed with dementia and every 4 minutes in Canada, the usefulness of this Guide now and in the future, is obvious.

The only regret I have as a person working in the field is, I didn’t have this resource many years ago. I would highly recommend it for any person diagnosed with a dementia and their caregivers.

J.K. Le Clair
Professor and Chair,
Geriatric Division Co-Director,
Centre for Studies in Ageing and Health Department of Psychiatry,
Queen’s University

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There are many more who have offered support and input over the past few years, while this project was just a dream, who deserve credit, but wish to remain anonymous. You know who you are! Thank you.

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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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