FLIPPING DEMENTIA STIGMA, AN ACTION GROUP'S GUIDE

"I like to think of [us all] as pioneers…" Donna, Action group member

INTRODUCTION

For dementia-related research to be effective, it must involve people with dementia. Full stop.

The Flipping Stigma on its Ear Toolkit is a beautiful example of this, as it originated from a Participatory Action Research study featuring insight and input from our group, a dedicated collective of people living with dementia. We worked alongside researchers to address the stigma and discrimination that frequently accompany dementia diagnoses and we developed an online resource offering practical suggestions on recognizing and responding to discrimination in all its forms.

From audio clips of action group members that detail our experiences, to provocative discussion prompts for family members and care givers around how best to support someone with dementia, the toolkit has become a powerful vehicle for change. It's been used as curriculum for workshops in care homes, neighbourhood houses, community centres and volunteer training programs, all of which have yielded overwhelmingly positive feedback.

The toolkit is being touted as a driving force in building more inclusive communities. It's educating medical professionals, health care workers, researchers, and other key community members in positions of influence.

THIS ACTION GUIDE

This guide was created by our Action Group (AG) members to provide direction for future research projects and collaborations, where people with dementia serve as co-researchers and partners in the change making process. It showcases what the group accomplished together, as well as what's possible for others who decide to jump in and effect positive change too.

In our case, we built an online toolkit for decreasing stigma, but the range and nature of projects you could take on with a group like this are endless.

This guide is meant to help give you a sense of what's been most important for us when establishing our group. It includes all the elements that helped us move forward into doing the work.

WHO WE ARE

We are a group of individuals living with dementia who have worked in partnership and collaboration with a University of British Columbia research team since 2019.

Though the specifics of our dementia diagnoses vary, what we share are strong values around the inclusion of people with dementia in all spheres of civic and social life. We also share a passion for changing perceptions of what it means to live with dementia.

We worked collaboratively on a research project called Reducing Stigma and Promoting Social Inclusion: Putting Social Citizenship into Practice. This was a four-year initiative funded by the Canadian Institutes of Health Research.

Current members: Donna, Lester, Myrna, Craig, Lynn, Granville Sherri
Past members: Sarah, Marcia, Tim, Rae, Karen, Geoff, Robert

WHAT WE BRING TO THE PROJECT

Lived experience: every member of the group lives with a form of dementia.

A sense of urgency: we're all driven to make life richer and more equitable for others with dementia.

Diverse backgrounds: we bring a range of viewpoints, skill sets, and professional backgrounds.

As you read through our bios, you'll hear about members with backgrounds in nursing, teaching, and administration; members with strong public speaking skills, networking, leadership, and abilities navigating committee dynamics. You'll learn our group includes researchers, artists, travellers, authors, and community engagement experts. There's no shortage of wisdom here, and what's extra special about the group is the way we hold space for one another, respect each other's sometimes differing opinions, and actively listen to new ideas.

Friendship and trust: we have, first and foremost, built friendships and a deep sense of trust in the group over the years which has laid the groundwork for real cohesion, empathy, support, and care.

**While some of us knew each other before hand from previous projects, others did not. So, when we came together in this new iteration, our first order of business was to establish a real foundation of mutual respect.

THE ACTION GROUP JOURNEY

HOW IT ALL STARTED

The idea of the Flipping Stigma project began with a small group of academics, but the creation of the toolkit and the real action didn’t kick off until we as people with lived experience came to the table.

In fact, this project was not successfully funded until the research team included an expert with lived experience of dementia.

As a diverse group of individuals, we were ready to join a team, establish some collective goals, and give all members a chance to share what they needed to feel safe and supported in the group.

We focused on establishing a common goal in our early discussions: thinking through how we thought people with dementia should be treated.
This led to conversations about “what the hell” social citizenship meant, which led us to stigma, and its drastic impact on the experience of living with dementia. That’s where we arrived at the toolkit title “Flipping Stigma.”

We created collages guided by the question, “What would flipping stigma look like to you?”

ACTION GROUP GOALS

“… we need to be more versed in what we want people to know… not only about ourselves but just about Alzheimer’s in general because we all have knowledge…” Donna, Action group member

“…the relationships…between…the action group members…is…of …foundational importance and consequently should be looked at even before we talk about what kind of purpose we want to create as a group. We need to have a real sense of the individuals involved in that group. And through that…group awareness, the purpose will evolve…” Granville, Action group member

WHY WE CAME TOGETHER AS A GROUP

We came together around a shared desire for change: to contribute to research and to make change happen. But before we could achieve this, we had to establish relationships and build trust as a team.

Once that sense of connection and camaraderie was in place, we really started growing and learning together. We built advocacy and self-advocacy skills with an enhanced sense of confidence and worked together to develop this incredible legacy project that's already prompted a broader sense of empathy and understanding in our community.

We were excited to contribute to research, "one of the vehicles" in which advocacy happens. We joined the project because we were ready to "get down to the grind" and make change happen.

"We don't do it to get fulfillment but we do receive fulfillment by accomplishing something that is useable and people go, 'hey that's really helpful." Craig, Action group member

ACTION GROUP GUIDELINES

1. It helps when there is flexibility and a sense that the work being done "really matters".
2. We need good facilitation (facilitation NOT direction) for the work to proceed. This includes regular housekeeping work such as scheduling meetings, providing agendas and technical support, etc.
3. Research team members always bring flexibility and an open mind to the meetings, and follow up regularly with members about their experience as part of the group.
4. Building relationships with others who have dementia, engaging with the broader community, and creating a sense of belonging within the group were identified as critical aspects of our group environment.
5. Setting ground rules in the beginning such as mutual respect, reciprocal listening, being patient with one another, and withholding judgment, was important.

GROUND RULES INCLUDED

1. Be open to everyone, respect and listen to everybody, let them contribute in the way they're most comfortable, and, lastly, listen, listen, listen.
2. It helps to have a sense of humour.
3. Research team members/ facilitators should set aside time in meeting agendas for casual catch up and updates so members can have the opportunity to connect.

BUILDING ADVOCACY AND SELF-ADVOCACY SKILLS

Enhanced advocacy and self-advocacy skills evolved in all of us as a direct result of this work together. We noticed huge personal growth, learning, and increased confidence all around. Having that tight-knit support network really facilitated that for us.

We made space for—and celebrated even—everyone’s strengths, weaknesses, and differences. We encouraged each other to participate with confidence and worked cohesively towards our shared goals.

LEAVING A LEGACY

There have been several lasting legacies from our work as Action Group Members. These include the Flipping Stigma Toolkit, the “Celebrate Life” T-shirts, and this guide.

We have been very effective at PROMOTING ADVOCACY: People who have been part of the Action Group have become more active advocates in community and have taken on other advocacy roles as well.

It is important to be focused on HOPE and CELEBRATING LIFE while living with dementia.

HOW CAN YOU CREATE A GROUP LIKE THIS?

1. See a need in your community and become curious: how could that need best be met?
2. Find a few people who align with you: people who are passionate about the same issue and keen to effect change.
3. Commit to meeting regularly to further explore what that "change" might look like.
4. As your group's connection deepen, and ideas become fleshed out, consider taking things further.

Check out our STEP-BY-STEP list below for more details and suggestions.

STEP BY STEP

1. Reflect on your journey with dementia and your relationship to the community. What could you do to make living with dementia better for yourself and others?
2. Share and examine your ideas with trusted contacts in your support group or social circle. Then consider opening the conversation up with people who may offer a different perspective.
3. Establish connections with people keen to pursue action around your idea or concept. This will help you develop a draft plan.
4. Allow your idea to evolve. Refine your goal(s) and express your priorities. Think about the big picture: is this a local issue or a wider concern? How can you fund the idea so it offers the greatest positive impact?
5. Engage a champion (a researcher, a community leader, or a social justice advocate). Meet to discuss your thoughts, get feedback and invite them to work

with your group. Determine if they are committed to listening, if they value your lived expertise, and if they can meaningfully engage with you.
6. Practice patience.The entire process will take time - lots of it. You'll first need to establish an intended outcome, a rough goal around timeframe, and a list of required skills and financial resources. This will help determine next steps.

It's a team effort, and it's possibly one of the most rewarding experiences you'll ever take on. We hope you'll pause from time to time along the way to acknowledge the important work you're doing to help move great ideas forward! Good luck!

REFLECTIONS FOR PEOPLE WITH LIVED EXPERIENCE INVITED TO JOIN A RESEARCH GROUP

1. Why am I being invited to participate in this study?
2. How will my expertise as a person with lived experience influence the research process, outcomes, or both?
3. Am I being included in defining the focus of the research?
4. How will my input be used?
5. Is my involvement being recognized as important?

REFLECTIONS FOR RESEARCHERS HOPING TO COLLABORATE WITH PEOPLE LIVING WITH DEMENTIA

1. Am I willing to learn from those with lived experience on my team?
2. Am I willing to listen to all research partners and, where appropriate, be flexible in my approach within funding parameters?
3. Do I have the resources to support active participation by people with lived experience?

"For a person with dementia, every day you wake up and put your shoes on, stand up without falling down, and find your way out of the room, is a day to celebrate.
"When life is essentially a ticking time bomb, we need to make the most of every tick. To celebrate it all. And to do that, we have to change our perspective. We can choose to seek out the joy by saying,"I'm going to make the most of my life as I have it." Granville, Action group member

We are so grateful you took the time to explore our action guide, and we're excited to see what you do with this information.

To learn more about dementia visit Flipping Stigma on its Ear Toolkit at:
www.flippingstigma.com
Stay in touch. email: flipping.stigma@ubc.ca

ACTION GROUP MEMBERS BIOGRAPHIES

Current Members

Donna Wager

Donna Wager has been living with Alzheimer's disease for about ten years now. "It's been ten years and I'm still upright," she jokes, but her sense of gratitude is palpable. Born and raised in Winnipeg, Manitoba, she now lives in Surrey, BC with her husband Mike and their new puppy, Gina, not far from her two sons and their families.

Donna worked as a consumer loan and mortgage lending officer for most of her career and has public speaking in her background as well. These days she keeps busy as a member of the Flipping Stigma Action Group advocating for others living with dementia. In her free time, she loves walking her dog, visiting her grandkids, and reading biographies.

When asked what she wanted the world to know, she said: "More and more people are being diagnosed with Alzheimer's Disease and various kinds of dementia, and I think we really need to have more compassion for them." When faced with the news of her own diagnosis almost a decade ago, people would often say things like "no you don't have that." And she emphasized how important it is to accept and validate the experience of someone dealing with the news of their new reality. It helps remove stigma from their experience and lends moral support when it's needed most.

Lester Gierarch

Lester lives with his wife, Cindy, in Burnaby, BC, Canada. He taught Adult Basic Education for 15 years at Milwaukee Area Technical College. Cindy and Lester met in the USA shortly after he received his Ph.D. in Educational Administration, from the University of Wisconsin. For the first 3 years of their marriage, they lived and taught at colleges in China, and Taiwan. After moving to Canada, Lester enjoyed a long career in teaching Adult Basic Education.

In 2019, Lester was diagnosed with early-stage Alzheimer's disease. Since then, he has enjoyed learning about dementia through reading, listening to others in support groups, and taking part in University of BC research projects.

He has especially enjoyed being a member of the Action Group since 2019.

Myrna Norman

My name is Myrna Norman. Coming from Maple Ridge BC, a suburb of Vancouver, my life has taken a significant turn after being diagnosed with Frontal Temporal Dementia in

2009. Currently my diagnosis is MCD after being diagnosed with Lewy body and my drivers license removed by the doc, and Alzheimers, confusion reigned.

Could I be the only one with all of the difficulties in diagnosing? Could my passion for advocacy have spurred the neutrons in my brain to make better connections, who knows. Maybe, part of my advocacy misdoing a peer group for those with memory issues in my home town. Fun events like 'Christmas in July, October Fest celebrations, Christmas light bus trips and experiences with art, quizzes etc are part of our get togethers. Some of the groups that offer highlights to my life are Early Persons Living with Dementia group, it's stimulating and energetic and enriching. The Dementia Sisterhood, the Action Committee, CCNA, Alzheimers Advisory, Dementia Advocacy Canada, Community Response Network, Dementia Friendly Task Force, Elder Law, Advance Care Planning and even more. Much to do and much to learn and to share, isn't that what life is all about? Won't you join me?

My involvement with Flipping Stigma unlocked and improved the neuron connections in my brain. Use it or loose it is so true. I am attempting to become a researcher and my first research project will be about 'sundowning'.

Craig Burns

Craig Burns was diagnosed with Alzheimer's dementia in 2016. Since his diagnosis Craig has been involved in 3 main focus areas; Education, Governance, and Research.

In education, Craig provides presentations to students in post secondary institutions, including medical school students in their educational development. Advocacy efforts are also provided to not for profit organizations, educating employees and clients. Craig is a governing board member for the Alzheimer Society of British Columbia. Decision making, policy and programming development are areas Craig is able to provide direction and expertise. In research, Craig is a volunteer patient in a clinical drug trial for Alzheimer's dementia, now in his seventh year of participation.

Lastly, Craig continues to participate and involve himself in the Flipping Stigma project.

Lynn Jackson

Lynn Jackson was born in Richmond, British Columbia and is a proud member of the Saulteaux or Plains Ojibwe, sometimes referred to as the Anishanaabe. She began her career as a Registered Nurse at the Royal Jubilee Hospital in Victoria, BC where she completed her education. She then worked at Toronto General Hospital for several years before moving to Mexico City (and later Puerto Rico) in the early 90's to pursue a job on the sales and promotional side of medicine. Lynn learned Spanish, joined a social running group, and made many lifelong friends there, several of whom she still connects with regularly. It was while living in Puerto Rico that she noticed something had changed for her and she pursued medical treatment resulting in a diagnosis of frontotemporal dementia.

Since then, Lynn has participated in numerous Alzheimer's Disease International working groups helping its member countries become more inclusive of people with dementia. She is one of the founders of Dementia Advocacy and Support Network International DASN (2001), the world's very first internet-based organization by and for people diagnosed with early-stage dementia. While DASN's website is no longer live, many of its members are still very involved in advocacy roles around the world, continuing to build on the momentum of what they started. And Lynn is no exception! She works with UBC's IDEA Lab on projects like their Telepresence Robot Study and Calm Robot Study, a study called "Implementing Dementia-Friendly Care for Cancer Patients Living with Dementia," and another called "Learning Health Systems for Dementia Care Transition." Lynn is a vital member of the Flipping Stigma Action Group, also through the University of British Columbia, and an End-of-Life Project through the University of Waterloo. She's collaborating on "Innovation for Indigenous-led Dementia Care to Enhance Safety" through the University of Calgary, and she co-wrote an academic journal article with Dr. Lillian Hung for Perspectives called, "The Story of Elder Alex, A Reflection on Gerontological Nursing Competency Standards."

Granville Johnson

Granville Johnson, B.Ed. (UVic), Assoc Diploma, Writing in New Media (CNC), living with a Vascular Dementia diagnosis since 2016 and Converted Disorder since 2010. Granville is a Black dual citizen of Canada and America, and a two tour Viet Nam War veteran (combat medic), the beginning of a life direction dedicated to service.

A life-long artistic career was enhanced by attaining his Bachelor of Education at University of Victoria, British Columbia, Canada in 1986, leading to seven years teaching in the Northern British Columbia Public School system, from Primary, Intermediate, Secondary, through Adult Basic Education. He danced professionally for ten years after multi-disciplinary dance training in Modern, Contemporary, Jazz, Afro-Jazz techniques and Choreography, for four years. His artistic evolution involved into musicianship as a percussionist specializing in the Djembe, an African hand drum. To promote his performance events, he developed his interest with multimedia digital collage to create and produce media materials.

His inherent literary interest and a need to document his life's journey as a survivor of long term sexual and physical abuse, led him to enrol in the Writing in New Media Program at the College of New Caledonia (CNC), to graduate with an Associate Diploma (2yr.). After which he went on to further develop his skill set writing fiction: poetry, short story writing, and as a novelist. Backstory: The Many Live of Granville

Johnson, his first volume of a four-volume series, is soon to be released in Canada. Information about the novel and its author can be found at granvillejohnson.ca.

“I feel that my varied creative experience has greatly infused the self-awareness of my inner topography, that is being affected by the Vascular Dementia and the Converted Disorder, in real time.

While my extensive teaching and performance experience, has enhanced my ability to communicate effectively to others how the realities of living with dementia are experienced. Thus, I can facilitate awareness and the understanding of the changes within someone living with dementia, particularly in early onset and/or pre-diagnosis, as well as work to counter-act stigma within society.”

Granville, with his wife, Birgit Luesgen, discovered their journey toward self-advocacy and dementia community by participating in a month-long support group for people living with dementia and their care-person(s). The group was facilitated and moderated by the Alzheimer’s Society of British Columbia, in Prince George, Northern BC. The group met on four consecutive Wednesdays. From that modest beginning, Laurie Decroos, Alzheimer Society of BC – Northern Resource Centre, suggested that Granville join the Action Group, Flipping Stigma Project. It was with that group that Granville began his transition toward advocacy.

The creation of the resource, flippingstigma.com, catapulted the project’s People Living with Dementia (PLWD) membership into high demand, within the expanding participatory partners in research trend. As with many of the Action Group. Members, Granville began receiving many invitations to work with committees on other research projects. Some of the national and international project groups have included: The National Dementia Guidelines (NDG) Black Community Working Group, The Alzheimer’s Society of Canada, The I’m Still Me Project: Brella Society, Reimagining Dementia: A Creative Coalition for Justice, The-End-of-Life Project, Univ. of Waterloo, Ontario, University of Ottawa – Air Travel dementia - friendly project, Centre for Research on Personhood in Dementia (CRPiD).

Granville has co-written, w/ Karen Wong and Deborah O’Connor: “Living with Dementia: Exploring the Intersections of Race, culture and dementia stigma.” Granville, continuing to answer his calling of service, has been an outspoken Dementia advocate for six years, building resilience within the dementia journey. Facilitating Ethno-Racial Inclusivity in Dementia Research.

Sherri Adams
Sherri is a dancer at heart and is a big part of her community in Summerland, BC.

She spends much of her days with friends and co-workers in her community and knows everybody she passes as she walks through town. She is always looking for more opportunities to connect with others and learn about what is happening in Summerland. Having danced at the Junos, Sherri lives her life with an intrinsic rhythm and can often be found singing and dancing wherever she goes.

Sherri has been a part of the Action Group since late 2020.

Past Members

Sarah King

Sarah's deep and abiding passion for all things theatre, provided her countless opportunities over five decades to ply her trade as a Stage Manager. She absolutely LOVED being in charge and 'running the show.' Although she did have a few choice words to say about 'actors.' A fiercely independent woman, her wicked sense of humour and sometimes-curmudgeonly attitude enfolded a generous heart that loved animals more than people. And if you ever needed something moved, Sarah had her van at the ready! Sarah enjoyed many things including: the ocean, swimming, water fitness classes, people-watching, daily crossword puzzles, reading fiction, breakfast (grapefruit juice, toast, cheese), pie, ice cream, dessert of almost any kind really, fireworks, afternoon naps, evening news, Jeopardy, PBS, English Murder Mysteries, the Nature Channel, sports on weekends (especially football, curling, figure-skating, and the Olympics), and above-all, singing! If there was a place to be noticed, you could bet that Sarah would find it!

Marcia

Using her friendly, outgoing spirit to her advantage, Marcia worked many years at the Vancouver International Airport before retiring and then continuing to use her knowledge as a Green Coat Volunteer.

When Marcia joins Zoom meetings and before her camera turns on, her photo is of a smiling Chow Chow. Having cared for many Chow Chows throughout her life, Marcia loves animals and speaks fondly of the dogs she raised.
Marcia joined the Action Group very early on – in 2019 when we were meeting in person in Vancouver before the pandemic hit.

Tim Eng

Born and raised in Vancouver, Tim grew up helping his dad at the local Cambie Appliances before going on to own and operate Eng Washing Machine Rentals.

Always a fan of the Rolling Stones, Tim started playing the bass guitar when he was in high school and started a band with his high school friends. This band still exists to this day and Tim enjoys playing his Fender bass guitar.

Tim always has a great sense of humour and cares about those around him – he is married and has raised three children and keeps up with many friends.

Karen

Karen was born in 1965 in Greytown, New Zealand. In the mid 80s, she came to Vancouver, Canada to work as a nanny. Karen married and had a daughter Lauren. She moved to the Okanagan and put herself through school as a single mother and started her 25 year career as a recreation coordinator in numerous extended care facilities. She then met and married the love of her life Steve and had a son, Jack and daughter, Morgan. They just returned from Mexico where her oldest daughter got married, prior to which Karen was blessed with two beautiful grandsons Auggie and Hollis who fondly refer to her as Lolly.

She enjoys her time with her new puppy Lola walking through town every day where they are both very well-known and popular in our town of Summerland where she’s lived for almost 30 years.

Geoff

Geoff is the third of seven brothers born in Brisbane and raised in a village north of Cairns, Queensland. While his brothers were encouraged to leave school after eighth grade, Geoff was inspired by a teacher who saw his potential and encouraged him to apply for scholarships to finish high school. He then applied to Military College and graduated with a Bachelor of Mechanical Engineering. While serving in the RAAF, Geoff pursued an Economics Degree part time. He married his Canadian wife Sharyn and they have two children. The family moved to Canada in 1978. His career in Canada included managing Edmonton Transit and properties for the City of Saskatoon, after which he became Associate Vice President of Land and Building Services at UBC in Vancouver.

Geoff is a great family man and an avid athlete. He played rugby, tennis, squash and completed The Ironman Canada Triathlon for ten consecutive years. Geoff retired from UBC in 2010 and continues to enjoy his family and his two dogs, Ozzie and Sugar. He walks twice daily, an average of three hours a day. He was diagnosed with dementia in 2015.

ACCESSIBILITY STATEMENT

The Flipping Dementia Stigma Action Group Guide is committed to providing a website that is accessible to the widest possible audience, regardless of circumstance and ability. We aim to adhere as closely as possible to the Web Content Accessibility Guidelines (WCAG 2.0, Level AA), published by the World Wide Web Consortium (W3C). These guidelines explain how to make Web content more accessible for people with disabilities. Conformance with these guidelines will help make the web more user friendly to everyone. Whilst the Flipping Dementia Stigma Action Group Guide strive to adhere to the guidelines and standards for accessibility, it is not always possible to do so in all areas of the website and we are currently working to achieve this. Be aware that due to the dynamic nature of the website, minor issues may occasionally occur as it is updated regularly. We are continually seeking out solutions that will bring all areas of the site up to the same level of overall web accessibility.

If you have any comments and or suggestions relating to improving the accessibility of our site, please don't hesitate to contact us at flipping.stigma@ubc.ca. Your feedback will help us make improvements.