Addressing the Stigma of Dementia on Social Media Workshop Report

Population Health and Aging Rural Research Centre

PHARR

May 14, 2025

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Recommended Citation

Bacsu, J., D'Souza, M., Gonzalez, C., Hulko, W., Kluch-Morrall, M., Vogt, K., Rakobowchuk, M., Virani, A., & Viger, M. (2025). *Addressing the Stigma of Dementia on Social Media Workshop Report*. Kamloops, BC: Population Health and Aging Rural Research (PHARR) Centre, Thompson Rivers University.

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Welcome Message

Greetings,

I am pleased to share this report from our Stigma of Dementia on Social Media Workshop hosted in Kamloops on May 14, 2025. The goal of the workshop was to identify innovative ways to address the stigma of dementia on social media. Our workshop was highly successful and attended by over 70 participants, including health professionals, organizational representatives, community leaders, students, researchers, policymakers, and people living with dementia and care partners.

The morning portion of the workshop featured a range of activities, including guest speakers, poster presentations, and a panel discussion with individuals living with dementia and their care partners. In the afternoon, participants engaged in a World Café session (https://theworldcafe.com/), which created a collaborative space to discuss key issues and identify priority actions to address dementia-related stigma on social media. The conversation highlighted the urgent need for multi-stakeholder partnerships to develop collaborative and innovative solutions to tackle the stigma of dementia on social media.

Our report provides an overview of the workshop, from the morning activities to the insights discussed during the World Café-styled conversation. In this discussion, participants worked together to identify specific actions to address dementia related stigma on social media. These findings provide important guidance for health professionals, policymakers, and community leaders working to reduce the stigma of dementia.

We also included quotes from World Café participants that highlighted the importance of sharing lived experiences, focusing on positive messaging, and offering practical tips for living well and overcoming challenges, rather than deficit-based messaging on social media. Many students shared that the workshop experience inspired them to consider further study in dementia research.

We hope this report inspires new ideas and supports ongoing conversation and partnership-building to challenge the stigma faced by people living with dementia. Together, we can move forward to end the stigma of dementia.

Best wishes,

Juanita

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Table of Contents

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Executive Summary

Dementia-related stigma remains one of the greatest barriers for people living with dementia. Stigma often leads to social isolation, delayed diagnosis, poorer mental health, and limited access to care. As social media continues to shape public perceptions, misinformation and negative portrayals online can further reinforce stigma and misinformation.

Recognizing these challenges, the *Addressing Stigma on Social Media Workshop* brought together researchers, health professionals, community leaders, and individuals with lived experiences to collaboratively explore how social media can both perpetuate and reduce stigma. Stigma, defined as the negative beliefs, stereotypes, and discriminatory attitudes directed towards individuals based on a particular condition, plays a powerful role in shaping how dementia is discussed and understood online. Through open dialogue and knowledge sharing, participants identified priorities and actions to promote dementia-friendly communication and enhance the visibility, inclusion, and well-being of people living with dementia on social media.

This report shares findings from the workshop funded by Michael Smith Health Research BC and the Alzheimer Society of British Columbia. Using a *World Café* methodology (https://theworldcafe.com/), the workshop provided an interactive and inclusive mode for participants to share perspectives and develop strategies for addressing dementia-related stigma on social media.

Purpose

This project's purpose was to foster collaboration and knowledge exchange among researchers and research users to identify actions to reduce the stigma of dementia on social media. The workshop aimed to: i) develop research priorities and actions to reduce the stigma of dementia on social media; and ii) promote knowledge sharing to support dementia awareness, inclusion, and respectful digital communication. Through an interactive and participatory approach, this project advances collective understanding and action towards reducing dementia-related stigma on social media.

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The Workshop Agenda

Addressing Stigma of Dementia on Social Media Workshop

May 14, 2025

Sandman Signature Hotel - Kamloops, British Columbia

9:30 am - 10:00 am	**Registration and Poster Viewing**
10:00 am - 10:05 am	Introduction - Juanita-Dawne Bacsu
10:05 am - 10:20 am	Land Acknowledgement – Elder Colleen Seymour
10:20 am - 10:40 am	Lived Experience Panel – Christine Aiken, Lynn Jackson, Janine Karlson, Tammy Kotyk, Jim Mann, and Myrna Norman
10:40 am - 11:00 am	**Coffee Break and Poster Viewing**
11:00 am - 11:30 am	Lived Experience Panel
11:30 am - 11:45 am	Tabel Discussion and Sharing
11:45 am - 12:45 pm	**Lunch Served**
12:45 pm - 12:50 pm	Overview of Afternoon and World Café Methodology
12:50 pm - 2:00 pm	Small Group Deliberations With Table Facilitators and Notetakers
2:00 pm - 2:15 pm	**Coffee Break and Poster Viewing**
2:15 pm - 2:30 pm	Full Group Discussion to Share Findings
2:30 pm - 2:45 pm	**Wrap-Up and Evaluation Forms** – Juanita-Dawne Bacsu

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Knowledge Synthesis Poster

Maya Kluch-Morrall, a 4th year nursing student and research assistant at the PHARR Centre, created a knowledge synthesis poster during the event that explores the stigma of dementia on social media through shared thoughts, ideas, and experiences.

Photo: Maya Kluch-Morrall standing next to knowledge synthesis poster.

Panelist Speakers

Myrna was diagnosed with frontotemporal dementia in 2009 and has since become a passionate advocate for dementia awareness and inclusion. She actively contributes to several initiatives, including the Engagement of Persons Living with Dementia, the Dementia Friendly Task Force, and the Purple Angel Memory Café. As a speaker and advocate, Myrna shares her experience to inspire and educate others on how people living with dementia can enhance their quality of life and continue to live well. In June 2020, she became part of the CCNA's Engagement of People with Lived Experience of Dementia, and is a member of the Alzheimer's Society of British Columbia's leadership council.

Myrna Norman

Jim is a dementia advocate, researcher, and published author who has been living with young-onset Alzheimer's disease since the age of 58. His work centers on consent, ethics, and improving the quality of life for people living with dementia. Jim served as co-chair of a national advisory committee through the Alzheimer's Society of Canada, contributing to the development of an ethical framework and resource guide for involving people with dementia in research. This work played a key role in the creation of the Canadian Charter of Rights for People with Dementia. Jim is widely recognized for challenging stigma and demonstrating that people living with dementia can continue to lead meaningful, purpose-filled lives. In recognition of his leadership and advocacy, Jim received an honorary Doctor of Laws degree from the University of British Columbia in 2020.

Jim Mann

When Christine received her diagnosis of vascular dementia at 55, she chose to live with intention and joy. She is an author, speaker, and dedicated advocate for people living with dementia. Christine sits on the board of Dementia Alliance International, contributes to Dementia Advocacy Canada, and uses her voice to show that a rich, meaningful life does not end with a diagnosis. Her book, *For This I Am Grateful: Living With Dementia*, captures the everyday moments of living with dementia that still bring laughter, purpose, and gratitude. On her blog, Chrissy's Journey, she writes honestly about her experiences about life after diagnosis.

Christine Aiken

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Panelist Speakers

Janine Carlson

Janine is a registered nurse with a graduate degree in counselling and more than 25 years of experience across diverse areas of health care, including acute pediatrics, wellness, and senior care. Janine was diagnosed with dementia at the age of 57 and has since chosen to use her lived experiences to advocate, educate, and reduce stigma. With support from her husband and the community, Janine continues to work, volunteer, and remain meaningfully engaged. Through her involvement with the Alzheimer Society of BC, she shares her story at speaking events across the province, offering insight, hope, and encouragement to others.

Tammy Kotyk

Tammy is a dedicated family care person supporting both of her parents, who are living with dementia. Through her personal experience navigating the complexities of the care system, Tammy has become a strong advocate for improved resources and support for families living with dementia. She leads community workshops focused on communication approaches, caregiving strategies, and the importance of self-care, encouraging care person to approach the journey with empathy, patience, and resilience.


Lynn Jackson

Lynn began her career as a registered nurse and is a proud member of the Métis Nation of British Columbia. After being diagnosed with dementia in 1999, she shifted her focus towards advocacy, education, and stigma reduction. Lynn is passionate about improving diagnosis, treatment access, and social inclusion for people living with dementia. She has spoken locally, nationally, and internationally, sharing her experiences to promote better understanding and awareness of Alzheimer's disease and related dementias. Lynn is a founding member of DASN International (Dementia Advocacy and Support Network), created in 2001 as an online organization run by and for individuals with early-stage dementia.

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Poster Session

The Stigma of Dementia Workshop provided attendees, including people with lived experience, policymakers, health professionals, students, and researchers with the opportunity to share knowledge, network, and present research.
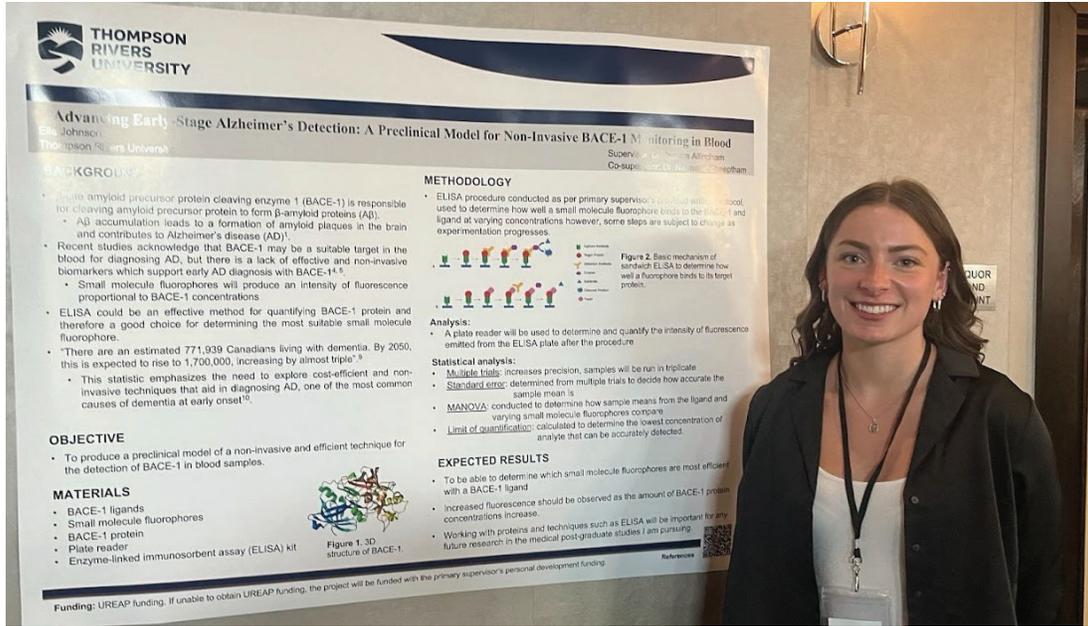
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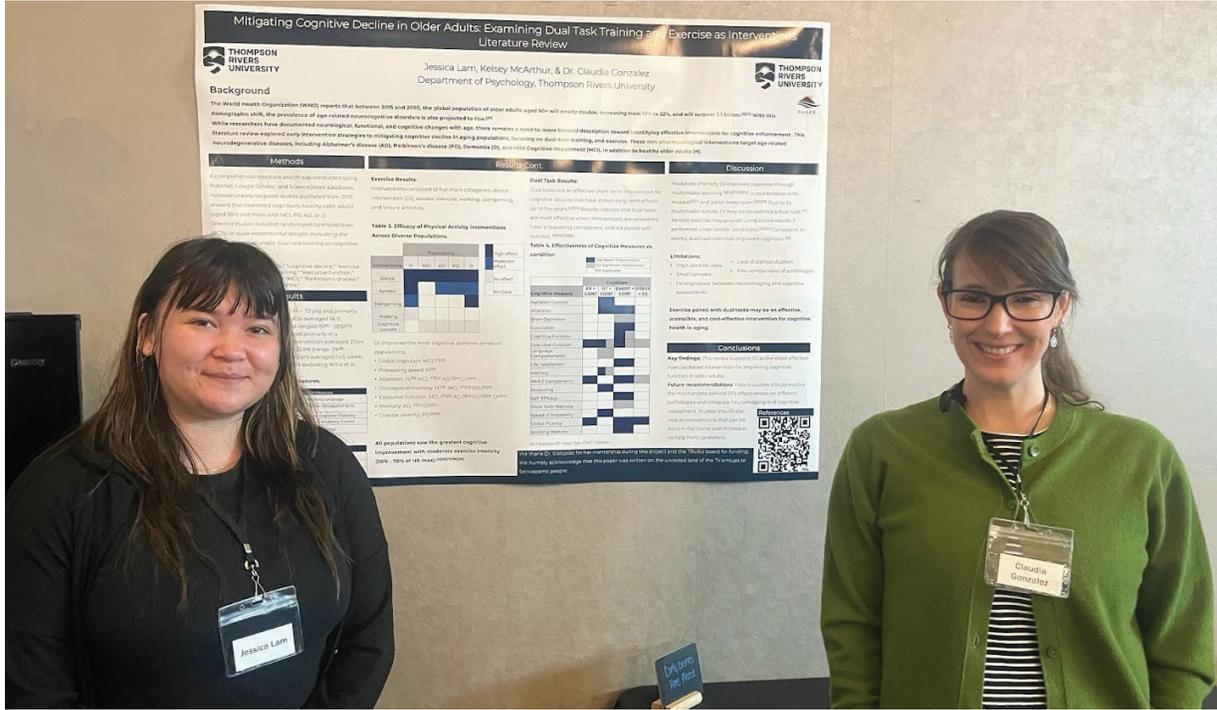
World Café Methodology

In the afternoon, a World Café-styled session (www.theworldcafe.com) was hosted to encourage open dialogue and brainstorm actions to reduce the stigma of dementia on social media. This World Café-styled approach typically includes three elements that are supported by a facilitator who guides the overall flow of discussion:

1. **Small Café-Styled Table Discussions**: Groups of 6-8 people convene at each table to explore the research questions. Each round lasts about 20-30 minutes, giving participants time to exchange perspectives and ideas.

2**. Rotating Tables**: When a round ends, participants rotate to new tables to mix with different people and build on previous discussions. The tables include a facilitator and a note taker to support the conversation and document key discussion points.

3. **Sharing Findings to Support Action**: After the table discussions conclude, everyone gathers together, and a facilitator leads a group conversation to identify guiding actions for change.

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World Café Questions

Using the World Café approach, participants rotated among tables to discuss different research questions, exchanging perspecting and building on insights. The session was designed to foster collaborative dialogue across all topics. The research questions explored were:

1. *What actions on social media would help to reduce the stigma of dementia?*

2. *What intergenerational activities would help to reduce the stigma of dementia?*

3. *Create an infographic to reduce the stigma of dementia on social media.*

4. *If you were creating a video for social media to challenge dementia-related stigma, what moments, messages, or experiences would you include?*

5. *If you were to create a podcast to address the stigma of dementia, what topics would you cover?*

6. *How can lived experience be shared on social media in ways that help challenge the stigma of dementia?*

World Café Findings

Question 1: What actions on social media would help to reduce the stigma of dementia?

- **Challenge misinformation and hate speech**

Spreading of misinformation and dementia-related stereotypes was identified as a major issue on social media. Participants described the need for myth-busting content (e.g., myth-vs-fact clips and did-you-know? clips) to challenge stereotypes and provide accurate information. Swap labels like "patient" or "case" for person-first terms and shared-human roles.

  ➤ *"I'm still a brother before I'm a 'case'."*

Participants also addressed the issue of dementia-related hate speech on social media and the need to remove hate speech and insults while balancing free-speech concerns.

  ➤ *"Delete the insults the way you'd delete other hateful language. Simple."*

- **Share lived experiences and positive messaging on social media**

Too often, dementia is portrayed within a deficit-based approach with little positive messaging. Participants shared the need for more lived experiences (e.g., day-of-the-life reels and vlogs on social media) that feature success stories of living well with dementia from the perspective of people living with dementia and care partners.

  ➤ *"Life is not over, it just shifts gears."*
  ➤ *"There is a life after diagnosis. It is not the end."*
  ➤ *"A dementia diagnosis is not the end. Life is still meaningful."*

Participants highlighted the need for improved technological support and built-in tools (e.g., larger font options) on social media to enhance usability and accessibility in posting and managing user content. In particular, social media would be more user-friendly with voice-to-text commands, one-tap upload options, and larger text for readability.

  ➤ *"Give my mom one-tap options and she'll post her garden pics all day."*

Question 2: What intergenerational activities would help to reduce the stigma of dementia?

- **Intergenerational education within classrooms**

Participants emphasized the value of regular learning opportunities about dementia from elementary school through university. Classroom modules could be reinforced through Q&A sessions with people with lived experience. Structured interviews allow students to learn life stories while residents share humour, resilience, and wisdom accumulated over decades.

> ➤ *"There is a wealth of knowledge and lived experience of people with dementia."*

> ➤ *Getting dementia into schools is key to understanding and reducing stigma."*

- **Shared hobbies, family, and everyday fun**

Simple activities (e.g., board games, baking, music, movie nights, coffee outings) help cultivate empathy and understanding without feeling like "lessons." Weekly routines and shared interests remind everyone of identity, connection, and belonging beyond the diagnosis.

> ➤ *"Common ground cuts the 'otherness' in half."*

> ➤ *"Keep the dynamic of family, no matter what."*

Question 3: Design an infographic to reduce stigma on social media.

- **Shared hobbies, family, and everyday fun**

Participants recommended leading with testimonials of people living with dementia and their care partners, using their stories to directly contrast misconceptions with real strengths and everyday capabilities. By highlighting individuals as volunteers, parents, students, and active community members, social media can push back against stereotypes and reinforce identity beyond the diagnosis.

> ➤ *"I've lost some memory, not my love of painting."*

> ➤ *"Stats stick when a face is right beside them."* Pair percentages or charts (e.g., "70% retain favourite hobbies") with a human photo or quote to ground the numbers.

- **Actionable support tips and resource access**

Infographics should offer concrete suggestions (e.g., appropriate language, ways to support independence, ideas for inclusive outings) so readers leave knowing how to help.

> ➤ *"Swap 'sufferer' for 'person living with'. Words matter."*

> ➤ *"Curious? Scan here for a five-minute beginner guide."* Every slide ends with information linking to websites, helplines, or local events; include QR codes for quick access.

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Question 4: If you were creating a video for social media to challenge dementia-related stigma, what moments, message, or experiences would you include?

- **Co-created storytelling and everyday life**

Participants emphasized that people with dementia must guide the narrative by providing input before filming and appearing on camera to tell their own story. Showing a typical day, routines, and favourite hobbies helps normalize dementia and highlight continuing abilities and identity.

> ➢ *"Show the person behind the diagnosis."*
> ➢ *"Acknowledge the ability of the person."*

- **Honest challenges and practical life hacks**

Videos should show both the evolving dynamics with families and the difference between meaningful support and unhelpful "fixing." They can highlight the creative strategies people use to adapt, the benefits of early diagnosis, and the value of supportive peer connections. Showing relatable moments (e.g., role changes in families, frustrations, humour) can help counter stereotypes. Addressing common stigmatizing experiences directly also helps viewers recognize and challenge stereotypes about dementia.

> ➢ *"You don't look like you have dementia."*
> ➢ *"Changing the term 'caregiver' to 'person' acknowledges who I still am."*

Question 5: If you were to create a podcast to address the stigma of dementia, what topics would you cover?

- **Real-life journeys: Living in the moment**

Podcasts could feature one-on-one conversations with individuals living with dementia to capture "their whole truth." Conversations with care partners can reflect on the joys, challenges, and meaningful moments to provide a hopeful and honest portrayal of life after diagnosis.

> ➢ *"Let me tell you the parts I love about my life now, not just what I've lost."*
> ➢ *"Today we laughed at the ducks. That's a good day."*

- **Cultural perspectives and translation**

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Episodes could spotlight the cultural lenses through which dementia is understood. Bilingual discussions or translated versions help reach communities underserved by current media.

➢ *"My grandma called it 'the forgetting sickness'. We need words that resonate in every language."*

- **Navigating resources and expert insights**

Participants highlighted the importance of practical guidance in episodes, such as breaking down community programs, financial supports, and referral pathways for easier navigation. Panel discussions with experts (e.g., doctors, researchers, people with lived experience) can further demystify research, treatments, and common misconceptions in plain language.

➢ *"Here's your hub. Skip the paperwork maze and get straight to help."*

➢ *"The 3 Ds, dementia, delirium, depression, sound alike but matter for totally different care plans."*

Question 6: How can lived experience be shared on social media in ways that help challenge the stigma of dementia?

- **Share lived experiences and myth-busting content**

Encourage people to share memories, skills, and everyday joys in ways that invite conversation. Pairing accurate information with real emotion can spark meaningful dialogue and help positive messages travel further through engagement algorithms.

➢ *"Throw me the ball. I'll throw it right back."*

➢ *"Knowledge lands when you add a beat people can hum, then TikTok does the heavy lifting."*

- **Immersive content**

Virtual-reality clips, first-person point-of-view videos, and sensory storytelling can help viewers better understand what cognitive fatigue, confusion, or overstimulation may feel like for someone living with dementia, fostering empathy and reducing judgement.

➢ *"Walk a corridor in my head for 30 seconds. It'll change how you talk to me for life."*

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Moving Forward: Next Steps

Outlined are the following next steps to build on the insights and momentum generated through this year's World Café workshop on the Stigma of Dementia on Social Media. These actions will guide our continued collaboration with community partners, people with lived experiences, and researchers.

- **Workshop Dissemination Video**: A short video summarizing key themes, participant insights, and workshop goals is to be developed. Once completed, it will be shared with workshop participants, stakeholders, and partner organizations.

- **Biannual Newsletters**: We will continue producing biannual newsletters to highlight workshop outcomes, share research updates, and communicate upcoming opportunities for involvement with the PHARR center. The most recent PHARR newsletter (Summer 2025) can be accessed here:
    - https://pharr.trubox.ca/wp-content/uploads/sites/2712/2025/09/PHARR-Newsletter-Final-Summer-2025.pdf

- **Workshop Report**: This document serves as the formal report of the *Stigma of Dementia on Social Media* workshop. It provides a summary of activities, key findings, and recommendations for advancing this work.

- **Journal Article**: A journal article will be developed to share the workshop findings, including themes and actions identified through the World Café discussions. This article will emphasize the role of social media as both a source of stigma and an opportunity for change.

- **Research Grant Submission**: We will identify and pursue research funding opportunities to support the next phase of work emerging from the workshop. Securing funding will allow us to continue collaborating with people with lived experience and advance stigma reducing initiatives, as well as future research activities.

Appreciation

Planning Committee

Interdisciplinary Faculty Members

- Wendy Hulko
- Anila Virani
- Florriann Fehr
- Melba D'Souza
- Mark Rakobowchuk
- Claudia Gonzalez

Community Partners

- Heather Cooke, Alzheimer Society of B.C.
- Jessica Clement, Ashcroft Hub
- Sherry Carroll (Lived Experience)
- Myrna Norman (Lived Experience)
- Marc Viger, Orchard Walk Medical Clinic

Student Trainees

- Adesewa (Ridah) Adeyemi-King, Psychology student, TRU
- Ava Ward, BSc student, TRU
- Dylan Fiske, BSc student, TRU
- Ella Johnson, BSc student, TRU
- Jessica Lam, TRU
- Kevin Bacon, TRU
- Keziah Vogt, BScN student, TRU
- Kiana Mero, Psychology student, TRU
- Maya Kluch-Morrall, BScN student, TRU
- Megan Funk, MSN Graduate student, TRU

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Thank you for your Support!

Michael Smith
**Health
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