

C.A.R.I.N.G



DEMENTIA COLLABORATIVE

Community Advancing Resources and Initiatives
for Nurturing Generations



VISION

ABOUT

We are a diverse team of interdisciplinary experts from the University of Victoria working together with persons with lived experience, care partners, and health and social care providers to enhance quality of life and improve the living environments of people with dementia and their families.

FALL 2024 UPDATE

We're working together to build capacity for interdisciplinary research that supports the quality of life and health of persons living with dementia, their family members, and care providers across diverse community settings with impact locally, regionally, nationally and internationally.

CAPACITY BUILDING TEAM MEETING 1

July 2024 Discussion Summary

WHO WAS THERE ?

- People living with dementia & care partners
- Funders & service providers
- Researchers & trainees

WHAT WAS SHARED?

What is dementia?

Different for everybody

- Physical, emotional, social & cognitive impacts

- Many types, stages & treatments

- Navigating changes

- Behaviours can change all the time & in different contexts

- Hospital settings are not dementia friendly

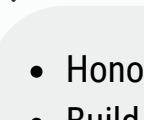
- Impacts community involvement

Frustrating & confusing

- Takes away the things you were most proud of
- Feel lost post diagnosis
- Making decisions about dementia is very complicated
- Heavy discourse in medical terms
- Scary and uncertain path for the individual & family
- Stigma & fear

Built & social environments play a huge role

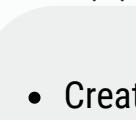
What are dementia friendly communities?



People



Places



Working Together

- Honour every life
- Build social & peer connections
- Provide support & coaching
- Engage people with lived experience as leaders
- Start with respect, enable autonomy & independence

- Have welcoming green spaces, benches on every block, clear consistent signage, public bathrooms
- Build supports at neighbourhood level
- Provide safe transportation options
- Provide programs within community spaces

- Create strong networks of advocates
- Learn from global dementia leaders
- Offer training & accreditation to businesses
- Reduce stigma by providing public education
- Include care homes as part of community

Working together for dementia inclusive communities

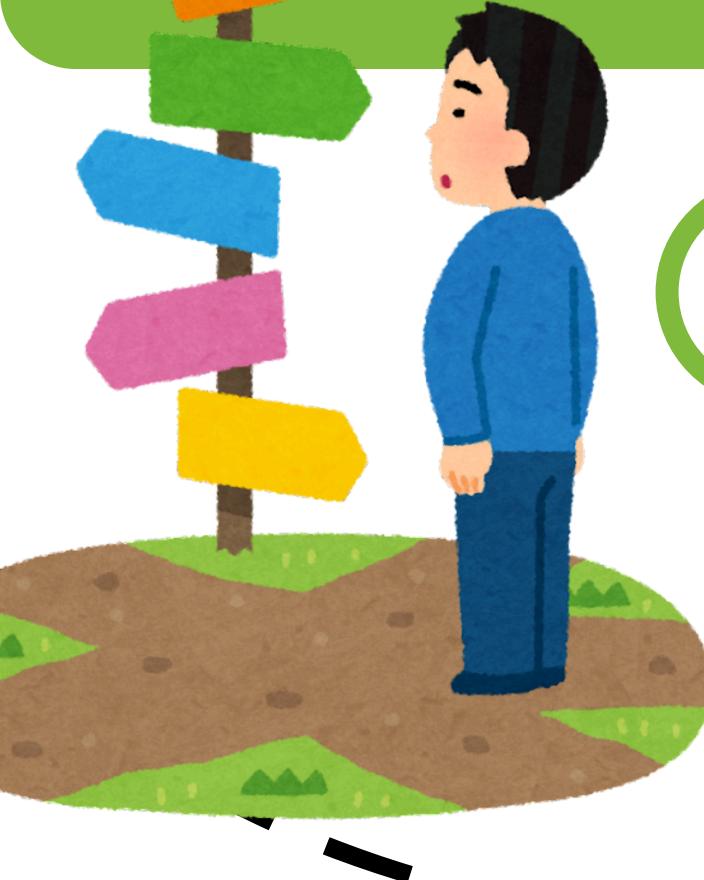
WHAT NEXT?

Listen

and build from there . . .

What is important to people living with dementia?

- Be careful not to use language that may place blame or imply a person hasn't done enough to prevent dementia
- Don't give false hope - what is knowledge vs research
- Emphasize dementia is variable for each person, each day
- Look to other countries and cultures for ideas
- Prioritize dignity and support independence



1

PRIORITY AREAS

Raise Public Awareness

- Grassroots - **hear more from people with dementia**
- Increase **knowledge and understanding** of dementia in the wider world
- It takes a village -neighbourhoods and communities empowered to **co-create culturally responsive** nourishing care and social supports

2

Create Education & Training Resources

- **Public education and intergenerational opportunities** build empathy and decrease stigma
- **Include prevention** - link with other health conditions
- Dementia research **funding to begin address knowledge gaps**
- Develop **knowledge mobilization** systems

3

Coordinate Systems

- **Consistent pathways** for diagnosis, information and ongoing support
- Optimize the built environment to **support all** neurodiverse people
- Authentic, diverse dementia community development - **hub for people to build relationships**

- **Develop options** – memory clinics, center for health aging, rehabilitation and exercise programs, care of care partners
- **Explore alternatives** – funding for care partners, alternative housing/care models

NEXT STEPS



Stay in Touch!

