BUILDING CAPACITY PROJECT

COMMUNICATION CARDS

Building Capacity Project

Communication Cards

First Edition

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Promoting Personhood and Citizenship (royal blue cards)

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Activity Examples

Building Capacity Cards

This beautiful set of 70 cards has been custom-designed and curated to foster thoughtful conversation about dementia, and how to engage people with lived experience of dementia in community. **They are safe conversation starters for a difficult topic.**

Each card features a quote from either someone with lived experience, a care partner, a research team member, or a community service provider. This accompanying book offers further context, meaning, and reflections for each quote, as well as a variety of suggestions for facilitators on how to use the cards in different settings and situations.

There are many ways to structure sessions around these cards. Whether you use "think, pair, share", flip chart activities, "carousels" or another option, you'll also find detailed tips in this book on the kinds of next-level conversations to anticipate.

Groups working through these cards may delve into implications for their context, and it's always good to have a sense of your thoughts on this ahead of time.

You are always, of course, welcome to adapt the suggestions and ideas to meet the needs of your group.

Cards Content

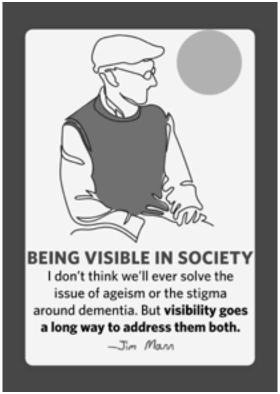
The cards' content falls into five categories:

1.Raising awareness and addressing stigma;
2.Promoting personhood and citizenship;
3.Finding hope, meaning and purpose;
4.Building community capacity; and
5.Engaging people with lived experience.

All five categories are geared towards shifting society's view of dementia away from "disability" towards "a way of living".

We hope you find them helpful!

RAISING AWARENESS CARDS



BEING VISIBLE IN SOCIETY

I don't think we'll ever solve the issue of ageism or the stigma around dementia. But having said that, visibility goes a long way to address them both.

Seeing people with dementia lead and collaborate on community initiatives helps the broader public see for themselves just how much capacity they have.

Reflections

How has personally knowing someone living with dementia shifted your view of the condition?

CO-CREATING CARE: LESSONS FROM THE MEMORY BUDDY PROGRAM

In our Memory Buddy program, we understood **the importance of flexibility, shared decision-making, and the freedom** to co-create programs.

—Thais Lopes

CO-CREATING CARE: LESSONS FROM THE MEMROY BUDDY PROGRAM

In our Memory Buddy program, we understood the importance of flexibility, shared decision-making, and the freedom to co-create programs.

The Kitsilano Neighbourhood House Memory Buddy program taught us that meaningful support emerges when we let go of rigid structures. By embracing flexibility, shared decision-making, and co-creation, we built a program that responded to real needs and honoured everyone's voice.

Reflections

In what ways do you think being flexible with program structure can create more inclusive and responsive experiences for people living with dementia?

What does shared decision-making look like in your work or community?

Have you ever co-created a program or activity with someone living with dementia or their care partner? If so, what made it meaningful or challenging?

DEMENTIA AS A COMMUNITY ISSUE

Dementia is not a single person issue. It's a family, community, and neighbourhood one.

—Myrna Norman

DEMENTIA AS A COMMUNITY ISSUE

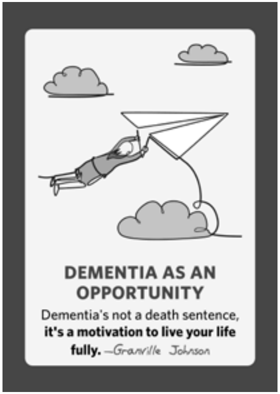
"Dementia is a not a single person issue. It's a family, community, and neighbourhood one."

Taking a community approach to dementia helps us become more supportive, inclusive, and aware. Our interdependence is innate, and we're at our best when we collaborate.

Reflections

How is dementia viewed in your community?

Describe the benefits and downsides to that view.



DEMENTIA AS AN OPPORTUNITY

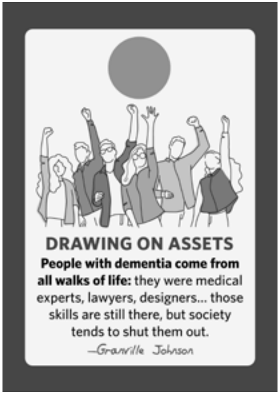
Dementia's not a death sentence, it's a motivation to live your life fully.

It helps to think of dementia as a gift rather than a curse, a chance to get clear about what's really important.

Reflections

How would things in your community shift if suddenly everyone saw dementia as an opportunity?

How would this shift impact your life, and the lives of the people around you?



DRAWING ON ASSETS

People with dementia come from all walks of life: they were medical experts, lawyers, designers... those skills are still there, but society tends to shut them out.

—Granville Johnson

DRAWING ON ASSETS

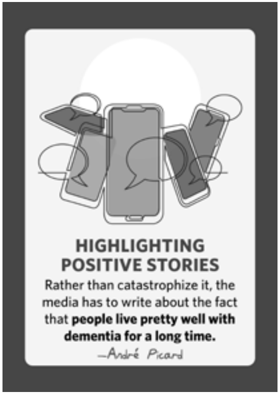
People with dementia come from all walks of life: they were medical experts, lawyers, designers… those skills are still there, but society tends to shut them out.

It helps to assume the best when it comes to capacity, to ask the questions and engage in conversation. More often than not, you'll be pleasantly surprised at what the people around you have to offer.

Reflections

How might you help someone with dementia identify their own personal assets?

How do you go about identifying your own?



HIGHLIGHTING POSITIVE STORIES

Rather than catastrophize it, the media has to write about the fact that **people live pretty well with dementia for a long time.**

—André Picard

HIGHLIGHTING POSITIVE STORIES

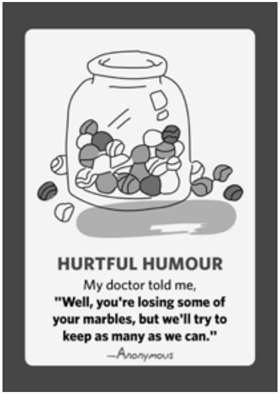
Rather than catastrophize it, the media has to write about the fact that people live pretty well with dementia for a long time.

The truth is: all dementias are different, and people have been known to go on for decades working, teaching and caring for others. Making this common knowledge would go a long way to reduce fear.

Reflections

What examples of this do you have from your own life, and from your community of someone living well with dementia?

If you don’t have any examples, why do you think that might be the case?



HURTFUL HUMOUR

My doctor told me, “Well, you’re losing some of your marbles, but we’ll try to keep as many as we can.”

The use of inappropriate humour when discussing dementia can be experienced as deeply hurtful. It creates an emotionally unsafe environment for someone with dementia to speak out and share their story.

Reflections

How can we work together to educate others on finding more constructive ways to speak about dementia?

What other ways do we perpetuate stigma through humour?

REMOVING SHAME HELPS PERSONAL GROWTH

People carry shame about their fears. If we can show them **fear is ok,** AND we have to walk through it, they'll feel safe to explore why they're scared, and make progress.

—Heather Neale

REMOVING SHAME HELPS PERSONAL GROWTH

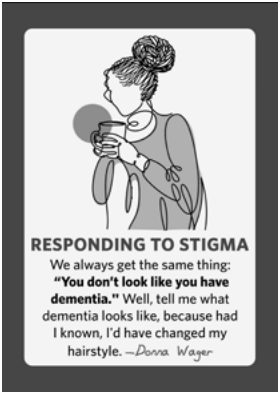
People carry shame about their fears. If we can show them fear is ok, AND we have to walk through it, they'll feel safe to explore why they're scared, and make progress.

If new community partners are fearful of using the word dementia, perhaps we can meet them where they are, remove the shame from their experience, and help them come to see it's safe to learn more about what dementia is really like.

Reflections

What is the fear of dementia all about, really?

If you were to break it down, what would those elements be?



RESPONDING TO STIGMA

We always get the same thing: **"You don't look like you have dementia."** Well, tell me what dementia looks like, because had I known, I'd have changed my hairstyle. —Donna Wager

RESPONDING TO STIGMA

We always get the same thing: "You don't look like you have dementia." Well, tell me what dementia looks like, because had I known, I'd have changed my hairstyle.

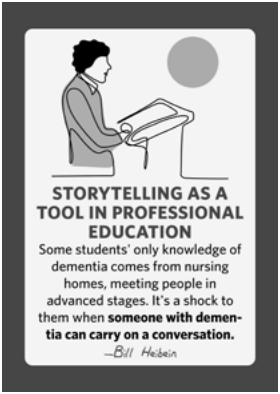
People living with dementia look just like people living without dementia. This invisible condition is steeped in misconceptions we're working to rewrite.

Responding to stigma, rather than staying quiet, holds great power.

Reflections

Why might someone make a comment like this?

And why might it feel stigmatizing, rather than complimentary, to the person with dementia?



STORYTELLING AS A TOOL IN PROFESSIONAL EDUCATION

Some students' only knowledge of dementia comes from nursing homes, meeting people in advanced stages. It's a shock to them when **someone with dementia can carry on a conversation.**

—Bill Heibein

STORYTELLING AS A TOOL IN PROFESSIONAL EDUCATION

Some students' only knowledge of dementia comes from nursing homes, meeting people in advanced stages. It's a shock to them when someone with dementia can carry on a conversation.

While course work and training definitely helps, it's just as--if not more-- important to have real-life interactions with people with dementia in order to understand: to listen to their story, engage, connect, and relate to their experience on a personal level.

Reflections

How can this insight be shared more widely in terms of community support?

In what ways can we introduce storytelling in professional training?

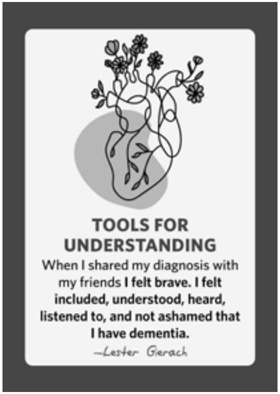
THE POSITIVE POWER OF BEING SEEN

The more people can see I can choose my own apples or operate well in a store, that has an impact. We will never know the impact. But I know it has one.

Having people with lived experience increasingly seen in community impacts not only the community at large in terms of their perception of dementia, but also empowers those with lived experience to feel safe being open about their diagnosis in community.

Reflections

How might seeing more people in community living with dementia impact society's views, and how might it impact the views and perceptions of people with lived experience?



TOOLS FOR UNDERSTANDING

When I shared my diagnosis with my friends **I felt brave. I felt included, understood, heard, listened to, and not ashamed that I have dementia.**

—Lester Gierach

TOOLS FOR UNDERSTANDING

When I shared my diagnosis with my friends I felt brave. I felt included, understood, heard, listened to, and not ashamed that I have dementia.

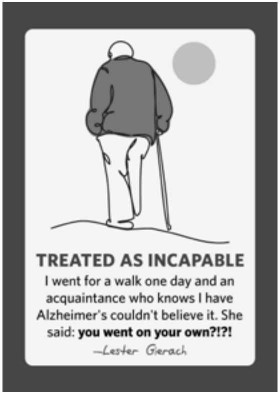
Sharing a dementia diagnosis can be difficult. The more we can raise awareness in community, using tools like the Flipping Stigma Toolkit, the easier it will be for people to come forward to self identify. They will feel more understood.

Reflections

In your community, how many people do you know who have a good understanding of dementia?

How often do you hear people speak about it from a place of fear or misunderstanding?

How can you help to change that?



TREATED AS INCAPABLE
I went for a walk one day and an acquaintance who knows I have Alzheimer's couldn't believe it. She said: **you went on your own?!?!**
—Lester Gierach

TREATED AS INCAPABLE

I went for a walk one day and an acquaintance who knows I have Alzheimer's couldn't believe it. She said: you went on your own?!?!

It's often assumed that because someone has dementia, they're suddenly incapable of being independent. That's just not the case. Everyone benefits when we all grant each other our own humanity and personal agency.

Reflections

How could you respond to someone who assumes you’re incapable of something, in a way that educates them and honours who you are?

TURNING SOMETHING DIFFICULT INTO SOMETHING BEAUTIFUL

Our Action Group decided to create **a toolkit focused on the stigma and discrimination** they faced, and offer it as a gift for others. —Alison Phinney

TURNING SOMETHING DIFFICULT INTO SOMETHING BEAUTIFUL

Our Action Group decided to create a toolkit focused on the stigma and discrimination they faced and offer it as a gift for others.

This action group learned a lot from each other and wanted to share it. They knew speaking up collectively from a place of personal experience could effect positive change. Sometimes difficult things can contribute to something beautiful.

Reflections

Have you had the experience of using a painful experience to help someone else in a similar situation?

What did that feel like?

How could this apply to your organization or community centre?

PROMOTING PERSONHOOD AND CITIZENSHIP CARDS

COMPASSIONATE CURIOSITY

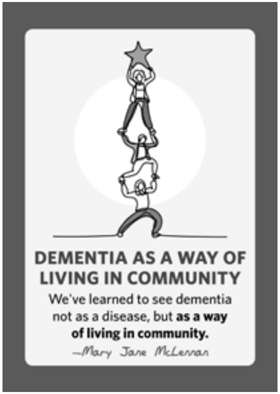
Approach people with dementia with compassionate curiosity. Just listen and show up for them.

A big part of supporting someone is taking their lead: practicing compassion, attuning to their needs and preferences. This cultivates a sense of connection and trust.

Reflections

How can we design and build programs that cater to the specific and unique priorities of the people attending?

How can we apply compassionate curiosity to program design and facilitation?



DEMENTIA AS A WAY OF LIVING IN COMMUNITY

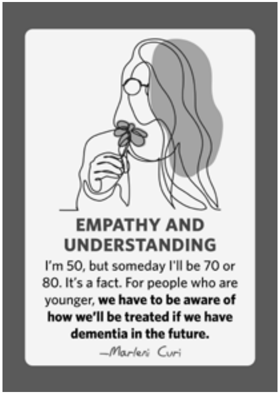
We've learned to see dementia not as a disease, but as a way of living in community.

Thinking about dementia in terms of a way of living in community opens up all kinds of opportunities for people with dementia to feel empowered in their life, to reclaim their personhood.

Reflections

How could your organization support this way of thinking, and help shift old ways of thinking?

What might it take for this change to occur?



EMPATHY AND UNDERSTANDING

I'm 50, but someday I'll be 70 or 80. It's a fact. For people who are younger, **we have to be aware of how we'll be treated if we have dementia in the future.**

—Marleni Curi

EMPATHY AND UNDERSTANDING

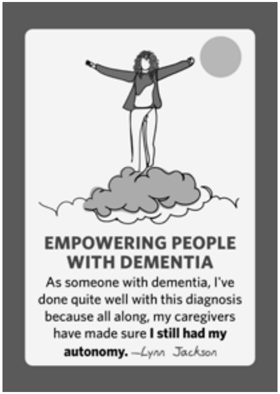
I'm 50, but someday I'll be 70 or 80. It's a fact. For people who are younger, we have to be aware of how we'll be treated if we have dementia in the future.

Thinking about what it might feel like for us to reach that age, receive a diagnosis, and navigate the world helps inform what we do now and how we engage with folks living with dementia.

Reflections

What elements do you think are most important for true understanding and active listening?

How can we ensure people with lived experience feel validated and appreciated?



EMPOWERING PEOPLE WITH DEMENTIA

As someone with dementia, I've done quite well with this diagnosis because all along, my caregivers have made sure **I still had my autonomy.** —Lynn Jackson

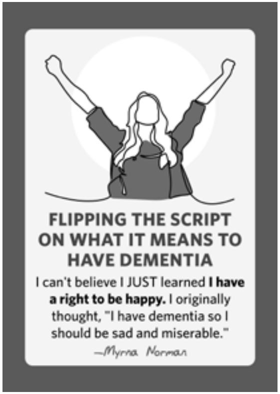
EMPOWERING PEOPLE WITH DEMENTIA

As someone with dementia, I've done quite well with this diagnosis because all along, my caregivers have made sure I still had my autonomy.

Giving people with dementia their autonomy looks like waiting until they ask for help rather than assuming they can't do something for themselves.

Reflections

What kinds of words and phrases could you use to communicate your support for someone while not taking over?



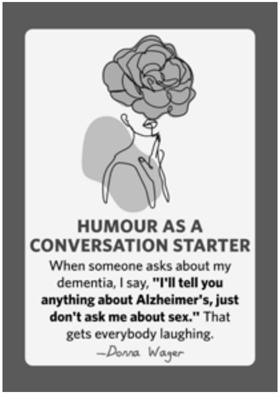
FLIPPING THE SCRIPT ON WHAT IT MEANS TO HAVE DEMENTIA

I can't believe I JUST learned I have a right to be happy. I originally thought, "I have dementia so I should be sad and miserable."

Can you imagine how many people with dementia would blossom and how much love and joy and excitement would come into their lives if they knew they could be happy? If they knew they had every right to be?

Reflections

How can program facilitators and service providers flip the script around what it means to be a person in the world living with dementia?



HUMOUR AS A CONVERSATION STARTER

When someone asks about my dementia, I say, **"I'll tell you anything about Alzheimer's, just don't ask me about sex."** That gets everybody laughing.

—Donna Wager

HUMOUR AS A CONVERSATION STARTER

When someone asks about my dementia, I say, “I’ll tell you anything about Alzheimer’s, just don’t ask me about sex.” That gets everybody laughing…

This humourous approach to questions on dementia helps remind others that no one loses their personhood when they are diagnosed. They are still themselves. They can still laugh and have fun!

Reflections

What approaches and strategies do you have in place within your organization that ensure fun and joy are always incorporated?

I AM HERE

We really have to fight not only for ourselves but for our very humanity. **We have to get people to understand we are still here.**

—Granville Johnson

I AM HERE

We really have to fight not only for ourselves but for our very humanity. We have to get people to understand we are still here.

People with dementia are often written off as no longer useful when they are still capable of so much.

Reflections

How can we help someone with dementia regain their sense of self?

JUDGED BY OTHERS

One of the biggest challenges people with dementia face is not their diagnosis, but the way they're treated because of their diagnosis.

The label "dementia" causes people to make assumptions and stop talking to the diagnosed person directly, addressing their caregivers instead. We need to shift this tendency as a society.

Reflections

Where can we start to shift perceptions about people with dementia?

Which key players could have the greatest impact in modelling that shift?

MAINTAINING CITIZENSHIP

You don't stop living or being an important member of the community when you receive a dementia diagnosis.

—Andrea Sara

MAINTAINING CITIZENSHIP

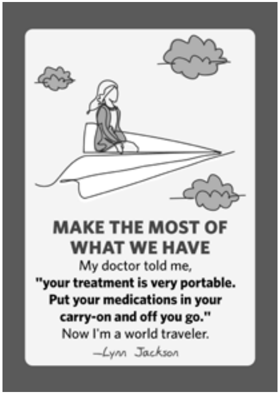
You don’t stop living or being an important member of the community when you get diagnosed with dementia.

Receiving the news of a diagnosis like this feels different for everyone, but it doesn’t take away from your identity, your accomplishments, your interests, or your value in community. You are always important.

Reflections

How can we ensure that individuals facing such diagnoses continue to feel significant and supported?

How can we maintain their social citizenship?



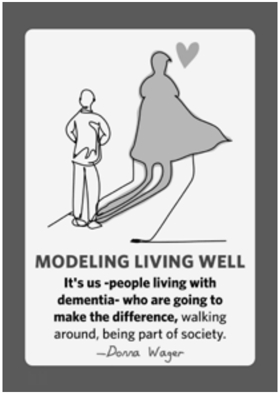
MAKING THE MOST OF WHAT WE HAVE

My doctor told me, "your treatment is very portable. Put your medications in your carry-on and off you go." Now I'm a world traveler.

Too often when people get diagnosed, the message conveyed to them is that their life is over. They are prescribed "disengagement" when they could be much better advised to “get out there and live!”

Reflections

How could we change the messages people hear in doctor’s offices when they’re first diagnosed?



MODELING LIVING WELL

It's us -people living with dementia- who are going to make the difference, walking around, being part of society.

—Donna Wager

MODELING LIVING WELL

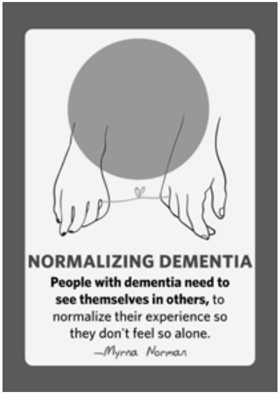
It’s us who are going to make the difference, walking around, being part of society.

Having the experience of meeting people walking, talking and living well with dementia takes the theoretical into the actual. It makes those living with dementia real people in the minds of the broader community.

Reflections

How have you incorporated people living with dementia in your programming, and program planning?

What has been the impact of that representation on others in your organization?



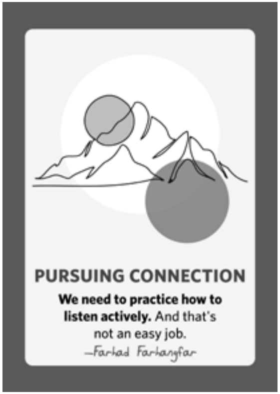
NORMALIZING DEMENTIA

People with dementia need to see themselves in others, to normalize their experience so they don’t feel so alone.

We all need a sense of shared experience to feel connected to others. It’s a human need.

Reflections

How are people with dementia represented and included in your programming?



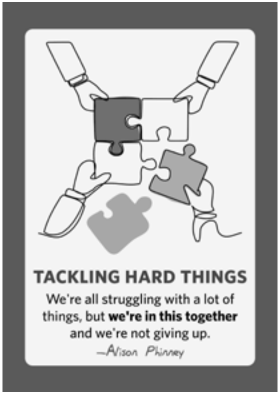
PURSUING CONNECTION

We need to practice how to listen actively. And that’s not an easy job.

Active listening helps the other person see we aren’t there to judge. We really want to connect and understand their experience.

Reflections

How can we apply the idea of actively listening at an organizational level?



TACKLING HARD THINGS

We're all struggling with a lot of things, but we're in this together and we're not giving up.

Tackling an issue in the face of difficulties and obstacles is always easier when you're not alone. Working as a cohesive group builds confidence and momentum.

Reflections

Name something you have overcome in a group setting that would have been much harder to handle alone.

How did the experience change you?

What did you learn?

FINDING HOPE, MEANING AND PURPOSE CARDS

ACKNOWLEDGING GRIEF

As a care partner, I sat with my pain, fear, and anger, **all feelings I needed to feel.** Because this is a grieving process that goes on for years. —Karen Rolston

ACKNOWLEDGING GRIEF

As a care partner, I sat with my pain, fear, and anger, all feelings I needed to feel. Because this is a grieving process that goes on for years.

As caregivers, it's important that we acknowledge our own feelings and manage them with support so we can show up fully present and attentive for the person for whom we care.

Reflections

What outlets can you draw on to support you through your feelings, so you can continue to connect to your purpose and maintain a sense of hope and meaning?

ACKNOWLEDGING OUR FEAR

Recognizing and accepting our fear will continue to be an important part of this journey.

Embracing fear as a natural response to this journey is an act of self compassion and acceptance. Granting ourselves the grace to experience all our emotions without judgment or criticism allows us to navigate change with greater resilience.

Reflections

How can we encourage self compassion and acceptance in those living with dementia?

What would help to normalize the experience?

ART AS A VEHICLE FOR CHANGE

The arts are a powerful way to emotionally connect with the public, and emotional connection is where attitudinal change begins.

Art is a powerful vehicle for shifting perceptions and shaping culture. And it’s one way of letting your voice be heard when the words themselves might be too hard to say. Expressing ourselves through art gives us an opportunity to share a deeper truth about our humanity free of labels, diagnoses, or categories. It’s an act of courage and a gift to others at the same time.

Reflections

Have you created a piece of art, poetry, music, or dance that has helped you to express yourself?

What did that feel like?

CONTRIBUTING IN MEANINGFUL WAYS

When I was diagnosed, I worried I wouldn’t be productive anymore. But I’m doing something everyday to improve lives around me. That feels good.

Ensuring opportunities for people with lived experience to drive/lead/collaborate on programming models builds capacity and a sense of meaning and purpose in the lives of everyone involved.

Reflections

What makes you feel you're contributing in meaningful ways?

How might you apply this to programming for others?

CREATIVE ENGAGEMENT

Offering opportunities to be creatively involved can help us disentangle some of the challenges we're facing.

Whether it's capacity issues or stigma, the creative outlet really helps us pull together and solve problems.

Reflections

Can you think of an example from your own life of a time when using a creative outlet helped clarify or resolve your feelings on something?

DEMENTIA AS AN EXPANSIVE HUMAN EXPERIENCE

If the world could see dementia as a call to arms rather than a death sentence- we could appreciate everything from the special occasions to the everyday realities at once.

Reimagining dementia is the work our society needs to do first and foremost. People with lived experience, carers, researchers and advocacy organizations can help shape world views on dementia for future generations, helping to normalize it and reduce the associated fear.

Reflections

What do you see as having the greatest impact on changing perceptions in society?

What would help most?

What happens when we take away the ‘limits’ society imposes on people with dementia?

DOING WITH, NOT FOR

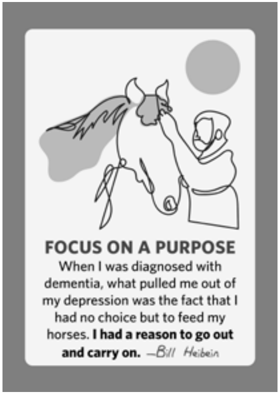
Many were excited to do something for people with dementia. But it was mostly planning FOR them. People with dementia weren’t part of the conversation.

When people with dementia are part of the planning and program design, the program has a much better chance of serving the clientele for whom it’s intended.

Reflections

What has been your experience with planning with people with dementia?

What did you all learn from the process?



FOCUS ON A PURPOSE

When I was diagnosed with dementia, what pulled me out of my depression was the fact that I had no choice but to feed my horses. **I had a reason to go out and carry on.** —Bill Heibein

FOCUS ON A PURPOSE

When I was diagnosed with dementia, what pulled me out of my depression was the fact that I had no choice but to feed my horses. I had a reason to go out and carry on.

Sometimes, adaptations can be made to support the engagement of someone living with dementia in the activities and passions that they have always enjoyed.

We need to move away from all-or-nothing thinking, and get curious about how we can make workable adaptations.

Reflections

What keeps you motivated?

How do you contribute to motivating others?

HOPE

Enabling people with dementia requires concrete actions: valuing our personage, treating us with the dignity we deserve, and helping us learn we have hope!

Hope, dignity, and personhood are basic human needs. They don't differ with a dementia diagnosis.

Reflections

What gives you a sense of hope?

How can you help foster that in others?

What are you hopeful for in the future?

ON CHOOSING JOY AND PURPOSE

We can be joyful, sad, happy or miserable, it's all up to us. We're responsible to take our dementia and **make it the best experience we can.** —Myrna Norman

ON CHOOSING JOY AND PURPOSE

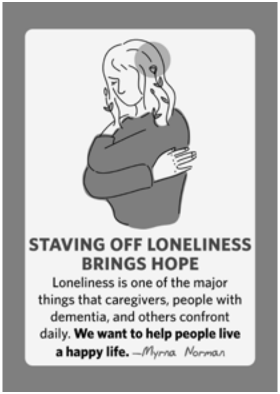
We can be joyful, sad, happy or miserable, it’s all up to us. We’re responsible to take our dementia and make it the best experience we can.

Why? Because we don’t have a choice-we’re living with this diagnosis, and it’s what we do with it--how we respond--that matters. That’s how we give our lives meaning.

Reflections

Connecting to a purpose helps all of us live happier, more balanced and meaningful lives.

How can we use this information to strengthen the community supports for those with lived experience of dementia?



STAVING OFF LONELINESS BRINGS HOPE

Loneliness is one of the major things that caregivers, people with dementia, and others confront daily. **We want to help people live a happy life.** —Myrna Norman

STAVING OFF LONELINESS BRINGS HOPE

"Loneliness is one of the major things care givers, people with dementia, and others confront daily. We want to help people live a happy life."

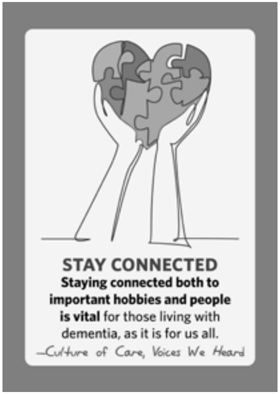
Connecting and engaging in community is one of the best ways to feel less lonely and alone in the world. Feeling that connection fosters belonging and a sense of hope.

Reflections

How and to whom are you connected in community?

What does that group/club/activity add to your life?

How can you offer connection and engagement to others?



STAY CONNECTED

Staying connected both to important hobbies and people is vital for those living with dementia, as it is for us all.

Maintaining connections offers a sense of purpose and belonging for people with dementia. Engaging with others not only reduces isolation and loneliness but also stimulates cognitive and emotional well-being.

Reflections

What specific community programs and services in the area stand out for you as being especially great at engaging people living with dementia?

What are they doing differently than other similar groups?

THE BEAUTY OF CONNECTION

When people walk through those doors, **we don't need to know their diagnosis.** They just come in, have a cup of coffee, and meet friends.

—Bill Heibein

THE BEAUTY OF CONNECTION

When people walk through those doors, we don't need to know their diagnosis. They just come in, have a cup of coffee, and meet friends.

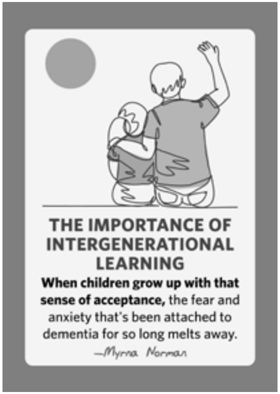
Social activities like dementia cafes are a great opportunity for people in the community to witness for themselves how important connection is for overall well being. That's true for everyone, diagnosis or not.

Reflections

What kinds of social activities are available in your area that are inclusive of people with dementia?

If you don't know of any, who could you call to ask?

Where could you create something new that gives people a chance to connect?



THE IMPORTANCE OF
INTERGENERATIONAL
LEARNING

When children grow up with that sense of acceptance, the fear and anxiety that's been attached to dementia for so long melts away.

—Myrna Norman

THE IMPORTANCE OF INTERGENERATIONAL LEARNING

When children grow up with that sense of acceptance, the fear and anxiety that's been attached to dementia for so long melts away.

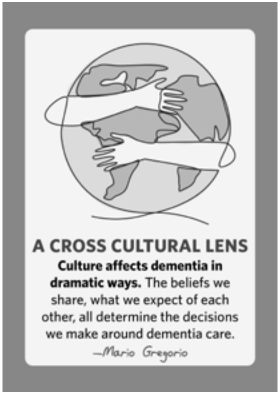
The more we know, the less frightened we feel, and the easier it is to live our lives with purpose and meaning.

Reflections

What first shaped your perspective on dementia, and how has it changed since?

What (or who) contributed to the change?

BUILDING COMMUNITY CAPACITY CARDS



A CROSS CULTURAL LENS

Culture affects dementia in dramatic ways. The beliefs we share, what we expect of each other, all determine the decisions we make around dementia care.

—Mario Gregorio

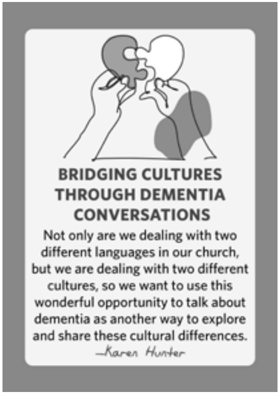
A CROSS CULTURAL LENSE

Culture affects dementia in dramatic ways. The beliefs we share, what we expect of each other, all determine the decisions we make around dementia care.

These cultural nuances can influence whether individuals seek professional help, opt for traditional remedies or rely on familial support networks. Acknowledging these differences is vital for providing effective care and support, leading to better outcomes along the dementia journey.

Reflections

How can community organizations and service providers account for and become more conscious of these diverse lenses and how they impact the ways in which people look for and engage with support?



BRIDGING CULTURES THROUGH DEMENTIA CONVERSATIONS

Not only are we dealing with two different languages in our church, but we are dealing with two different cultures, so we want to use this wonderful opportunity to talk about dementia as another way to explore and share these cultural differences.

—Karen Hunter

BRIDGING CULTURES THROUGH DEMENTIA CONVERSATIONS

Not only are we dealing with two different languages in our church, but we are dealing with two different cultures, so we want to use this wonderful opportunity to talk about dementia as another way to explore and share these cultural differences.

Cultural diversity enriches communities, turning conversations about dementia into profound exchanges on aging, memory, and care. Instead of viewing cultural differences as barriers, we embrace them as pathways to deeper understanding and connection.

Reflections

In what ways might cultural perspectives shape how dementia is understood and approached in your community or organization?

How can we create inclusive spaces where diverse cultural experiences with dementia are shared and valued?

BUILDING AN INCLUSIVE CONGREGATION

By understanding how different groups and cultures react to dementia, we can help shape responses that benefit everyone.

Taking a culturally sensitive, approach to learning about dementia and those living with it goes a long way to preventing unnecessary pain and emotional damage.

Reflections

How could we make dementia-focused programs more culturally inclusive?

BUILDING INCLUSIVE COMMUNITIES

"The most important support is the one from communities we're already a part of."

The people who know us best are the ones most likely to invest in our wellbeing. Looking close to home for supports can be as big as asking family for respite, or as small as frequenting the same coffee shop and talking to the same barista each morning.

Reflections

Who do you see throughout your week, and who, of those people, is inclusive and supportive of the person you care for?

How could you foster a greater sense of support for yourself and your family or organization?

CONSIDER ADVOCACY

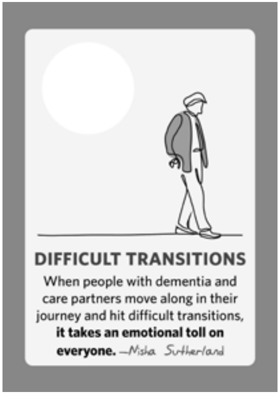
We need advocates in every community, showing us what it looks like to live a good life, to be productive.

Advocates with lived experience have become an indispensable voice of validation and support for people living with dementia, bringing energy, compassion, and a deep love for reminding people of their own strength and value.

Reflections

Think of people who’ve advocated for a cause close to your heart.

What aspect of their work did you feel inspired by, what aspect of their work interested you, motivated you to get involved?



DIFFICULT TRANSITIONS

When people with dementia and care partners move along in their journey and hit difficult transitions, **it takes an emotional toll on everyone.** —Misha Sutherland

DIFFICULT TRANSITIONS

When people with dementia and care partners move along in their journey and hit difficult transitions, it takes an emotional toll on everyone.

It’s important to acknowledge that this is one of the realities in dementia care, and we need to be mindful of looking after ourselves while supporting others in order to keep our capacity and our own wellness thriving.

Reflections

What could you incorporate into your programming to account for this reality?

How might your organization offer support in these difficult moments of transition?

FINDING LIKE-MINDED PEOPLE

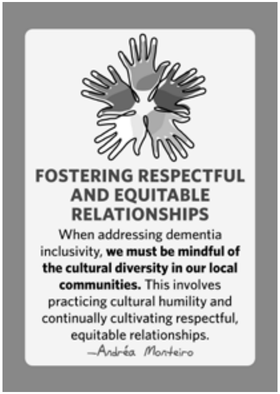
Advocacy can't be all on one person's shoulders.

Finding like-minded people who are passionate about the same things you are helps build momentum and confidence. When like-minded folks come together, sharing a common goal, it creates a synergy that propels advocacy forward.

Reflections

Brainstorm a list of people you know who share your ideals, values, and goals.

What one thing could you do today to help make life more engaging for people with dementia in your community?



FOSTERING RESPECTFUL AND EQUITABLE RELATIONSHIPS

When addressing dementia inclusivity, **we must be mindful of the cultural diversity in our local communities.** This involves practicing cultural humility and continually cultivating respectful, equitable relationships.

—Andréa Monteiro

FOSTERING RESPECTFUL AND EQUITABLE RELATIONSHIPS

When addressing dementia inclusivity, we must be mindful of the cultural diversity in our local communities. This involves practicing cultural humility and continually cultivating respectful, equitable relationships

Dementia care flourishes through relationship building, humility, and respect,

embracing diverse stories and perspectives. In inclusive spaces, each person's identity is valued, mutual respect is upheld, and diverse cultures are celebrated.

Reflections

Why is it important to recognize and value different identities and cultural backgrounds when supporting people with dementia in the community?

How can we celebrate cultural diversity while creating inclusive spaces for people living with dementia and their care partners?

Name three ways to help create respectful and inclusive spaces in your community/organization.

POOLING HUMAN RESOURCES

None of us individually has enough capacity, but pooling our resources and supporting each other, we could really do some great things.

Connecting with community groups who share your goals really helps with forward momentum.

Reflections

Who have you partnered with to achieve a goal that wasn't as easily pursued on your own?

How did things work out? What was the experience like?

SAFE OUTDOOR SPACES

It's important to create inviting outdoor spaces where **people with dementia can feel safe socializing.** —Andrea Sara

SAFE OUTDOOR SPACES

It's important to create inviting outdoor spaces where people with dementia can feel safe socializing.

Finding these spaces supports inclusion, provides a great opportunity to take in fresh air, and it sparks environmental awareness and social engagement.

Reflections

How could your organization incorporate more outdoor opportunities for the community to access?

STRENGTH IN NUMBERS

Bringing a group of people with dementia together, to support and advocate for each other, to share experiences, **offers a sense of strength in numbers.**

—Alison Phinney

STRENGTH IN NUMBERS

Bringing a group of people with dementia together, to support and advocate for each other, to share experiences, offers a sense of strength in numbers.

A group is a wonderful way to connect, foster a shared sense of purpose, and challenge stigma. Individual members feel more resilient as they're lifted up by the power of the group.

Reflections

Reflect on a group you've been part of, whether dementia related or not.

What did the group give you in terms of positive benefits?

How did it enhance/enrich your life?

THE HEART OF PROGRAM DESIGN: JOY, CONNECTION AND SHARED BELIEFS

The secret sauce of program design is seeing the joy on people's faces, their need to be together, and your belief in what you are doing

—Dana Garcia

THE HEART OF PROGRAM DESIGN: JOY, CONNECTIONS AND SHARED BELIEFS

The secret sauce of program design is seeing the joy on people's faces, their need to be together, and your belief in what you are doing.

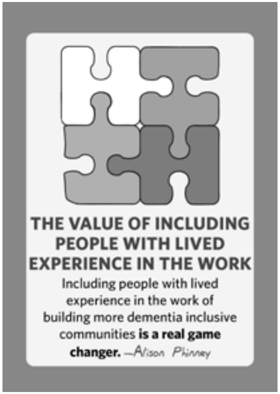
Successful programs extend beyond logistics. They cultivate joyful spaces for deep connections and purpose. They remind us that authentic relationships and meaningful engagement are essential to enriching experiences.

Reflections

In what ways can a program foster a genuine sense of belonging and purpose among participants living with dementia and their care partners?

What strategies can be used to ensure that a program's design aligns with the needs and desires of people living with dementia?

How can program design contribute to a community's capacity for support and inclusivity?



THE VALUE OF INCLUDING PEOPLE WITH LIVED EXPERIENCE IN THE WORK

Including people with lived experience in the work of building more dementia inclusive communities **is a real game changer.** —Alison Phinney

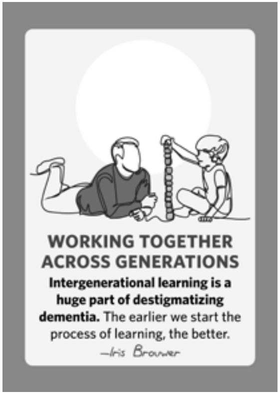
THE VALUE OF INCLUDING PEOPLE WITH LIVED EXPERIRENCE IN THE WORK

Including people with lived experience in the work of building more dementia inclusive communities is a real game changer.

We need to have people with dementia sitting on boards, committees, and in research groups on which they get a real vote in the outcomes of important decisions. They are the foundation of all aspects of positive change.

Reflections

How have you incorporated people with lived experience into your decision making processes?



WORKING TOGETHER ACROSS GENERATIONS

Intergenerational learning is a huge part of destigmatizing dementia. The earlier we start the process of learning, the better.

Talking to children about dementia helps them understand from early on there's nothing to fear about talking to people living with it. This helps eradicate isolation and builds an intrinsic sense of support into the broader community.

Reflections

Where do you see room for more intergenerational programming in your community or organization?

What could that look like?

ENGAGING PEOPLE WITH LIVED EXPERIENCE CARDS

A CAREGIVER'S PERSPECTIVE

Three things that make all the difference when you're a caregiver: 1) Cherish the now, 2) Embrace their world, 3) Accept what is.

—Karen Rolston

A CAREGIVER'S PERSPECTIVE

Three things that make all the difference when you're a caregiver: 1) Cherish the now, 2) Embrace their world, 3) Accept what is.

Try to tune into the person's needs rather than seeing their responses to those needs as resistance or defiance. Being present is a huge part of this.

Reflections

How can we apply “cherishing the now” and being present into program design?

ALTERNATE WAYS OF ENGAGING

When people with dementia lose their ability to communicate in the ways we're used to, **they're taken away from society.**

—Elaine Wiersma

ALTERNATE WAYS OF ENGAGING

When people with dementia lose their ability to communicate in the ways we’re used to, they’re taken away from society.

If we don’t expand our ways of thinking about communication, and our modes for doing so, isolation intensifies leading to increased feelings of depression and hopelessness.

Reflections

What are some alternate ways of tapping into someone’s thoughts, ideas, and feelings if speaking isn’t as easy anymore?

AMPLIFYING DIVERSE VOICES

The arts amplify voices.
Especially the voices of those who may have lost some of the words along the way. —Elaine Wiersma

AMPLIFYING DIVERSE VOICES

The arts amplify voices. Especially the voices of those who may have lost some of the words along the way.

For people with dementia, creative outlets like painting, music, or dance become powerful tools to convey emotions, memories, and experiences that might otherwise remain unspoken.

Reflections

How is your organization using artistic modalities to amplify the voices and priorities of people with lived experience?

If they aren’t, how could they?

CENTERING PRIORITIES OF PEOPLE WITH LIVED EXPERIENCE

We really have to read the people coming into the group, **understand their likes and dislikes.**

—Myrna Norman

CENTERING PRIORITIES OF PEOPLE WITH LIVED EXPERIENCE

We really have to read the people coming into the group, understand their likes and dislikes.

There’s something about the way our services are set up that still favours the voices of the care givers.

Reflections

How have you pivoted or adapted a program or service to meet the needs of someone with lived experience?

How did the change work out?

CENTERING THE VOICES OF
PEOPLE WITH LIVED
EXPERIENCE OF DEMENTIA

In our society, we tend to hear care partners' voices over those of people with dementia. **How do we find ways for those voices to be heard?** —Elaine Wiersma

CENTERING THE VOICES OF PEOPLE WITH LIVED EXPERIENCE OF DEMENTIA

In our society, we tend to hear care partner's voices over those of people with dementia. How do we find ways for those voices to be heard?

There's something about the way our services are set up that still favours the voices of the care givers.

Reflections

How can we change things so the voices of people with dementia are centred when it comes to their care, and their community involvement?

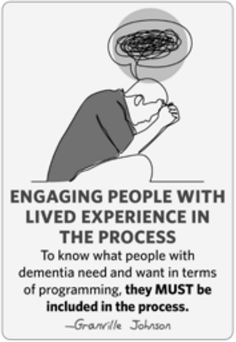
DIFFERING PREFERENCES

Activities are great, and I'm not diminishing them, but sometimes we just want to sit and talk.

Maintaining a sense of flexibility and a willingness to respond to feedback and the needs and priorities of the group is important.

Reflections

As a program facilitator, how do you navigate different priorities coming from different group members?



ENGAGING PEOPLE WITH LIVED EXPERIENCE IN THE PROCESS

To know what people with dementia need and want in terms of programming, **they MUST be included in the process.**

—Granville Johnson

ENGAGING PEOPLE WITH LIVED EXPERIENCE IN THE PROCESS

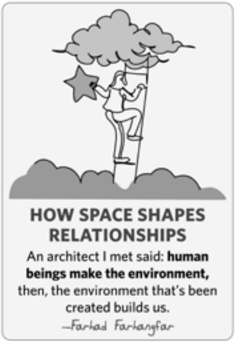
To know what people with dementia need and want in terms of programming, they MUST be included in the process.

Incorporating the voices of people with lived experience into planning and decision-making processes is vital. Their insights and experience tailor initiatives that directly impact their lives to be exactly what they need.

Reflections

If you had the opportunity to rewrite policy around this, what you would say?

How would you restructure things?



HOW SPACE SHAPES RELATIONSHIPS

An architect I met said: **human beings make the environment,** then, the environment that's been created builds us.

—Farhad Farhangfar

HOW SPACE SHAPES RELATIONSHIPS

An architect I met said: human beings make the environment, then, the environment that's been created builds us.

Creating the right kind of space is so important for fostering a sense of belonging and connection.

Reflections

What kinds of space considerations do you incorporate when you're planning a program or club?

What factors might be most important?

LANGUAGE BARRIERS

If we can't speak in the language that people understand, that's a big barrier.

If we don't share a language or have cultural beliefs in common, it's important to find ways to connect and to honour those beliefs.

Reflections

What kinds of things can we do to bridge cultural disconnects or language barriers?

What experiences have you had related to navigating cultural differences or language barriers?

LEARNING FROM PEOPLE WITH LIVED EXPERIENCE

I've learned far more FROM people with lived experience than I have from reading ABOUT them.

Researchers talk about the complementary nature of training and education on one hand, and engaging with people with lived experience on the other. It is both easy and dangerous to lean too heavily on the research alone.

Reflections

Can you talk about the relationship between training and experience?

How does talking with someone with lived experience impact the training you've had, and vice versa?

LISTENING RATHER THAN READING

Sometimes it's difficult to read and have the words actually stay in our brain, but **hearing voices has huge impact.**

—Myrna Norman

LISTENING RATHER THAN READING

Sometimes it's difficult to read and have the words actually stay in our brain, but hearing voices has huge impact.

The power of the Flipping Stigma Toolkit is hearing the voices of people with dementia directly, and the emotional nuance they convey. Hearing the voice of a storyteller is really powerful.

Reflections

How can you apply this knowledge to your programming and the way it's presented to the public?

OVERCOMING FEAR

There's so much fear for so many of us on this care giver journey, but there's still so much we can do.

Many of us hold back from interacting with people with dementia out of fear of not knowing what to say. But silence is a terrible distancer--it pushes people away, makes them question their worth. Starting small even with a light conversation is better than avoiding it altogether.

Reflections

What do you think the fear is about for someone with lived experience?

What about the fear for people in proximity to someone with lived experience?

What might calm this fear?

THERE'S NO PLACE FOR RIDICULE

"Some of the aids at my mother's care home made gestures (circling fingers) to indicate my mother wasn't "all there."

Humour at the expense of someone's condition is cruel, derogatory, and insulting not only to them, but to their family and community.

Reflections

What kind of response could you offer in this situation to make it a teachable moment?`

THE VALUE OF MUSIC

Music can elicit **powerful memories and connections for people living with dementia.**

—Rob Dramer & Lillian Ireland

THE VALUE OF MUSIC

"Music can elicit powerful memories and connections"

Music is deeply tied to memories and experiences. It's a wonderful tool for reaching people who may not be able to communicate verbally. It's also a wonderful tool for connecting people to each other.

Reflections

Can you describe a time you were part of a shared experience created through music?

How did the music trigger that experience?

ACTIVITY SAMPLES

ACTIVITY 1: INTRODUCING THE BCP CARDS

Objective

To introduce the BCP cards as a tool to foster meaningful conversations about dementia, build connections, and promote emotional well-being related to the topic of dementia within community groups and organizations.

Duration

90 – 120 minutes

Materials

- BCP Card deck
- Chairs and tables arranged in a circle
- Whiteboard and markers
- Tea and cookies (optional)

Welcome and icebreaker (15 minutes)
1. Welcome participants and offer a land acknowledgement

2. Share the session's purpose: to create a space for open, reflective dialogue about dementia using the BCP cards

3. Icebreaker activity:
   - Participants introduce themselves
   - Share either:
     One thing they appreciate about their community OR *A personal connection they've had with someone with lived experience of dementia*

Introducing the BCP cards (15 minutes)
1. Explain what the BCP cards are:
   - A deck designed to spark thoughtful conversation, reduce stigma, and build community capacity related to dementia
   - A tool for exploring thoughts, feelings, and personal or community experiences

2. Emphasize that the cards support safe, authentic sharing, where all voices are welcome

Group discussion and card activity (30 minutes)
1. Seat participants in a circle and distribute a card to each person (or allow them to choose, or choose some yourself you feel would be a good fit with your group)

2. Instructions:
   - Each person reads their card aloud (a statement or a question)
   - They then share a thought, feeling, or story that the card brings up

3. Ground rules:
   - Practice active listening
   - Hold space for each voice without interruption or judgment

Sample prompts from the cards:
- How can you establish a safe and inclusive space for people living with dementia?

- How can you contribute to addressing the stigma of dementia?

- How can you communicate dignity and respect when engaging with people with dementia?

Guided reflection (15 minutes)
1. Lead a reflective group discussion

2. Ask participants to consider:
   - What insights or emotions came up during the card sharing?
   - Did any stories or experiences resonate with you personally?

3. Invite a few volunteers to share reflections with the larger group

4. Explore common threads or values that emerged in the conversation

Building connection and community sharing (10 minutes)
1. Open the floor for any additional thoughts or stories people would like to share

2. Invite participants to express appreciation for each other's openness and courage in sharing

3. Highlight how storytelling and listening build stronger, more inclusive communities

Application and action steps (10 minutes)
1. Group brainstorm:
   - How can we apply what we learned today to support people living with dementia in our communities?
   - What small, practical actions could we take to promote inclusion and reduce stigma?

2. Encourage participants to write down one action or idea to take forward

Closing and Appreciation (5 minutes)

1. Summarize the session's key insights and themes

2. Thank everyone for their time, honesty, and engagement

3. Remind participants that creating spaces for meaningful conversation helps build empathy and resilience

Follow-Up

- Share information about relevant community events or opportunities (e.g. focus groups, buddy programs, awareness campaigns, dementia-friendly training, etc.)

- Suggest continued use of the BCP cards in their community/organization, and refer to other resources from the Building Capacity Project (buildingcapacityproject.com)

- Share the Flipping Stigma Toolkit for further engagement with the topic of Dementia (flippingstigma.com)

Evaluation and Notes

- Hand out or email a short evaluation survey
- Have the facilitator complete observation fieldnotes post-session to reflect on: participant engagement, quality of discussion and key themes or needs that emerged

ACTIVITY 2: DEEPENING UNDERSTANDING THROUGH DIALOGUE

Objective
To use the BCP cards within a Think-Pair-Share model to encourage collaborative learning, deepen understanding of dementia-related experiences, and support empathy and connection within community groups or organizations.

Duration
90 – 120 minutes

Materials
- BCP Card deck
- Chairs and tables arranged in pairs or small clusters
- Whiteboard and markers
- Sticky notes, paper and pens
- Tea and cookies (optional)

Welcome and context setting (15 minutes)

1. Welcome participants and offer a land acknowledgement

2. Share the session's purpose: to reflect more deeply on the emotional and social dimensions of dementia through shared stories and conversations

3. Quick icebreaker: Ask participants to pair up and take 2 minutes each to answer: "What is one thing you've learned or unlearned about dementia in your life so far?" Then regroup briefly to share some highlights.

Introducing the BCP cards (10 minutes)

1. Explain the purpose of the BCP cards:
- A tool to spark thoughtful dialogue and reflection on living with or supporting someone with dementia
- Each card includes quotes, reflections, or questions intended to surface meaningful insights

2. Emphasize the focus on compassion, curiosity, and active listening

Think-Pair-Share activity (40 minutes)

Think (10 minutes)

1. Each participant selects a BCP card from the deck

2. Ask them to reflect individually in writing or silence, using guiding questions such as:
- What feelings or memories does this card bring up?
- How does this relate to your understanding or experiences of dementia?
- What might this card reveal about the needs or strengths of people living with dementia?

Pair (15 minutes)

1. Invite participants to share their reflections with their partner

2. Encourage them to listen actively, without interrupting or judging

3. After each person has shared, ask them to write a few words or a phrase on a sticky note that captures the essence of their partner’s insight

Share (15 minutes)

1. Bring the group back together

2. Ask pairs to place their sticky notes on the whiteboard or a large sheet of paper

3. Facilitate a group discussion:

- What themes are emerging from the shared reflections?
- Did any perspectives surprise or inspire you?
- How might this shared understanding influence how we show up for people living with dementia?

Reflection and integration (15 minutes)

1. Lead a guided group reflection

2. Prompts may include:

- What did you learn about yourself or others during this activity?
- What assumptions or biases were challenged for you?
- How might we carry this awareness into our communities or workplaces?

Application and commitment (10 minutes)

1. Invite participants to write one personal commitment or next step on a new sticky note:

- Something they will do, change, or explore further

2. Optionally, form a ‘commitment wall’ with everyone’s notes

3. Brief group share of select commitments (voluntary)

Closing and appreciation (5 minutes)

1. Recap the key takeaways

2. **Acknowledge** the courage and generosity that participants brought to the conversation

3. **Express gratitude** and share follow-up resources or opportunities to stay connected

Follow-up

- Provide a list of local or online initiatives aligned with dementia awareness and support
- Suggest continued use of BCP cards in their community/organization, and link them with other resources from the Building Capacity Project (buildingcapacityproject.com)
- Share the Flipping Stigma Toolkit for further engagement with the topic of Dementia (flippingstigma.com)

Evaluation and notes

- Hand out or email a short evaluation survey
- Have the facilitator complete observation fieldnotes on group dynamics, quality of dialogue, participant engagement and key themes or needs that emerged