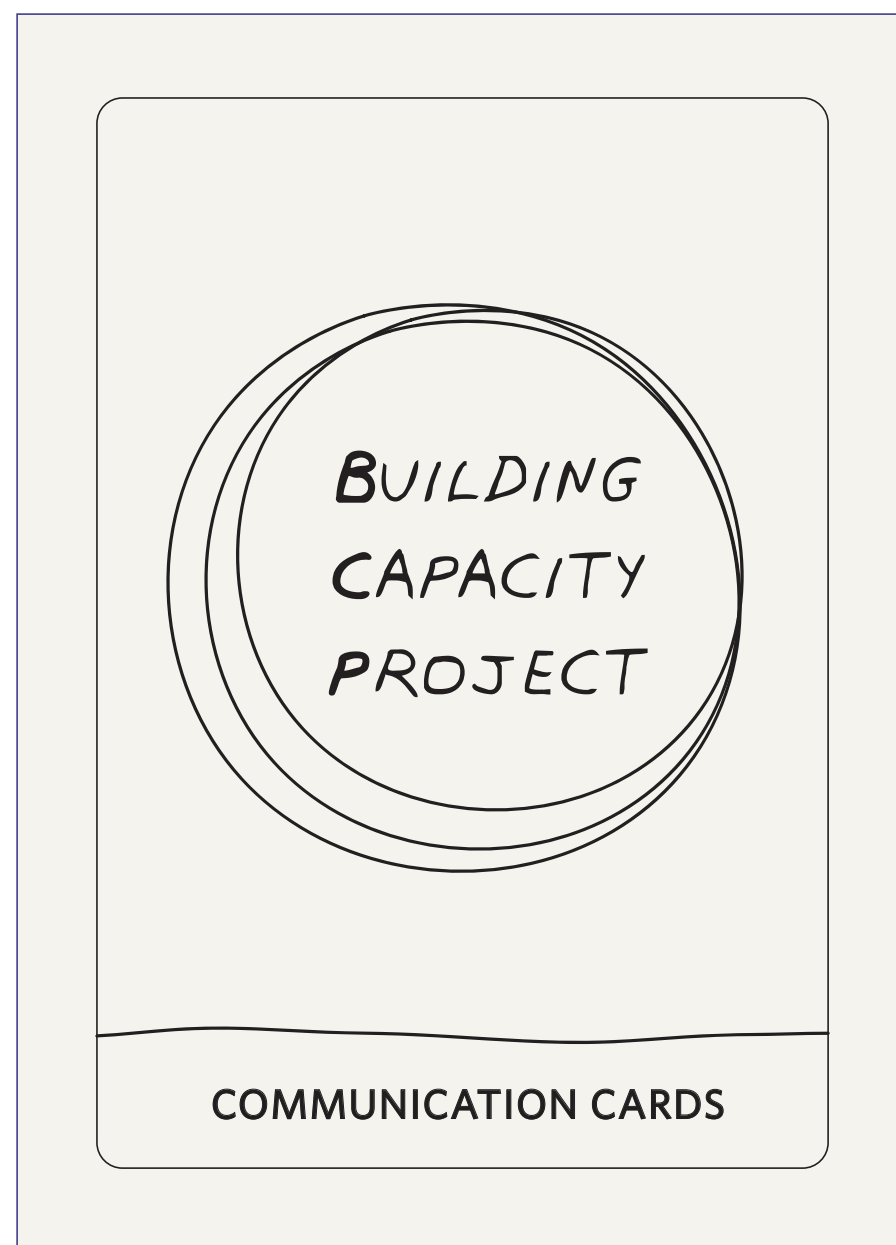





Building Capacity Project

C o m m u n i c a t i o n C a r d s



1




BEING VISIBLE IN SOCIETY
I don't think we'll ever solve the issue of ageism or the stigma around dementia. But **visibility goes a long way to address them both.**
—Jim Mann

2



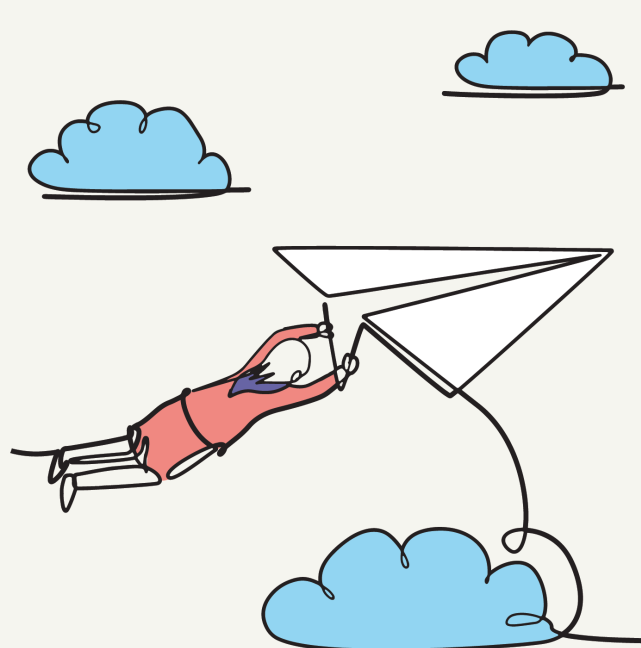
CO-CREATING CARE: LESSONS FROM THE MEMORY BUDDY PROGRAM
In our Memory Buddy program, we understood **the importance of flexibility, shared decision-making, and the freedom to co-create programs.**
—Thais Lopes

3




DEMENTIA AS A COMMUNITY ISSUE
Dementia is not a single person issue. It's a family, community, and neighbourhood one.
—Myrna Norman

4



DEMENTIA AS AN OPPORTUNITY
Dementia's not a death sentence, **it's a motivation to live your life fully.** *—Granville Johnson*

5




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

6



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

7



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."**
—Anonymous

8



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

9



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*

10

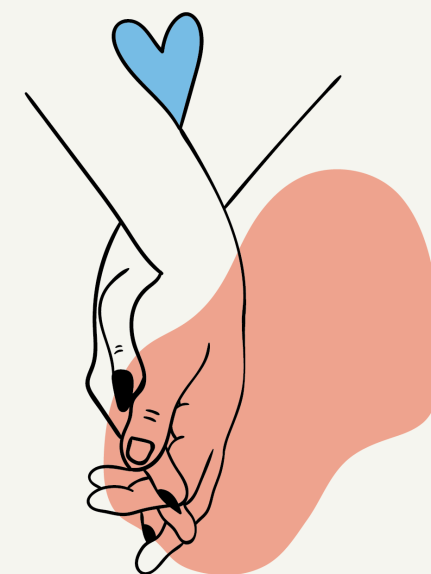


STORYTELLING AS A TOOL IN PROFESSIONAL EDUCATION

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

11



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.

—Jim Mann

12

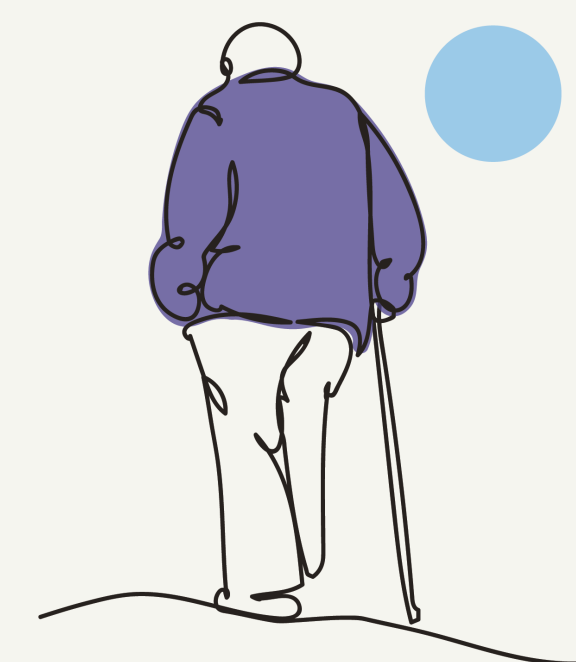


TOOLS FOR UNDERSTANDING

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

13

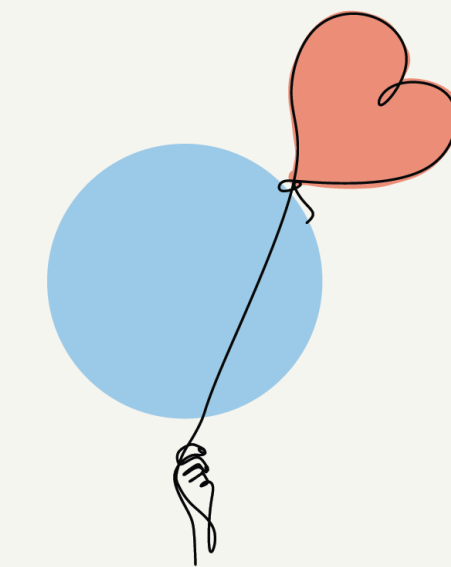


TREATED AS INCAPABLE

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?!?!**

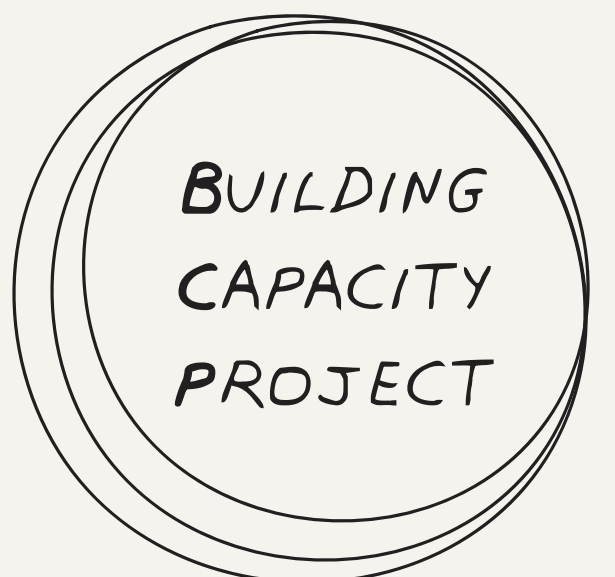
—Lester Gierach

14



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



**BUILDING
CAPACITY
PROJECT**

COMMUNICATION CARDS

15

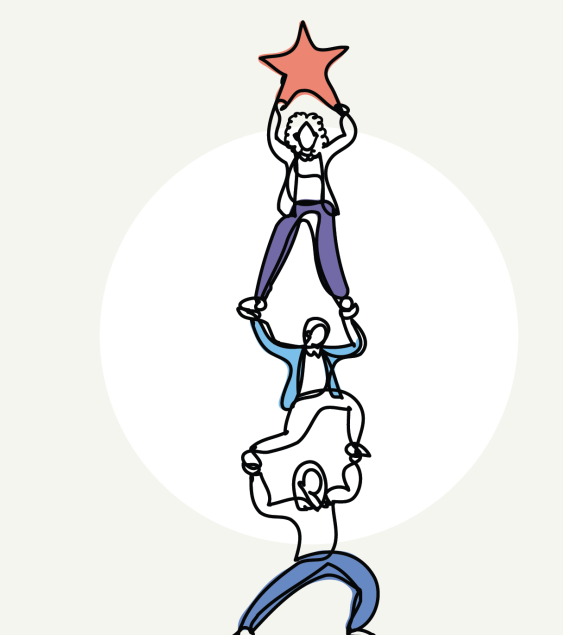


**COMPASSIONATE
CURIOSITY**

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

—Lynn Jackson

16

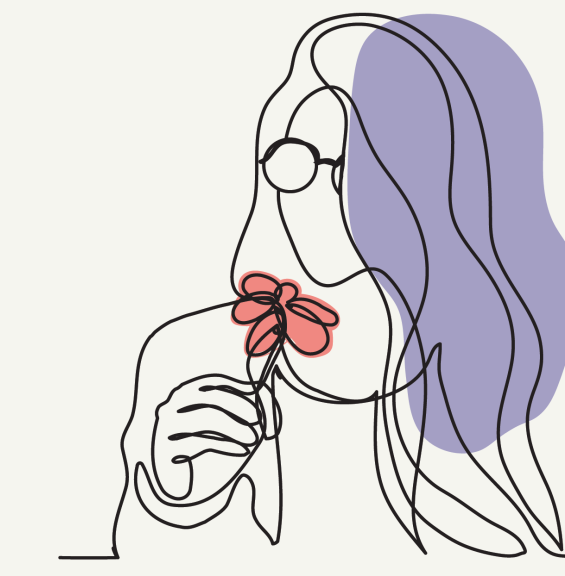


**DEMENTIA AS A WAY OF
LIVING IN COMMUNITY**

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

—Mary Jane McLennan

17



**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

18




**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

19



**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."

—Myrna Norman

20

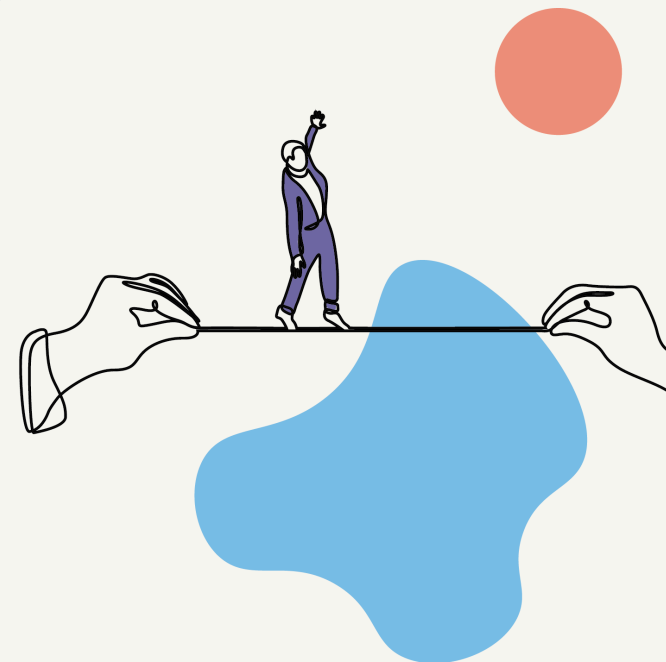


**HUMOUR AS A
CONVERSATION STARTER**

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

21



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

22



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**.

—Elaine Wiersma

23



**MAINTAINING
CITIZENSHIP**

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

—Andrea Sara

24

MAKE 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.
—Lynn Jackson

25

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

26

NORMALIZING DEMENTIA

People with dementia need to **see themselves in others**, to normalize their experience so they don't feel so alone.
—Myrna Norman

27

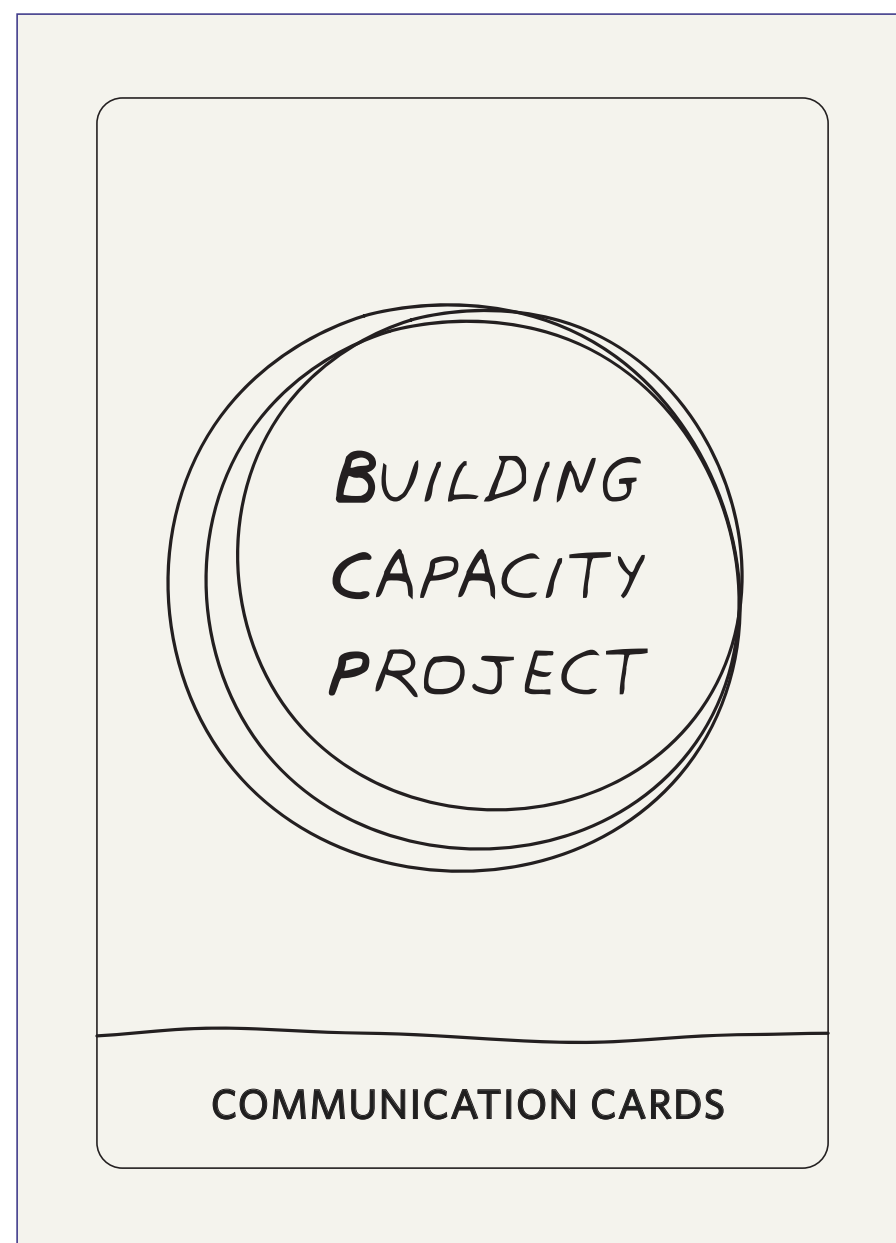
PURSUING CONNECTION

We need to practice how to **listen actively**. And that's not an easy job.
—Farhad Farhangfar

28

TACKLING HARD THINGS

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



29



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

30



ACKNOWLEDGING OUR FEAR

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

31



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.** —Elaine Wiersma

32



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. —Myrna Norman

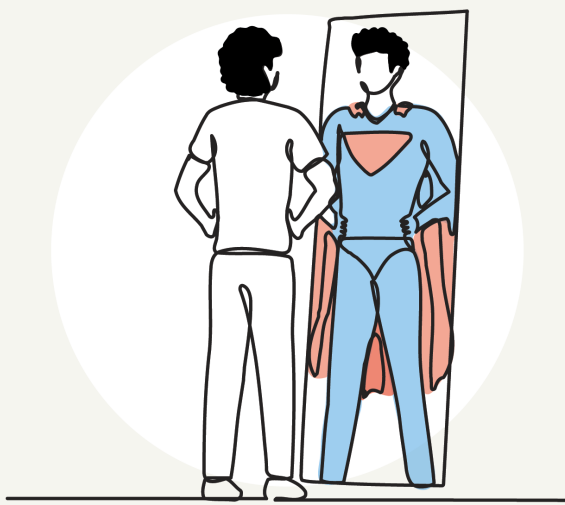
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CREATIVE ENGAGEMENT

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

34



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.** —Granville Johnson

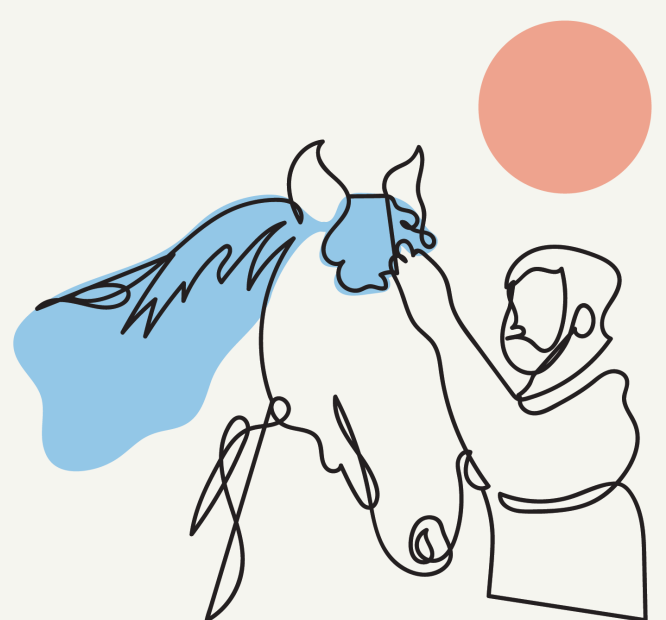
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DOING WITH, NOT FOR

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. —Alison Phinney

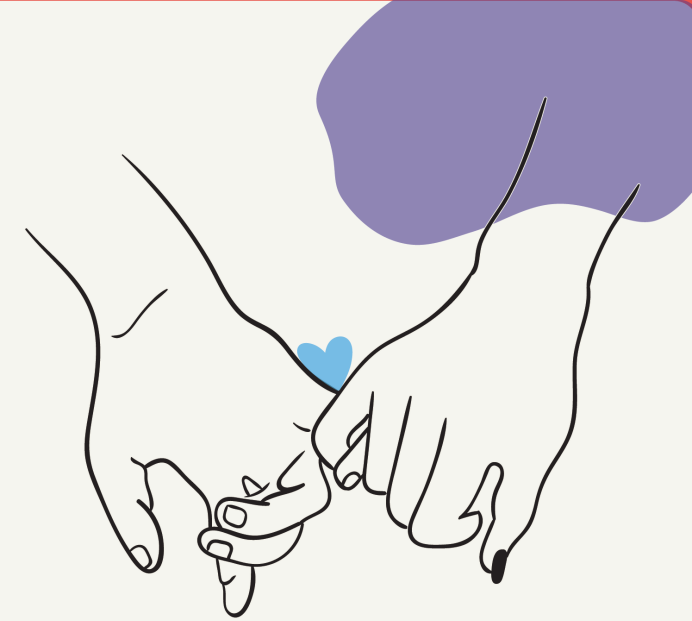
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FOCUS ON A PURPOSE

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 Heibin

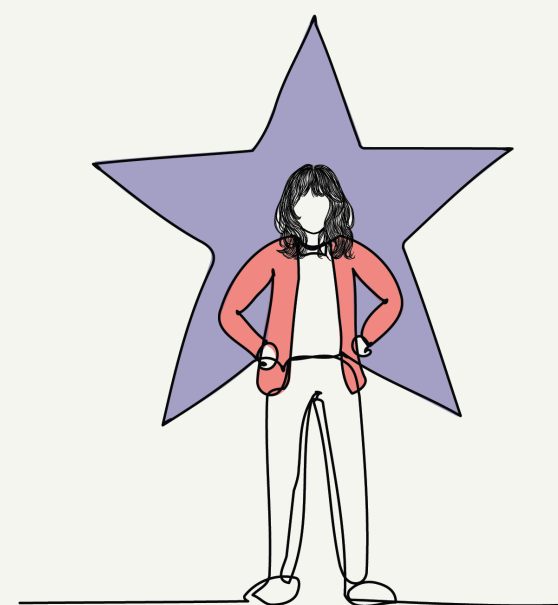
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HOPE

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

38



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

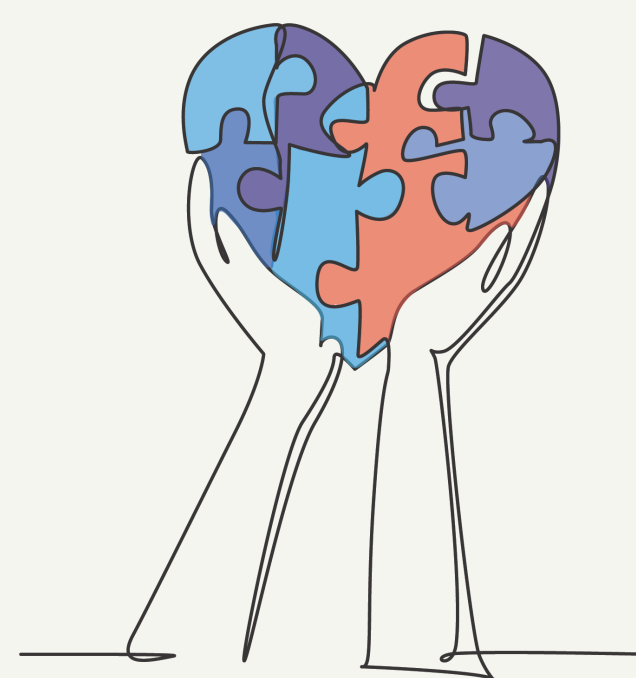
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STAVING OFF LONELINESS BRINGS HOPE

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

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STAY CONNECTED

Staying connected both to important hobbies and people is vital for those living with dementia, as it is for us all. —Culture of Care, Voices We Heard

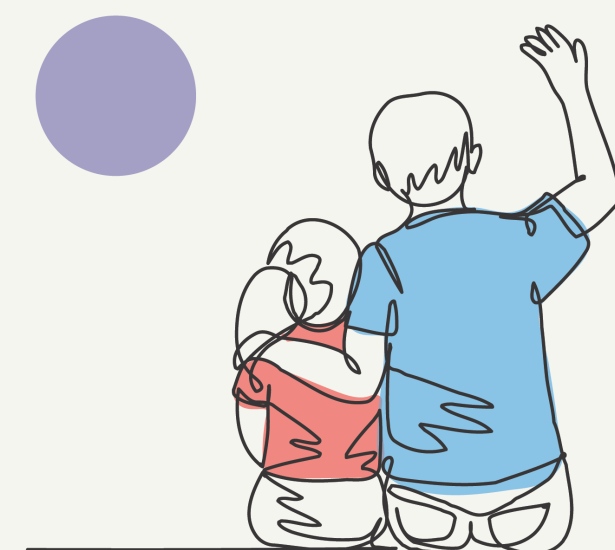
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THE BEAUTY OF CONNECTION

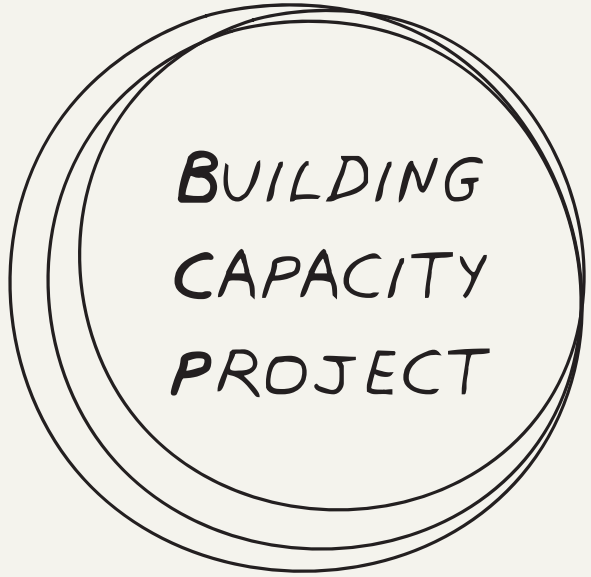
When people walk through those doors, **we don't need to know their diagnosis.** They just come in, have a cup of coffee, and meet friends. —Bill Heibin

42




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



**BUILDING
CAPACITY
PROJECT**

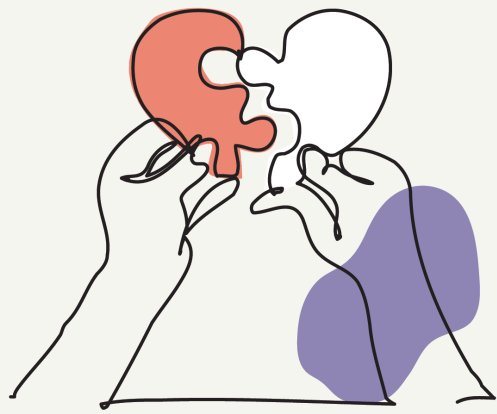
COMMUNICATION CARDS

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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

44

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

45

BUILDING AN INCLUSIVE CONGREGATION

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

—Karen Rolston

46

BUILDING INCLUSIVE COMMUNITIES

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


—Pastor Deborah Lang

47

CONSIDER ADVOCACY

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

—Myrna Norman

48

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.**


—Nisha Sutherland

49

FINDING LIKE-MINDED PEOPLE

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

—Alison Phinney

50

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

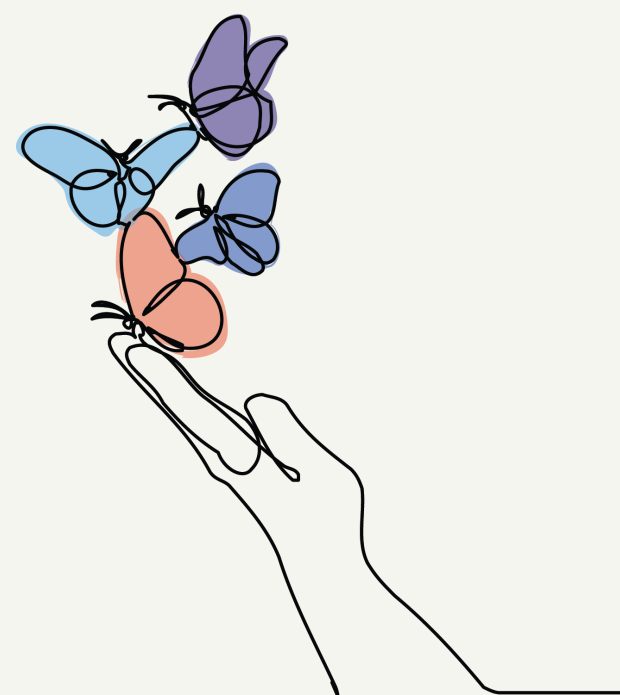
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POOLING HUMAN RESOURCES

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

—Andrea Sara

52



SAFE OUTDOOR SPACES

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

53



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

54

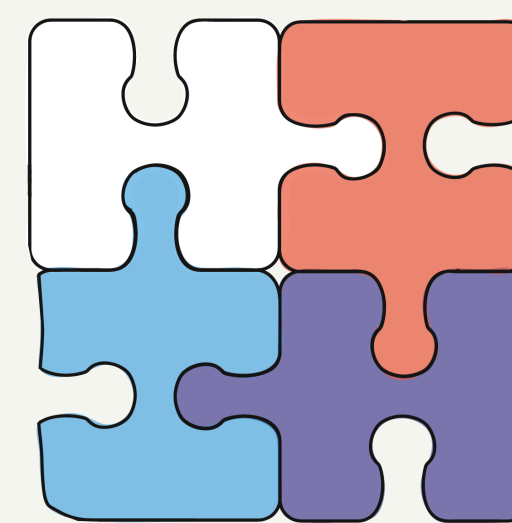


THE HEART OF PROGRAM DESIGN: JOY, CONNECTION AND SHARED BELIEFS

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

—Danna Garcia

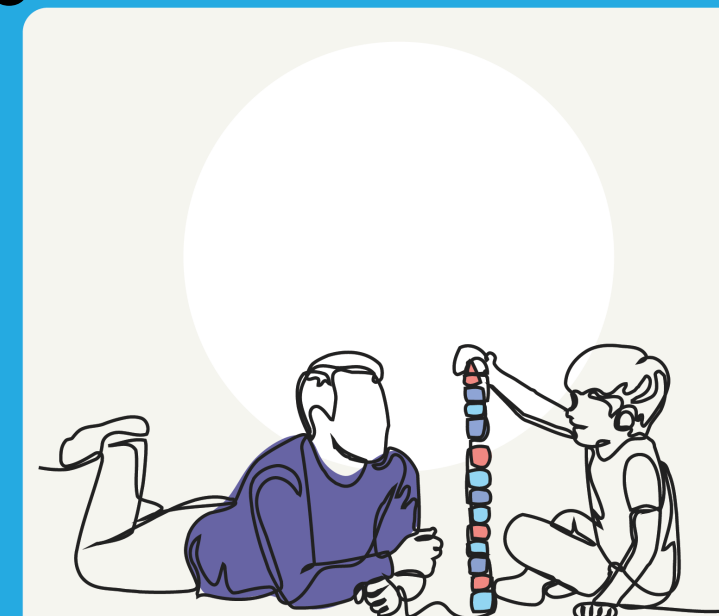
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THE VALUE OF INCLUDING PEOPLE WITH LIVED EXPERIENCE IN THE WORK

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

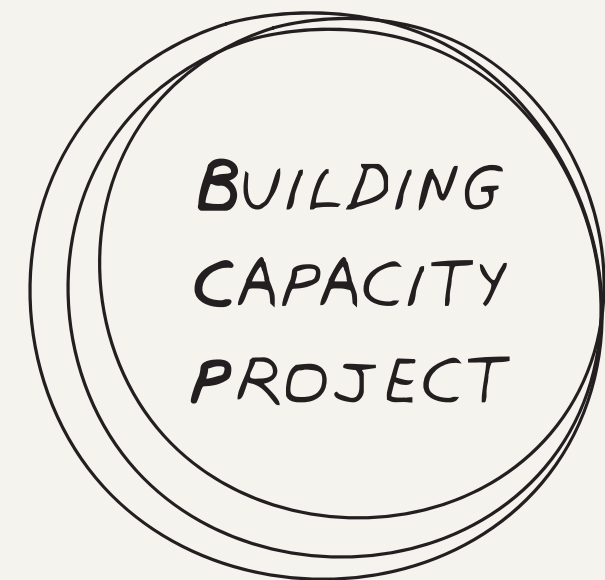
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WORKING TOGETHER ACROSS GENERATIONS

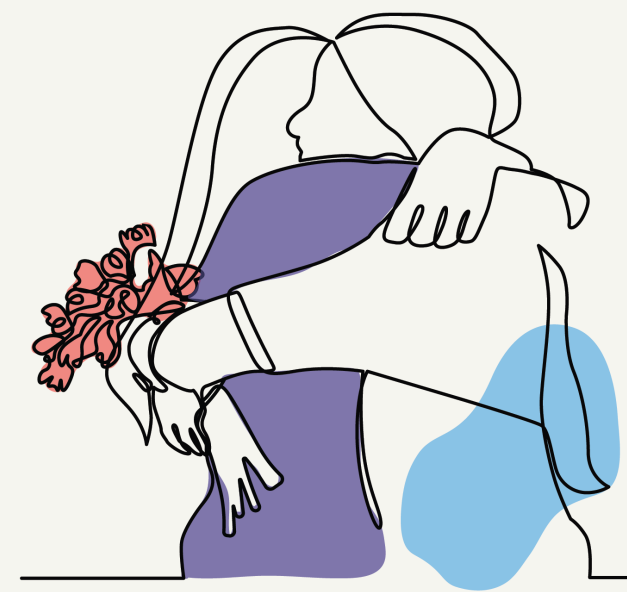
Intergenerational learning is a huge part of destigmatizing dementia. The earlier we start the process of learning, the better.

—Iris Brouwer



COMMUNICATION CARDS

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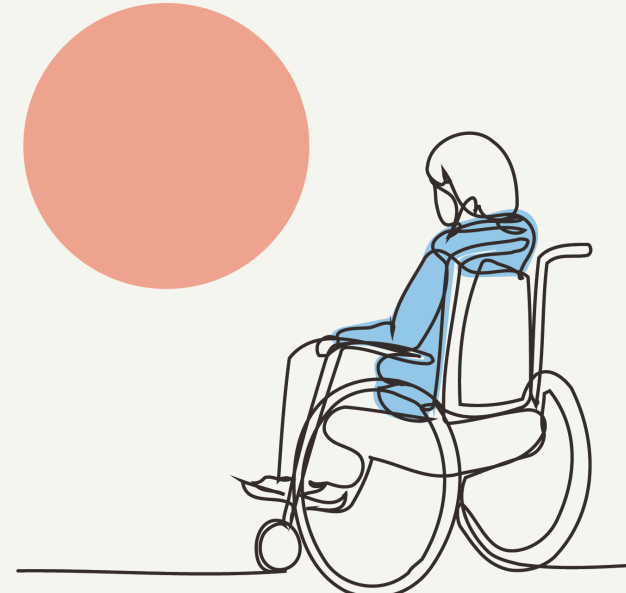


A CAREGIVER'S PERSPECTIVE

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

58



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

59



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

60



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

61



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

62



DIFFERING PREFERENCES

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

—Nisha Sutherland

63



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

64



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

65



LANGUAGE BARRIERS

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

—Mariko Sakamoto

66



LEARNING FROM PEOPLE WITH LIVED EXPERIENCE

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

—Alison Phinney

67

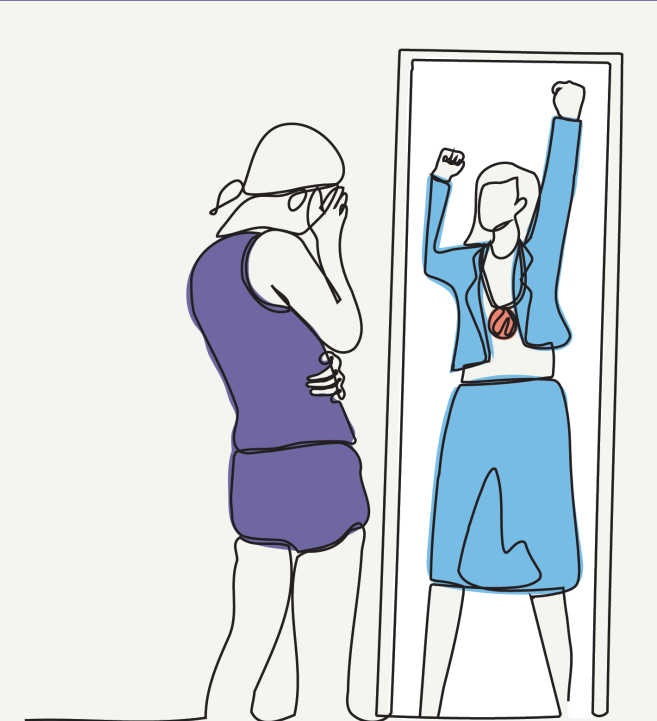


LISTENING RATHER THAN READING

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

—Myrna Norman

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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.**

—Karen Rolston

69

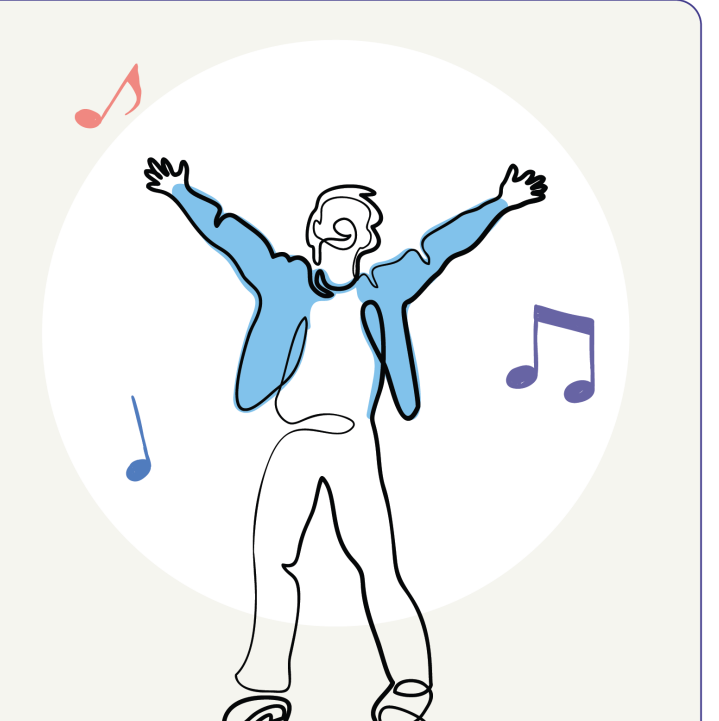


THERE'S NO PLACE FOR RIDICULE

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

—Anonymous

70



THE VALUE OF MUSIC

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

—Rob Dramer & Lillian Ireland