



Reimagining Dementia

A Creative Coalition for Justice

Reimagining Dementia Summary of December 8, 9, and 10 Member Gatherings

What follows is a collection of narratives from the three Reimagining Dementia Coalition gatherings in December 2020, which were attended by 108 members, some 30 of whom were new (the Coalition now has over 410 members from 20 countries). In building on the conversations begun in October, participants explored the essence of the coalition, their own roles in advancing reimagining dementia (both the concept/practice and the Coalition), and what this diverse and passionate community can collectively move forward and maximize its impact. Through a variety of artful and creative presentations, members shared their insights, lived experiences and options, the most salient of which are shared below.

Our Mission

We are an international coalition dedicated to eliminating stigma-related inequities that undermine the principles of a caring and inclusive society, promoting inclusion by using imagination to encourage human flourishing.


We pay attention to the “how” of our work in addition to the content. That “how” will always be creative, always be inclusive, and always come from the bottom up.

We embrace nourishing rituals, expanding our consciousness and expanding ourselves, invigorating communities through creativity and all art forms!

We imagined meeting Oprah Winfrey in an elevator, and what we would say if she asked, “How are you reimagining dementia”:

How are YOU reimagining dementia?

Spreading a new understanding of Love as LUVE (Listened too, Understood, Valued, and Empowered) through the arts, storytelling, and dance!



Going with the flow! Leaving a gift to the next generation as an example of how to face great adversity. We want to be examples of people faced with a disease that can't be cured, showing how to have joy, laughter, and life.

Promoting positive intentions toward all people. Using language to change the way we think. Words make a world; language must be followed by practice! The etymology of the word dementia is "without mind." Do we need to reinvent a new word?

Addressing disparities and racism in dementia care with the hope of eradicating the disparities and challenging stigma.

Learning that we can communicate in new ways--thru music, sound, dance, poetry gibberish and touch—without words and with love.

Appreciating the many lessons we can learn from people living with dementia and the ways of knowing and seeing they contribute to their communities. We appreciate so many forms of diversity; we should appreciate cognitive diversity too!

A poem, sung by a member:

Creativity sparks the story
We are myth poppers
One size doesn't fit all
If you met a person with dementia
You met only one person
It's like a typewriter missing some keys
You hit a key and it opens up a whole lot of memories
A light comes on
The memory happens with music and dance
We talk with our bodies
Every person living with dementia is a person
Singing is a kind of communication that keeps going long after speech

What would we say if Oprah asked:

Why have a Reimagining Dementia coalition?

What does the coalition mean to you?

Our coalition is a knitted vest of questions and perspectives. It is imperfect but perfectly supportive. The shape and pattern represent how we are in relation with each other. Our vest – our coalition – asks the necessary questions and we move forward being comfortable in the unknowing, determined in our intention to shift the conversation and the language surrounding dementia.

One member captured this idea to song:

There's power in numbers
It's a meeting of the minds
Language shapes the world we live in
It's about creating possibilities

So if you want to go quickly, go alone
If you want to go far, go together
If you want to go quickly, go alone
If you want to go far, go together

It's a meeting of the minds
It's a meeting of the minds

Albert Einstein said: “We can't solve problems by using the same kind of thinking that created them.” Gathering together is like getting a new pair of glasses. We see in new ways!

The coalition is a remedy to isolation: a chance to be with others who understand life with dementia. It gives us the inspiration and energy we need to make change.

Reimagining Dementia means the opportunity to discover purpose and meaning in all of our lives.

How can we grow the Reimagining Dementia coalition?

The many wonderful suggestions from the memberships as to how to move the work of the coalition forward will be sent out in a separate document.

Summary

We got to know each other better.

We explored our innate human ability to create.

We shared our roles as individuals and the perspectives we bring to the coalition.

We discovered the magic behind the coalition: simply being together!

We charted a few potential paths and exciting steps forward.

We did important work toward changing the narrative, and we had fun doing it!

And to finish, in the pages below, please find two poems written and shared by members.

Yes, Let's

By Carmela Mulroe

Yes, let's reimagine our way through this tangled mess
that weaves in out of lines that won't hold still causing us
to chase the clouds, that form pictures of what we left behind.

Yes, let's reimagine a shift which challenges all the perceptions
of what it means to forget while holding onto the memory of how
you slighted all the wisdom you should have seen reading in between the lines.

Yes, let's reimagine a new dictionary in which respect, inclusion and acceptance
are the first words leading down the pathway of revolution armed with love,
compassion and empowerment for me, myself and I decry the idea of a
'dead man walking'.

Yes, let's reimagine breaking down the walls which separate you from I
forming the WE needed to create the foundation upon which to
build equality and justice replacing stigma with individuality.

Yes, let's reimagine connecting- grasping hands as old friends telling
thrilling tales worth sharing over the table of tea and treats knowing
that we stand equal in our foibles and talents alike.

Yes, let's reimagine giftings shining from the soul which hosts them
under the love and care community brings creating excitement for the dawn of
each new day to reimagine all that life can hold, yes let's!!

Arts based (not clinical)

By Rubén, Robin, Rob, Susan, Corie and Ryan

What goes on on your show Oprah? Stories?

Well we're telling a new story with a new language

Bridge connecting possibilities

Elevator on an endless path to tell all the ways to unlock the narrow medical view

Burst it open

You are not your disease

You have your humanity

Artists and creatives solve problems

with a different mindset

Do we really have to "battle" "suffer from" dementia?

Why these words?

This way?

"Non-Pharmacological Intervention"

How awful sounding

yet how wonderful it really is

Don't make arts an intervention!

Reimagine!

Not a problem to be solved

Something we create together

Normalize dementia

Normalize arts

Normalize social justice!

Everyone's included

Everyone is an artist or artist to be

Creativity is available to all of us

Art is engaging but maybe the language is not

Sterile museums like sterile clinics

Both can be a space for healing

But the museum can have more boundaries

Emphasize the process, not the product

Art is ephemeral

Memory is Ephemeral

Life is ephemeral

Arts based Not clinical

Reimagining Dementia: A Creative Coalition for Justice

Thoughts on how to move forward from RDC members

This document reflects ideas generated by RDC members during the three December gatherings. Unless indicated otherwise, the first suggestions listed are those the Coalition is already doing or could probably be implemented using the resources we currently have.

The second set of suggestions are those that can might be implemented with greater member involvement and an investment of other resources (including financial support).

It should be noted that, while there was some support for creating play/work groups (outreach, networking, advocacy and programming were named) with “topics and activities within Reimagining Dementia,” members really value the gatherings and want to continue using them to have, as some of our members wrote, “Wonderfully creative discussion to keep things open” and “Time to bond and get to know each other.” It was also suggested that we focus on “what we want to accomplish as a first step” and that “Grassroots organizing is the way to go!”

The suggestions are organized under five basic categories:

- Sharing and staying connected
- The Arts
- Policy and advocacy
- Outreach
- Networking with other organizations and with each other

Sharing and staying connected

- Create spaces for sharing work, techniques and strategies – perhaps direct “show and tell” (SSC)
- Provide a platform for connecting people who want to work together on projects (for example, Nicolette in Arizona said she wanted to work with others on community education and ways to live well with dementia)
- Create a series of creative conversations between dementia stakeholders (PLWD, care partners, health care and dementia care professionals, etc)
- Put together an online directory of coalition members
- Ask members to use the #reimaginingdementia hashtag more widely, regardless of whether they are communicating about the Coalition
- Sally Fox wants to share her blog and network
- Shelley King wants to share her experience as an arts educator and puppeteer
- Create a blog, a newsletter and a YouTube channel
- Host a conference and/or a festival

The Arts

- Creating educational art performances (Andrea Del Valle from Costa Rica suggested this and she is already working a performance piece)
- Develop arts- and creativity-based responses to dementia-related issues
- Create an international celebration of people living with dementia, and find other arts-based ways to share the stories of PLWD and others impacted by dementia
- Make dementia and arts connection a full-blown campaign
- Create a Reimagining Dementia Dictionary
- Dance based programming (not sure what about dance-based programming)

Policy and advocacy (all of these are longer term)

- Develop ways we can bring our “arts and creativity” lens into existing policy and advocacy conversations around the world.
- Post-pandemic, take to the streets, perhaps a march in Washington DC
- Involve medical school reps in our conversations and figure out how to help medical trainers imagine how to re-humanize their patients living with dementia
- Change dementia definitions, especially regarding long term care policies and insurance

Outreach (this process has begun)

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- Recruit more members from underrepresented communities and reach out to diverse groups of people
- Reach younger people through social media
- Connect with professional and family care partners
- Networking with other organizations and groups and with each other (this process is underway, though should address how to involve more members in this activity)
- I like the idea of local networks and would be happy to be in a local network myself (Karen Tyrell)
- Introduce ourselves to many organizations and governments and make connections across the world with others passionate about social justice and dementia
- Identify and connect with networks of people who have this new vision of dementia (i.e. people involved in leading memory cafes)
- Establish a clearinghouse of existing resources that bring about the dementia we imagine as well as making our own resources (Kyrie)