



Reimagining Dementia

A Creative Coalition for Justice

Summary of October 27, 28 and 29 Member Gatherings

This is a collection of narratives from the Reimagining Dementia Coalition's first three gatherings in October, where participants had the opportunity to get to know each other, have some creative fun together, and begin sharing what reimagining dementia means to them. The conversations were insightful and playful, and the narratives reflect many of the thoughts, feelings, and imaginings of the members who participated in these gatherings.

WHO WE ARE

We share a love for creativity as arts therapists, music lovers, performers, innovators, improvisors, administrators, academics, program builders, people living with dementia, people who partner with people with dementia.

We are people who value connection, bridge building, breaking out of our silos, discovering new ways of being and seeing, breaking down the hierarchies, who all live with fear, love pets and value improvisation.

Who like to play together and value play and improvisation in our work. We want to build new partnerships, to express our freedom, to touch each other and work across disciplines, ages, and cultures.

One group's slogan: *Remembering yesterday, playing today*

We are committed to culture change no matter where we stand as we discover new ways of changing the culture of dementia. In joining together, we are finding new possibilities in joining together

- To impact on stigma
- To shift our gaze from the medical model and really see each other
- To value the relational and relationality
- To value the multicultural intersectional multigenerational
- To include, hear, and learn from people living with dementia

What we have learned from the COVID experience

- To make intimate and long-lasting zoom connections
- To have and appreciate pointless conversations
- To get out of our silos
- That people with dementia have much to teach us about living in an uncertain and out-of-kilter world.

WHAT DOES REIMAGINING DEMENTIA MEAN TO US?

We have a disaster. We have to stop putting bandages on a broken culture. To reimagine dementia, we have to blow up what is and redo it.

Thru dance, art, laughter, poetry, performance we can shift the paradigm. No tragedy, no stigma, no obsession with cognition to one that spills off the page with possibilities, humanity, relationality, open to all ways of knowing, including touch, words, music and play.

To reimagine dementia our language needs to change.

- Language supports the myths and stigma. People are called “wanderers” and are placed on locked wards.
- Words make a world. Language must be followed by practice.
- If you don’t know what to say, just say hello.
- To respect each other’s culture and how we see and relate to dementia.
- Arts change the world, and not just in an airy, fairy kind of way.
- To reimagine dementia we must listen to and really hear the voices of people who live with dementia day to day.

What two members said about their relationships with husbands living with dementia.

"My relationship with my husband, who lives with advanced dementia, has deepened and developed over time. Since his language has failed, we speak, feel, love and communicate with touch."

"Since John was diagnosed our relationship has only deepened over time. We grow closer thru John’s art which he has learned since dementia entered our lives."

A note on reimagining dementia to the researchers, scientists, academics and policy makers.

- Thru playing together we can flatten the hierarchy.
- Can we make the arts, play, performance the centerpiece of dementia care?
- When studying brain health look at it throughout the life span. Stop monitoring decline!
- We need a lifelong curriculum that focuses on growth, relationships, that is open ended and studying real activity and meaningful connections
- If people do not have new experiences, how do we create new ways of seeing?
- Give people opportunities and permission to break out of their boxes.
- Life with dementia is fluid and it is not all the same for every person. We are all unique human beings.
- In reimagining dementia, it is our wish that the best of creativity, arts and music therapies, play, joy and relationality should extend to all our communities, those with means and those without.

Reimagining dementia means that we address the profound disparity of resources, creativity and health that exists between our impoverished communities and communities of color and others in the world.

Here are some of the hopes and dreams expressed for Reimagining Dementia:

- To reach a point where we are no longer monitoring decline but rather celebrating growth.
- Focusing on the can and not the cannot or can no longer
- Seeing the person not the diagnosis
- Focus on meaning enabling and living well
- Make relational care the dominant approach
- Our imagination is not limited to the way things are

If you are not stepping on toes, you are not making change! We will determine our own goals and strategies.

SUMMARY

- We shared some laughs, our contact information, our hopes and our dreams
- We met old friends and made new friends
- We could create space for voices of people living with dementia to be heard and responded to
- We learned from each other
- We want to continue building the coalition