



# Reimagining Dementia

A Creative Coalition for Justice

*Reimagining Dementia: A Creative Coalition for Justice* is an international group of dementia activists and allies – health professionals people living with dementia (young and old); carers/care partners; family and community members; advocates, artists, academics, policy makers and others - who share a diverse and humanizing vision of care and support that promotes inclusion, relationality, creativity, joy and the possibility of growth for *everyone* living with, and impacted by, dementia.

It is estimated that there are almost 6 million people living with dementia in the U.S. in 2020, a significant number of whom are LGBTQ; thus, we invite LGBTQ individuals and LGBTQ-serving organizations to join us in this effort.

Reimagining Dementia focuses on developing projects, programs, policies and approaches that successfully use play, performance, improvisation and the arts to creatively challenge the biomedical and institutional approaches to care, and the fear, stigma and hopelessness they perpetuate. In the midst of a global pandemic, we are mobilizing tens of thousands of people with dementia and their families - together with the communities and care settings in which they live - to create environments in which everyone is supported to thrive and to grow.

We join with millions of people across the globe in calling for an end to racial, social, environmental, and economic injustice in all sectors of society. No human life is disposable! As part of this international uprising, we issue a specific call for the radical transformation of the very attitudes and conditions that are contributing to the isolation, abuse, and neglect within and outside of long-term and community-based care settings by means of, for example, the pathologizing of human experience, and the use of chemical, physical, and environmental restraints.

We are also committed to challenging the insensitivity (or worse) to the particular concerns of LGBTQ people, who are more likely to exhibit

vulnerabilities such as disproportionately high levels of social isolation and stigmatization that can exacerbate how dementia manifests and make it difficult to find support. Older LGBTQ adults also express understandable fears pertaining to the possibility of living in long term care (LTC) communities. These fears include potential rejection or neglect by healthcare providers, lack of acceptance and respect by fellow residents, and the feeling that it is necessary to hide their sexual orientation or “return to the closet.” In addition, adult children who are LGBTQ and have no children of their own are often seen by siblings as the “natural choice” to care for a parent, regardless of their ability to do so. They may also be caring for a parent who does not accept their identity, relationship, or gender expression, adding to the psychological burden of providing care.

There are most certainly compassionate, innovative, and deeply caring health professionals in the system; but this is often despite a system that devalues them, not because of it. This broken system of care has created a perfect storm in which COVID-19 has disproportionately claimed the lives of older citizens across the world. This international atrocity has made it transparently and tragically clear that these systemic vulnerabilities are of our own making; we are failing our oldest, our poorest, and our most vulnerable populations.

Inspired by other dementia activists, it is our contention that we can and must do better. We can and must seize this moment to come together in new and more powerful ways. We can, and must, find ways to leverage our collective resources, expertise and passion to organize and mobilize a grassroots force that can move the conversation about aging and dementia in a positive, creative, inclusive, just and life-affirming direction.

If you are interested in:

- Transforming the broader culture that produces and reproduces the stigma associated with aging and dementia;
- Reforming the culture and practice of health and wellness, dementia, and aged care and support;
- Challenging the ethics and assumptions of institutionalized care and advocating for creative, relational, and inclusive approaches that support ongoing growth and development for all in caring contexts;

- Amplifying the voices of people living with dementia, and finding ways to share with the world what they and the dementia community have learned about living more joyfully with uncertainty, fear and isolation;
- Advancing the role that art + activism + technology can play in raising awareness and promoting social transformation; and
- Bringing play, performance, improvisation and the arts into homes, organizations, communities and dementia care and support settings.

...we hope you will work with us in making a difference at the local, national, and/or global level. Whether you can do a little or a lot, you are welcome. We are in this for the long haul, so we hope you will join us in making sure our impact is felt long after this crisis has ended.

[Sign up](#) as a member of Reimagining Dementia and endorse the Call to Action.

For a list of Reimagining Dementia members and endorsers, click [here](#).

If you have questions, or want to connect with Reimagining Dementia, contact our Coordinator, Mary Fridley, at [reimaginingdementia@gmail.com](mailto:reimaginingdementia@gmail.com).

We look forward to creating with you!