Dementia Friendly Communities?

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• Over 47 million people currently diagnosed with dementia globally (WHO, 2015)

• Worldwide, 1 new diagnosis every 4 seconds (ADI, 2013)

• **Terminal** progressive illness

• Treatment for some types of AD, **no cure**
Dementia friendly means including us

• People without dementia cannot really know what it means to live with dementia
• We can inform you on what it means to be dementia friendly to us
• No longer ‘about us, without us’
• We can educate and raise awareness
• This will will empower others with dementia
Friendly:

a. Characteristic of or behaving as a friend: a friendly greeting; is friendly with his neighbors.
b. Outgoing and pleasant in social relations: a friendly clerk.
c. Favorably disposed; not antagonistic
Respect:

1. To feel or show deferential regard for; esteem or admire: All the other scholars respect her.

2. 
   a. To avoid interfering with or intruding upon: Please respect my privacy.
   b. To avoid violating: I respected the speed limit throughout the trip.
Equality:

1. The state or quality of being equal.
Accessible:

1. Easily approached or entered.
2. Easily obtained: e.g. *accessible money*.
3. Easy to talk to or get along with: *an accessible bank teller*.
4. Easy to understand or appreciate: *an accessible library*.
Autonomy:

1. The condition or quality of being autonomous; independence.
Inclusion:

1. The act of including or the state of being included.
Supporting disAbilities

People with dementia speaking at conferences being asked to shorten their speech without sufficient notice, simply to accommodate the short notice insertion of another speaker ahead of them...

This is not dementia friendly.
Not dementia friendly...

Letting the audience know that 10% of the delegates are people with dementia, and asking the audience to look around the room to see if they can pick us is dementia friendly.

Making us stand up to be viewed like specimens, simply to make the same point, is not.
A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value, and where they are included in EVERY CONVERSATION ABOUT THEM.
A dementia-friendly community is about accessible communities

It’s about our basic human rights
Being dementia-friendly community is about being treated under the guidelines of the UN Convention on the Rights of Persons with Disabilities, and within the Disability Discrimination Acts around the world.
NOTHING SHOULD HAPPEN WITHOUT THE INTEREST, INCLUSION AND COMMITMENT FROM PEOPLE WITH DEMENTIA
OUR JOURNEY OUR VOICE

• BY RE-EMPOWERING PEOPLE LIVING WITH DEMENTIA TO SPEAK UP, FOR THEMSELVES, IT WILL MAKE IT POSSIBLE FOR PEOPLE WHOSE VOICES HAVE PREVIOUSLY SELDOM BEEN HEARD, TO CONTRIBUTE TO SHAPING THE MATTERS THAT AFFECT THEM.

• NO LONGER WILL WE BE TOLD BY PEOPLE WITHOUT DEMENTIA, HOW WE FEEL OR WHAT IS BEST FOR US, AND WHILST WE STILL HAVE A VOICE OF OUR OWN, WE WILL BE ABLE TO ADVOCATE FOR OURSELVES.
Key Steps To Dementia Friendly

1. Establish a **Local Dementia Advisory Committee** of people with dementia

2. Establish a **Local Dementia Alliance or working Group** that will work together with people with dementia

3. **Support local organisations and businesses** to become dementia friendly through making small changes that will have large impacts on the lives of people with dementia.

4. **Raise awareness of dementia**

5. Working with organisations to promote volunteering, employment and other **meaningful engagement opportunities for people** with dementia.
Be dementia friendly

• Include people with dementia at every step
• The environment, including signage, noise levels, and location is imperative
• Support for disAbilities, in the same way as any other disAbled person
• Be respectful with the language you use
• Treat us as equals
Dementia friendly also means

• Providing us with a more ethical post diagnostic pathway of care and support, one that is enabling AND INCLUDES REHABILITATION, not disabling and which leads us only to aged care and death.

• It also means supporting us to remain employed, if that is our choice
Treat the symptoms of dementia as disabilities so that we are offered the same support as people with other disabilities.
DFC also equals Dignity in Care

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people’s privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people’s loneliness and isolation.

Dementia friendly is about full inclusion, accessibility, enablement, equality, autonomy, respect, dignity, the right to be employed, and the use of enabling and respectful language;

without these our communities will never become dementia friendly.
“We are just changing in ways the rest of you aren’t, we have increasing disabilities and the sooner it is looked at that way instead of the stigmas, misunderstandings and complete lies, the better for all of us living with dementia. We desperately need others to enable us, not further disable us!”

(John Sandblom, 2013)
OUR LIVES BEGIN TO END THE DAY WE BECOME SILENT ABOUT THINGS THAT MATTER

Martin Luther King Jr.