



# **Dementia Friendly Communities: Past, Present and Future**

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*Support and Advocacy: Of, by and for people with dementia*

# Nothing about us, without us

A dementia-enabling 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 we are included

# Why **include** people with dementia?

- People without dementia cannot really know what it means to live with dementia
- We can inform you on what it means to us
- No longer ‘about us, without us’
- We can educate and raise awareness
- This 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

# Dementia friendly communities

- Respect and dignity
- **Empowering and respectful language**
- Human rights
- Equal access
- Non discrimination
- **Full inclusion**
- Support for disAbilities
- Our right to full citizenship
- Autonomy
- **Equality**
- Equity
- Dementia Enabling Environments
- ↓ Stigma

# 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

# 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.

A dementia-friendly community is  
about respectful, accessible,  
enabling and inclusive communities

**IT 'S ABOUT OUR BASIC  
HUMAN RIGHTS**

Being a 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 & commitment  
of **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 must be included 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 a more ethical post diagnostic pathway of care and support, one that is enabling & **INCLUDES REHABILITATION**, not which leads us only to aged care and death
- Research into better care, not only research for a cure
- It also means supporting us to remain employed, if that is our choice



A dementia friendly community supports the symptoms of dementia as

**disAbilities**

in the same it supports other people with other disabilities

# Language is a powerful tool



*Our words do reflect our thoughts and feelings, and can show respect or disrespect; they also show how others feel about us.*

(Sabat 2001; Parker 2001; Hoffert 2006)

# Language matters

➤ ***Suffering/sufferer/demented/dementing*** ✘

(disempowering, disabling, disrespectful)

VS



➤ ***Diagnosed with or living dementia*** ✔

(empowering, enabling, respectful)

# Alzheimer's Australia

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## Language Guidelines 2014

**SEE THE PERSON**

**NOT THE DEMENTIA**

<https://fightdementia.org.au/sites/default/files/language%20guidelines.pdf>

# **Dementia friendly = Dignity in Care**

## **10 Dignity in Care Principles**

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.

(10 Dignity in Care Principles,

<http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/clinical+programs/dignity+in+care>)

# **DFC's: a human right**

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 be 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)

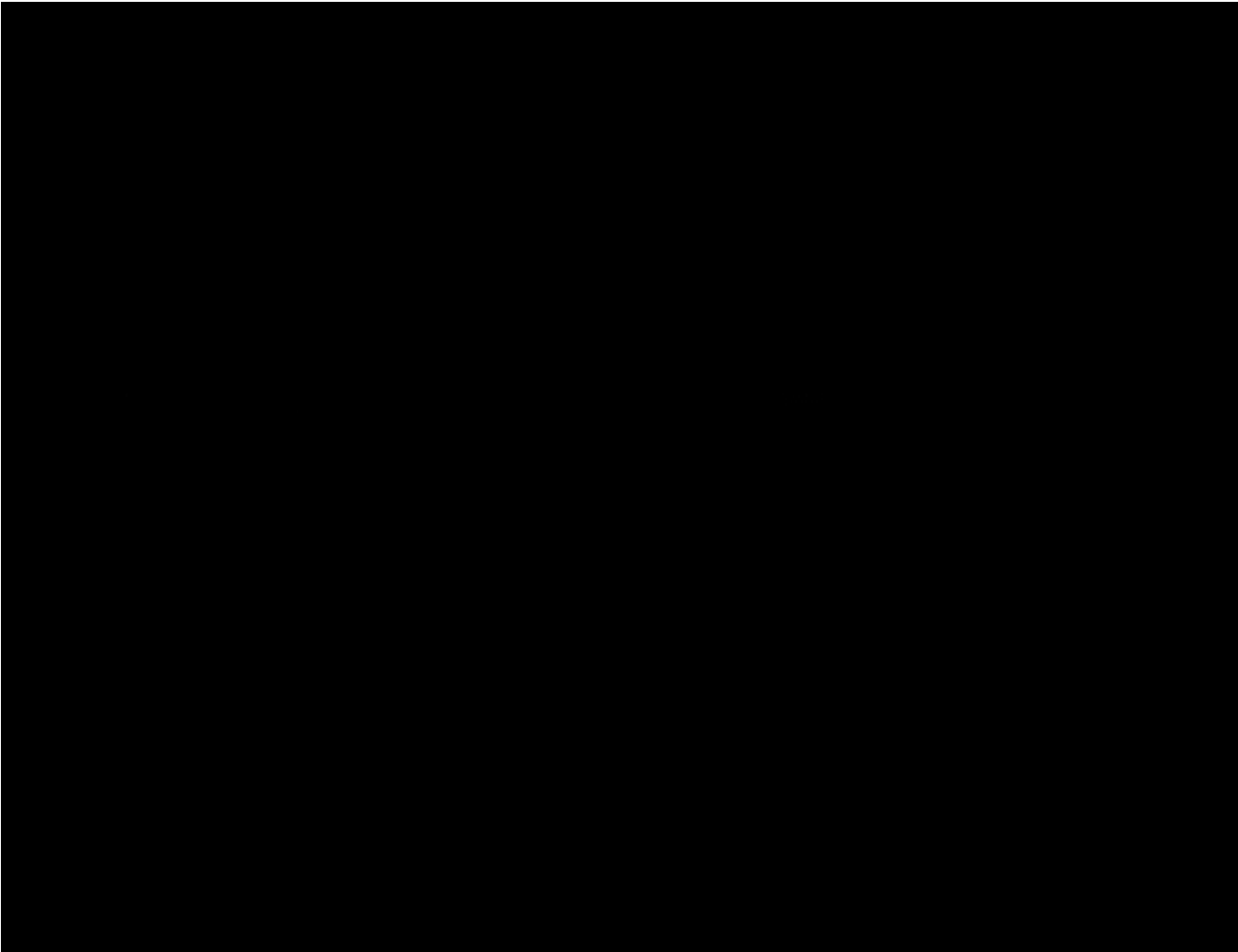


# Kiama Dementia Friendly Communities Pilot Project

- Local Dementia Advisory Group (DAG's) of people with dementia and their supporters
- Local Alliance/Working group which is guided by the Dementia Advisory Group

# Kiama Dementia Advisory Group

Veda Meneghetti: a story about dealing with dementia



# The future

- It will stop being a competition about the number of Dementia Friends a country has signed up.
- It will stop being about marketing of or fundraising for organisations, or careers for people without dementia
- It will be about the quality of our relationships, the quality of the disability support and care provided, and equal inclusion.

# The DFC Litmus test

- People with dementia are employed in DFC campaigns
- People with dementia are the ones who are invited and funded to attend and present or co-present on the initiatives in their community at conferences and other events

## **Support for people with Dementia**

- Exclusive membership to PWD
- Weekly online support groups
- 24/7 chat rooms
- Monthly online cafes
- Monthly webinars
- Master classes
- <http://www.infodai.org>
- <http://www.joindai.org>



# Thank you

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**DEMENTIA  
ALLIANCE  
INTERNATIONAL**

**SEE THE PERSON**

**NOT THE DEMENTIA**