

Alzheimer's Disease Association and Lien Foundation launch Dementia Language Guidelines booklet

As part of the Forget Us Not movement, "Changing Words, Touching Lives" is a guidebook that reveals how using the right or wrong words on the dementia community can make a difference.

Singapore, 6 April 2020 - Alzheimer's Disease Association (ADA), Singapore's leading Social Service Agency in specialised dementia care, and Lien Foundation, a Singapore-based philanthropic house, have launched their latest educational materials on dementia awareness – a guidebook of appropriate and inappropriate words and phrases to use when dealing with or speaking about dementia. The **Dementia Language Guidelines** is available as a hardcopy book, as well as easily downloadable glossaries in Singapore's four official languages from the ADA website.

Adapted from Dementia Australia's 2018 language guidelines, ADA realised a need to produce a similar version for Singapore. This localised version lists out preferred words and phrases, as well as terms to avoid, and is applicable in all situations – from casual conversations to social media posts and publicity materials relating to persons with dementia. For example, "dementia sufferer" is usually avoided when referring to someone with dementia, as "sufferer" contains negative undertones of someone who is disempowered or a victim. Instead, "person with dementia" or "person living with dementia" is preferred.

The Guidelines also include words and phrases in the Mandarin, Bahasa Melayu and Tamil mother tongues, allowing ADA to identify local slang words and offer more ideal translations. To achieve this, ADA worked with a network of persons with dementia, caregivers and volunteers from the various races and communities. Formal and colloquial terms were identified and discussed, as well as the context of when and where the terms would normally be used. From there, terms with negative connotations or those which may perpetuate the dementia stigma were then labelled as those to avoid.

"For me, respect is paramount when engaging anybody and this includes persons living with dementia. If the term used is not empowering but puts the elderly in a place of need and helplessness, it is not good. For instance, the Mandarin word 'chi dai' (痴呆)¹ is very negative, yet is still used today in the Chinese community," said Ms Wendy Wei, caregiver to her mother who lives with dementia.

¹痴呆 (pronounced chī dāi) - 痴: suggesting someone who is silly/foolish, and 呆: dull/slow-witted



A lasting scar in the form of the word "demented".

Bearing the theme "words can hurt", the book contains visuals of scarred human skin, with the scars spelling out hurtful words such as "empty shell", "hopeless" and "demented". The visuals are also printed on pull-out transition tabs on their respective pages. When readers pull the tabs, the hurtful words smoothen out and disappear. These jarring visuals coupled with the interactive element illustrates that the wrong words used can have a lasting impact on the dementia community, but that when proactive steps are taken to use the appropriate words, the hurt can start to heal.

"The way we talk about dementia and people living with dementia affects how others view the condition. So communication is important in our fight against dementia stigma and must come before true inclusion in our societies can happen," said Mr Jason Foo, CEO of ADA.

"By adopting a person-centred care approach and being sensitive when talking about dementia and interacting with persons living with the condition, we can proactively acknowledge their feelings and behaviours, lest we run the risk of hurting them or perpetuating a negative stereotype and stigma about dementia," Mr Foo added.

The Dementia Language Guidelines is part of the Forget Us Not initiative by the Lien Foundation, Khoo Teck Puat Hospital and ADA, that seeks to build a dementia-friendly community that enables persons with dementia to lead active, engaged lives for as long as they can.

Lien Foundation's CEO Mr Lee Poh Wah highlighted how the kind of language used to describe dementia can reflect and define a society's attitudes towards people living with the condition.

"Language has the power to shape our perception of reality and influence our behaviour. The use of inappropriate words, ill-informed or hurtful expressions about dementia can insidiously undermine the ongoing efforts to build a dementia-friendly Singapore as they tend to reinforce poor stereotypes and misperceptions. We hope that members of the media, healthcare sector and community at large will not only adopt these guidelines to speak about dementia in a

respectful and non-judgmental manner, but they will also, in so doing, gain a better understanding of persons with dementia and their families,” said Mr Lee.

For more information or to download the Dementia Language Guidelines, visit www.alz.org.sg/wordshurt.

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About Alzheimer’s Disease Association (ADA) (<http://alz.org.sg/>)

ADA was formed in 1990 because of a growing concern for the needs of persons living with dementia and their caregivers. The Association hopes to reduce stigma by increasing awareness and understanding of dementia; enabling and involving persons living with dementia to be integrated and accepted in the community; and leading in the quality of dementia care services for persons living with dementia and their families. Striving towards a Dementia Inclusive Society through its four strategic service pillars – Centre-Based Care, Caregiver Support, Academy and Community Enabling – ADA aims to advocate and inspire the society to regard and respect persons living with dementia as individuals who can still lead purposeful and meaningful lives.

About the Lien Foundation (www.lienfoundation.org)

The Lien Foundation is a Singapore philanthropic house noted for its model of radical philanthropy. It breaks new ground by investing in innovative solutions, convening strategic partnerships and catalysing action on social and environmental challenges. The Foundation seeks to foster exemplary early childhood education, excellence in eldercare and effective environmental sustainability in water and sanitation. It supports innovative models of eldercare, advocates better care for the dying and greater attention on dementia care.

In 2016, Lien Foundation pioneered Singapore’s first dementia-friendly community, starting with Yishun in partnership with Khoo Teck Puat Hospital and began a nationwide movement called Forget Us Not to build communities of care, where as many people as possible - from hawkers and shopkeepers to bank tellers and public servants – are trained to support persons with dementia so that they can lead engaged lives for as long as possible.

About Forget Us Not (www.forgetusnot.sg)

This is an independent nationwide initiative organised by Lien Foundation, Khoo Teck Puat Hospital and Alzheimer’s Disease Association. The Forget Us Not initiative aims to raise awareness of the growing number of persons living with dementia and their unique needs, and build a community of care where the condition is normalised and accepted as a disability. To date, the movement has drawn close to 200 organisations from different sectors and industries as partners and more than 32,000 people have been trained with practical know-how of how to support the persons with dementia they may encounter.

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