

# Voices for Hope

TOOLKIT



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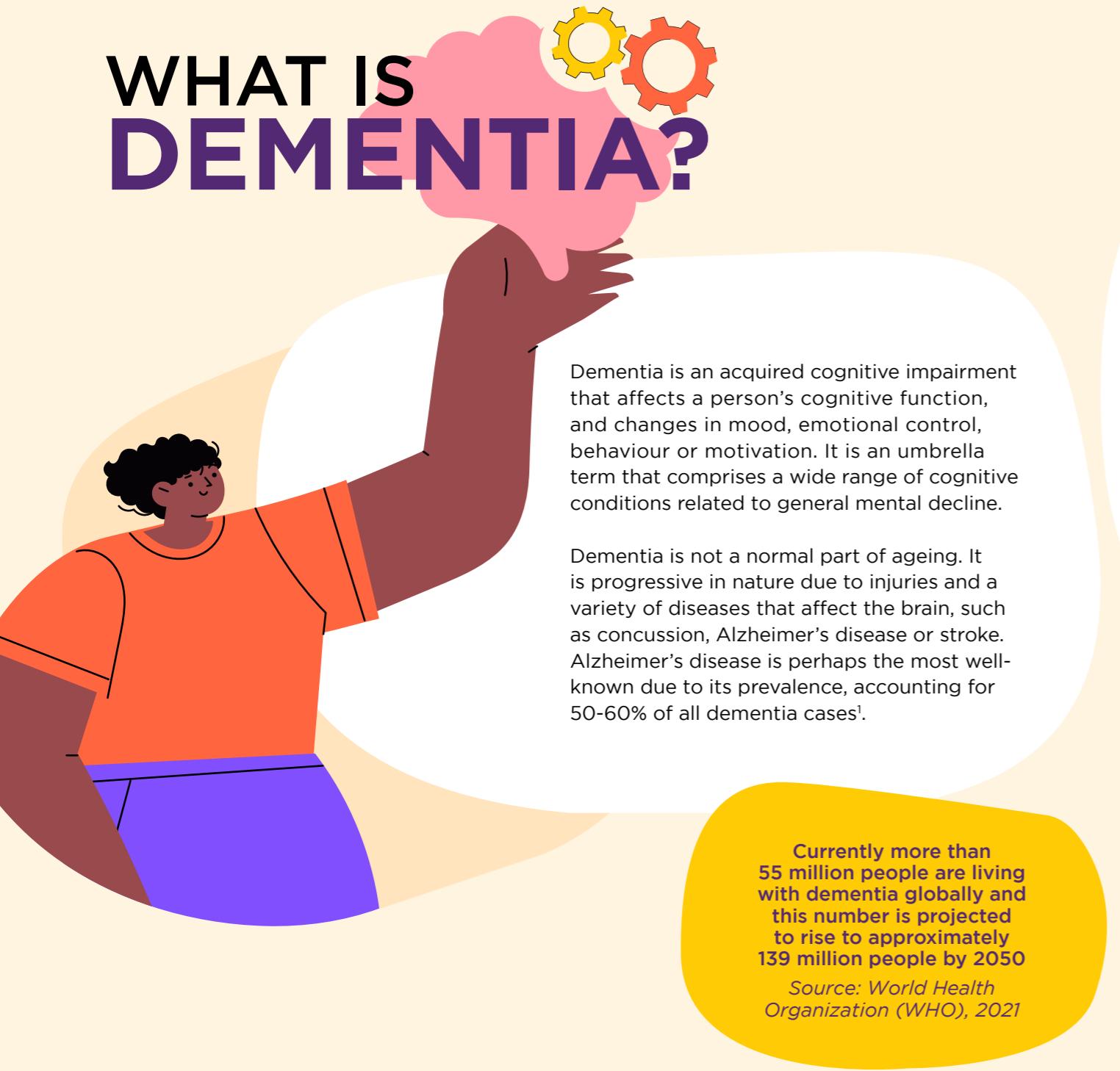
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# 01

## WHAT IS DEMENTIA?



## ABOUT DEMENTIA SINGAPORE

Dementia Singapore was formed in 1990 as the 'Alzheimer's Disease Association' to better serve Singapore's growing dementia community, increase awareness about dementia, and reduce the stigma surrounding the condition.

As Singapore's leading Social Service Agency (SSA) in specialised dementia care, Dementia Singapore aims to **advocate** for the needs of people living with dementia and their families; **empower** the community through capability-building, knowledge and consultancy; and deliver quality, **person-centred care innovations**.

With eyes firmly set on this vision and mission, **Voices for Hope** is one of the flagship programmes run by Dementia Singapore.

In Singapore, around 1 in 10 aged 60 and above had been diagnosed with dementia. With Singapore's increasing life expectancy and rapidly ageing population the number of persons living with dementia is expected to continue to rise. By 2030, Singapore could be home to 152,000 people with dementia.

Source: Ministry of Health (MOH), 2022

**Vision:**  
A Dementia-Inclusive Society.

**Mission:**  
To improve the well-being of people impacted by dementia through Care Innovation, Advocacy and Empowerment.



# DEMENTIA IS AN INVISIBLE DISABILITY

It is challenging to live with dementia. In addition, the World Health Organisation (WHO) had identified stigma and discrimination as forces that heighten the already significant psychological, social, emotional and financial effects it has on individuals, their Care Partners, loved ones and communities. There is a need to raise public awareness and improve understanding of dementia. To best serve and support persons living with dementia (PLWDs), efforts should take a **ground-up approach** before being implemented at a national level to involve more stakeholders in a **sustainable and meaningful manner**.

The Dementia-Friendly Singapore (DFSG) movement is a national initiative announced by the Ministry of Health in 2016 to address dementia prevalence in Singapore. Under DFSG, the Agency for Integrated Care (AIC) and community partners come together with the objective to build dementia-friendly communities to support PLWDs through a **3Es strategy – Engage, Empower and Enable**. The intended outcomes are clear:

1. Facilitate early identification,
2. Promote preventive activities and
3. Provide care and support.

## Dementia-Friendly Community Framework

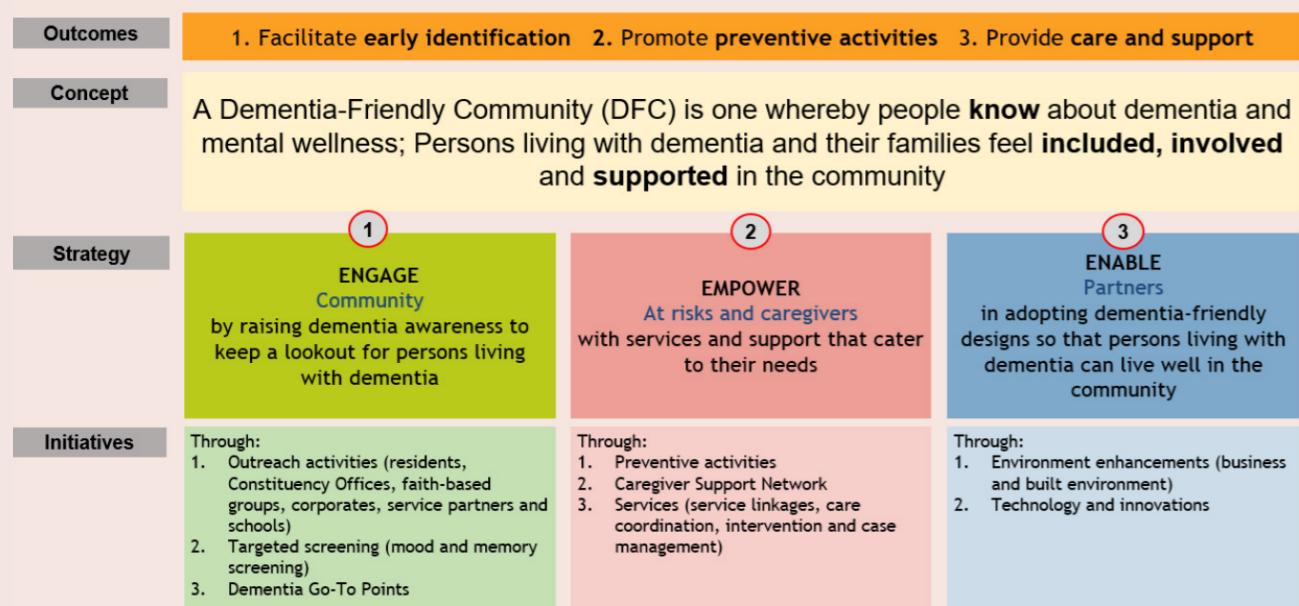


Figure 1: Framework by Agency for Integrated Care (AIC).

Voices for Hope aims to

1. Change societal attitudes,
2. Reduce the stigma of dementia, and
3. Improve the landscape of how PLWDs are perceived and supported.

Through this programme, we hope that the strengths of the dementia advocates will be celebrated and their voices, heard.

Organised by Dementia Singapore, Voices for Hope is a 10-week **empowerment programme for PLWDs and Care Partners**. The programme was introduced and piloted in 2019, to

1. Equip participants with relevant skills, and
2. Foster confidence to actively share their stories, needs and views publicly.

“Participants demonstrated an increase in self-esteem, passion for dementia advocacy and an invaluable peer support network.”

Source: Wewalaarachchi, Sidhu & Ng, 2022



“I was inspired by Kate Swaffer who asked, “Why do you sit in a room and decide for persons living with dementia what is good?” This assumes the group can’t think or decide for themselves. Nobody had bothered to ask them what they were going through in their lives and what would make sense. Letting the group have a say in what we are doing – this is empowerment.”

Jason Foo,  
CEO of Dementia Singapore.





PLWDs and Care Partners participating in the Non-verbal Expression activity.



Collage made by Peter Lim (PLWD, dementia advocate) and family with their messages to the world despite dementia.



Lim Swee Har (PLWD, dementia advocate) and Tan Lai Pin (Care Partner, dementia advocate) sharing their journey of living with dementia at the Cohort 5 Voices for Hope Graduation Ceremony.



Steven Lau (PLWD, dementia advocate) and Wong Lai Quen (Care Partner, dementia advocate) in an interview by CNA938 host, Susan Ng, on the topic of "Living with Dementia" on 22 June 2019.



Voices for Hope cohort meeting with Kate Swaffer, a dementia advocate and campaigner for the rights of PLWDs.

### 1.3 PURPOSE OF TOOLKIT

Based on activities conducted and learnings drawn from running 10 cohorts of the Voices for Hope programme, the toolkit is intended to serve as a **practical resource and guide for**

1. Organisations that are serving PLWDs with mild-stage dementia
2. Graduates of the Voices for Hope programme who are keen to pay-it-forward and participate as co-facilitators

**Immediately, this toolkit offers guidance and resources to kickstart a new programme node. In the long run, it seeks to cultivate wider and stronger representation within the dementia community.**

In the spirit of empowerment, this toolkit has been **crafted in close partnership with PLWDs and their Care Partners**. They speak through their lived experience with dementia as well as reflections as a Voices for Hope participant.

In other words, the real-life application of this toolkit by co-facilitators, who are themselves confident graduates of the Voices for Hope programme, bears testament to Thomas Ong's (PLWD & dementia advocate) deep-held belief that "Dementia is not the be-all and end-all of things."



Thomas Ong and Michelle Ong (Care Partner, dementia advocate) facilitating Voices for Hope Cohort 8 session.

# 02

DESIGN

2.1 INSPIRATION:  
EMPOWERMENT & ADVOCACY

## WHAT IS EMPOWERMENT?

*Disabled*  
by Kate

*Chapter 17: Dementia as a DisAbility*

I am able  
To perform activities  
Willing to operate  
At my own level  
I may be challenged  
but I am capable  
And operating  
Not inoperative  
I can function  
And I am only restricted  
By those around me  
Who choose to dis me  
Yes I am able  
Capable and talented  
Equipped to live  
A worthwhile life

Empowerment allows PLWDs to share openly their preferences and wishes and to have a say in what they are doing. This increases independence and in turn, contributes to a positive sense of well-being.

The concept of empowerment underpins the design of Voices for Hope. In this toolkit, empowerment:

1. Increases a person's ability to participate in and influence matters that affect his or her life.
2. Is characterised by strength, choice, ability to make decisions, possessing control and dignity
3. Translates into taking charge of one's life and ownership of issues that may arise

Empowerment is the “process by which individuals, groups and/or communities become able to take control of their circumstances”.

Source: Bryant, 2016

Empowerment is the expansion of assets and capabilities of people in vulnerabilities such that they may participate in, negotiate with, influence and hold accountable institutions that affect their lives.

Source: World Bank, 2002

## WHAT CAN ADVOCACY LOOK LIKE?

Co-facilitation is a hallmark of Voices for Hope because it embodies the spirit of the programme and transforms PLWDs into active contributors rather than passive recipients of care, fundamentally changing the power relationship.

On one hand, this serves as a clear signal from the organization that the PLWD's knowledge, concerns and preferences are valid and valued.

On the other hand, the diversity in perspectives and experiences serves as an acknowledgement that there ought not be a one-size-fits-all approach to self-advocacy -in its message, its form and its channels.

“Advocacy - how can I be a better, more effective advocate. What sort of programmes and opportunities can Voices for Hope create to tap on MY ability.”  
-Thomas Ong

Together, the journey of co-creation gifts PLWDs and caregivers a chance to “re-conquer power in their lives”  
-SEMPRE, 2019



#### Empowerment through voice and community

- Speaking up to reduce stigma
- Public speaking to be a spokesperson for the cause
- Building inclusive connections
- Demonstrating social-emotional support with own communities

Dementia Singapore embarked on a special short film, titled "1000 Paper Cranes", to spotlight the profound impact dementia can have on families and celebrate the love and bond they share through their unique journeys. Peter and Evon Estrop (PLWD and Care Partner respectively, dementia advocates) were invited as panellists in a post-film panel discussion during the launch event on 21 September 2022, World Alzheimer's Day.



PLWDs as well as dementia advocates, Emily Ong and Mohammed Bin Rosli (affectionately known as Anjang), at the 'Find Your Way' launch at Toa Payoh Bus Interchange on 7 February 2022. They were advisors in this initiative to help PLWDs navigate public transport nodes with ease, with the help of directional floor stickers and colour-coded murals.



*Media interview with Wong Loke Kit (Care Partner, dementia advocate) and Sim Peck Hoon (PLWD, dementia advocate) at the National Gallery Singapore to launch a dementia-friendly engagement programme, titled "Art with You".*



*Filming with Emily Ong and Dr Chen Shiling for AIC's video segment on "How to Get Diagnosed" in the series titled "Ask the Expert"*

## 2.2 CRITERIA FOR PARTICIPATION IN VOICES FOR HOPE PROGRAMME

**Voices for Hope** is best suited for persons who are diagnosed with **mild-stage dementia**, **fairly proficient in communication and articulation**, and with **stable care arrangements**.

Aside from a doctor's diagnosis and referral, the programme manager may assess the relevance and efficacy of the programme when identifying participants, based on the support strategies PLWDs are motivated by and the adaptive tasks he/she is engaged in.

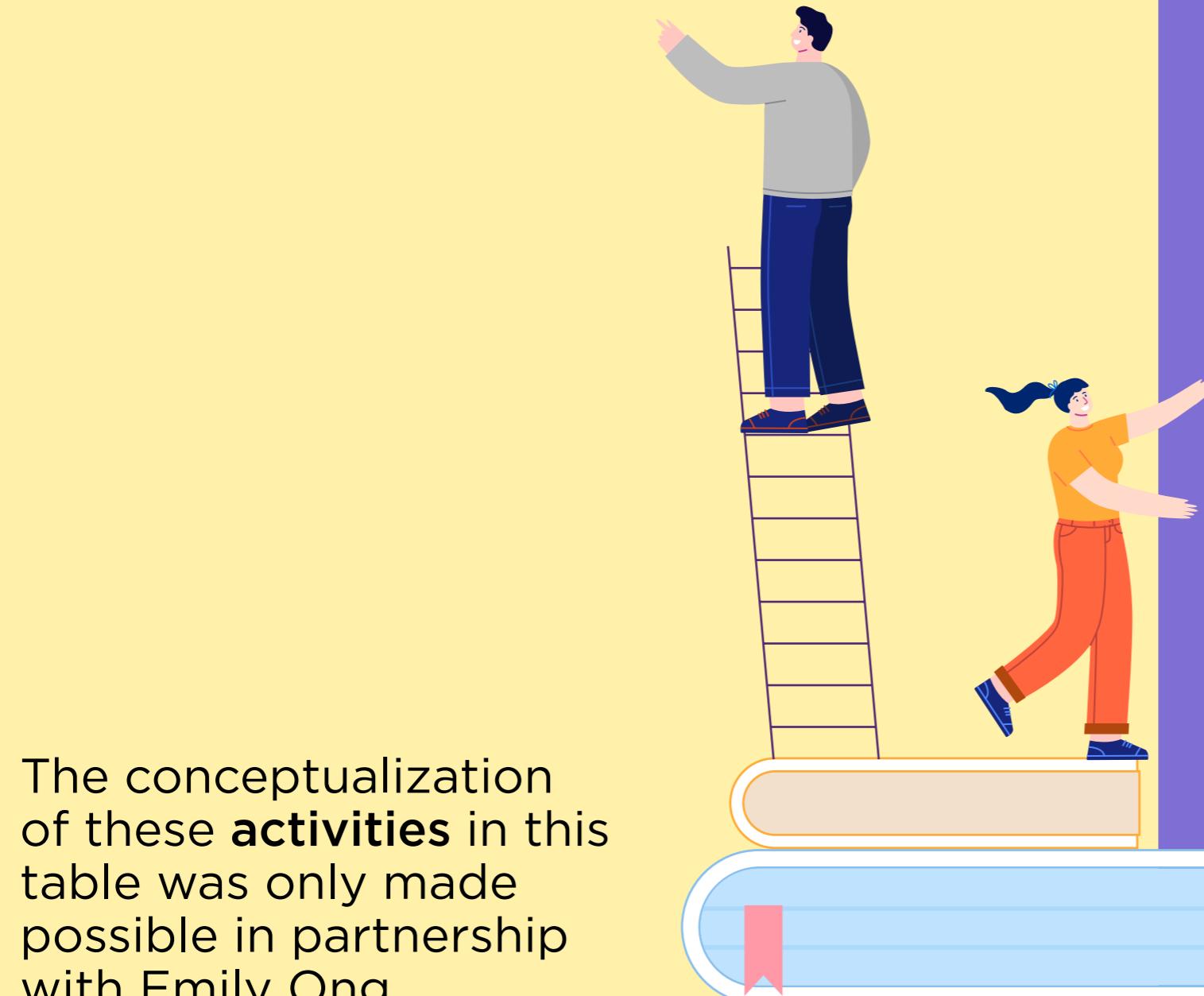
The Rosenberg Self-Esteem Scale, which is an established measure of self-esteem, is also administered pre-programme as a profiling tool to aid curriculum design and tracked after the completion of the programme as a form of impact review.

*Refer to Appendix A for the Rosenberg Self-Esteem Scale.*



# 03

## OVERVIEW OF PROGRAMME



The conceptualization of these **activities** in this table was only made possible in partnership with Emily Ong.

### RESOURCES

### ACTIVITIES FOR PARTICIPANTS

Theme	Focus	Activities for Participants
Breaking the Silence	Creating familiarity and trust: Knowing and bonding with one another	<ul style="list-style-type: none"> <li>a. Drawing of Hands</li> <li>b. Sharing of dementia-related pre- and post- diagnosed life*</li> </ul>
Dementia & Me/ Us	Gaining a deeper understanding of living with dementia as an individual and as a family to build confidence	<ul style="list-style-type: none"> <li>a. Mini Lecture: The Brain, the Person, the Disease</li> <li>b. Bringing-in-the-Expert: Medication &amp; Dementia Care</li> </ul>
Stigmas & Impacts	Increasing awareness of language use and its effects	<ul style="list-style-type: none"> <li>a. Communication strategies*</li> <li>b. Statement: Reactions Exercise</li> <li>c. Letter writing to a loved one/ significant person*</li> </ul>
Living well despite Dementia	Living a meaningful and purposeful life	<ul style="list-style-type: none"> <li>a. Personal Goal Setting (Ideals &amp; Goals)</li> <li>b. Sharing on Compensatory Strategies</li> </ul>
Advocacy & Change	Understanding Advocacy and cultivating self-advocacy skills  Being involved in and stepping up to contribute to your networks and the community	<ul style="list-style-type: none"> <li>a. Graduation</li> <li>b. Postgraduation Engagements with public, media, policymakers</li> </ul>

\*Asterisk indicates recommendation for care partners & PLWDs to have split sessions.

# 04

THE END OF ONE JOURNEY,  
THE BEGINNING OF ANOTHER!

4.1 HEROES



Voices for Hope alumni sharing during cohort 11 about advocacy efforts and experiences.

The **Voices for Hope programme** engages PLWDs and their Care Partners as a pair. This approach acknowledges the concept of family in our cultural context and celebrates the considerable participation and support Care Partners involve themselves in.

Some segments of the programme are run with PLWDs and Care Partners separated so as to facilitate deeper discussions, with prompts catering to the needs of the respective groups.

Our graduates have since gone on to be active dementia advocates engaged in a wide variety of public engagements on different platforms. The following 6 heroes spotlighted in this toolkit have pioneered advocacy in the local dementia landscape and are role models to a growing community of PLWDs and their Care Partners.

“

**“To speak out about dementia helps me to define myself by things other than a person with forgetfulness, or odd behaviour, or a wanderer, or someone who is unemployed and therefore often undervalued. Advocacy gives me a reason to get up in the morning and work on my large list of interventions, in particular because it is meaningful.”**

*-Kate Swaffer, Chapter 10: Advocacy as an Intervention for Dementia of What The Hell Happened To My Brain*

**“Voices for Hope is a very interesting, wholesome and enlightening programme for participants living with dementia like myself. I am given many opportunities to intermingle, to openly express my feelings, desires and hopes. Like the others, I feel important, needed, useful and accepted and I can have an enjoyable, happy and fruitful and successful future.**

**Through its activities, I got to understand more about dementia and how to handle it without fear or feeling unduly downhearted. Most importantly, I am empowered to take hold of my life, to look at the present situation together with what I am endowed with and take steps to ensure that I can progress satisfactorily and happily into the future.”**

*-Thomas Ong, Voices for Hope Cohort 5*

**“We are Care Partners, not caregivers... I don’t say yes, till after discussion with Peter (Estrop)”**

*-Evon Estrop, Voices for Hope Cohort 8*

”

04



## HERO 1: EMILY ONG

*Emily Ong as a co-facilitator during cohort 10*

Emily joined the 3rd cohort of **Voices for Hope** and has ceaselessly stepped up to participate in the later cohorts as well as continued her advocacy journey as a board member of the Dementia Alliance International (DAI). She was diagnosed with provisional frontotemporal dementia.

At DAI, **Emily** started a global group called **Environment & Dementia: Special Interest Group**, where professionals convene to provide expert advice on working towards a dementia-enabling design in the community to improve the quality of life. She is also an advisor to the grassroots leader in Kebun Baru, in conceptualising the designs and placement of wayfinding murals to help PLWDs navigate spaces in the community.

**“** My insights throughout the dementia journey:

Advocacy depends on the comfort level and strengths of the advocate.

To me, having a dementia advocate involved in the planning and facilitation of a programme (i.e. Voices for Hope) is critical to achieving the programme/s goal of encouraging people living with and affected by dementia to step up. It is also about embracing an inclusive work culture within (Dementia Singapore) to ‘walk the talk’ of including persons living with dementia in the workforce.

The silent killer is Stigma – it is so pervasive and so damaging.



### UNDERSTANDING AND ACCEPTANCE OF DEMENTIA: WHERE ARE WE NOW?

**By Emily Ong**  
Co-facilitator of “Voices for Hope”  
Global Dementia Observatory Focus Group member  
Dementia advocate

*Emily Ong, dementia advocate, sharing her journey living with dementia. 20*

### THE END OF ONE JOURNEY, THE BEGINNING OF ANOTHER!

#### 4.1 HEROES

## HERO 2: MOHAMMED BIN ROSLI (AKA ANJANG)

in dementia education within the Malay community and deeply believes that “to be a better person, **one** needs to help others”.

Together with his Voices for Hope cohort mate, Emily, he serves as an advisor to the grassroots leader in Kebun Baru, in planning what picture to go onto the wall for wayfinding for PLWDs in the community.

**Anjang** worked with **SMRT**, was active in drama and also performed in TV shows. His last job was with a chemical petroleum company for more than 20 years. **Anjang** was diagnosed with young-onset dementia at 50 years old. In 2017, he was diagnosed with Lewy Body Dementia and joined **Voices for Hope** cohort 3. He was 50 years old.

Despite dementia, Anjang actively educates others and helps them understand more about dementia. He is exceptionally active

**“** Why being a dementia advocate is important to me:

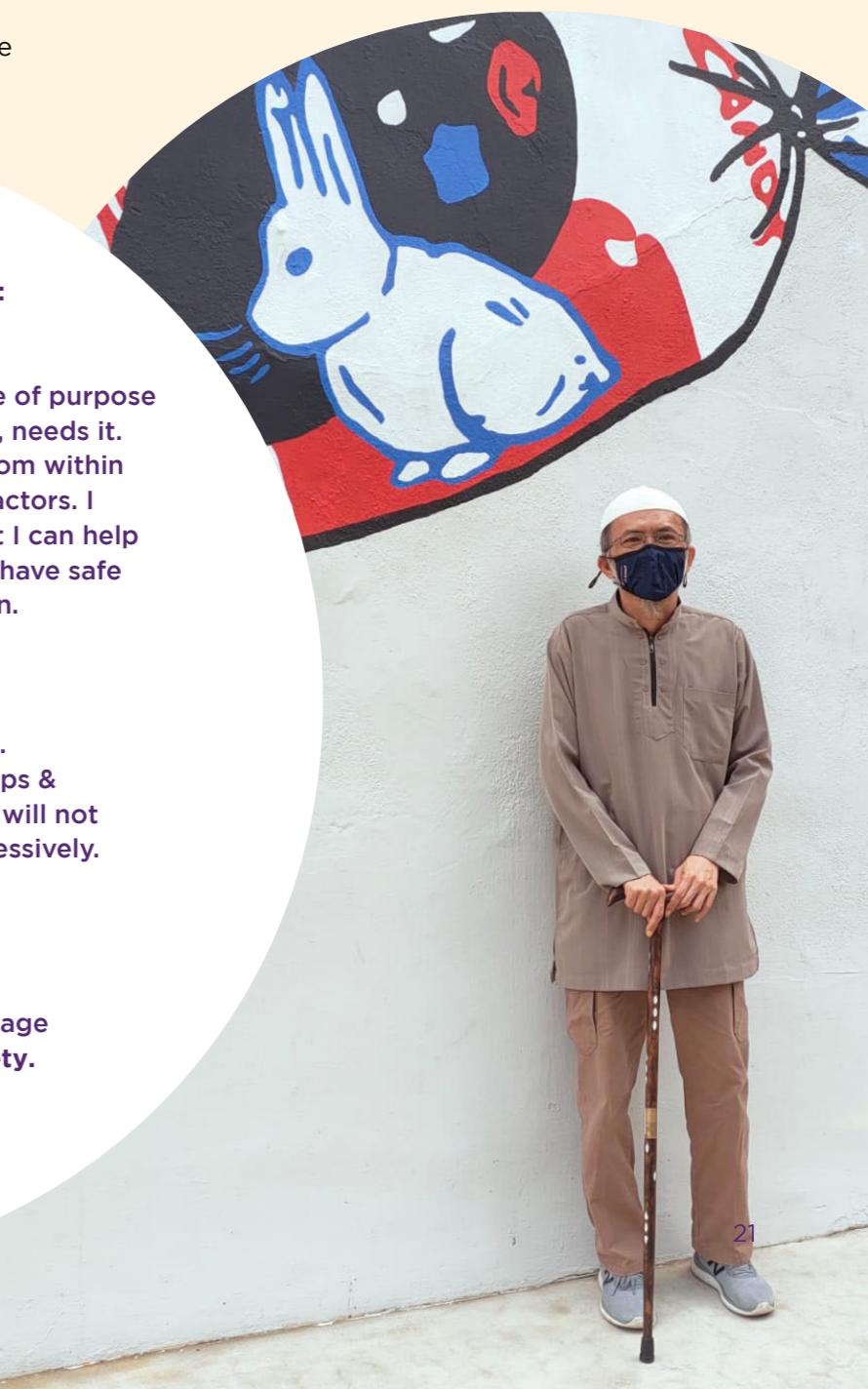
Being a dementia advocate gives a sense of purpose & objectives. A PLWD in order to sustain, needs it. Motivation to help other PLWD comes from within yourself, it doesn't come from external factors. I have to learn as much as possible so that I can help other PLWDs to empower & ensure they have safe routines to sustain their current condition.

I'm a PLWD who has managed to sustain. I want to guide, encourage, give useful tips & valuable knowledge so that other PLWD will not lose hope & succumb to dementia progressively.

We need to prepare ourselves with knowledge which is critical to better engage PLWDs and ever level of the wider society.

**“**

**”**



## HERO 3: THOMAS ONG



I am Thomas Ong, a teacher, a principal, a school counsellor and an advisor to the Juvenile court. As a retiree, I spend my time counselling and giving Math tuition and find enjoyment in creative art – visual and written.



**Thomas** is 84 years young today and was first diagnosed with mild Alzheimer's Disease in 2019. He joined the 5th cohort of **Voices for Hope** and later continued to pay it forward as a co-facilitator from cohorts 7 onwards.



### First impressions by Ruth:

"My deepest impression of Thomas? He possesses a beautiful voice, is talented and sensitive to the nuances of language. Teaching must be his calling!"

### Forget Me Not

1 Forget me not  
The day my memory  
Of you was almost down to nought  
In trying to think of you daily

2 Forget me not  
When I don't remember  
Your name or thought  
You are some stranger

3 Forget me not  
When my parents, siblings, children  
And others I have not sought  
Especially my granddaughter my sweet little wren

4 Forget me not  
When I miss your birthday  
And the memories which you brought  
In a most unforgettable way

5 Forget me not  
When we celebrate your birthday occasion  
With the many wonderful gifts they brought  
You in every kind and fashion

6 Forget me not  
When I am angry  
For not knowing that you ought  
To remember me

7 Forget me not  
For fearing the day  
I would be fraught  
Not remembering my way

8 Forget me not  
Knowing that many things that I have learnt  
Have been lost or not sought  
But into my lasting memory burnt

9 Forget me not  
As the day fades into the twilight  
With the weeks we slowly forgot  
And the months fall out of sight

10 Forget me not  
For not writing in reply  
To your letter in which you sought  
Help and required my advice

11 Forget me not  
When I had to move to another state  
Due to work that brought  
Me a new fate

12 Forget me not  
As we grow old  
Drifting apart as we ought  
Looking at our future as it unfold

13 Forget me not  
As we fade away  
Leaving behind our hard fought  
Life as it goes on its way

14 Forget me not  
As I travel towards the long road  
Hoping to be guided and brought  
Finally to my heavenly abode.

by Thomas Ong

"Forget-Me-Not" poem by Thomas Ong published on thehomegroundasia.com

## HERO 4: MICHELLE ONG

**Michelle** is Thomas' daughter and has coached executives and managers in a professional context for the past 15 years. She has developed her coaching capabilities in leadership, performance and coaching, having coached leaders from a variety of industries, including advertising, finance, IT, consumer products, education, government and industrial products.



Michelle Ong's zoom sharing of her journey as the primary care partner

She joined the 5th cohort of Voices for Hope with her father and continues as a co-facilitator across cohorts 7 and onwards. Michelle has been full of energy and is an active contributor across Dementia Singapore and related initiatives – together with Thomas and Jason Foo (CEO), she was featured in the corporate video for Dementia Singapore to raise awareness of the work they do. She also participated in the AIC video production on Communication with PLWDs.

I agreed to be a Voices for Hope co-facilitator as acts of service is high on the list for both of us. It is also an activity we can do together.



To keep engaged and active,  
Thomas Ong paints



Michelle and Thomas Ong were invited to share their journey on Living Well Despite Dementia with Standard Chartered Bank



Michelle participated with AIC video production on "Communication with persons with dementia". <https://www.youtube.com/watch?v=5bf-fzMMzNw>

**HERO 5:  
PETER  
ESTROP**



I am Peter Estrop and I spent 37 years in the military. At the end of it, I was facilitating at SAFTI MI, at ACTA. We now have a young daschund, Camo.

I've always been a person to take chances and if I feel up to it, I will do so. Besides, if I have the opportunity to help somebody [as a co-facilitator], why not? The best thing - who is helping us, is us.



Some of the meaningful events in my 37 Years in the Military

- A privilege to be selected Regimental Sergeant Major for the SAF Parade (6 months of commitment, sweat and tears)
- Experience in Afghanistan often times we take peace for granted

Powerpoint slide from Peter Estrop's sharing of his journey with dementia as a co-facilitator for Voices for Hope cohort 10 24

Peter was involved in high profile operations such as the 2001 SIA hijacking and the Cable Car Incident. He retired with the position of Chief Warrant Officer and Commanding Officer of Special Operations Tactics Centre. With his wife, they raised 4 children together and was first diagnosed with mild Alzheimer's Disease in late 2020. He joined the 8th cohort of **Voices for Hope** and later continued to pay it forward as a co-facilitator.

**4.1 HEROES**



"1000 Paper Cranes" was launched on World Alzheimer's Day at National Gallery Singapore, followed by a thought-provoking film panel discussion with, Peter and Evon Estrop



Voices for Hope co-facilitators, Peter and Evon Estrop, in action at Voices for Hope Cohort 10 sessions

**HERO 6:  
EVON  
ESTROP**

Evon runs an expatriate relocation business for many years. As the wife and primary care partner of Peter, she joined the 8th cohort of **Voices for Hope** and later continued to pay it forward as a co-facilitator.

“

Being a co-facilitator is giving back. Through Voices for Hope, we went from not knowing anything to the whole family being in the boat, sailing with Peter as captain.

”

*First impressions  
by Yasmin:*

"Evon and Peter, they have created a spirit that is so uplifting for us in Voices for Hope."

# INSIGHTS AND OPPORTUNITIES

## MESSAGE FROM THE PROGRAMME MANAGER

November 2022 marked the Voices for Hope Graduation Ceremony for the 10th cohort<sup>2</sup>. Having run considerable iterations of the programme since 2019, we decided to pull together a toolkit that weaves together the programme content and refinements made over time. Even so, I believe there will be persisting challenges and new opportunities that will be revealed as the programme continues to run. I hope that the toolkit, as a living document that evolves, will **serve our growing community and kickstart a virtuous cycle of documenting resources and sharing best practices** in support of PLWDs and their Care Partners who have to navigate care and support post-diagnosis.

**Inherent to the Voices for Hope programme is the concept of Empowerment.** In my own journey as a programme manager for the programme, I have found the phrase “nothing about us, without us” to guide my communication with others – language empowers as much as it possesses the power to stigmatize. In this aspect, I have learnt to **be mindful, inclusive and respectful with words** I use to convey my intentions and aspirations for the programme and encourage others to do the same as they embark on running the Voices for Hope programme. For example, when I “invite” participants to the programme, PLWDs and their families have the agency to decide if they will commit to the programme along with me.

Further, the spirit of Empowerment has to permeate the everyday running of the programme and role-model how to enable and engage PLWDs and Care Partners. Since Voices of Hope began, it has been intentional that the sessions involve PLWDs in every detail of the session, as far as possible – from the setting up of the classroom to the taking of orders during tea break; and from the selection of catering packages to the programme planning of a graduation event they will call their own.



Featuring the programme manager, Ruth Wong



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## 4.2 MESSAGE FROM THE PROGRAMME MANAGER

Featuring Anjang, an advisor of the ‘Find Your Way’ Initiative, attending the launch at Toa Payoh Bus Interchange.



“For those newly diagnosed with dementia. It is not the end. We can do BETTER.”

- Sim Peck Hoon

“Empowerment starts with people’s wishes, needs and dreams to make a change in their lives... In order to support people to act in a different, more liberating way, the [programme owner] must build an environment based on opportunities for increased knowledge, self-realisation, learning and competences...”

- SEMPRE, 2019



“Dementia does not define me”

- Peter Estrop

At this stage, we have seen our fair share of Heroes emerge and step up on different platforms. Already, we have witnessed key milestones such as having Mr Henry Quek join us at the Voices for Hope Cohort 3 session which opened up opportunities for Emily and Anjang to be advisors heavily involved in the Kebun Baru Wayfinding Project, which subsequently led to their involvement in the Find Your Way initiative. I am optimistic and thrilled that Voices for Hope has the potential to scale further and serve as a platform for PLWDs and Care Partners to celebrate their unique capacities – dispositions, competencies, drive, expectations and needs that they each possess—eventually, opening more doors to cater to PLWDs and Care Partners as they identify their own advocacy messages moving forward.

<sup>2</sup> See Voices for Hope: Aspiring Dementia Self-Advocates, <https://dementia.org.sg/2022/12/01/voices-for-hope-aspiring-dementia-self-advocates/>, for more information.

Commissioned by **Dementia Singapore** to consolidate the **Voices for Hope programme** resources for facilitators' reference and use, this toolkit is intended to be a living document: launched to kickstart a virtuous cycle of sharing and feedback as more organisations run the programme.

We are deeply grateful to our Voices for Hope heroes, and the staff and volunteers of Dementia Singapore, for the time, reflections, and encouragement they had so generously shared along the way. We would also like to thank the programme's co-facilitators for the meaningful input they had provided on the earlier versions of this resource.

Not least of all, our heartfelt thanks and appreciation go to Voices for Hope enablers, the National Council of Social Service and Keppel Corporation, and Huo Yasi for authoring the toolkit.

**When building the contents of this toolkit, references were drawn from sources listed below:**

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