

2021

**eCALD® Cross-Cultural Interest Group (CCIG)  
In-person and Zoom Presentation**

**Addressing the needs of Chinese with  
dementia: A cross-community  
organisation and academic approach**

**Rhonda Preston-Jones (Dementia Auckland)**

**Ray Law (Age Concern Auckland)**

**Gary Cheung (University of Auckland)**

**Date: 16<sup>th</sup> March 2021 (Tuesday) 6.30pm to 8.30pm)**



## Agenda

- Journey through Dementia
- Introducing Dementia Auckland
- Introducing Age Concern Auckland
- University of Auckland research
- Age Concern Auckland's Chinese carer focus group
- What we are doing together – the proposal for improving services for Chinese people living with dementia



2021



# Rhonda Preston-Jones

Clinical Lead  
Registered Occupational Therapist

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March 21

## Service from Waiuku to Wellsford

### The team

- CEO
- Clinical Lead
- 3 Marketing & Fundraising Team
- 1.5 Educators
- 8 Keyworkers
- 3.5 Living Well Team
- Accountant
- Administration



Four offices – Grey Lynn, Pakuranga, Henderson and Orewa



# **Making life better for all people affected by dementia**



Kia piki te ora mo nga tangata mate porewarewa



## Purpose, beliefs and values

### Purpose

We enable all people affected by dementia to live their best life

### Beliefs

- We see the person, not the condition – I am still me
- We use clinical expertise to empower people, side by side through their journey
- We help navigate the new normal
- We support and respect diversity
- We have the courage to ask for resources
- We do this with kindness

### Values

Kindness



Empathy



Respect



Community



Acceptance



Professionalism

## Service Team Structure



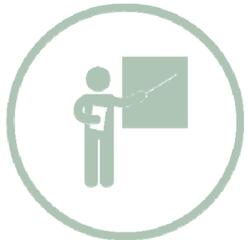
### **Keyworkers**

8 - Funded by the DHBs



### **Living Well Team**

3.5 - Unfunded



### **Educators**

1.5 - Under funded by the DHBs

# Keyworkers



Nicola Brenton  
Brenda Kearns  
Jo Temple

(SW)-West  
(EN)-North Shore  
(RN)- Rodney



Jemma Heap  
Bronwen McGregor

(RN)-West  
(RN)- East



Nicola Fletcher Williams (RN)- East  
Lesley Sowden (RN)- Central  
Julie Kerr (OT)- South



## Keyworker Support Service

- For care partners and families

- 1:1 support, information, resources and advice
- Face to face, email, phone
- Navigation through the health system
- Support Groups
- Young Ones Support Group



## Living Well Team

### Team Leader:

- Sarah K at Grey Lynn office

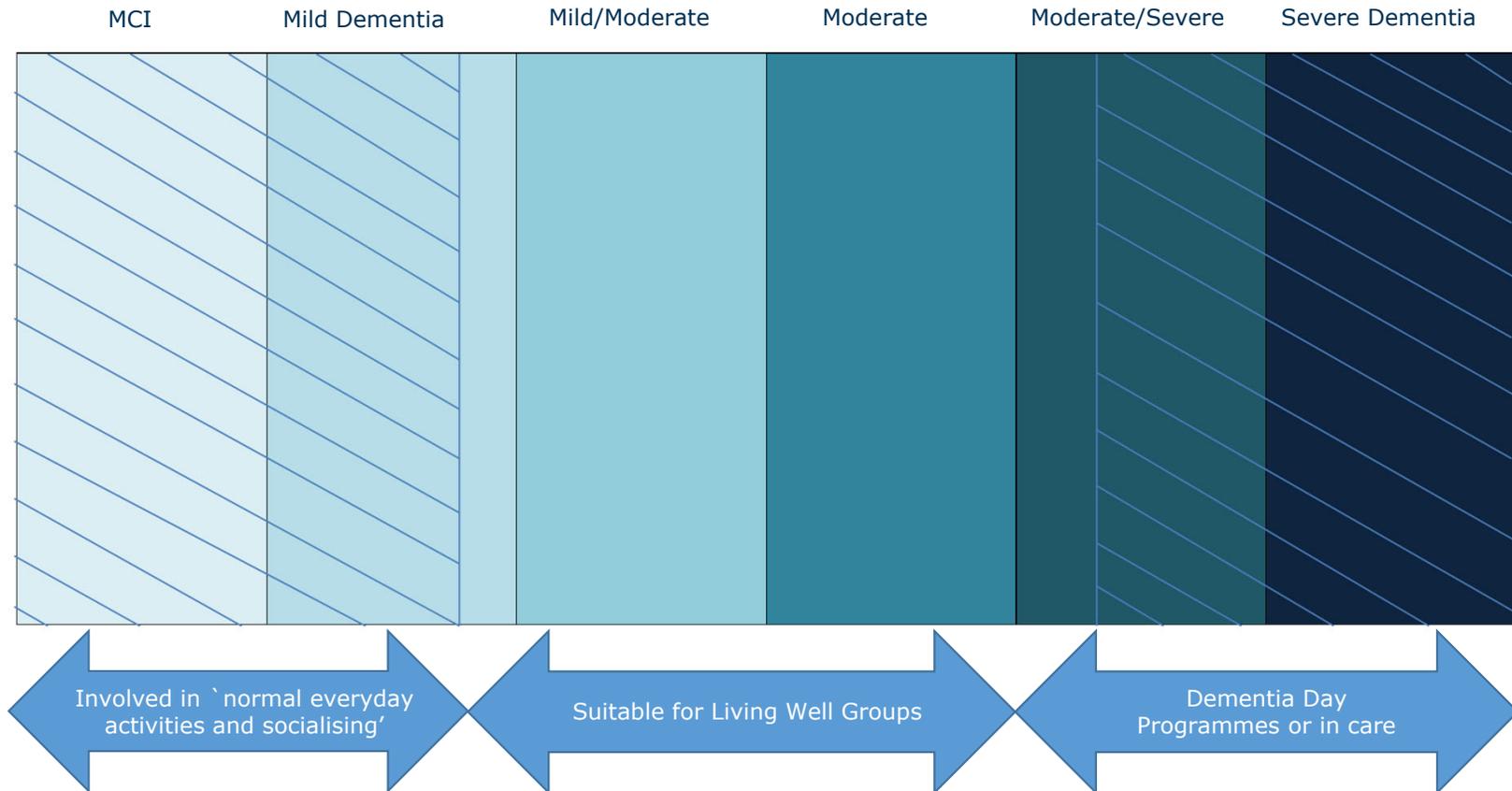
### Group Facilitators:

- Kelly in South Auckland
- Terry in Central Auckland
- Lynn in West Auckland
- Sarah D on the North Shore
- Sarah K on mCST & CST
- Gill (Pukekohe on Contract)



## The Dementia Journey

Dementia is a slowly deteriorating neurological condition. The Living Well Team aims to provide a bridge between people's normal everyday activities and social contacts and the programmes / services funded by the Ministry of Health for people with more severe dementia.



## Living Well Services

**The Aim** of the groups is to provide:

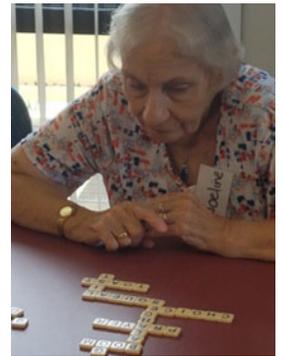
- Opportunities for **socialising** for people with dementia & their carers
- Stimulating, **normal, meaningful** activities for adults.
- **Graded and modify activities** to facilitate participation for people with dementia at whatever level they can within the group activity
- Activities focused on well **preserved old skills** rather than requiring new learning
- A **non-judgemental** environment where people with dementia can participate and socialise thus experiencing **mastery, success, pleasure and fun**
- Carers a predictable opportunity to have **a break or respite** from the person they are supporting for a few hours



## Living Well Groups

- For people living with dementia

- Cognitive Stimulation Therapy
- Maintenance CST
- Walking Groups
- Singing Group
- Exercise Groups
- Art Groups
- Dancing Group
- Book Club
- Petanque Group
- Creative Eco Group
- Men's Gym Group
- Young Onset Group



## Educators

➤ Maria Co – Fulltime

➤ Rhonda, Winifred – part time



➤ Carer Education Programs

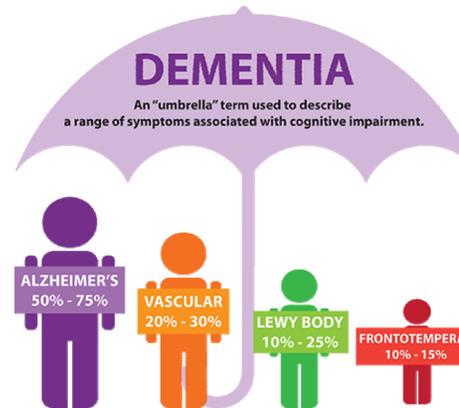
➤ Masterclasses

➤ Dementia Talks

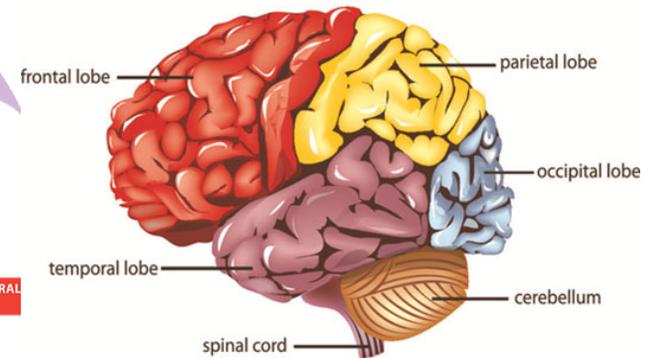
➤ Community Education

➤ Professional Education

➤ Brain Health Coaching (Sally)



## Parts of the Human Brain



## Marketing and Fundraising Team

- Public awareness and anti stigma campaigns
- Mind Matters Newsletter
- Social media – Website, Facebook
- Media releases, television appearances
- Fundraising events





# Age Concern Auckland

*Serving the needs of older people*



*Ray LAW*  
*Asian Services Manager*  
*Registered social worker / counsellor*



- **The vision of Age Concern Auckland is for older people to live a valued life in an inclusive society.**
- **We are committed to promoting wellbeing, rights, respect and dignity for older people.**

Photo sources: Google Image



**Each year our services directly help 18,000  
older people & provide information & advice  
to 40,000**



# Our **3** offices in Auckland:

**57 Rosebank Road, Avondale (Central and West)**

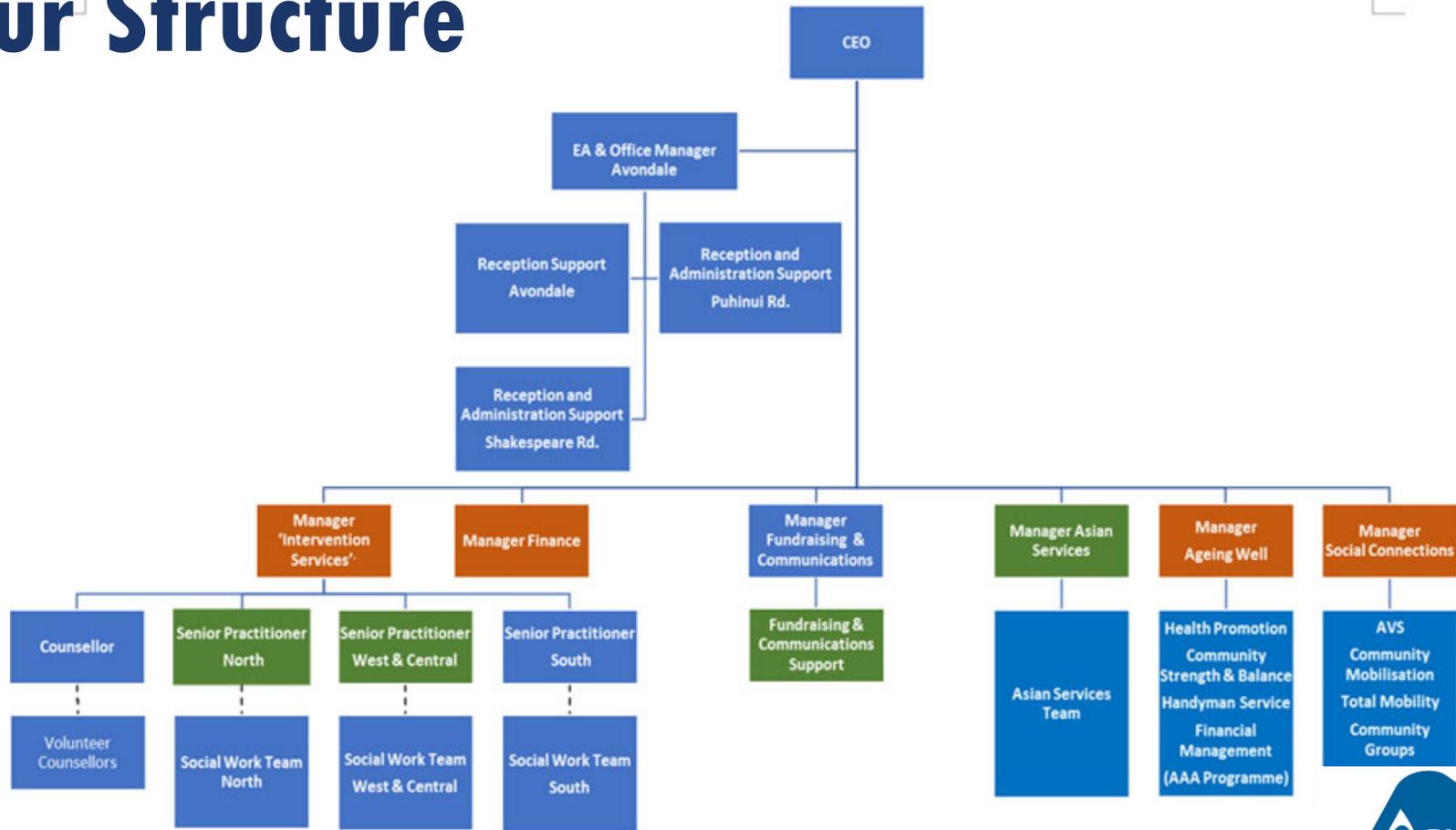
**250 Puhinui Road, Papatoetoe (Counties Manukau)**

**177B Shakespeare Road, Milford (North Shore)**

- **45 paid staffs (full time and part time)**
- **Around 550 volunteers**



# Our Structure



# Services deliver in Age Concern Auckland

- **Information about local communities group**
- **Field Work Service**
- **Elder Abuse and Neglect Prevention Service**
- **Social Connect Services**
- **Health Promotion**
- **Total Mobility Scheme**
- **Asian Services**

**Our services and support cover all parts of Auckland**



# Asian team's support toward people affected by dementia

- Individual and family case work
- Arrange volunteers visit
- Deliver health talks on EPoA, ACP and Will
- Talks on brain health and early signs of dementia
- Deliver activities in rest home to stimulate resident's cognition responses

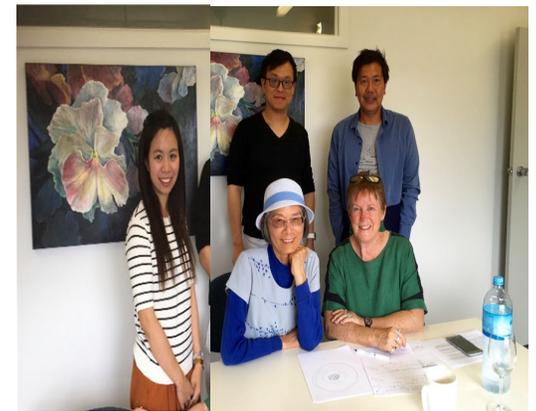


# Services for Asians Whose Lives Are Affected by Dementia

Who are we talking about?

Where do they live?

Health Services - Who is doing what, where ?



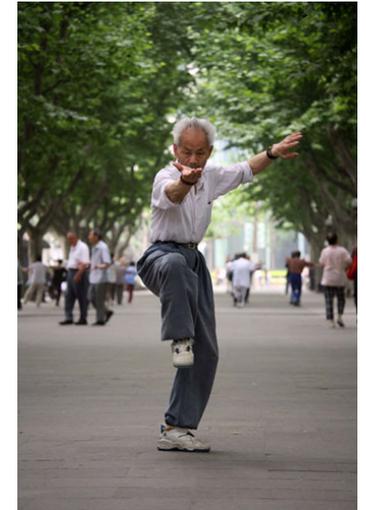
## Who – Auckland Population

Auckland is a culturally diverse community

|                            |        |
|----------------------------|--------|
| Maori                      | 23.9%  |
| Pacifica                   | 16 %   |
| Asian and South East Asian | 28.2 % |
| Indian subcontinent        | 10 %   |
| Middle Eastern             | 2.3 %  |

## Who comes under the category of "Asian"

- New Zealand born and raised Asians
- New arrivals from:
  - Mainland China
  - Hong Kong
  - Taiwan
  - Vietnam
  - Cambodia
  - Burmese
  - Lao
  - Thailand
  - Malaysia
  - Singapore
  - Indonesia



## Are Asians an homogenous group?

- No! Of course not!
- Different countries of origin, different, cultures, languages, religions
- Chinese families 4th or 5th generation New Zealanders
- New immigrants
- Large families
- Very small families
- People living alone

## Where does the Asian population live in Auckland?



All over Auckland with some concentrated pockets in East Auckland and on the North Shore

## What issues do Asian families living with dementia face?



# What issues do Asian families living with dementia face?



# University of Auckland Research

Dr Gary Cheung (Old Age Psychiatrist)



THE UNIVERSITY OF  
**AUCKLAND**  
Te Whare Wānanga o Tāmaki Makaurau  
NEW ZEALAND

**MEDICAL AND  
HEALTH SCIENCES**

# The LiDiA study

(Living with Dementia in Aotearoa)



Sarah Cullum (PI)  
Makarena Dudley (Māori)  
Fiva Fa'alau (Samoan)  
Etuini Ma'u (Tongan)  
Tony Kautoke (Tongan Co-Lead)  
Rita Krishnamurthi (Indian)  
Gary Cheung (Chinese)  
Adrian Martinez-Ruiz  
Susan Yates  
Ngaira Kerse



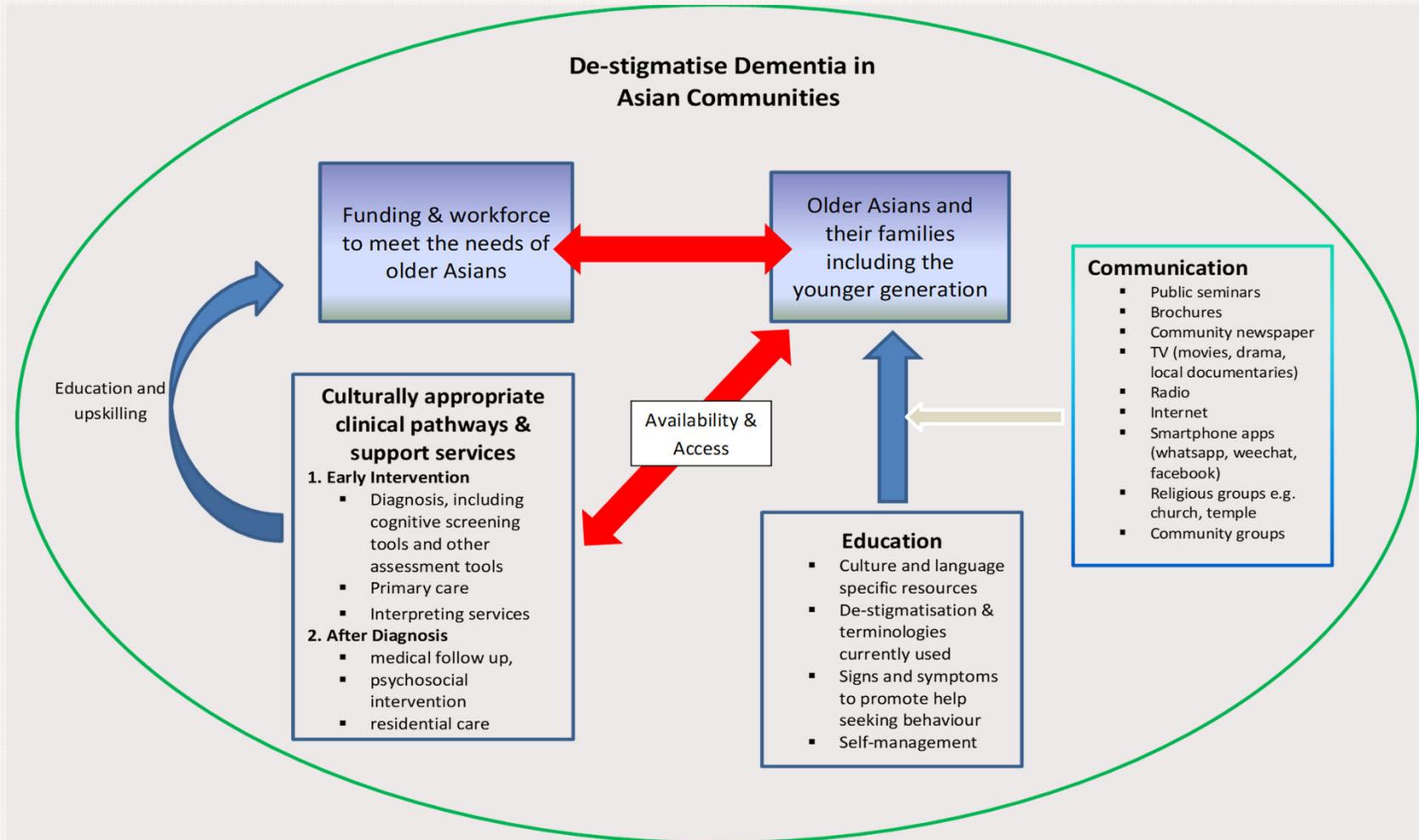
# Study 1: Engaging Asians in dementia care and research: The clinicians' perspectives

## Stage 1: 4 focus groups in a research workshop; video-taped

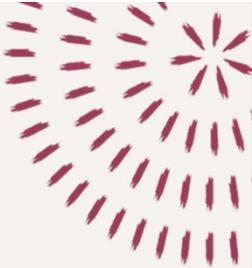
- 30 HCPs who have experience and/or an interest in working with Asian people on dementia care
- Nursing (23%), social work (20%), medical (10%) and occupational therapy (10%)
- 63% Chinese, 20% European, 10% Korean, 7% Indian



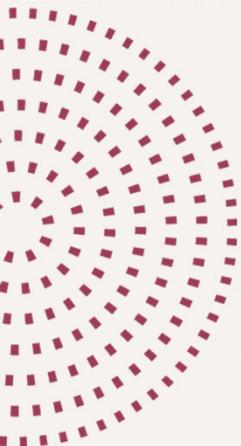
# Stage 1



# Study 1: Engaging Asians in dementia care and research: The clinicians' perspectives



## Stage 2: Selected participants from Stage 1; audio-taped

- 11 HCPs
  - Nursing (36%), community support worker (18%), social work (18%), and occupational therapy (18%)
  - 82% Chinese, 9% Korean; 9% Indian
- 

# Stage 2: 4 main themes

Theme 1: Cultural interpretations of dementia

Theme 2: Stigma

Theme 3: Filial piety and collectivism

Theme 4: Inequality in availability of resources

- Disparities in available information
- Disparities in services
- Opportunities for education

Received: 15 April 2019 | Accepted: 5 August 2019

DOI: 10.1002/gps.5189

**RESEARCH ARTICLE**

WILEY Journal of  
Geriatric Psychiatry

**Perspectives of dementia from Asian communities living in New Zealand: A focus group of Asian health care professionals**

Gary Cheung<sup>1</sup>  | Kerry Appleton<sup>2</sup> | Michal Boyd<sup>3</sup> | Sarah Cullum<sup>1</sup> 

# Study 2: The understanding and experiences of living with dementia in Chinese New Zealanders

Other authors: April Su, Karen Wu, Blake Yue, Susan Yates, Adrian Martinez-Ruiz, Rita Krishnamurthi, Sarah Cullum

## 16 study participants:

- 5 dyads of a person with mild dementia and a care partner (husband: n=1; wife: n=1; son: n=2)
- 1 person with mild dementia
- 5 care partners of people with more severe dementia (wife: n=2; daughter: n=2; son: n=1)

# Study 2: 5 main themes

- Theme 1: Understanding of dementia
- Theme 2: Impact on the person living with dementia
- Theme 3: Impact on family carers
- Theme 4: Stigma
- Theme 5: Experience with health care and support services: cultural expectation, language barrier and the importance of professionalism
  - Positive remarks on NZ services

*“Overall, I am blessed and very happy with everything here in NZ.”*
  - The emotional support from clinicians has been very valuable for family members

*“Health care professionals should be compassionate and have “heart” when caring for people living with dementia.”*

## Feedback from Chinese carer support focus groups

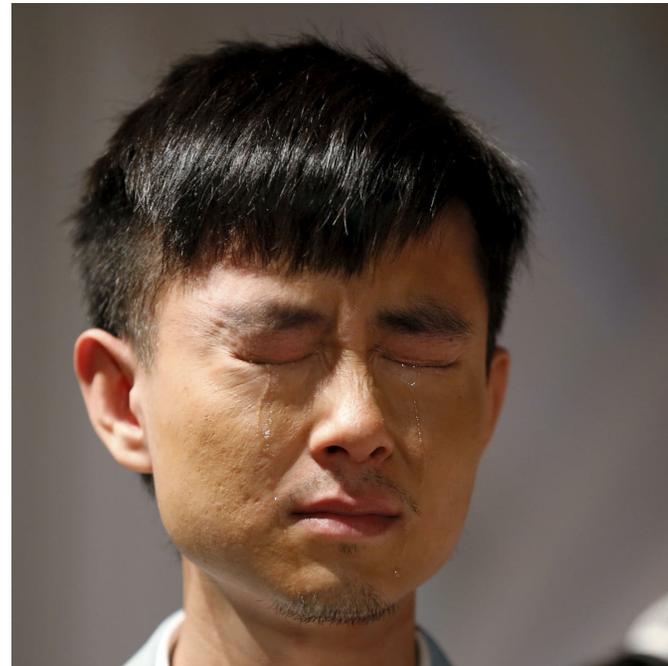


- To have more information on care and support, having channel to ask and receive information in Chinese.
- To have support group to ventilate the carer's stress – smoothing group
- Lack of understanding of dementia among the Chinese community – education on Dementia
- Lack of understanding about medication and it's side effect. Client would concern and worries when GP mentioned about the negative side effect.
- To learn more ways/skills to communicate and interact with client.
- Learn to self care and self-adjustment.
- The dementia service and support can be developed more.
- Can be able to form a stronger unify support group.

From the findings and discussion, most agreed that 1) increase awareness about dementia is the most important, then is 4) carer's support.

## What issues do Asian families living with dementia face?

- Language
- Cultural
- Different health beliefs
- Stigma
- Isolation
- Lack of support
- Cost
- Low health literacy



## What does the New Zealand Health System offer Asian Families?

- DHBs – assumption that one size fits all
  - Culturally inappropriate support services eg: NASC services
- Random allocation of bilingual/bicultural Asian staff
- Interpreters
- Private practicing bilingual/bicultural Asian – GPs, Physios, Chinese medicine practitioners

## Why do we need to do something different?

Unique issues of:

- Lack of awareness and understanding
- Stigma
- Misunderstanding and distress
- Isolation
- Health needs not addressed
- Carer stress
- Families caring in challenging situations with the minimum of knowledge, information, support, services and recourses

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# The journey through dementia

|                        |                       |   |   |                         |                     |                                   |                                |                  |
|------------------------|-----------------------|---|---|-------------------------|---------------------|-----------------------------------|--------------------------------|------------------|
| Knowing about Dementia | Recognising the signs | Doing something about it in a timely manner | Getting some support to navigate the system | Getting support to cope | Gaining information | Making the best of the good years | Managing the challenging years | Managing the end |
|------------------------|-----------------------|---|---|-------------------------|---------------------|-----------------------------------|--------------------------------|------------------|

## Services required:

|  |                                   |   |  |                             |                                   |  |  |                                     |
|--|-----------------------------------|---|--|-----------------------------|-----------------------------------|--|--|-------------------------------------|
| Public awareness of dementia and anti-stigma campaigns | Pre-diagnostic advice and support | Assessment and diagnosis of dementia, planning for the future | 1:1 Support, advice and navigation through the journey of dementia | Carer/Family Support Groups | Carer/Family Education programmes | Living Well groups/ activities for people living with a diagnosis of dementia (PLWD) | Managing challenging behaviours and the severe dementia, | Managing end stage dementia at home |
|--|-----------------------------------|---|--|-----------------------------|-----------------------------------|--|--|-------------------------------------|

Provided by Dementia Auckland

Provided by the DHB's

# The journey through dementia

|                        |                       |   |   |                         |                     |                                   |                                |                  |
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|------------------------|-----------------------|---|---|-------------------------|---------------------|-----------------------------------|--------------------------------|------------------|

## Who provides Culturally appropriate Services for Asian families ?

|  |                                   |   |  |                             |                                   |  |  |                                     |
|--|-----------------------------------|---|--|-----------------------------|-----------------------------------|--|--|-------------------------------------|
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|--|-----------------------------------|---|--|-----------------------------|-----------------------------------|--|--|-------------------------------------|

No one                      Done well by the DHB's                      Done poorly by Dementia Auckland                      Done poorly by the DHB's

## **JOINT PROPOSAL**

**To develop better Chinese  
Services for people whose  
lives are affected by Dementia**

## The proposed plan

|                      |   |
|----------------------|---|
| Establish priorities | <ul style="list-style-type: none"><li>- Increasing Awareness in the Asian community</li><li>- Education and Support for Carers/families</li></ul>   |
| Work collaboratively | Age Concern Auckland, Dementia Auckland, local cultural communities and the local DHB and PHO's will need to work together to develop and fund these services.  |
| Design a Service     | <ul style="list-style-type: none"><li>- The service to be staffed by Asian health professionals, with a background in working in dementia services, skilled to work as Key Workers and Educators.</li><li>- A minimum of two staff</li><li>- Staff, resources, education and support services would need to be able to tri-lingual ( Cantonese, Mandarin and English).</li><li>- Expand to other cultural communities</li><li>- Increase services by recruiting volunteers from each community to support people living with dementia and their families.</li></ul> |

## The steps involved in developing a new service

| What                                       | Progress  |
|--|---|
| 1) Research the needs within the community | Done  |
| 2) Consult with stakeholders               | Health Professional Consultation meeting planned for late March |
| 3) Develop and plan                        | Started   |

| What  | How   |
|---|---|
| 4) Seek funding   | The funding would need to come from a DHB allocation, grant applications to community trust and fundraising within the Asian community.   |
| 5) Engage researchers to study the process                            |   |
| 6) Launch a trial project   | It is recommended that this project start with a small manageable trial in a specific area such as the Chinese community in the Howick/Botany/Pakuranga area, thus involving the CMDHB. |
| 7) Write the trial up and report back to stakeholders                 |   |
| 8) If successful expand and embed the service into a wider population |   |



# Thank you

Unity is Strength

团结就是力量

