PARADIGM SHIFT FROM HOSPITAL TO COMMUNITY CARE
13th Hong Kong East Cluster Symposium on Community Engagement
June 23, 2018

WeRISE
Stroke Family Empowerment Project

Health and Social Collaborative Care that Empowering Stoke Families: A Two-Tier Care-Management Intervention

醫社共生支援中風家庭：雙層個案管理干預

Dr. Vivian W.Q. LOU
Sau Po Centre on Ageing
The University of Hong Kong

CONTENTS

01 – BURDEN OF STROKE

02 – STROKE CARE CHALLENGES

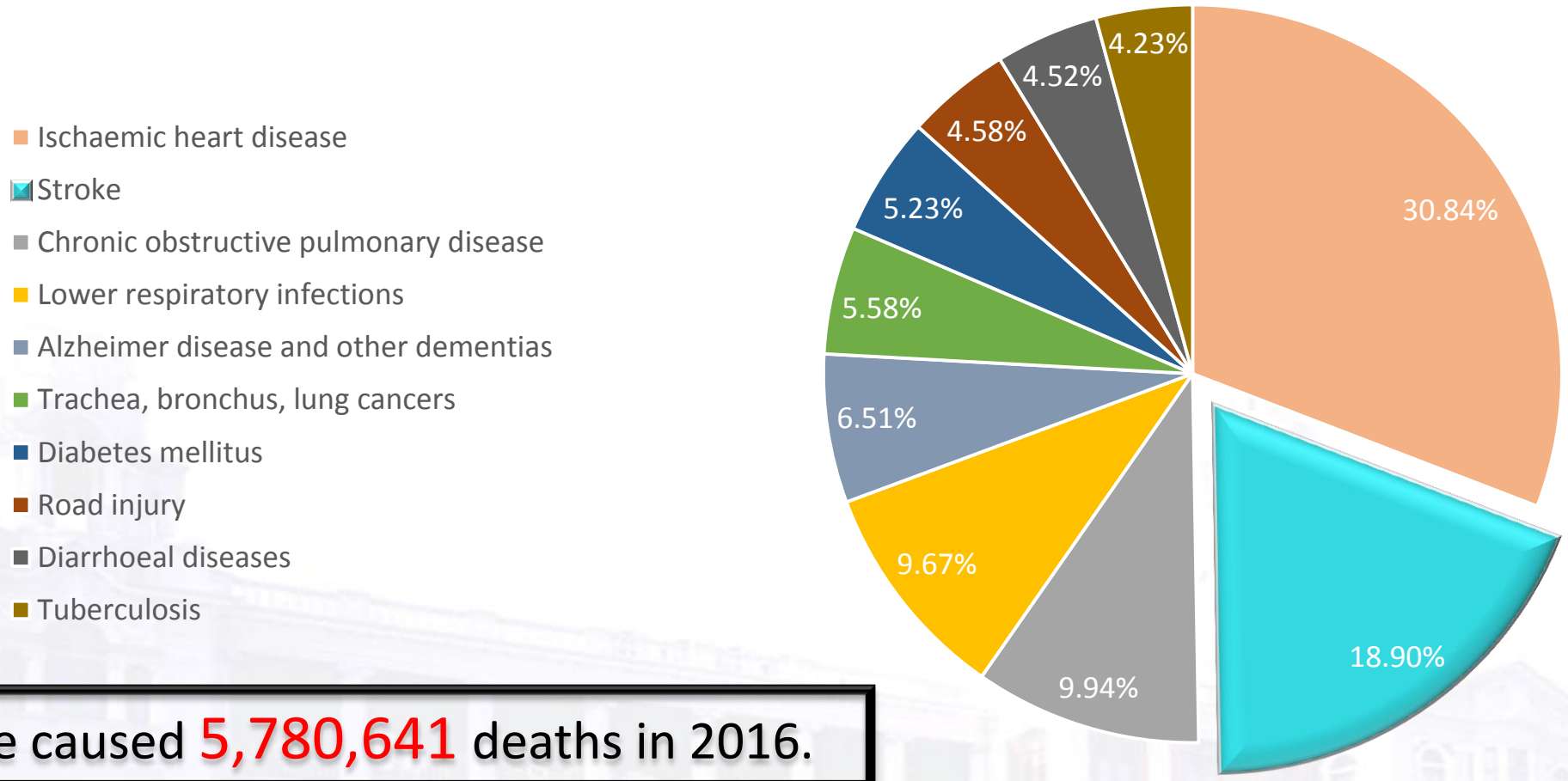
03 – WERISE: STROKE FAMILY EMPOWERMENT PROJECT

04 – EFFECTIVENESS & LESSONS LEARNED

05 – CONCLUSIONS

STROKE: THE OVERLOOKED KILLER

Global Health Estimates 2016: Estimated deaths (Top 10 killers)



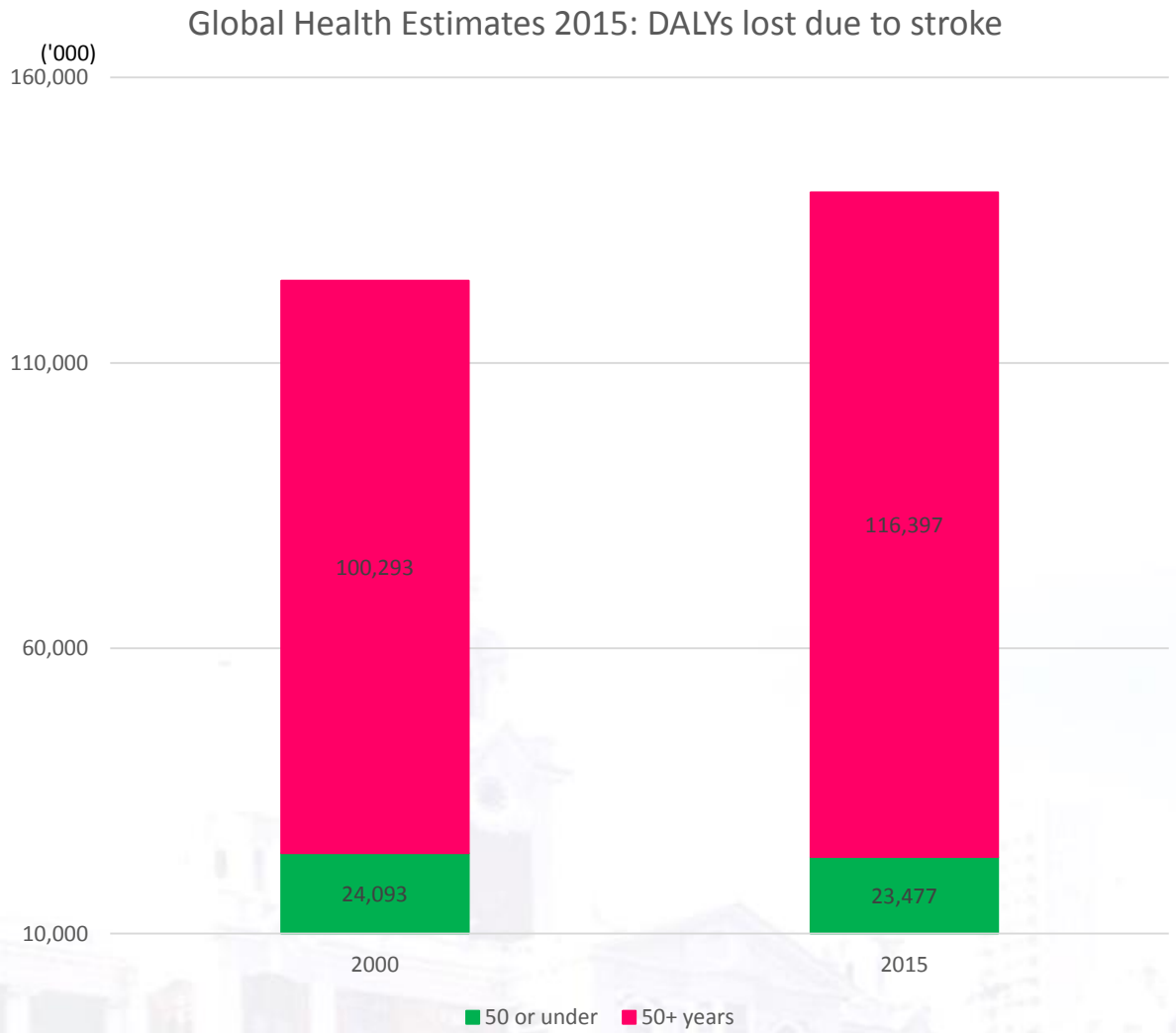
Stroke caused 5,780,641 deaths in 2016.

Source: World Health Organization, 2018

True Burden of Stroke

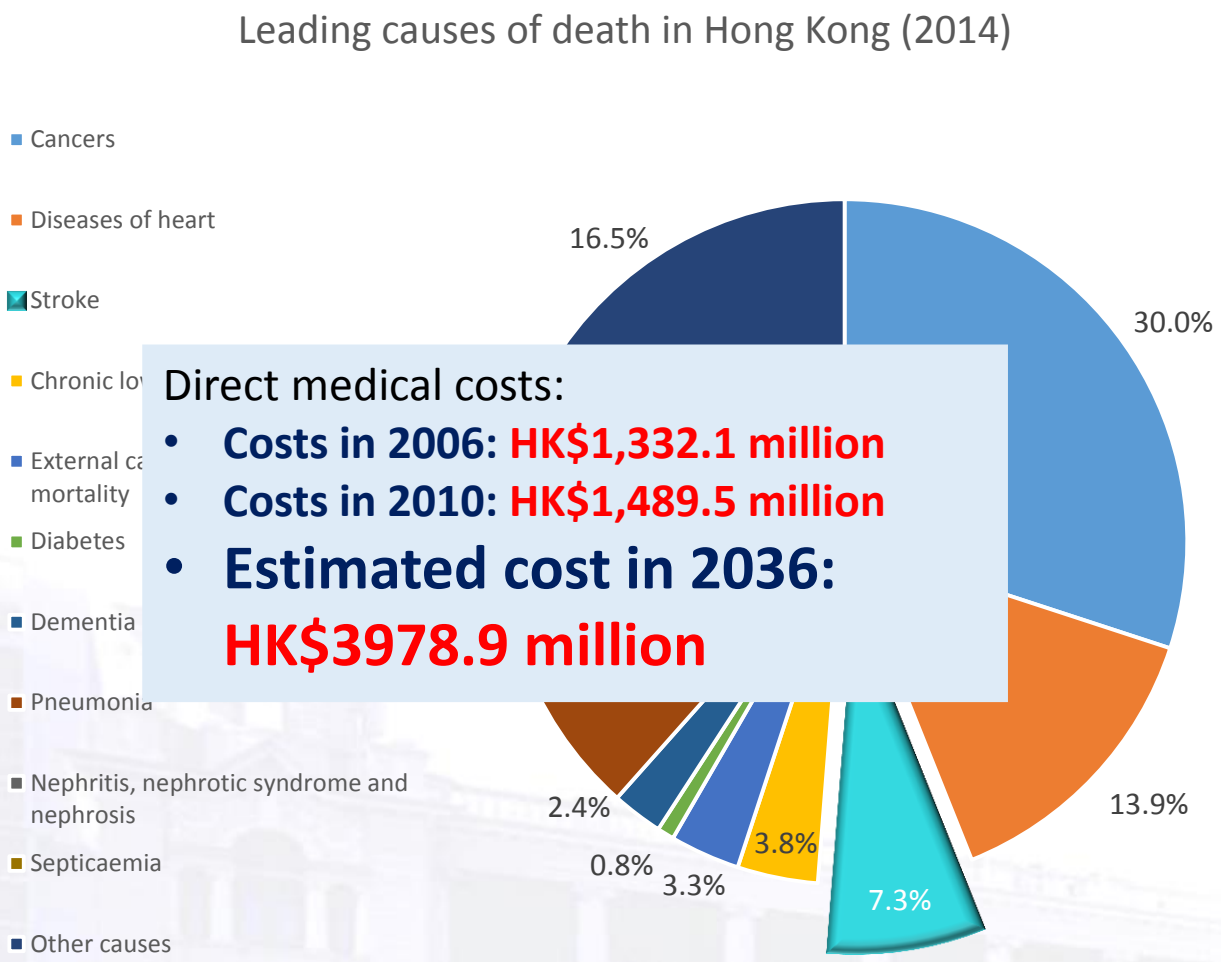
Why we care?

- True burden of stroke is **chronic disability** rather than death
- Approximately a third of stroke survivors are functionally dependent at 1 year
- 10-year survivors % (95%CI)
  - Barthel index severe disability 14.4% (11.3-18.2)
  - Barthel index Moderate disability 12.2% (9.4-15.8)
  - Frenchay Activities index inactive 49.5% (44.5-54.5)
  - HAD's depression 35.6% (30.9-40.6)
  - HAD's anxiety 31.4% (26.9-36.3)
  - Cognitively impaired 28.0% (22.7-34.1)



Sources: MacDonald BK et al., 2000; Murray CJL et al., 2012; Rothwell PM, 2001; Saka O et al., 2009; Siobhan L Crichton et al., 2016; World Health Organization, 2015

Stroke in Hong Kong



Direct medical costs:

- **Costs in 2006: HK$1,332.1 million**
- **Costs in 2010: HK$1,489.5 million**
- **Estimated cost in 2036: HK$3978.9 million**

Every year, around **22,000** people who suffer form stroke discharge to home or institutional care

60 families start to take care of a stroke patient every day!

Sources: Ching, 2013; Department of Health, 2016; Yu et. al., 2016

Stroke Care Challenges

Acute Setting

Convalescent

Community

A&E

Unstable condition

General medical wards

Acute Stroke Unit

Neurosurgical wards

Assessed by a multidisciplinary team:
- doctors
- nurses
- physiotherapists
- occupational therapists
- speech therapists

Direct discharge

Transfer to convalescent

Stabilisation

Treatment by a multidisciplinary team:
- doctors
- nurses
- physiotherapists
- occupational therapists
- speech therapists

Institutions

CGAT follow-up

short-term institutionalization (depends on condition)

Home

Services:
- information, support and training
- community resources
- discharge plan
  - OT suggested home modifications

Regular medical follow-up
- SOPC (2-3 years after d/c)
- GOPC
- Family Medicine (stable condition)
- Geriatric (patients with comorbidity)

Community Rehabilitation

Carer support group (self-help)

Source: Informal communication with medical practitioners,2018)

Supporting Complex Needs Across the Care Continuum

Acute Care

Medical

Information

Financial

Family needs:

- What are treatment choices?
- Handle sudden change in job / family arrangement.
- Any consequences? Rehabilitation potential?

Transit from Hospital to Home

Medical

Practical

Psychological

Family needs:

- Shall I quit job / take leave?
- Shall we do home modification?
- Where to get walking aids and how to use it effectively?
- Shall we go for alternative?
- How I can do ADL care?

Community re-habilitation

Medical

Psycho-social

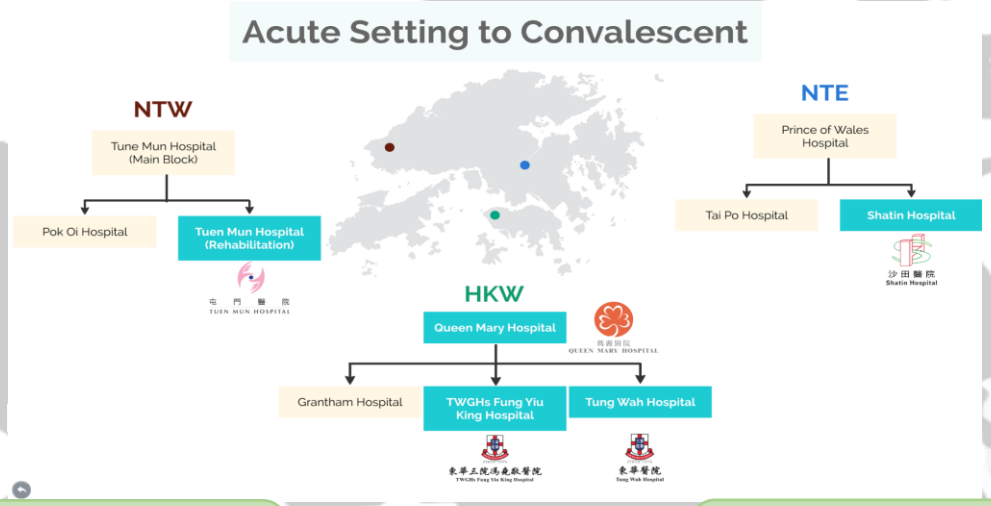
Family needs:

- What I can do more to motivate rehabilitation?
- Would it be too selfish to “take a break”?
- Am I the only one who should take care of the patient and/or my family?
- How we can cope better when feel frustrated?
- What would be our family goals?

WeRISE

Stroke Family Empowerment Project

HEALTH AND SOCIAL CARE COLLABORATION



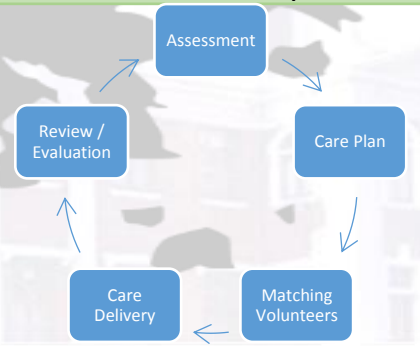
FAMILY ORIENTATION

We believe family resilience!

CARE MANAGEMENT

Professional led

Trained volunteers partnered

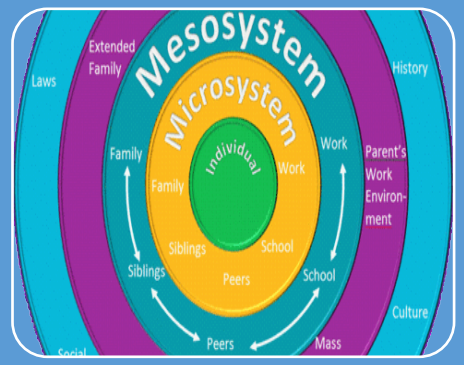


香港大學秀圖老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

OBJECTIVES

1. Enable a new family equilibrium
2. Empower a better community integration
3. Nurture a caring community

Theoretical Base



System theory

- The whole is more than the sum of the parts
- Circular causality for goal achieving
- Positive feedback / communication is the key

Empowerment

- Families are able to work out solutions for new system equilibrium given appropriate opportunities
- Six attributes of empowerment

Six Attributes of Empowerment

Active participation that values self & others (family)

- Knowledge to problem solve (positive coping)
- Self-care acceptance, responsibility (also being cared by families)
- Informed change (feedback on rehabilitation; participatory decision-making)
- Presence of client competency (preserve; restore, and transform)
- Control on health & life (let go; forgive)

Two-tier Care Management Intervention

Comprehensive Assessment

Family-oriented Care Plan (FCP)

Professional led

4+2

1. Goal setting
2. Relationship, care and support
3. Family and the caregiving context
4. Family conference

- Dementia
- Domestic Helper

Volunteer partnered

On Need Base

1. Self care
2. Caregiving skills (ADL)
3. Communication and swallowing challenges
4. Speech training
5. Health impacts after stroke
6. Cognitive training
7. Home-based exercise
8. Medication management
9. Home safety and emergency care
10. Communication with health care professional
11. Community resources

- ✓ Close Case
- ✓ Referral to Other Services
- ✓ Peer Group

Review / Evaluation

Effectiveness & Lessons Learned

- Inclusion & Exclusion Criteria
- Effectiveness on Key Outcome Measures
- Lessons Learned

Inclusion & Exclusion Criteria

Caregiver

Inclusion

- Age 18 or above
- Cantonese-speaking
- Provides at least 10 hours (including supervising domestic helper if applicable) of care per week
- Primary family caregiver
- Experiences caregiving challenges
  - Perceived burden
  - Depressive mood
  - Family dysfunctioning
- Voluntary

Exclusion

- Suffer from acute health conditions

Patient

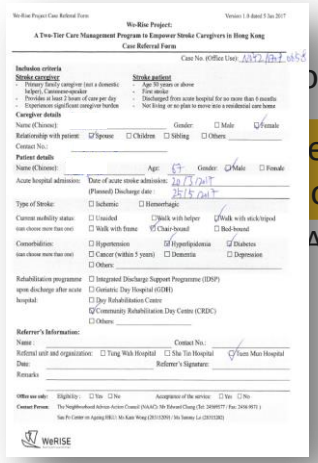
Inclusion

- Age 50 years or above
- First ischemic or hemorrhagic stroke
- Discharged within six months
- Community-dwelling

Exclusion

- Transient ischemic attach (TIA)
- Plan to move into residential care within 6 months

RESEARCH SCHEMA



ospitalization

erral from
ospitals

After discharge

Collaborated Medical Team

Eligibility Screening

N

Excluded from the study

Obtain Informed Consent

N

Excluded from the study

R

Experimental group

Control group

Before intervention

First assessment

First assessment

Two-tier Care Management Intervention

Volunteer-led Psychoeducation intervention

One month after intervention

Second assessment

Second assessment

Three months after intervention

Third assessment

Third assessment

香港大學秀圖老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

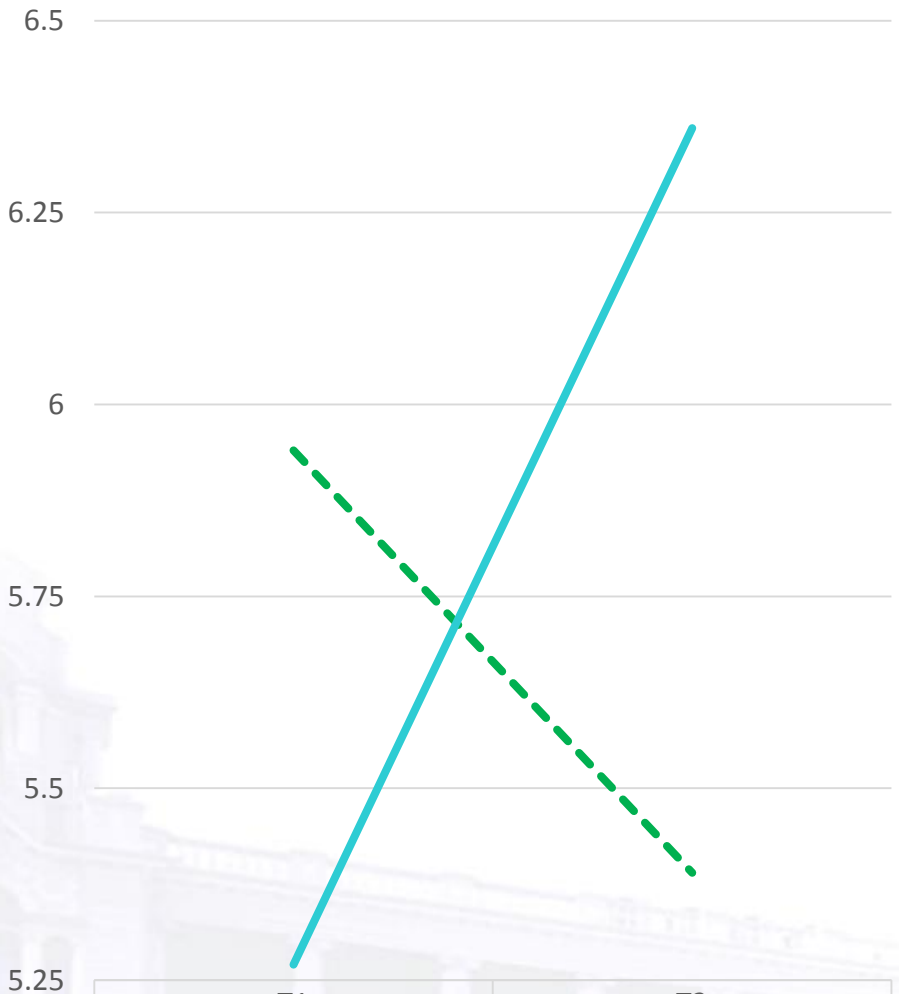
PATIENTS' CHARACTERISTICS (N=85)

	Control Group (n=42)	Intervention Group (n=43)
Gender (%) Female Male	 57.1 42.9	 41.9 58.1
Age Range Mean (SD)	 50-94 68.67 (13.60)	 52-93 70.19 (11.17)
Education (%) Primary School or below Secondary School or above	 57.1 42.9	 61.9 38.1
Employment before stroke (%) Yes No	 26.2 73.8	 34.9 65.1
Living with caregiver (%) Yes No	 88.1 11.9	 76.7 23.3
Comorbidities Range Mean (SD) Median	 0-4 1.88 (1.09) 2.00	 0-6 2.41 (1.52) 2.00
Activities of daily living Range Mean (SD)	 17-95 60.41 (22.55)	 0-95 62.30 (27.61)
Instrumental activities of daily living Range Mean (SD)	 0-12 4.66 (3.57)	 0-18 5.39 (5.08)

CAREGIVERS' CHARACTERISTICS (N=85)

	Control (n=42)	Intervention (n=43)
Gender (%)		
Female	69.0	74.4
Male	31.0	25.6
Age		
Range	25-81	22-82
Mean (SD)	55.10 (12.59)	53.07 (13.89)
Education (%)		
Primary School or below	42.9	25.6
Secondary School or above	57.1	74.4
Employment (%)		
Yes	45.2	44.2
No	54.8	55.8
Personal monthly Income (%)		
Below $10,000	60.0	68.3
$10,000 or above	40.0	31.7
Length of caring (month)		
Range	1-114	1-84
Mean (SD)	6.39 (17.90)	5.57 (13.12)
Median	2.00	2.50
Weekday daily time of caring (hour)		
Range	0-18	1-24
Mean (SD)	9.30 (5.13)	8.88 (5.77)
Weekend daily time of caring (hour)		
Range	0-42	0-36
Mean (SD)	11.39 (7.61)	10.57 (7.03)

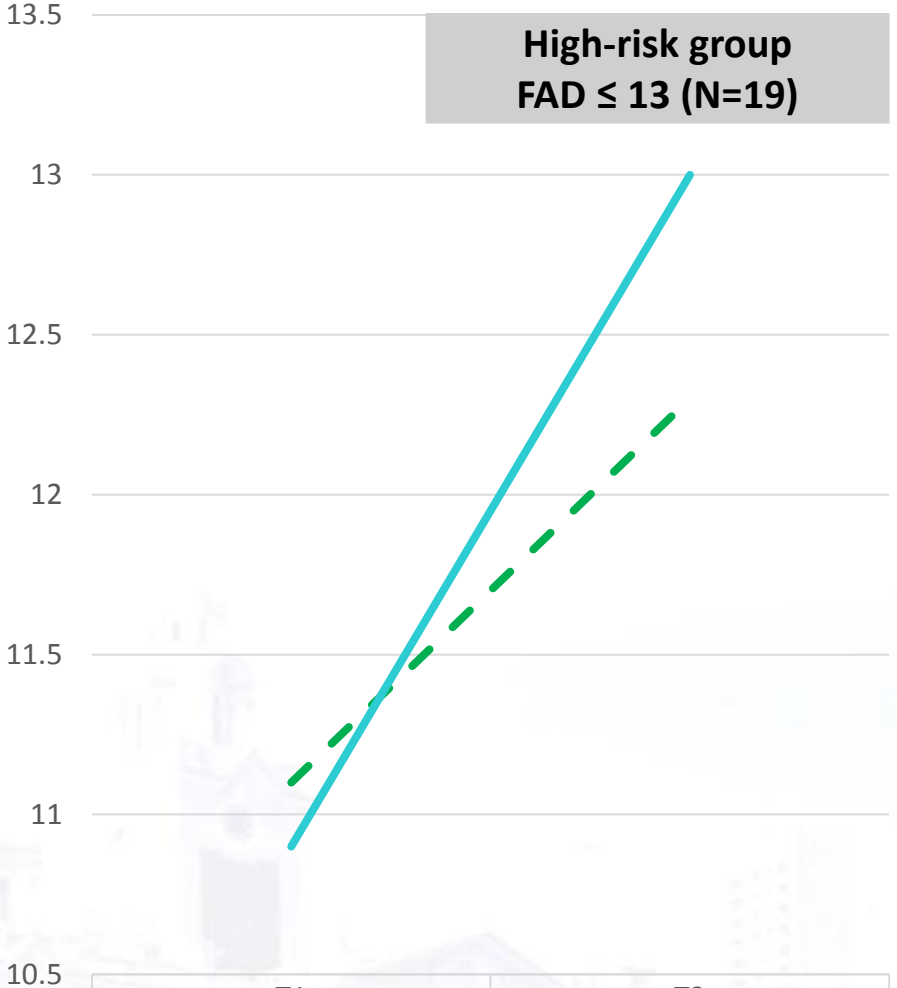
Stroke Knowledge & Family Functioning



	T1	T2
Control group	5.94	5.39
Intervention group	5.27	6.36

Control group Intervention group

High-risk group
FAD ≤ 13 (N=19)

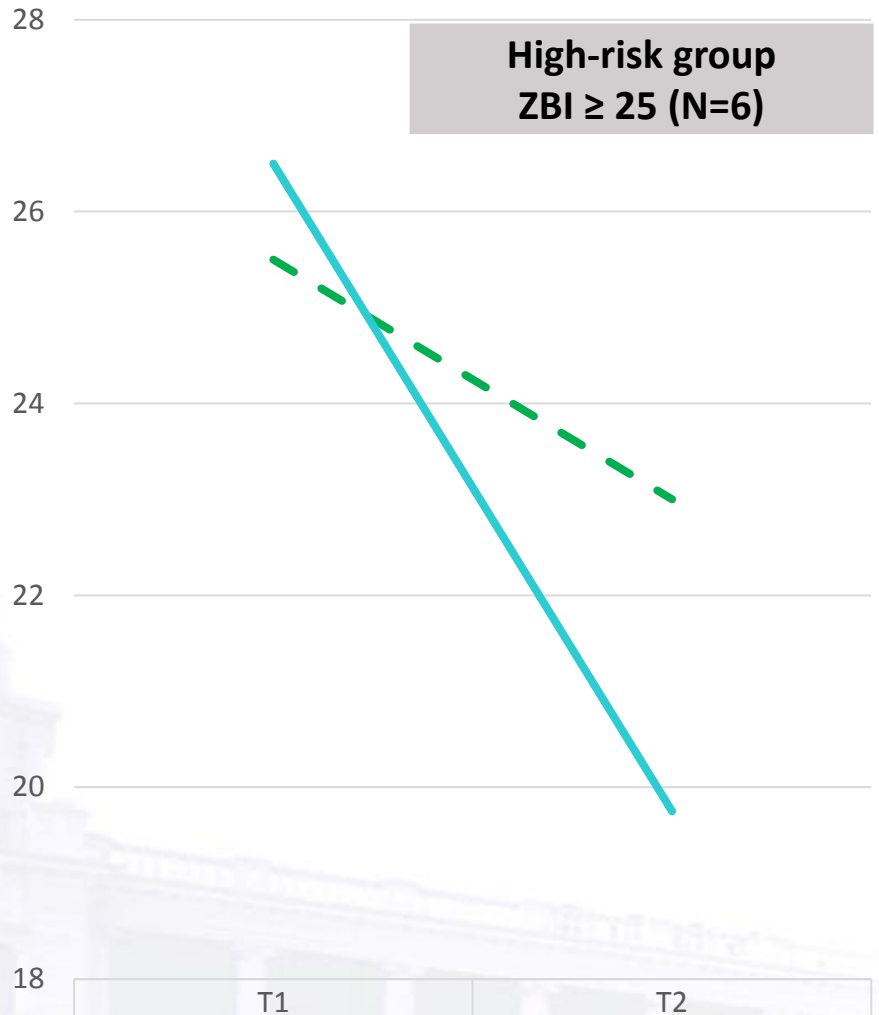


	T1	T2
Control group	11.1	12.3
Intervention group	10.9	13

Control group Intervention group

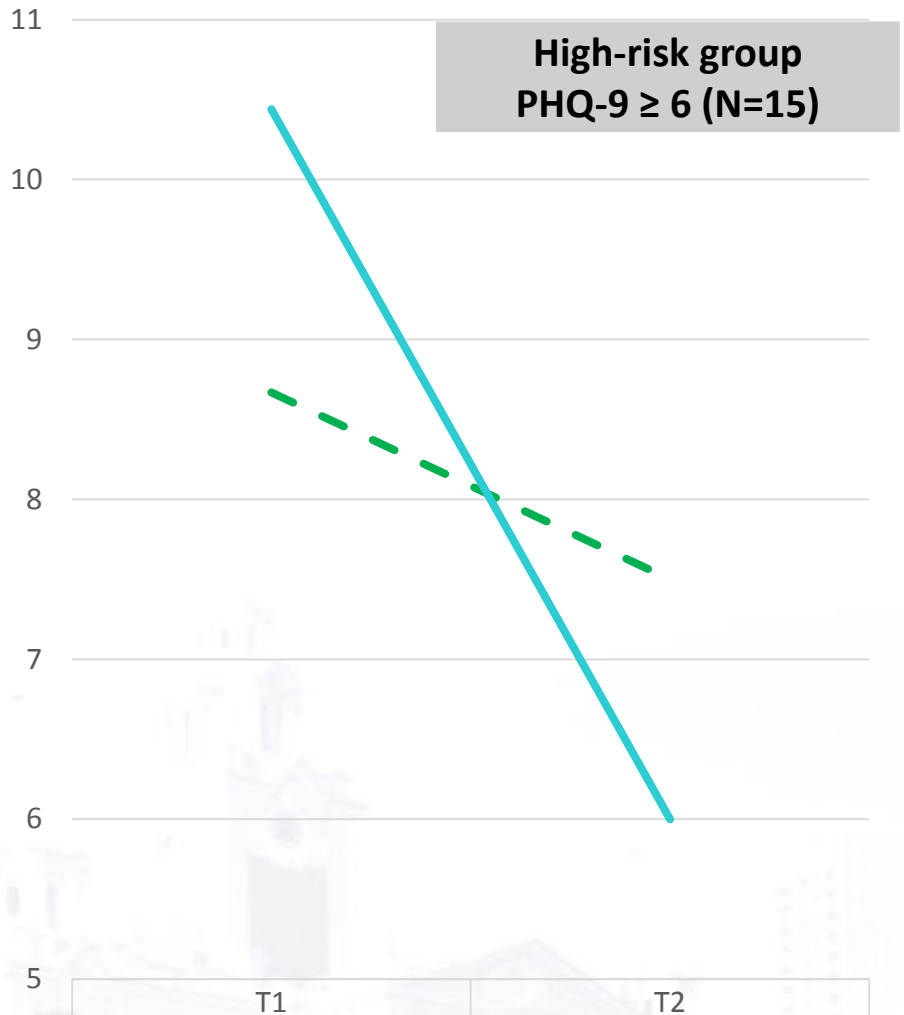
香港大學秀圖老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

Caregiver Burden & Mental Health



	T1	T2
Control group	25.5	23
Intervention group	26.5	19.75

Control group Intervention group



	T1	T2
Control group	8.67	7.5
Intervention group	10.44	6

Control group Intervention group

香港大學秀圖老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

IMPACTS ON FAMILIES

風起航中風家庭支援行動是很有意義，除佐幫助我媽媽之外，其實我覺得最大得益是家人。因可以減低家人壓力，而通過這個風起航行動，可以加意認識對中風都了解，而令到我在日常生活當中去照顧我媽媽！所以我覺得非常感激有風起航這個行動。除了之外，亦要多謝幫過我媽媽的義工及姑娘。

謝謝！

18-5-2018.

Lessons Learned I – Care Pathway

Patient:

- Male
- Ische
- Onse
- Disc
- Strok

After WeRISE Intervention:

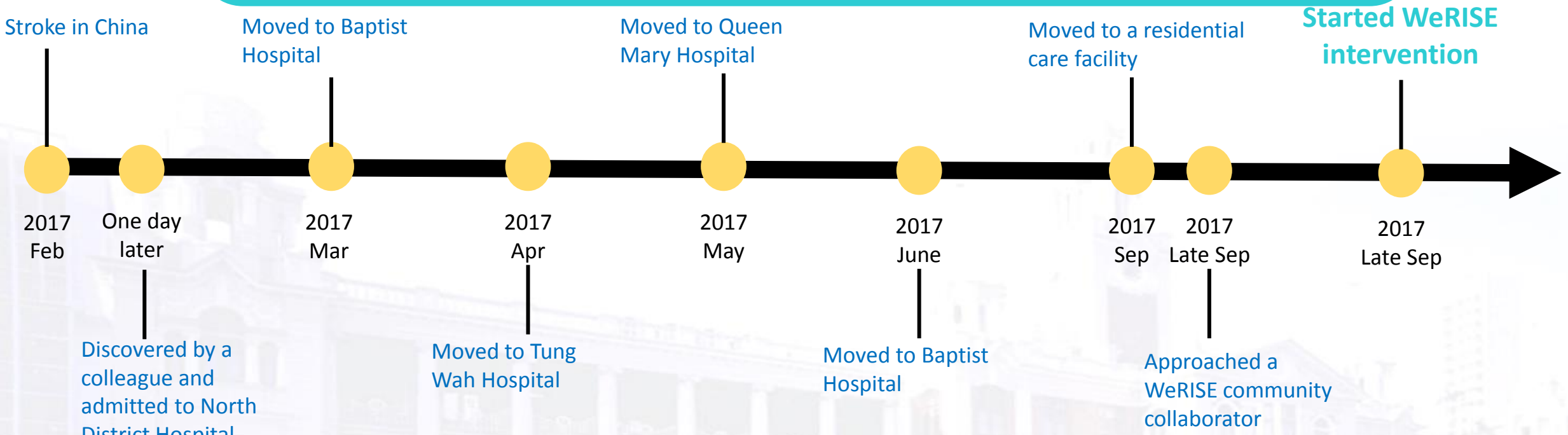
① Family new equilibrium has been built:

-husband motivates to keep on rehab

-wife learns to cope with role constrains (caregiver vs. self-development)

② Better community integration – outing, volunteer visits, peer group

③ Empowered the whole family including her two daughters



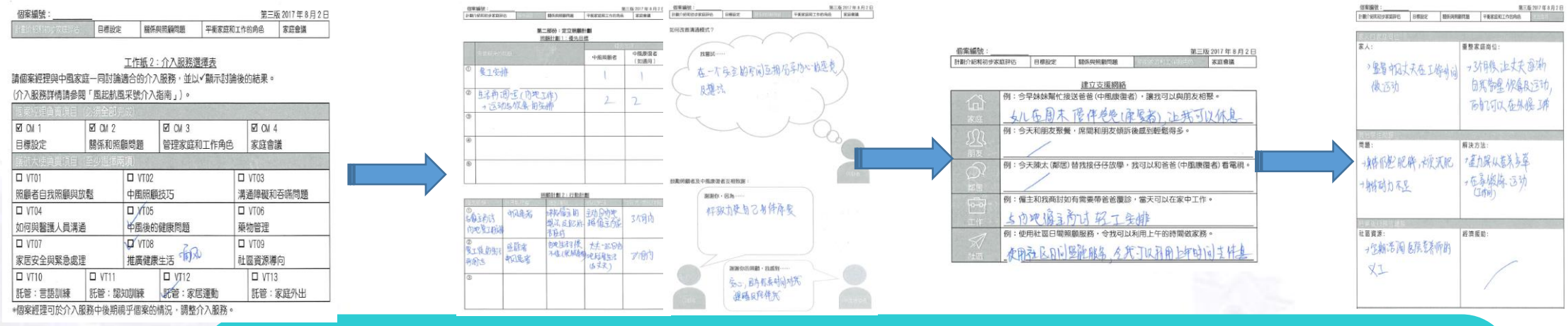
LESSONS LEARNED II – HOLISTIC "REHABILITATION"

Patient:

- Male (56 yrs)
- Hemorrhagic stroke
- Onset date: 2017 Nov
- Discharge date: 2018 Jan
- Worked in China (managerial position - engineer)

Caregiver:

- Patient's wife (50 yrs)
- Was studying Master of Arts (Dance) in Taiwan, decided to defer study and take up the caregiver role
- Has a daughter (studying bachelor in Taiwan)
- Perceived burden is high (ZBI-4 ≥ 6)



After WeRISE Intervention:

① Community re-integration: Back to work with continuous rehabilitation exercise & diet-cautious lifestyle; wife resumed study in Taiwan

② Family new equilibrium: reduced conflicts in lifestyle (exercise, diet, and work)

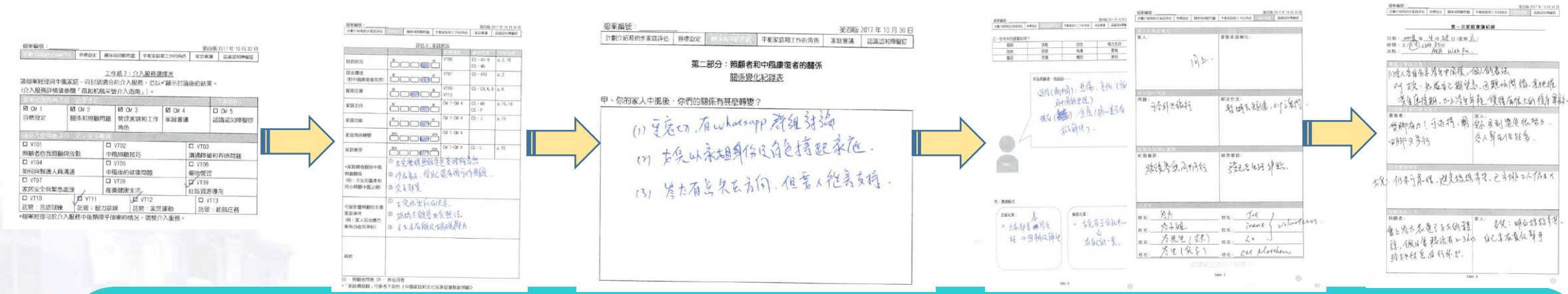
Lessons Learned III – Family Empowerment

Patient:

- Male (68 yrs)
- Hemorrhagic stroke
- Onset date: 2016 Nov
- Discharge date: 2017 Mar

Caregiver:

- Patient's wife (64 yrs)
- Felt stressful and wanted to join WeRISE
- Daughter thought home visits would disturb patient
- Joined WeRISE without notifying her daughter

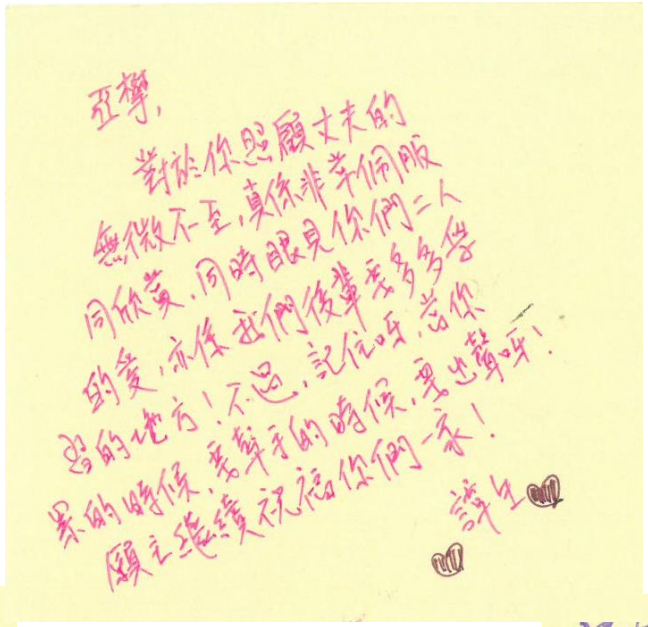


After WeRISE Intervention:

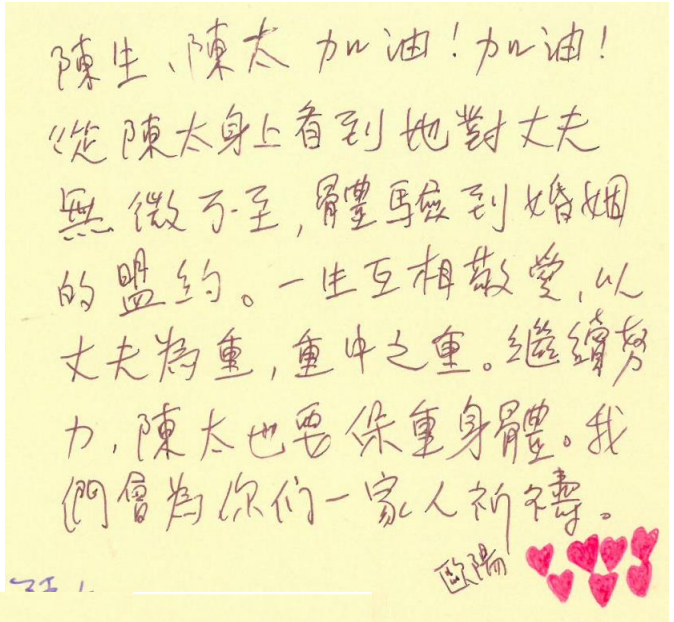
① Family new equilibrium established: supportive family as a whole

② Better community integration: peer support, community activity

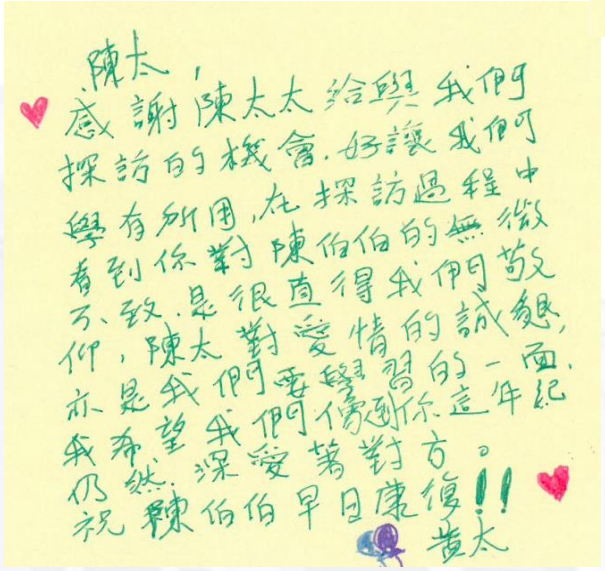
Reflections by Care Managers



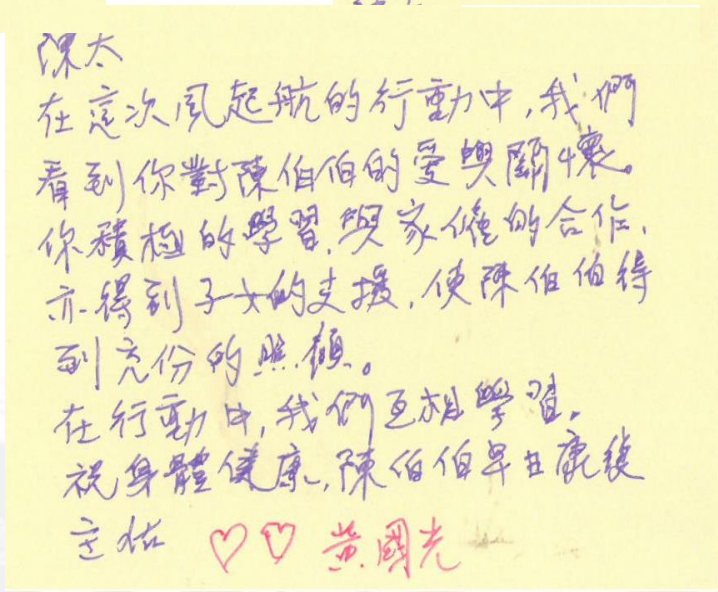
亞攀，
對於你照顧丈夫的
無微不至，真係非常佩服
同欣賞，同時眼見你們二人
的愛，亦係我們後輩要多多學
習的地方！不過，記住呀，當你
累的時候，要幫手的時候，要出聲呀！
願主繼續祝福你們一家！
譚生



陳生、陳太 加油！加油！
從陳太身上看到她對丈夫
無微不至，體驗到婚姻
的盟約。一生互相敬愛，以
丈夫為重，重中之重。繼續努
力，陳太也要保重身體。我
們會為你们一家人祈禱。
歐陽



陳太，
感謝陳太太給與我們
探訪的機會，好讓我們
學有所用，在探訪過程中
看到你對陳伯伯的無微
不致，是很值得我們敬
仰，陳太對愛情的誠懇，
亦是我們要學習的一面，
我希望我們像到你這年紀
仍然深愛著對方。
祝陳伯伯早日康復!!
黃太



陳太
在這次風起航的行動中，我們
看到你對陳伯伯的愛與關懷。
你積極的學習與家僱的合作，
亦得到子女的支援，使陳伯伯得
到充份的照顧。
在行動中，我們互相學習。
祝身體健康，陳伯伯早日康復
主佑 ♡♡ 黃國光

Nurture a Caring Community

Website

E-learning Course

Booklets

Facebook & Instagram

hkucoa.werise

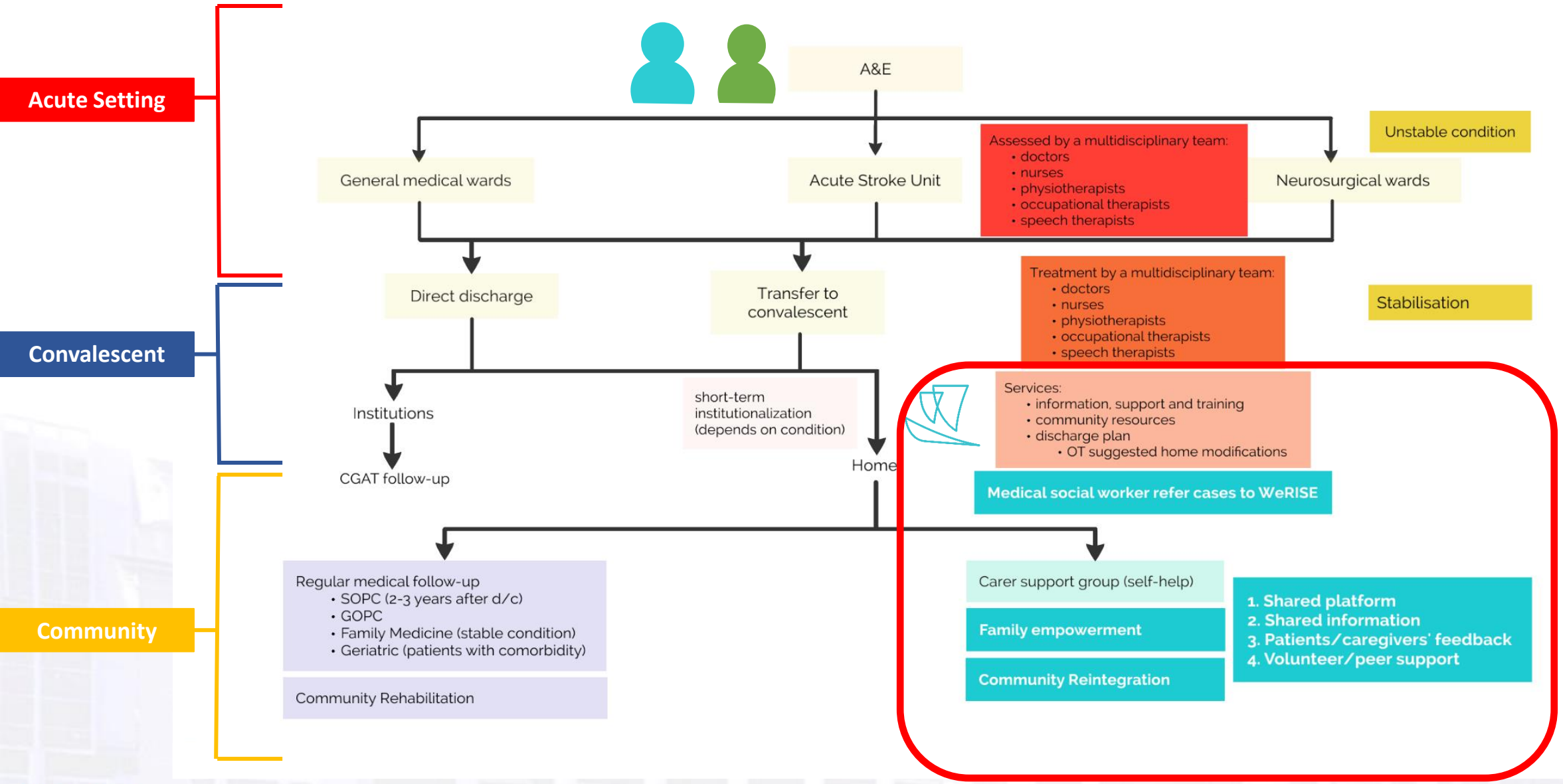
hkucoa.werise

香港大學秀圃老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

WALKING TOWARD OUR DREAMS

1. A seamless pathway for both patients and families (available & assessable)
2. Empower family's optimal equilibrium across the care continuum
3. Enable a better community-reintegration via a caring community

Health and Social Collaborated Care Pathway



ACKNOWLEDGEMENT

- Project Team
- Advisory Team
- Community Partner Team
- Care Manager training Team
- All WeRISE Participants

Strategic Partner & Sponsor:

利希慎基金
LEE HYSAN FOUNDATION

香港大學秀圖老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

THANK

WeRISE: Stroke Family Empowerment Project

2/F, The Hong Kong Jockey Club Building for Interdisciplinary Research
5 Sassoon Road, Pokfulam

Tel: (852) 2831-5210
Fax: (852) 2540 1244
Email: werisecoa@gmail.com
Homepage: http://we-rise.hku.hk