

## **National & local dementia strategy in Japan: Living with Dementia in the Community**

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## **Outline**

- ▶ **International Comparison on National Dementia Strategy**
    - ▶ Focusing on Palliative Care Contents
  - ▶ **Transition in Long-term care in Japan**
    - ▶ Population aging in Japan
    - ▶ Long-Term Care Insurance System(2000-)
    - ▶ toward Community-based Integrated Care system
  - ▶ **Orange Plan, National dementia strategy in Japan**
    - ▶ Background
    - ▶ Orange plan, New Orange plan
  - ▶ **Engaging Communities**
    - ▶ Fujinomiya-city
    - ▶ And more
- ▶ 2

## **International Comparison on National Dementia Strategy -focusing on Palliative Care Contents-**

### Reference

Nakahishi M, Nakashima T, Shindo Y, Miyamoto Y, Gove D, Rudbrush L, van der Steen JT. An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper. Int Psychogeriatr (in press), doi:10.1017/S1041610215000150

## **Palliative care**

### **Definition by WHO**

- ▶ An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
- ▶ Affirms life and regards dying as a normal process
- ▶ Intends neither to hasten nor to postpone death
- ▶ Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated

## Palliative care for elderly

### Palliative Care for Older People: Better Practices

- ▶ Published by WHO Europe in 2011
- ▶ In the past, palliative care was mostly offered to people with cancer in hospice settings
- ▶ Palliative care must now be offered more widely and integrated more broadly across health care services
- ▶ Example of good practices for older adults with dementia
  - ▶ Multidisciplinary guidelines
  - ▶ Education for care home staff and general practitioners
  - ▶ A guide for caregivers

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## Palliative care in dementia

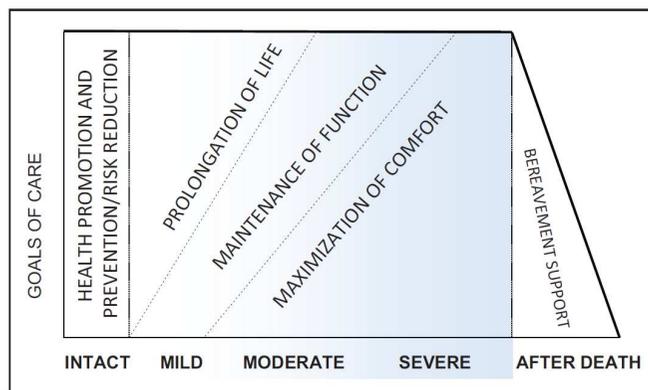
### EAPC white paper in 2013 (van der Steen et al., 2014)

1. Applicability of palliative care
2. Person-centred care, communication and shared decision making
3. Setting care goals and advance planning
4. Continuity of care
5. Prognostication and timely recognition of dying
6. Avoiding overly aggressive, burdensome or futile treatment
7. Optimal treatment of symptoms and providing comfort
8. Psychosocial and spiritual support
9. Family care and involvement
10. Education of the health care team
11. Societal and ethical issues

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## Model of changing care goals

### Dementia progression and suggested prioritizing care goals (van der Steen et al., 2014)



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## Palliative care in national dementia strategy

### Methods

- ▶ Qualitative evaluation of national dementia plans from 14 countries
- ▶ Focus on palliative care content using EAPC white paper

### Results

- ▶ Not explicitly referred in the eight of the 14 countries
- ▶ All countries lacked “prognostication and timely recognition of dying” and spiritual caregiving (Nakanishi et al., in press)

#### Reference

Nakahishi M, Nakashima T, Shindo Y, Miyamoto Y, Gove D, Rudbrush L, van der Steen JT. An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper. *Int Psychogeriatr* (in press), doi:10.1017/S1041610215000150

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## Independent section

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### England

- ▶ **Objective 12:** Improved end of life care for people with dementia.

### Northern Ireland

- ▶ **Action 29.** Develop palliative and end of life care services for people with dementia within the framework of the palliative and end of life care strategy.

### Sweden

- ▶ **Palliative care in the final stages of life** (71-72 in the list of conditions and treatments)

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## Some sentences

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### Scotland

- ▶ **Right-based care:** We will take more action specifically in relation to dignity and respect, including attention to human rights and the principles and requirements of mental health and incapacity legislation, including: earlier identification of people with palliative care needs, to promote advance care planning, to facilitate the sharing of key information across settings through the development and roll out of the Electronic Palliative Care Summary.

### Finland

- ▶ **3 Proper treatment and care is a worthwhile investment:** he provision of timely support, care and services is based on (...) c) good palliative and end-of-life care when prolonging life is no longer meaningful.

### Australia

- ▶ **Key Priority Area 1: Care and Support Outcomes:** Palliative Care.

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## Some sentences, not palliative

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### Japan

- ▶ The national government will continue additional benefit schedules for “coordination system with healthcare provider” and “provision of end of life care” under the public long-term care insurance program to enhance service provision for increasing impairment and end-of-life care of residents in “group homes”.

### Wales

- ▶ UHBs and LAs to publish plans for developing specialist dedicated young onset and rare dementia services. Plans to be based on the following principles: (...) end of life care.

### South Korea

- ▶ Medical practices that are unlikely to have effects on people with dementia at last stage should be avoided. The guideline should be established and disseminated for management of people with dementia at end-of-life stage to provide high-quality care services.

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## Call for palliative care

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### Palliative care and dementia statement

- ▶ First WHO ministerial Conference on Global Action against Dementia, March 16-17th, 2015
- ▶ Worldwide Hospice Palliative Care Alliance (WHPCA) published the statement:

*The WHPCA requests ministers to ensure that:*

1. *National dementia strategies are developed which include explicit reference to palliative care. Palliative care is a person-centred approach and should be available from the point of diagnosis. However, we particularly call on ministers to ensure the inclusion in national dementia strategies of prognostication, timely recognition of dying and preparations for the last phases of life. These are areas, which have been shown to be neglected.*

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## Transition in Long-term Care in Japan

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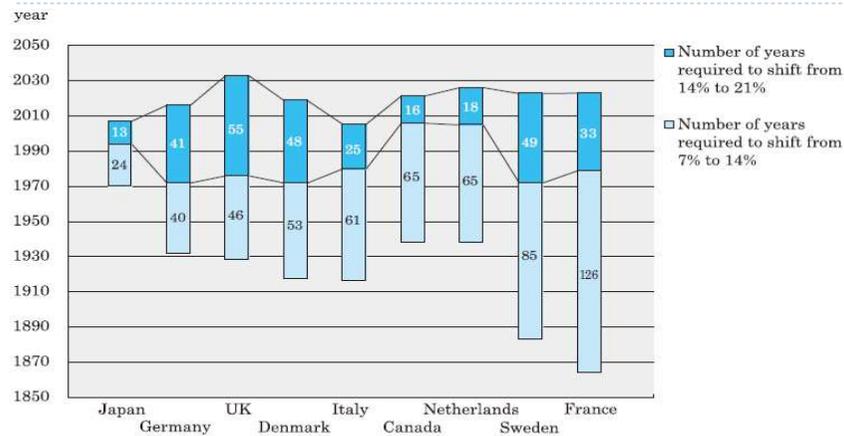
## Life Expectancy at Birth

Country	Life expectancy (years)				Country	Life expectancy (years)			
	Males	Rank	Females	Rank		Males	Rank	Females	Rank
Brazil	67	21	74	19	France	76	12	83	3
Canada	78	2	83	3	Germany	76	12	82	9
USA	75	15	80	17	Italy	78	2	84	2
China	70	19	74	19	Netherlands	77	8	81	14
India	61	23	63	23	Norway	77	8	82	9
Israel	78	2	82	9	Portugal	74	17	81	14
Japan	79	1	86	1	Russia	59	24	72	22
South Korea	73	18	80	17	Spain	77	8	83	3
Malaysia	69	20	74	19	Sweden	78	2	83	3
Singapore	77	8	82	9	Switzerland	78	2	83	3
Pakistan	62	22	63	23	UK	76	12	81	14
Finland	75	15	82	9	Australia	78	2	83	3

Source: WHO, "The World Health Report 2006"  
"Rank" is the order of the 24 countries listed, from longest to shortest life expectancy.

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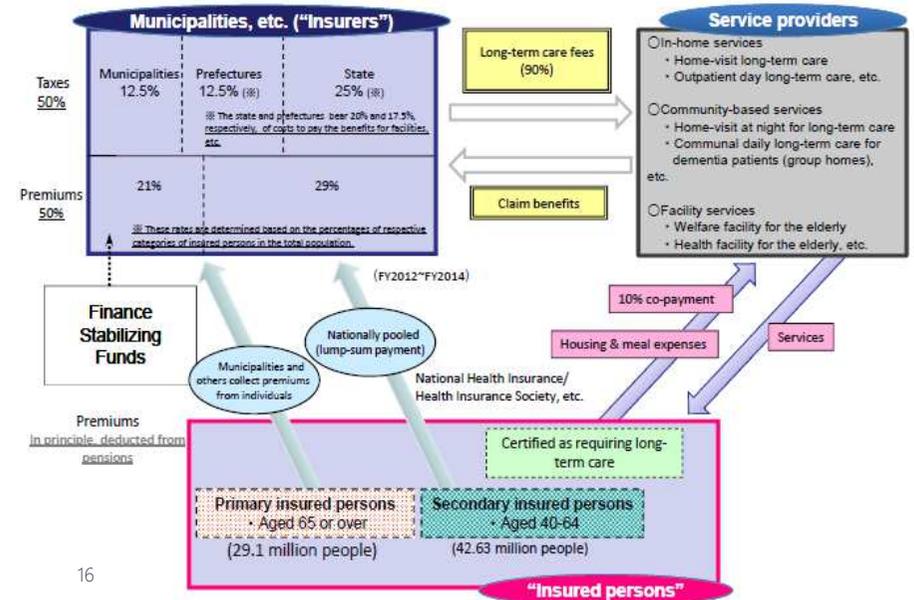
## Speed of Population Aging (year)



1950 and before except Japan : UN, *UN Aging of Population and Its Economic and Social Implications (Population Studies, No.26, 1956)* and *UN Demographic Yearbook*.  
After 1950 except Japan: UN, *UN World Population Prospects : The 2010 Revision*  
Japan : Ministry of Internal Affairs and Communications, *National Population Census Survey* and National Institute of Population and Social Security Research, *Population Estimates (2012)*

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## Structure of Long-term Care Insurance System

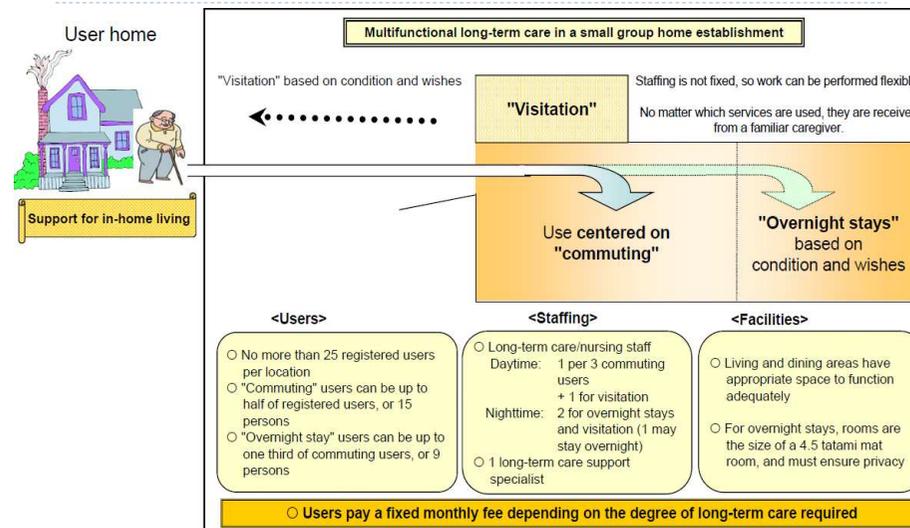


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## Long-term care services

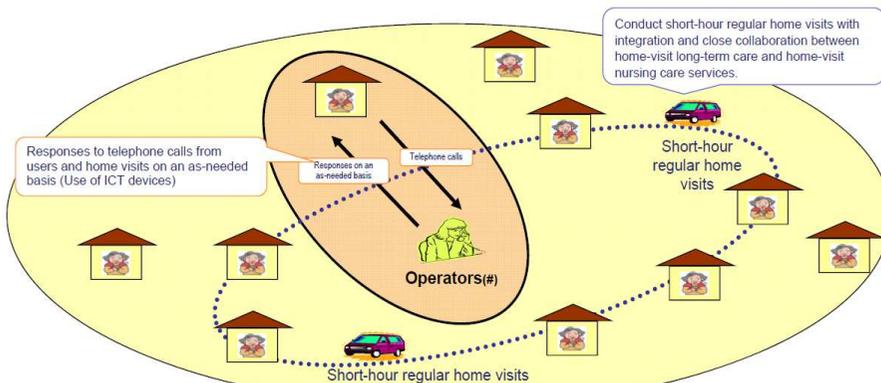
<p><b>Community-based services</b></p> <ul style="list-style-type: none"> <li>Regular visiting/on-demand response long-term care</li> <li>Home-visit at night for long-term care</li> <li>Outpatient long-term care for a dementia patient</li> <li>Multifunctional long-term care in a small group home</li> <li>Communal daily long-term care for a dementia patient (group home)</li> <li>Daily life long-term care for a person admitted to a community-based specified facility</li> <li>Admission to a community-based facility for preventive daily long-term care of the elderly covered by public aid</li> <li>Combined service</li> </ul>	<p><b>In-home services</b></p> <p><b>[Home-visit services]</b></p> <ul style="list-style-type: none"> <li>Home-visit long-term care (home help service)</li> <li>Home-visit bathing long-term care</li> <li>Home-visit nursing</li> <li>Home-visit rehabilitation</li> <li>Guidance for management of in-home medical long-term care</li> <li>Daily life long-term care admitted to a specified facility</li> <li>Sale of specified equipment covered by public aid</li> </ul> <p><b>[Commuting services]</b></p> <ul style="list-style-type: none"> <li>Outpatient day long-term care (day service)</li> <li>Outpatient rehabilitation</li> </ul> <p><b>[Short-stay services]</b></p> <ul style="list-style-type: none"> <li>Short-term admission for daily life long-term care (short-stay)</li> <li>Short-term admission for recuperation</li> <li>Rental service of equipment for long-term care covered by public aid</li> </ul> <p><b>In-home long-term care support</b></p> <ul style="list-style-type: none"> <li>Facility covered by public aid providing long-term care to the elderly</li> <li>Long-term care health facility</li> <li>Sanatorium medical facility for the elderly requiring long-term care</li> </ul>	<p>Covered by care benefits</p>
<p><b>Community-based services for preventive long-term care</b></p> <ul style="list-style-type: none"> <li>Preventive long-term care for a dementia outpatient</li> <li>Multifunctional preventive long-term care in a small group home</li> <li>Preventive long-term care for a dementia patient in communal living (group home)</li> </ul> <p><b>Preventive long-term care support</b></p>	<p><b>Preventive long-term care services</b></p> <p><b>[Home-visit services]</b></p> <ul style="list-style-type: none"> <li>Home-visit service for preventive long-term care (home help service)</li> <li>Home-visit bathing service for preventive long-term care</li> <li>Home-visit nursing service for preventive long-term care</li> <li>Home-visit rehabilitation service for preventive long-term care</li> <li>Management and guidance for in-home medical service for preventive long-term care</li> <li>Daily preventive long-term care admitted to a specified facility</li> <li>Sale of specified equipment for preventive long-term care covered by public aid</li> </ul> <p><b>[Commuting services]</b></p> <ul style="list-style-type: none"> <li>Outpatient preventive long-term care (day service)</li> <li>Outpatient rehabilitation for preventive long-term care</li> </ul> <p><b>[Short-stay services]</b></p> <ul style="list-style-type: none"> <li>Short-term admission for daily preventive long-term care (short-stay)</li> <li>Short-term admission for recuperation for preventive long-term care</li> <li>Equipment rental for preventive long-term care covered by public aid</li> </ul>	<p>Covered by prevention benefits</p>
<p>Services designated/supervised by <u>municipalities</u></p>	<p>Services designated/supervised by <u>prefectures, designated cities, and core cities</u></p>	

## Small scale multifunctional in-home care



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## 24 hour round-the-clock care



\* This is to be carried out through close collaboration between home-visit long-term care and home-visit nursing, either through unified provision of home-visit long-term care and home-visit nursing by a single enterprise or performance of home-visit long-term care in close collaboration with an external enterprise providing home-visit nursing.

\* Collaboration with community healthcare institutions such as in-home treatment support clinics is also important.

\* They will be positioned as community-based services, with municipalities (insurers) as the actors, and services prepared in each area.

# Actual distribution of operators is currently being studied. Conceivably, they might be located in a single site, or respond uniformly from multiple sites, or be part of facilities that already work round the clock, or workers with mobile phones from a single location might respond.

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## Transition needed!

- ▶ **Demographic change** (Ageing, declining birth rate)
  - ▶ **Disease structure change** (Multi-morbidity, Continuous → Chronic care, long term "care-cycle")
  - ▶ **Change in definition of "Health"**
  - ▶ **Change in concept of "Support"** : Medical model to **Ecological model, ICF**
- Quality of Life** (context, narrative × individual, family, community), sustainability
- ▶ **Fragmentation** of care and support, lack of continuity
  - ▶ **Emerging (total and useless) cost**
  - ▶ ...and shortage of **Care workforce**

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## Community-based integrated care: 2 concepts bringing together

### Community-based care

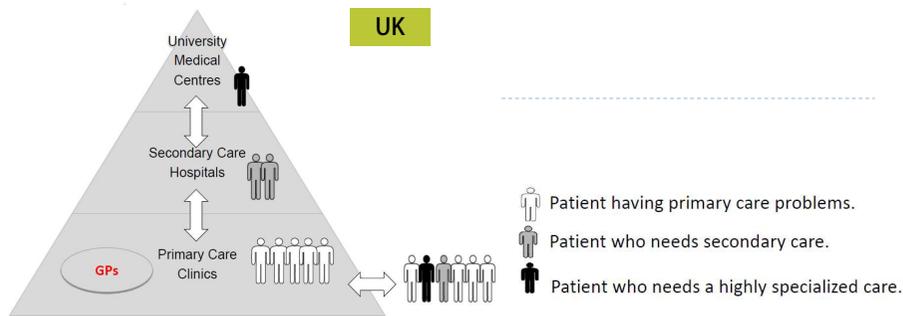
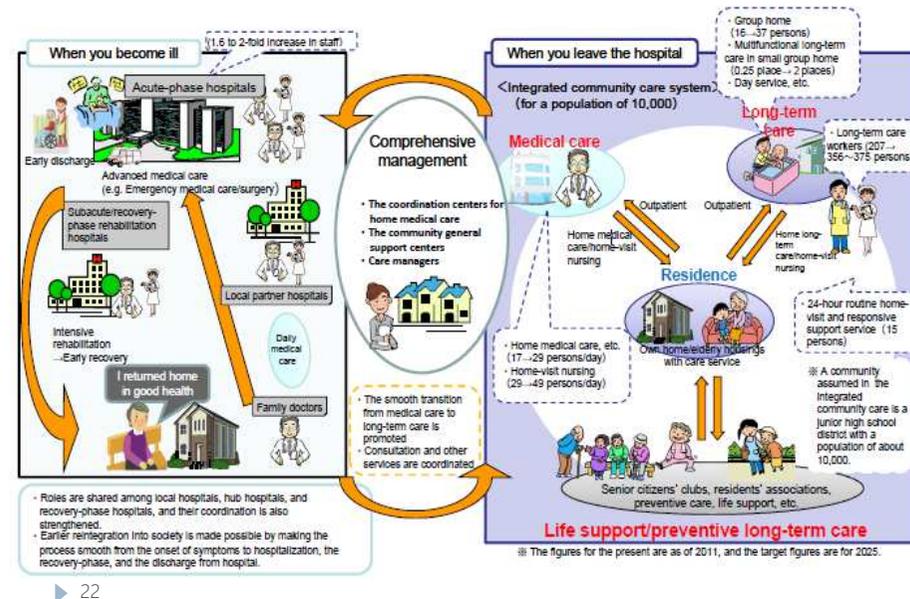
Community-based care features a health system that is based upon and driven by community health needs. Moreover, it is tailored to the health beliefs, preferences, and societal values of that community and assures a certain level of 'community participation' [Ploch and Klazinga (2002)]

### Integrated care

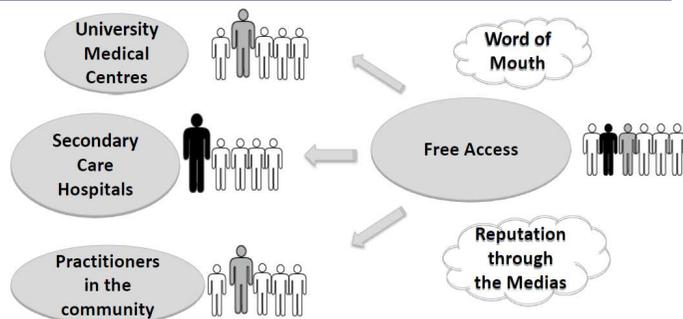
a discrete set of techniques and organizational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels [Kodner and Kyriacou (2000)]

Local Optimum

## Toward community-based integrated care



### Japan



## Orange Plan:

### Five-Year Plan for Promotion of Measures against Dementia

## Background

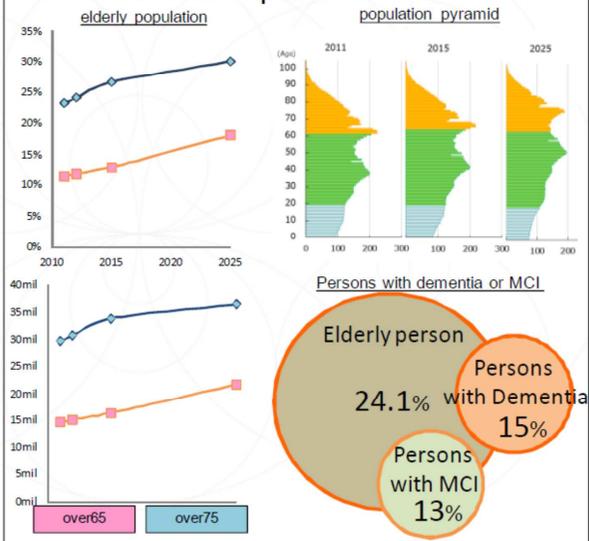
in 2012

**One-fourth**  
of aged over 65  
is either persons with  
dementia or MCI.

**4.62 million**  
(One in seven)  
is persons with dementia.

**4.00 million**  
is persons with MCI  
(Mild Cognitive Impairment)

## Super Aging Society and Dementia Prevalence in Japan



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## Prevalence Projection

Prevalence in 2025

**7,000,000**

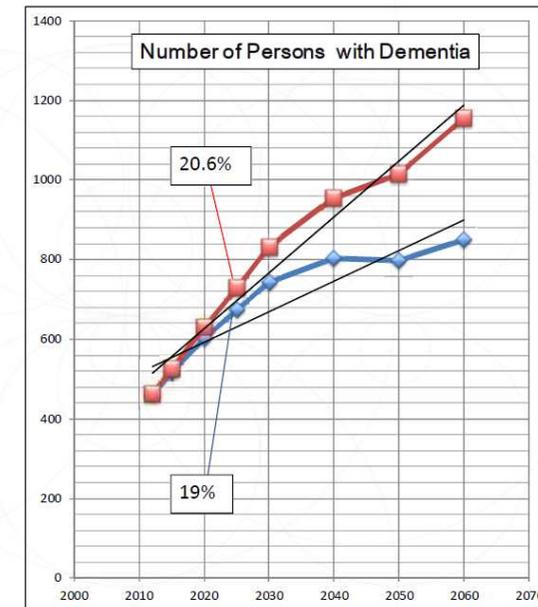
One in Seven in 2012

→

One in five in 2025  
(of aged over 65)

**19%**: if the rate of each  
generation is stable.

**20.6%**: if the rate  
increases along with the  
increase of diabetes mellitus.



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## History of dementia care policy

- 1987 Reports by "MHW Headquarters for the Promotion of Dementia Elderly Measures"
  - Promotion of "Wards for dementia elderly"
  - Establishment of "Day-Service Center for Dementia"
- 1994 Reports by "The Committee for Dementia Elderly Measures"
  - Establishment of "Group Home for Dementia"
  - 2000 Enactment of "Long-Term Care Insurance Act"
  - 2004 Change of the Japanese terminology for "Dementia"
- 2005 Launch of "ten-year conception of raising awareness and community development for dementia"
  - Launch of "Training of Dementia Support Doctors"
  - Launch of "Dementia Supporters Training Program"
- 2008 Reports by "Emergency Project for Improvement of Medical Care and Quality of Life for Persons with Dementia"
  - Prevalence survey of dementia
  - Promotion of Medical Center for Dementia
- 2012 Reports of "Direction of Future Dementia Measures"
  - Development of Dementia Care Pathway
  - "Five-Year Plan for promotion of Dementia Measures (Orange Plan)"
  - Development of "Initial Phase Intensive Support Team"
- 2015 "Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan)"

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## Current issues on dementia care

- The symptom of dementia aggravate due to delayed consultation and intervention
- Prolonged hospitalization in psychiatric hospitals
- Difficulty in admitting general hospitals which persons with dementia occasionally experience
- Qualitative/quantitative shortage of LTC care services for supporting persons with dementia to keep living in familiar communities
- Insufficient community support for persons with dementia and their families
- Coordination between healthcare and LTC care professionals being not always seamless

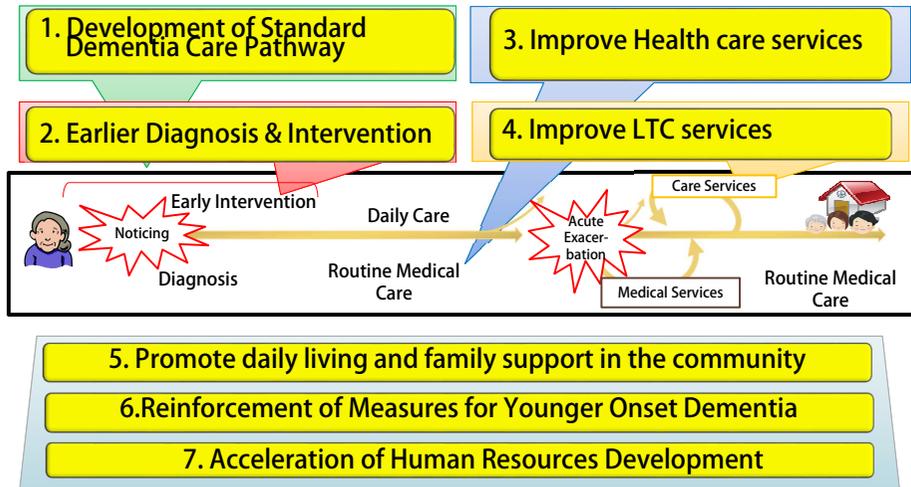
Reactive,  
post-crisis care



Proactive care

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## Orange Plan



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## Training Programmes

- ▶ For anyone(2005-)
  - ▶ Caravan Mates (6h)
  - ▶ Dementia Supporters (90 min) 4.7 million(2013)
- ▶ For LTC Professionals
  - ▶ Dementia Care Leader Training
  - ▶ Practice Leader Training
  - ▶ Practitioner Training
- ▶ For Doctors in the community
  - ▶ Dementia Support Doctors
  - ▶ Seminar for doctors in clinics
- ▶ For Doctors and Nurses in General Hospital

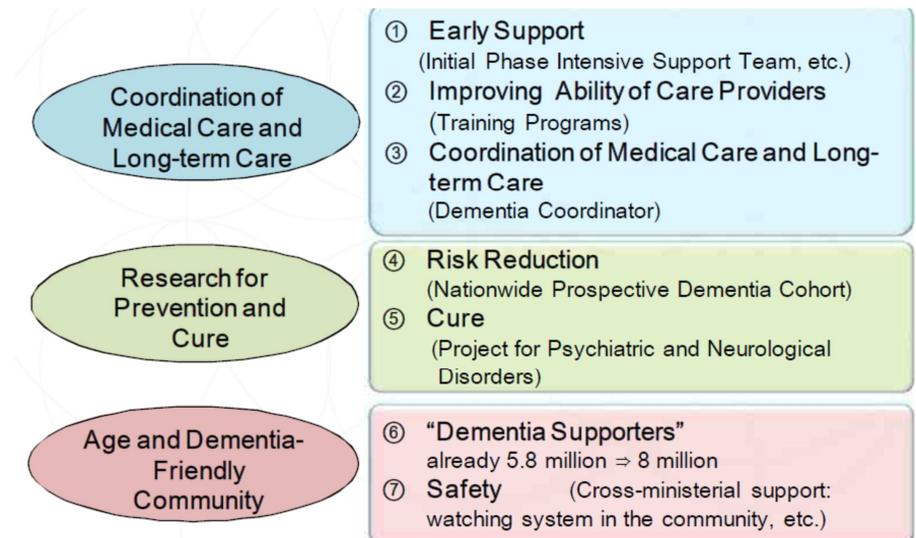
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## Dementia Life Support Model: Normative Integration

- ▶ Principles of dementia care
  - ▶ Person-centered care
  - ▶ Care in the community promoting participation to the society
  - ▶ Activating self care, decision making
  - ▶ Continuous support from early-stage to end of life
  - ▶ Supporting family carers
  - ▶ Integrated support : community/social care/health care
- ▶ Dementia Life Support Model: Integrated **life support** including health and social care
- ▶ Dementia Life Support training (4h)

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## New Orange Plan



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## Dementia Measures in Japan

### Strong Political Leadership



“Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan)”

### Age and Dementia Friendly Community

“Integrated Community Care System”



### Raising awareness

Dementia Supporters Program

- ✓ Voluntarily
- ✓ with proper knowledge and understanding
- ✓ in communities and work places



“5.8 million participants (2014) ⇒ 8 million participants (FY 2017)”

### Public Health System

“Universal Health Coverage”  
“Long-Term Care Insurance”

### Dementia Care and Risk Reduction

“Next-gen Dementia Cohort”  
“Information and Communication Technology”  
“Robotics”



## Innovations in Fujinomiya-city as a case of Engaging Communities

Special thanks to Mr.Koji INAGAKI, Fujinomiya city office

## Quick Scan

- ▶ Population: 135,492
- ▶ 65+ : 31,980(23.6%)



- ▶ People with dementia: 3,000

- ▶ Caravan Mate : 250
- ▶ Dementia Supporter: 9,000(6.6%)



## Principle of dementia care policy

- ▶ Starting from People with dementia and carers need
- ▶ Creating tailor-made network around EACH of them
- ▶ Harmonizing individual support network and community care network in Fujinomiya-city
  - ▶ NOT making Dementia SPECIFIC network
  - ▶ Enrich community care network, community involvement through focusing on dementia care

## 1 Creating dialogue: Mr.&Mrs.Sano's story

- ▶ 2008 Mr.&Mrs.Sano came to community general support center (Mr.Sano with YOD)



- ▶ 2013 Mr.and Mrs.Sano became Caravan Mate!!!

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## 2 Sharing social issues in the community

- ▶ With local carers association(2008,2013)
  - ▶ Workshop to share burdens, problems and solutions
- ▶ With local citizens(2008-)
  - ▶ promote dementia supporters programme starting from happenings in the community
- ▶ With LTC service providers(2008-)
  - ▶ All careworker survey to sort out issues and training need
- ▶ With doctors(2008-)
  - ▶ Establish dementia support medical care providers network committee
- ▶ With various stakeholders(2008-)
  - ▶ Connecting findings, ideas and suggestions between people working in the community
- ▶ With schools(2009-)

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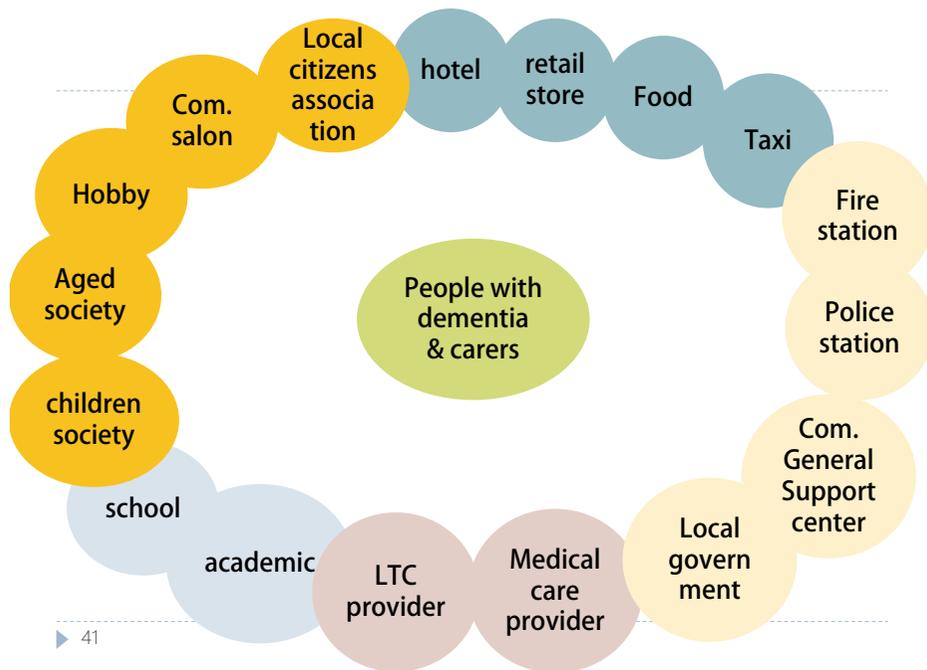


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## 3 Team building in the community

- ▶ With local citizens(2008-)
  - ▶ Educate caravan mate , support voluntary activities
- ▶ With LTC service providers(2009-)
  - ▶ Support trainings organized by LTC service providers association
- ▶ With doctors(2009-)
  - ▶ Doctor→caravan mate→dementia support doctor
- ▶ Seminar for networking

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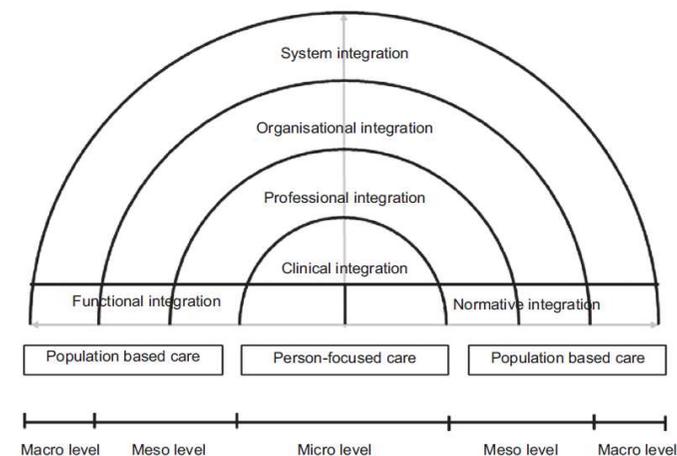
#### 4 Continuous dialogue and practice around each cases

- ▶ **Care conference**
  - ▶ Community care conference(2009-): each case
  - ▶ Case conference in community general support center(2010-): sort out community issue
  - ▶ Multidisciplinary care conference: involve family, local citizens, caravan mate, professionals, community general support center, local government...
- ▶ **Doctors study group on memory loss(2010)**
- ▶ **Chief care managers activate local resources and networking(2011-)**
- ▶ **Seminar for care managers(2011-)**

#### Future Issues in Fujinomiya-city

- ▶ **Multidisciplinary care conference**
- ▶ **Promote professional integration in 14 areas**
- ▶ **Promote network between PWD and develop "Dementia Friendly" evaluation framework**
  - ▶ Collaboration with DFJI
  - ▶ Definition of DFC from PWD perspective
  - ▶ Dementia strategy evaluation framework involving PWD's participation
- ▶ **Promote social involvement for better QOL**
  - ▶ Action meeting(2013-)
  - ▶ Dementia Support Tourism(2013-)
  - ▶ Employment support(2012-)
  - ▶ Run-tomorrow2013

Conceptual framework for integrated care based on the integrative functions of primary care



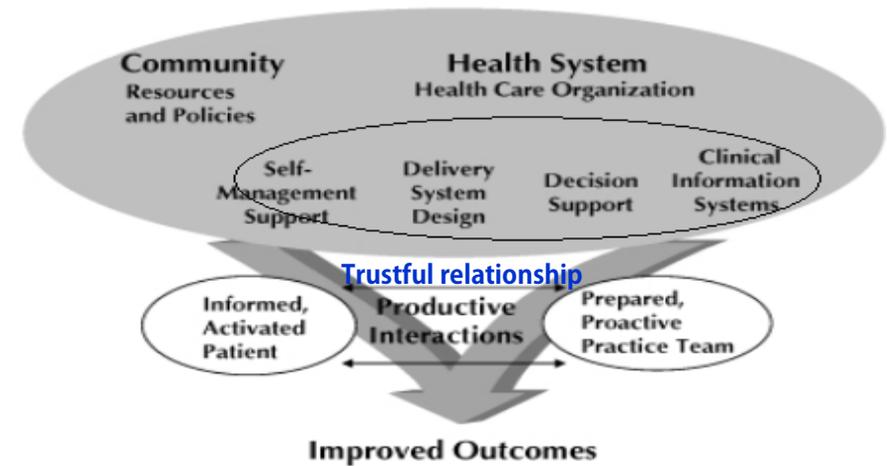


## Transition needed!

- ▶ **Demographic change** (Ageing, declining birth rate)
  - ▶ Disease structure change (**Multi-morbidity**, Continuous → **Chronic care**, long term “**care-cycle**” )
  - ▶ Change in definition of “Health”
  - ▶ Change in concept of “Support” : Medical model to **Ecological model**, ICF
- Quality of Life** (context, narrative  
× individual, family, community), sustainability
- ▶ **Fragmentation** of care and support, lack of continuity
  - ▶ Emerging (total and useless) **cost**
  - ▶ ...and shortage of **Care workforce**

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## Chronic Care Model(Wagner et al.)



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## core competencies for caring for patients with chronic conditions

WHO (2005)

- |  |  |
|--|--|
| <p><b>1. Patient-centred care</b></p> <ul style="list-style-type: none"> <li>• Interviewing and communicating effectively</li> <li>• Assisting changes in health-related behaviours</li> <li>• Supporting self-management</li> <li>• Using a proactive approach</li> </ul> <p><b>2. Partnering</b></p> <ul style="list-style-type: none"> <li>• Partnering with patients</li> <li>• Partnering with other providers</li> <li>• Partnering with communities</li> </ul> <p><b>3. Quality improvement</b></p> <ul style="list-style-type: none"> <li>• Measuring care delivery and outcomes</li> <li>• Learning and adapting to change</li> <li>• Translating evidence into practice</li> </ul> | <p><b>4. Information and communication technology</b></p> <ul style="list-style-type: none"> <li>• Designing and using patient registries</li> <li>• Using computer technologies</li> <li>• Communicating with partners</li> </ul> <p><b>5. Public health perspective</b></p> <ul style="list-style-type: none"> <li>• Providing population-based care</li> <li>• Systems thinking</li> <li>• Working across the care continuum</li> <li>• Working in primary health care-led systems</li> </ul> |
|--|--|

- ▶ **Continuous dialogues**
  - ▶ Start from PWD
  - ▶ Promote sense of ownership
  - ▶ Across the sector
  - ▶ Across the community
  - ▶ Individual – Community issue
  - ▶ Promote HAPPINESS in the community as a whole
  - ▶ Promote shared community management
- ▶ **Global innovation platform on DFC**
  - ▶ Exchange best practices
  - ▶ Share definition, principle
  - ▶ Share process, framework
  - ▶ Promote knowledge translation

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**Run 伴 TOMO-RROW2013 Hokkaido to Osaka 1700km**

認知症の人でも、そうでない人も、ひとりの力をみんながつながって、ゴールを目指す。全国のひとつひとつの町が、そんな町になれば...そんな想いを込めて、走ります(歩くのも可)

START

GOAL

主催 NPO法人認知症フレンドシップクラブ RUN 伴2013実行委員会

北海道 7月25日(水)～29日(日)

東北 8月1～4日(金)～10日(木)

関東 8月24日(土)～29日(木)

甲信 9月28日(土)～29日(日)

関西 10月11日(土)～14日(月)夜

※日程は変更になる可能性があります。ご了承ください。

詳しくはホームページをご覧ください。  
http://runamc-jimco.com

Run 伴:Organized by Dementia Friendship Club