

International comparison of dementia care models

13:00-14:30, 18th May 2015

Miharu Nakanishi

Tokyo Metropolitan Institute of
Medical Science



Key points

Development of national dementia plan in Japan

- Integrated Community Care system
- Emergency Project 2008
- Orange Plan 2013-2017

International comparison

- Dementia care pathway
- Palliative care contents in national dementia plans

Development process

Report “Long-Term Care for the Elderly 2015”

- Published at 2003 by a research committee under the Ministry of Health, Labour and Welfare
- Estimated the total number of people with dementia: 2.50 millions in 2015, 3.78 millions in 2045

Integrated Community Care system

- Suggested as a new care model for people with dementia
- Introduced into the LTCI program to establish a community general support centres in local authorities



Emergency Project

Report in 2008

- Public LTCI system covered most persons with dementia
- Lack of early diagnosis and coordination between health and social care services caused some unsuccessful cases

Unsuccessful cases

- Individuals with earlier onset dementia did not have access to care services
- Those with severe challenging behaviours were admitted to psychiatric beds (Nakanishi and Nakashima, 2014 Alzheimers Dement)



International comparison

- 2010-2011: Institute for Health Economics and Policy

Orange Plan 2013-17

- Five-year plan for promotion of measures against dementia (Nakanishi and Nakashima, 2014 Alzheimers Dement)
- 2012-2013: Tokyo Metropolitan Institute of Medical Science (International Symposium on National Dementia Strategy in Tokyo)
- 2014: National Centre for Geriatrics and Gerontology (Global Dementia Legacy Event Japan, joint commission with Ministry of Health, Labour and Welfare and Tokyo Dementia Care Training and Research Centre)



First project

Comparison of dementia care pathways

- Management of challenging behaviours
- Dementia care coordination
- Family support and advocacy

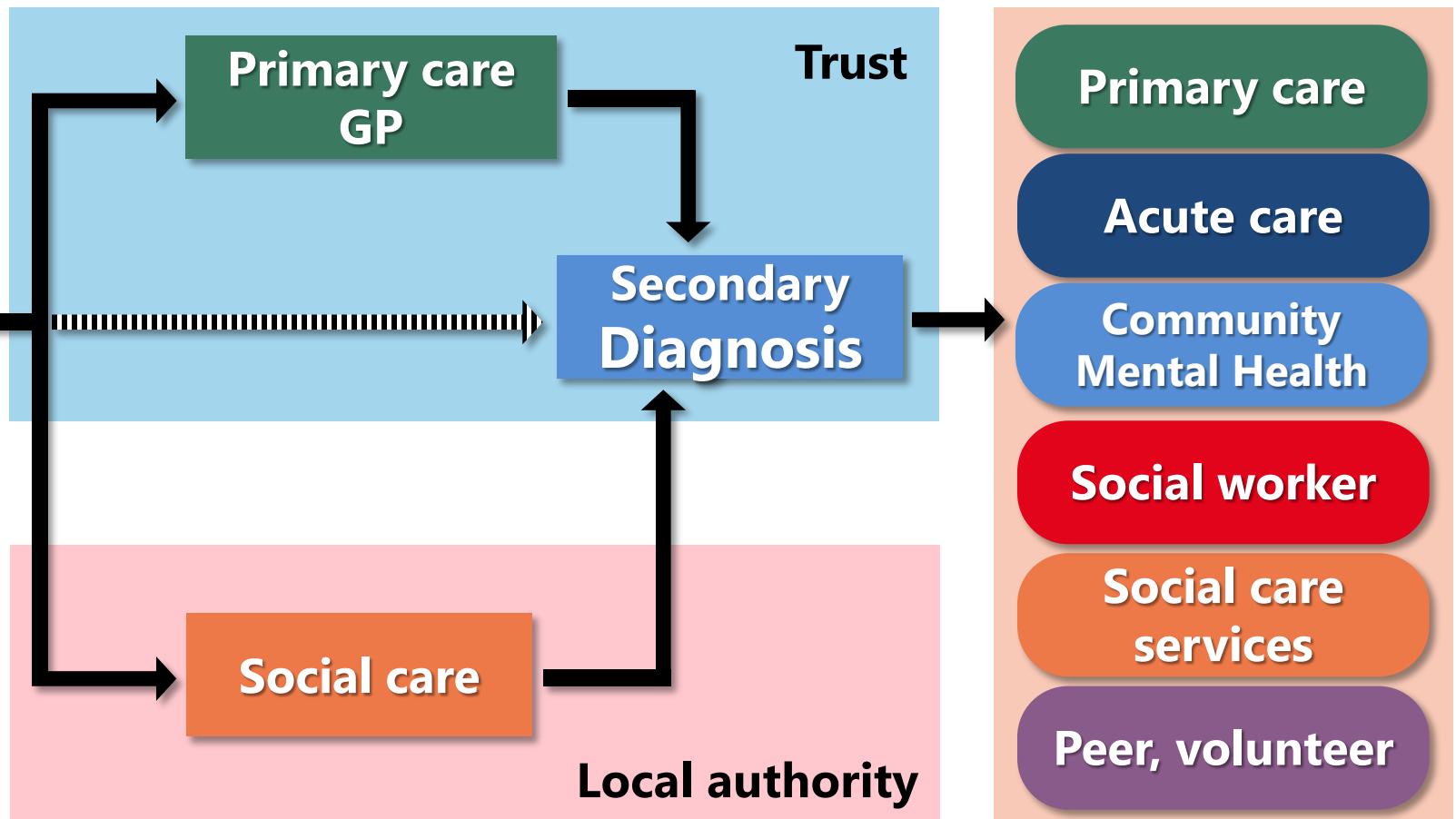
Method

- Bibliographical survey, field survey, and online case vignette survey
- Australia, Denmark, England, France, South Korea, Sweden, the Netherlands and Japan



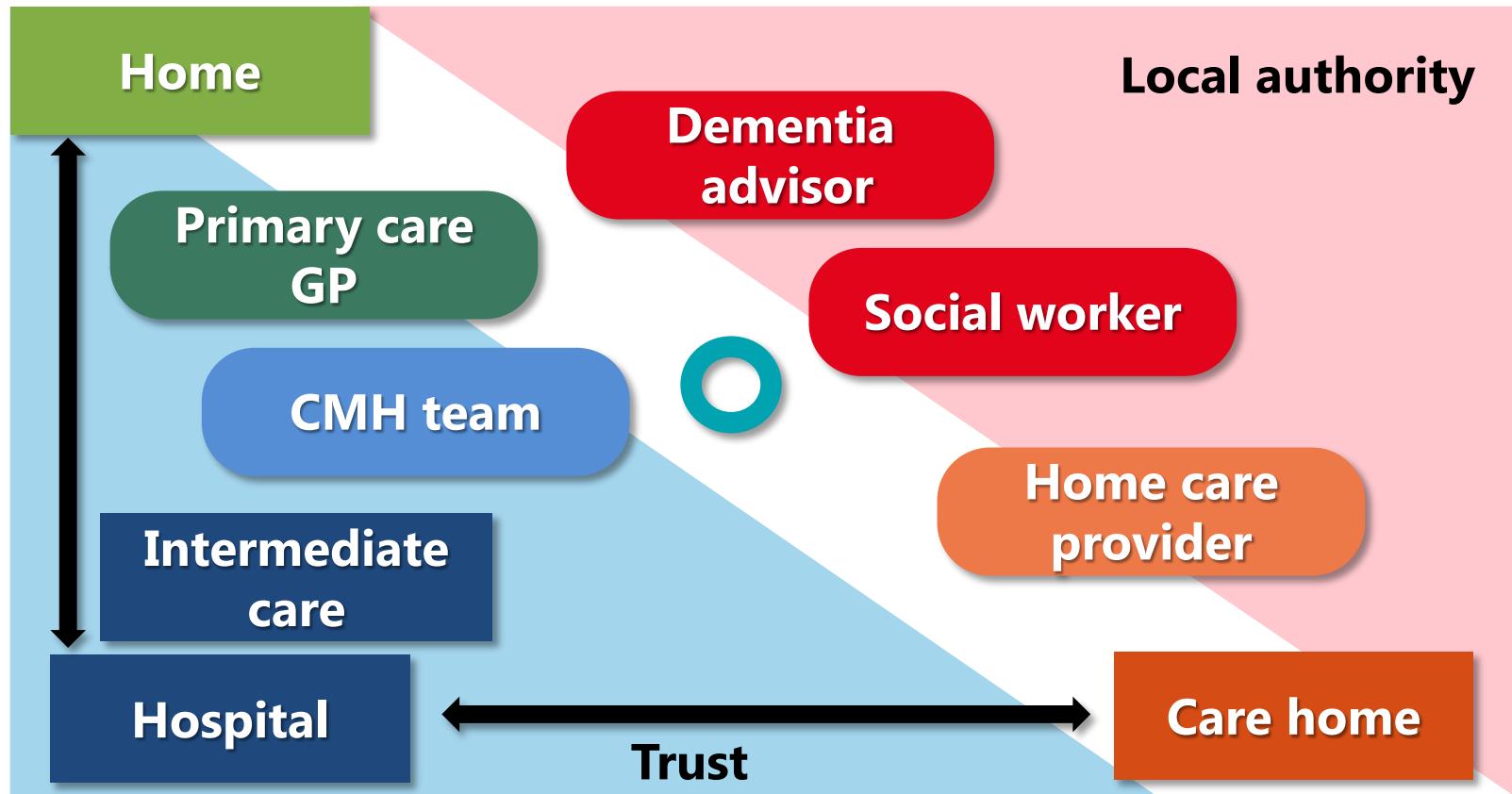
England

Pathway



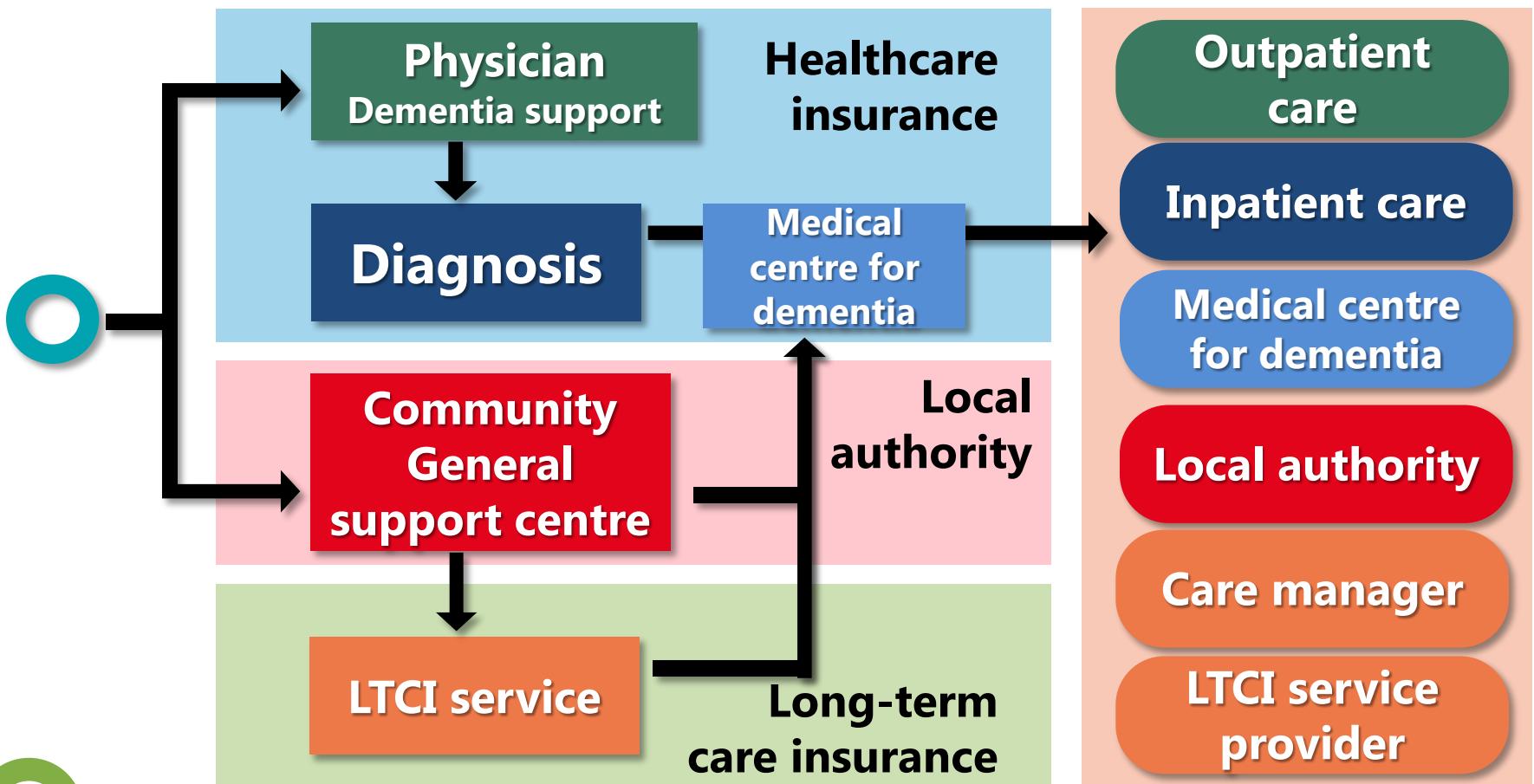
England

Care team



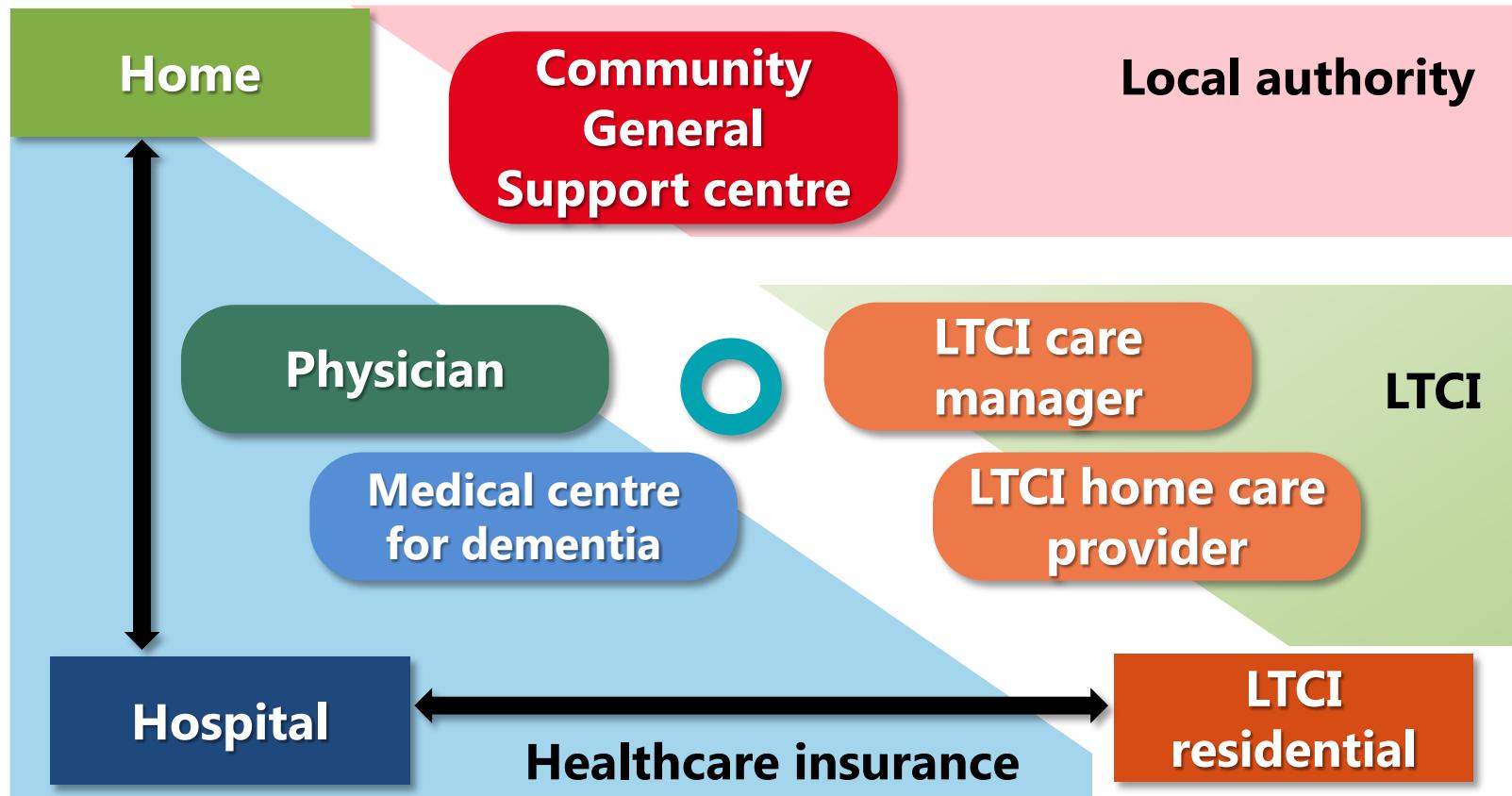
Japan

Pathway



Japan

Care team



Suggestions for Japan

Management of challenging behaviours

- Establish secondary mental health care services

Dementia care coordination

- Enhance function of LTCI insurer and care manager
- Packaged home care services

Family support and advocacy

- Establish national carer strategy



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**



Palliative care in dementia

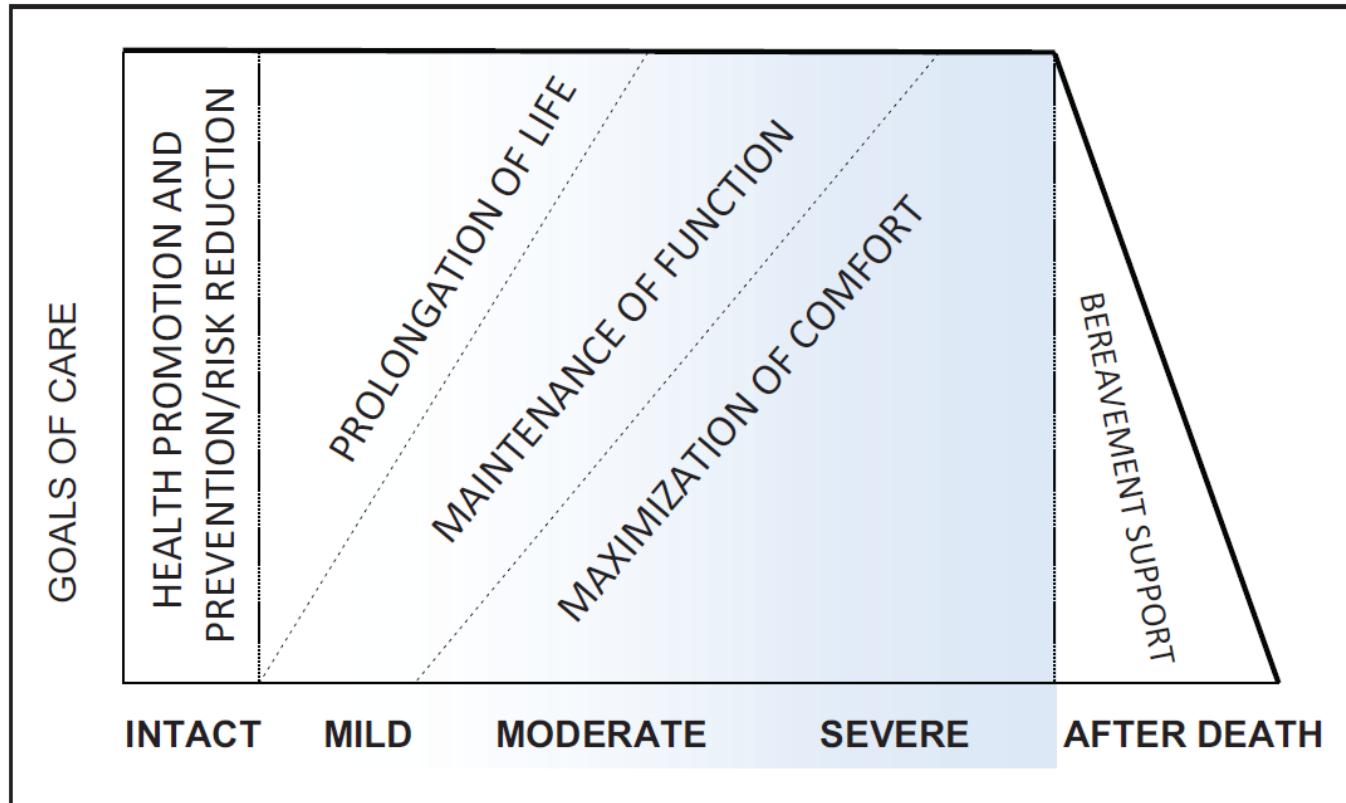
EAPC white paper in 2013 (van der Steen et al., 2014 Palliat Med)

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



Model of changing care goals

Dementia progression and suggested prioritizing care goals



van der Steen JT, Radbruch L, Hertogh CMPM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RTCM, Volicer L on behalf of the European Association for Palliative Care (EAPC) (2014) White paper defining palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 28(3): 197–209.

Palliative care in national plan

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 Int Psychogeriatr)



Independent section

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)



Some sentences

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:** the 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.



Some sentences, not palliative

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.



Call for palliative care

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.*



Information tool development

Comfort care booklet on dementia

- Developed by Dr. Marcel Arcand in collaboration with the Alzheimer Society of Canada (Arcand et al., 2009 JAMDA)
- Aimed to guide and inform families on palliative care
- “Good example” in WHO Europe report

International adaptation study

- Translation and adaptation of the booklet into Italy, the Netherlands, and Japan (van der Steen et al., 2013 JME)



Japanese adaptation

Japanese comfort care booklet

- Adapted where necessary to the Japanese environment
- Revised based on the first evaluation in 2009 to make statements on palliative care more neutral

Difference between Japan and Western countries

- Public healthcare insurance scheme allows use of morphine only for cancer pain
- “Care workers” in long-term care are differentiated from nurses (including nursing assistants and aids)



Usage as an educational tool

Change in perspectives among nursing home staff

- Evaluated using Questionnaire on Palliative Care for Advanced Dementia (qPAD)
- Participants of a short intervention using the booklet showed significantly increased knowledge and more positive attitudes (Nakanishi et al., in press Int J Palliat Nurs)

Future study should explore...

- How to achieve quality dementia care at home that integrates person-centred care and palliative care



Global action against dementia

World Dementia Council

- Formed following G8 Dementia Summit in December 2013

Global Dementia Legacy event

- London (June 2014), Canada (September 2014), Japan (November 2014)
- Japanese Prime Minister had stated a new national dementia plan
- Global young leaders



New Orange Plan in Japan

Revision announced on 27 January 2015

1. Promote dissemination and raise awareness of dementia recognition
2. Provide health and social care services that are timely and appropriate to condition or stage of dementia
3. Reinforce strategies for people with younger onset dementia
4. Support for carers (families) of people with dementia
5. Enhance creation of elderly-and dementia-friendly communities
6. Promote research and development and the dissemination of research outcomes
7. **Respect the views of people with dementia and their families**



Remaining challenges

Family support and advocacy

- Supporting carers in their new roles as proxy decision makers
- Court appointed adult guardians are not allowed to be involved in decision making on health and social care

End of life care

- The New Orange Plan refers a decision making issue on life-prolonging treatment
- No explicit mention of either advance care planning or shared decision making



Right-based care

Standards of Care for Dementia in Scotland

- Based on the Charter of Rights developed by the Parliamentary Cross Party Group on Alzheimer's disease

Second Dementia Strategy in Scotland

- Support and promote best practice in advance care planning
- The assessment of capacity to consent to treatment
- Adherence to proper procedures for making decisions for people with dementia who lack capacity



Glasgow Declaration

Alzheimer Europe, Oct 2014

- Create European Dementia Strategy and national strategies in every country in Europe
- Promote the rights, dignity and autonomy of people living with dementia
- Every person living with dementia has the right to:
 - A timely diagnosis;
 - Access quality post diagnostic support;
 - Person-centred, coordinated, quality care throughout their illness;
 - Be respected as an individual in their community.



Further questions

Navigation throughout the dementia trajectory

- Coordination or one-stop service (packaged care)?
- Coordination by public or private sector?
- Where to obtain end-of-life care for dementia?