UNECE POLICY SEMINAR ON AGEING

Informal care for persons with dementia

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DEMENTIA: A GLOBAL CHALLENGE

Population aged 60+ (2015-2050)

Populations are getting older

Percentage aged 60 years or older:
- 30% or more
- 10 to <30%
- <10%

2015

Increase in dementia numbers (in million) by country income group
Number of people with dementia in Europe

2015

US$818 billion
direct medical and social care costs and costs of informal care

2030

US$2 trillion

Nearly 10 million new cases every year
One every 3 seconds

50 million people worldwide
Set to triple by 2050

Majority of people who will develop dementia will be in low- and middle-income countries
Costs of dementia in Europe

Source: Alzheimer’s Europe, Cost of illness and burden of dementia in Europe – prognosis to 2030 (2009).
COSTS OF INFORMAL CARE

WOMEN’S ROLE IN DEMENTIA CAREGIVING

- Care responsibilities can result in financial hardship and social isolation as well as mental and physical health problems
- Women more likely than men to reduce working hours or stop working entirely

Internationally two out of three primary dementia care partners* are women

Source: Dementia and Women – a global challenge (GADAA, 2017 with contributions from WHO)
IMPACT OF CAREGIVING

Caregiving stress results from:

- Time spent caring
- Social isolation
- Changed behaviour in the person with dementia
- Role strain

Caregiving impacts:

- Deterioration in mental and physical health
- Loss of productivity and income
- Breakdown of home care, leading to institutionalization
WAYS TO SUPPORT DEMENTIA CARERS

- **Dedicated policy response**
  - Often carer needs are not adequately addressed by policies

- **Implement carer support services through health and social care**
  - e.g. respite, training, counselling

- **Role of civil society in supporting carers**
  - in many countries carer support is organized by civil society

*In Europe, the majority of people with dementia receive care at home, or in general nursing homes.*
GLOBAL DEMENTIA ACTION PLAN

access action plan here
STRATEGIC LINKS

Global disability action plan 2014-2021

UN CRPD

Global action plan for the prevention and control of noncommunicable diseases 2013-2030

2030 Agenda for Sustainable Development & Sustainable Development Goals

Global strategy and plan of action on ageing and health 2016-2020

Comprehensive mental health action plan 2013-2030

Global action plan on the public health response to dementia 2017-2025
WHO TOOLS TO SUPPORT COUNTRIES

**Dementia as a public health priority**
- Policy guide

**Dementia awareness & friendliness**
- Dementia-friendly toolkit

**Dementia risk reduction**
- Dementia risk reduction guidelines

**Dementia treatment, care & support**
- mhGAP toolkit for health & community workers

**Support for dementia carers**
- iSupport

**Information systems for dementia**
- GDO e-tool and platform

**Dementia research & innovation**
- BRAINS for dementia

**Global Dementia Observatory (GDO)**

**Global targets**
- 75% Member States have national plans
- 100% Member States have awareness raising campaigns
- 50% have DFIs
- Member States reach NCD targets
- 50% Member States reach at least 50% diagnostic rate
- 75% Member States provide carer training and support
- 50% Member States collect and report on key dementia information
- Double research output
ISUPPORT – WHO TRAINING PROGRAMME FOR CARERS OF PEOPLE WITH DEMENTIA

www.iSupportfordementia.org

iSupport Overview

Lessons

- Introduction to dementia: 1 lesson
- Being a carer: 4 lessons
- Caring for me: 3 lessons
- Providing everyday care: 5 lessons
- Dealing with behaviour changes: 10 lessons

Modules

Online/hardcopy

iSupport

Contributions

The lessons have been developed with contributions from Stanford University, Flinders University, Trimbos-institute and an international expert panel under the guidance of the World Health Organization.
Request 72-hrs access code via whodementia@who.int
iSupport helps to provide good care and to take care of yourself.

At this Home page, you can add lessons, about the topics you want to learn more about, to 'My plan'. We advise you, to first click on each of the 5 themes below to find out which lessons are available. There are 23 lessons in total.

By clicking on a lesson, you will be asked whether you want to add it to 'My plan' or want to start the lesson now. We advise you to first add as many lessons as you wish to 'My plan'. Once you are done, go to 'My plan' to start the lessons in the order you wish. You can always adapt your selection of lessons.

For more help, start the demo.

- Introduction to dementia (1 lesson)
- Being a caregiver (4 lessons)
- Caring for me (3 lessons)
- Providing everyday care (5 lessons)
- Dealing with challenging behaviours (10 lessons)
Memory loss

Why is this lesson important?
Memory loss can be frustrating for the person with dementia and the caregiver.

How will this lesson help me?
In this lesson you will practice several ways to respond to memory loss, and find out what may help you deal with the person's increasing forgetfulness.

What will I learn?
- Memory loss is common in people with dementia
- Different ways to deal with memory loss
- Not to blame the person with dementia, because memory loss is part of the disease
Frustration about memory loss

Olivia has dementia and lives with her husband Jacob. During the past few months, Olivia's memory loss seems to be more frequent. The last few times Olivia went shopping, she could not remember what to buy. She came home with the wrong things which was frustrating.

How should Jacob approach Olivia about what happened?

- Leave Olivia alone and see what happens.
- Ask Olivia to ‘work harder’ to remember things.
- Do not let Olivia shop anymore.
- Ask Olivia how she feels about her memory loss.
- Do not blame Olivia, but make a shopping list together with her each time prior to the shop.
Your answers

You think that Jacob should approach Olivia in the following way:

- Leave Olivia alone and see what happens.

This is not a helpful response, because Olivia and Jacob both feel frustrated. To stay connected it is important to talk about their frustration and worries about the future.
Congratulations!

This is your certificate for practicing 7 communication skills:

- Check ability to hear and see
- Get attention in a respectful way
- Keep it simple
- Take the person seriously
- Pay attention to reactions
- Give compliments
- Show compassion

To print your certificate, click here.
ISUPPORT - ONGOING PROGRESS

- iSupport is currently being implemented in 12 countries, with expression of interest from many others.

- Focus on integrating user feedback and enhancing uptake of iSupport.

- Building a community of practice for iSupport.

  → 25 November 2019: iSupport implementation webinar

  → 9 December 2019: iSupport research webinar

- To express interest please send an email to whodementia@who.int
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Thank you