

# UNECE Policy Seminar on Ageing Informal care for persons with dementia

## Summary report

The second Policy Seminar on Ageing, which took place on 20 November 2019 at the Palais des Nations in Geneva, Switzerland, focused on support for informal carers of people with dementia. The Policy Seminar was well attended by over 50 participants – representatives of 24 UNECE member States, civil society and international organizations.

In the afternoon, participants visited the Applied University of Social Work (HETS, HES-SO)<sup>1</sup> in Geneva where they had a unique opportunity to learn about informal care policy in Switzerland, the dementia action plan of the Canton of Geneva and support measures by the canton and city of Geneva. A site visit was organised to the day care service OASIS run by Pro Senectute Geneva.

The concept note, programme and presentations are available for download on the meeting page: <http://www.unece.org/index.php?id=50637>

### I - Setting the scene: dementia facts

The day was introduced by Vitalija Gaucaite Wittich, Chief of the Population Unit at UNECE, who gave a brief overview of challenges faced by informal carers for persons with dementia.

#### *Dementia*

Dementia is a syndrome usually of a chronic and progressive nature, associated with a decline of brain functioning. Alzheimer's disease is the most common type of dementia (60-70 per cent of cases), and the other common types are vascular dementia, mixed dementia, Lewy body dementia, and frontotemporal dementia. Although dementia is not part of normal ageing, it affects mainly older people. Young-onset dementia (symptoms begin before the age of 65 years) accounts for up to around 10 per cent of cases.

#### *Prevalence of dementia*

Dr. Tarun Dua<sup>2</sup>, Department of Mental Health and Substance Use, World Health Organisation (WHO) gave an overview of dementia incidence and prevalence. Every 3 seconds, there is a new case of dementia in the world. Presently, 50 million people have dementia, and due to population ageing the number is expected to triple by 2050. The majority of people with dementia live in low- and middle-income countries (LMICs) where most of the increase through to 2050 will occur. In the UNECE region, dementia currently affects 10 million people and it is expected to double by 2030. Women experience

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<sup>1</sup> <https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/9-Geneva-School-of-Social-Work-HETS.pdf>

<sup>2</sup> <https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/1-Informal-Care-Person-Dementia-WHO.pdf>

higher dementia prevalence rates than men and face gender-specific barriers to living well with the condition.

### *Becoming a carer - by choice or by default*

Most people will be carers at some point in their lives – for their spouse, children, parents, friends or relatives. The growing life expectancy of the population, decreased fertility rate, increased geographical mobility and women's increased participation in the labour market mean that there is a risk that fewer people will be able to provide informal care for older persons in the future. Some people see taking on a care role as their duty that they take on willingly; others see it as their responsibility due to cultural expectations, lack of formal care arrangements, or simply lack of information about the alternatives. Furthermore, some informal carers do not consider themselves as carers, they see themselves as simply playing a supportive role. Several participants emphasized during the discussion that everyone should have the right to choose whether they want to be a carer, and to what extent.

### *Prevalence of informal care provision*

In Europe, 12 per cent of people of working age (18-64 years) provide regular care – several days a week or every day – for a disabled or infirm person. However, the proportion of people providing regular care varies widely between countries mainly due to: (1) ability to access and afford formal care and (2) societal expectations of families to provide care for their relatives. For example, family care provision is low in Sweden, in which formal care is developed, well regulated, and public coverage is comprehensive. Rates of caring (at least once a week) for a disabled or infirm person are highest among the older working-age population (ages 50-64), of whom most are in employment and women. Also, most of the intensive carers, who provide more than 20 hours of care per week, are between 50 and 64 years old.

Stecy Yghemonos<sup>3</sup>, Executive Director of the Eurocarers, presented the Eurocarers' estimate on the prevalence of informal carers of persons with dementia – 10 million in the European Union (EU), and they predict to be over 18 million by 2050.

### *Gender inequality in dementia caring*

Dr. Tarun Dua highlighted that internationally two-thirds of informal carers of people with dementia are women. Across all regions of the world, women (especially spouses, daughters, and daughters-in-law) spend more time on care work than men. They are more likely than men to reduce working hours or to stop working. Men are more likely to become carers at older ages, when they are no longer in employment. This unequal distribution of caring responsibilities is largely due to stereotypes about traditional gender roles and gendered social norms.

### *Costs of dementia care*

Dr. Tarun Dua presented the costs of dementia care. In 2015, the global costs of dementia – direct medical and social care costs, and costs of informal care – were 818 billion US dollars. This is equivalent

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<sup>3</sup> [https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/SY\\_-\\_UNECE\\_Policy\\_Seminar\\_on\\_Informal\\_Care\\_for\\_Persons\\_with\\_Dementia\\_-\\_November\\_2019.pdf](https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/SY_-_UNECE_Policy_Seminar_on_Informal_Care_for_Persons_with_Dementia_-_November_2019.pdf)

to around one per cent of the global gross domestic product (GDP). Estimated costs associated with dementia in the region are around 300 billion US dollars, more than one-third of global costs<sup>4</sup>. Of these costs, 40 per cent were related to informal care in high-income countries. Conversely, in LMICs informal care costs predominate. It is expected that these costs will double by 2030, challenging social and health care systems around the world.

## II - Policy response

### *International policy response*

Dr. Tarun Dua emphasized that supporting dementia carers requires a dedicated policy response, as carer needs are often not adequately addressed by policies. She reminded participants about international commitments such as the G8 dementia summit: Global action against dementia, the G7 Dementia Legacy events, the Okayama Declaration of the G20 Health Ministers and the WHO Global action plan on the public health response to dementia 2017-2025. The latter comprises seven action areas, and each has a global target. WHO developed tools and resources aimed at supporting countries in implementing the Global action plan and achieving the targets. WHO also developed the Global Dementia Observatory (GDO) a web-based data and knowledge exchange platform, which also supports countries in monitoring progress on dementia actions.

Stecy Yghemonos shared that Eurocarers – the European association of carers' organisations, universities and research institutes – launched its proposal for an EU Strategy entitled „Enabling carers to care“ in 2018<sup>5</sup>. The Strategy defines 10 steps designed to help policymakers and other stakeholders acting at EU, national and regional level to support and empower informal carers.

### *National strategies/plans*

Vitalija Gaucaite Wittich reminded that currently 18 countries in the UNECE region have a national dementia strategy or plan. Several national/regional dementia policies were presented during the seminar: the Austrian Dementia Strategy „Living well with dementia“<sup>6</sup>, the dementia strategy for Canada: „Together We Aspire“<sup>7</sup>, the National Strategy for Dementia in Malta „Empowering change 2015-2023“<sup>8</sup>, the Swiss National Dementia Strategy<sup>9</sup> and Action Plan for Informal Carers<sup>10</sup> and at cantonal level the

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<sup>4</sup> <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/areas-of-work/dementia>

<sup>5</sup> <https://eurocarers.org/publications/enabling-carers-to-care/>

<sup>6</sup> [https://www.demenzstrategie.at/fxddata/demenzstrategie/prod/media/Demenzstrategie\\_Neu\\_englisch.pdf](https://www.demenzstrategie.at/fxddata/demenzstrategie/prod/media/Demenzstrategie_Neu_englisch.pdf)

<sup>7</sup> [https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy\\_ENG.pdf](https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy_ENG.pdf)

<sup>8</sup> <https://www.um.edu.mt/library/oar/handle/123456789/27845?show=full>

<sup>9</sup> <https://www.bag.admin.ch/bag/en/home/strategie-und-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie.html>

<sup>10</sup> <https://www.bag.admin.ch/bag/fr/home/strategie-und-politik/politische-auftraege-und-aktionsplaene/aktionsplan-pflegende-angehoerige.html>

Geneva plan for dementia 2016-2019<sup>11</sup> and Geneva action plan for informal caregivers 2017-2020<sup>12</sup>. A national dementia strategy is currently being developed in Germany and planned to be launched in 2020.

In her presentation of informal care policies for people with dementia in Switzerland, Prof. Dr Barbara Lucas<sup>13</sup>, Geneva School of Social Work (HETS), University of Applied Sciences and Arts Western Switzerland (HES-SO), drew attention to the different ways in which informal carers are “framed” by the policy design of dementia care policy in the different Swiss cantons. She distinguished between “natural carers” where care responsibilities are mainly placed on the family, reinforcing traditional gender roles, “care entrepreneurs” where informal carers are consumers of care services and the state is seen as regulator of a new care market (a model that also reproduces gender inequalities) and finally “care partners” where state policy supports diversity of carers’ life choices and gender inequalities are reduced.

### **III - Challenges experienced by informal carers of persons with dementia**

Dr. Tarun Dua and Stecy Yghemonos provided an overview of the impact of caring. Caregiving stress results from significant time spent caring, as the disease progresses the caregiving might become a full-time occupation; social isolation; changed behaviour in the person with dementia, which is distressing for both people with dementia and their carers; and role strain. Caring may cause deterioration in mental health (high levels of distress, depression, and anxiety), physical health, loss of productivity and income, which may lead to the institutionalization of a person with dementia. It can be difficult to combine paid work with caring duties and carers may choose to quit paid work, to reduce the work hours or to take less demanding jobs, which increases the risk of poverty. Unemployed carers are more likely to be in the worse social and economic situation and to have a lower quality of life – showing that employment is a way to avoid social exclusion and negative impact of caring on health.

Margaret Gillis, of the International Longevity Centre of Canada, reminded that caring can be beneficial and rewarding. Stecy Yghemonos and Maciej Julian Kucharczyk, AGE Platform Europe emphasized that if informal carers are not adequately supported they might become patients themselves.

### **IV - How can informal carers be supported in their role?**

#### *Recognition and support of informal carers*

Informal carers should be recognised as they perform a socially useful and difficult task. They represent the backbone of the formal care system. The estimated economic value of informal caring exceeds the economic value of formal care, and Stecy Yghemonos emphasized that the estimated value of informal care in the EU varies between 50 and 90 per cent of the overall costs of “formal” long-term care (LTC) provision. Furthermore, the budgetary impact of the progressive shift from informal to formal care by

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<sup>11</sup> <https://www.ge.ch/document/plan-cantonal-alzheimer-2016-2019/telecharger>

<sup>12</sup> <https://www.ge.ch/document/programme-soutien-aux-proches-aidants-du-canton-geneve-2017-2020>

<sup>13</sup> <https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/8-Informal-Care-Policy-for-People-with-dementia-in-Switzerland.pdf>

2070 would mean an increase of 130 per cent in the share of GDP devoted to LTC on average for the EU.

### *How can informal carers be supported?*

Dr. Tarun Dua and Stecy Yghemonos provided an overview on ways to support dementia carers. Civil society provides a great deal of carer support, and in many countries they are the only source of support. Carers could be supported through: (1) addressing work-life balance issues through more choice and flexibility – flexible working and leave from work – to provide carers sufficient income and a social network through work (2) introducing cash support – carer’s allowances and cash benefits paid to the care recipients – to recognise and compensate carers for their efforts (3) introducing pension credits for care time to prevent old age poverty (4) introducing support services, such as respite care, training, and counseling to ensure quality of care and improve carers’ wellbeing (5) providing evidence-based information, especially from health professionals (6) increasing the availability and accessibility to integrated formal care – to allow carers to choose their role and the intensity of care provided (7) formal definition and recognition of informal care and informal care status (8) identifying carers through actors that carers see regularly – General Practitioners, nurses, pharmacists and other health professionals – who are well placed to recognise and advise carers about available and appropriate services or to refer them to more specialised sources of information and advice (9) assessing the needs of carers.

### *Support services*

Several measures to support informal carers, such as respite care, training, and counseling were presented at the seminar. Dr Katrin Seeher presented iSupport<sup>14</sup>, the WHO training programme for carers of people with dementia that is available as an online course and hardcopy manual. iSupport consists of five modules: general information about dementia, information related to being a carer, self-care, providing care for the person with dementia, and dealing with behaviour changes. Carers can select the lessons that are the most relevant to them. iSupport is available in English and countries can adapt it to their national or local contexts and needs. It is currently being implemented in 12 countries.

A challenge related to training for informal carers, as Erika Winkler from Austria pointed out, is that carers usually have little time to devote to training, and that older carers might not use online learning platforms. Stecy Yghemonos highlighted that according to research the most successful training methods are mix methods that combine face-to-face and online training.

Erika Winkler<sup>15</sup> shared examples of formal care services available to dementia carers in Austria. Dr. Anneli Rüling<sup>16</sup> presented the results of the Programme „Local Alliances for People with Dementia“ (2012-2018), in which two-thirds of the German counties participated. Cynthia Formosa<sup>17</sup> presented the work and activities of two Dementia Activity Centres in Malta, which provide day respite care. Galina Poliakova<sup>18</sup> shared insights on self- and mutual-help groups in Ukraine.

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<sup>14</sup> <https://www.isupportfordementia.org/en>

<sup>15</sup> <https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/3-Austrian-dementia-strategy.pdf>

<sup>16</sup> [https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/4-Local\\_Alliances\\_for\\_people\\_with\\_Dementia\\_in\\_Germany.pdf](https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/4-Local_Alliances_for_people_with_Dementia_in_Germany.pdf)

<sup>17</sup> [https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/5-Dementia\\_Activity\\_Centres\\_Malta.pdf](https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/5-Dementia_Activity_Centres_Malta.pdf)

<sup>18</sup> [https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/6-Self-and\\_mutual\\_help-Ukraine.pdf](https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/6-Self-and_mutual_help-Ukraine.pdf)

Derek Christie and Thierry Monod<sup>19</sup> shared examples of available services to support informal carers of persons with dementia in Canton of Geneva: a Caregiver Institutional Charter (partners who sign the charter recognize a carer as a full partner), an emergency card (to avoid a break in care if an informal caregiver has an accident/emergency), a modular training programme, financial and administrative support, respite measures (home respite services, respite within institutions, holidays for two), places for listening and support, and psychological support.

Giovanni Martinelli, Coordinator prevention, Geneva Cantonal Police and Sophie Courvoisier, Director of the Geneva section of Swiss Alzheimer<sup>20</sup>, shared outcomes and plans of a training programme for professionals of the City of Geneva, which aims to create a dementia-friendly community. Cantonal neighborhood police, city janitors and collaborators of the Department of social work have mandatory training on how to help people with dementia and treat them with dignity. The plan is to expand the training in other cantons and to the other personnel groups within public services.

During the afternoon sight visit Claudio Testori, manager of the Daycare center OASIS and Joël Goldstein Director, President of the NGO Pro Senecute Geneva, presented activities of the daycare centre OASIS. The daycare centre provides relief and support for carers, and enables older persons to stay at home as long as possible. Various individual and group activities are organised according to the wishes and needs.

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<sup>19</sup> <https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/7-Geneva-action-plan-for-dementia-2016-2019.pdf>

<sup>20</sup> [https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/10-P\\_Training\\_programme\\_20.11.2019.pdf](https://www.unece.org/fileadmin/DAM/pau/age/WG.12/Presentations-PS/10-P_Training_programme_20.11.2019.pdf)

# Informal care for persons with dementia

Wednesday 20 November 2019, 9:30 -17:00 | **Room V**, Palais des Nations

- 09:30 – 10:00**      **Welcome and setting the scene**  
*UNECE & Swiss delegation*
- 10:00 – 10:20**      **The growing prevalence of dementia in the UNECE region and the international policy response**  
*Dr. Tarun Dua, Department of Mental Health and Substance Use, WHO*
- 10:20 – 10:45**      **What are the challenges experienced by informal carers of persons with dementia?**  
*Stecy Yghemonos, Executive Director, Eurocarers*
- 11:00 – 12:30**      **How can informal carers be supported in their role?**  
Provision of adequate formal care services and their integration with informal care  
- Austrian Dementia Strategy - *Erika Winkler*  
Local Alliances for People with Dementia in Germany - *Anneli Rüling*  
Dementia Activity Centres in Malta that provide respite day care and enable informal carers to work - *Cynthia Formosa*  
Self-and mutual help groups of informal carers of persons with dementia in Ukraine - *Galina Poliakova*  
  
*Sharing of policy approaches by participants & discussion*
- 12:30 – 14:00**      **Lunch break**  
Transfer to the Applied University of Social Work Geneva (HETS)
- 14:00 – 15:15**      **Welcome by Joëlle Libois, Director of HETS, HES-SO**  
  
**Informal care policy for people with dementia in Switzerland** *Professor Barbara Lucas, HETS, HES-SO*  
  
**Geneva Action Plan on Dementia and services to support informal carers of persons with dementia**  
*Derek Christie and Thierry Monod, General Directorate of Health, Department of Security, Employment and Health, Canton of Geneva*  
  
**Introduction of site visit**  
*Sophie Courvoisier, Director Geneva Section of Swiss Alzheimer*
- 15:15 – 16:00**      **Training programme for professionals of the City of Geneva: towards an Alzheimer friendly community (HETS, Room D107)**  
*Sophie Courvoisier, Director of the Geneva section of Swiss Alzheimer and Lieutenant Giovanni Martinelli, Coordinator Prevention, Geneva Cantonal Police. (Innovative Police training programme in Switzerland)*
- 16:15 – 17:00**      **Visit of the day care centre OASIS and presentation of care relief services for informal carers in Geneva**  
<http://www.foyers-jour-nuit.ch/oasis/>  
*Claudio Testori, manager of the Day care center OASIS and Joël Goldstein Director, President of the NGO Pro Senecute Geneva*
- 17:00**                **Farewell aperitif, HETS, Room A006**