



**The CARE4DEM model
of online facilitated Mutual Aid Group**

**An innovative approach towards supporting efficiently
informal carers of people with dementia**

**ONLINE SEMINAR
25 June 2020 9.15 – 12.30**



CONCEPT NOTE & PROVISIONAL PROGRAMME

Our societies rely on informal carers, they should be able to expect adequate support

Informal carers, who provide over 80% of all care, are a corner stone of our health and social care systems in the EU. Without their contribution, it would be impossible to address the needs for long-term care of our ageing population. In particular, a large number of informal carers provide care to relatives living with dementia, allowing them to live an active life as far as possible, and preventing their institutionalisation.

Providing care for a loved one can be a choice based on personal preferences, and a source of satisfaction. Though, caring responsibilities come with a cost. Evidence show that, when not adequately supported, the quality of life of carers is generally poorer than for society as a whole. Being a carer is often associated with poverty, isolation, frustration, ill health and depression. Informal carers of working age face significant difficulties to combine care and employment. In times of crisis, as experienced during the outburst of the COVID 19, their difficulties and isolation are exacerbated.

As a consequence of demographic change, more and more people endorse informal caregiving activities, making it all the most important to support them adequately in order to prevent the degradation of this vulnerable group's health and well-being. However, support remains largely insufficient, or simply out of reach for informal carers lacking the availability to participate in face-to-face interventions such as training, counselling or mutual support groups.

Building on the potentialities of ICTs, the CARE4DEM model tackles carers' isolation and offers a space for mutual empowerment

Providing care for people affected by dementia proves particularly challenging for their relatives, who face acute difficulties, notably to maintain the relationship and to address challenging behaviours. The CARE4DEM's project has developed an innovative tool to support dementia carers, combining the tracked added-value of Mutual Aid Groups (MAGs) in terms of empowerment with the potentialities of ICT-based solutions, accessible to informal carers who face practical obstacles to attend face-to-face interventions. At the end of this project, partners are in a position to offer a comprehensive model of a MAG for informal carers facilitated online. A particular attention has been given to the role of the facilitator, which can be endorsed either by a professional or/and by an experienced informal carer.

While the CARE4DEM's MAG model is tailored for people taking care of a relative with dementia, most of its content is not disease-specific and might support interventions towards carers confronted with other diseases.

A hands-on seminar discussing the practical implementation of the CARE4DEM model

During the seminar, the project partners will present the CARE4DEM comprehensive set of tools and guidelines, enabling stakeholders to implement easily the model and engage a commonly left out group into adult learning. Together with carers and professionals involved in the intervention, partners will share the learnings of the intervention's piloting in Portugal, Spain, Italy and Romania.

A discussion with stakeholders: how to move forward and ensure adequate support to informal carers online?

The seminar will also offer an opportunity to discuss further CARE4DEM's take-aways and the conditions which must be fulfilled in order to ensure that informal carers can rely on adequate support online in the foreseeable future. Representatives of key institutions such as of the European Commission, local authorities, health mutual cooperatives, as well as users' representatives are invited to contribute to the discussion.

This online event is open to all relevant stakeholders upon registration. It is aimed in particular at professionals and volunteers in the areas of care and caring, digitalisation of health and care systems, social protection, long-term care, and adult learning.



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PROVISIONAL PROGRAMME

Chair: Licia Boccaletti, President, Anziani e Non Solo

9.15 - 9.30

Opening welcome

- **Elisabetta Gualmini**, MEP (video message)
- **Elizabeth Hanson**, Eurocarers' Vice-President Research

9.30 - 9.50

Setting the scene: how are carers' needs being addressed today?

- The situation of informal carers in the EU: where are we now? (**Stecy Yghemonos**, Executive Director, Eurocarers)
- Web-based mutual aid groups for informal carers of people with dementia: an evidence review (**Claire Champeix**, Eurocarers)
- Q/A

9.50 - 10.30

The CARE4DEM model: a comprehensive set of tools

- The C4D Model of online Mutual Aid Group (**Licia Boccaletti**, ANS)
- 'The C4D Facilitator's Competence Profile and Self-evaluation Tool' (**Claire Champeix**, Eurocarers & **Elena Patlagica**, EaSi)
- The C4D Blended Training for Facilitators (**Joana Portugal**, Aproximar)
- Q/A

10.30 - 10.45

Break

10.45 - 11.15

Learnings from the piloting

- Feed-back from participants: testimonies from facilitators and informal carers
- Feed-back from partners' organisations: what have we learnt from the piloting ?
- Q/A

Chair: Stecy Yghemonos, Executive Director, Eurocarers

11.15 - 12.15

Panel discussion: how to make relevant support accessible to all informal carers through ICT-based solutions?

- **Irina Kalderon Libal**, Policy Officer, DG Connect
- **Borja Arrue**, Project and Policy Officer, AGE-Platform
- Eurocities, tbc
- **Jessica Carreño Louro**, Project Manager, International Association of Mutual Benefit Societies
- Q/A

12.15 - 12.30

Concluding remarks

- **Elizabeth Hanson**, Eurocarers Vice-President Research
- **Licia Boccaletti**, President, ANS