What are the challenges experienced by informal carers of persons with dementia?

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The Eurocarers Network

European network of carers’ organisations and relevant research & development organisations

68 member organisations in 26 countries

Who are the (informal) carers?
A carer is any person who provides care - usually unpaid - to someone with a chronic illness, a disability or any other long-lasting care needs, outside a professional or formal framework.
Prevalence and impact of dementia care

Long-term decrease in cognitive abilities:
→ Memory and communication
→ Changes in mood
→ Changes in behaviour
→ Medical and physical issues
→ Daily life

More than 10 million carers for people with dementia in EU-28 today, over 18 million by 2050. (Eurocarers estimate)
According to research:

- Informal carers are the largest providers of health and social care support.
- Make up about 10-25% of the total EU population.
- Women provide 2/3 of care mainly as daughters (in law) and spouses/partners.
- Usually between 45 and 75 years.
Caring for disabled/infirm relative or friend

Proportion of workers providing care at least once a week – EQLS 2016
## The cost of dementia care

<table>
<thead>
<tr>
<th>WHO region</th>
<th>Direct medical costs</th>
<th>Social sector costs</th>
<th>Informal care costs</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oceania</td>
<td>7,99</td>
<td>5,02%</td>
<td>63,49</td>
<td>19,36%</td>
</tr>
<tr>
<td>Asia</td>
<td>5,74</td>
<td>3,61%</td>
<td>11,97</td>
<td>3,65%</td>
</tr>
<tr>
<td>Europe</td>
<td>59,26</td>
<td>37,22%</td>
<td>120,89</td>
<td>36,87%</td>
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<tr>
<td>North America</td>
<td>61,08</td>
<td>38,36%</td>
<td>115,52</td>
<td>35,23%</td>
</tr>
<tr>
<td>Latin America</td>
<td>15,74</td>
<td>9,89%</td>
<td>14,36</td>
<td>4,38%</td>
</tr>
<tr>
<td>Africa</td>
<td>9,41</td>
<td>5,91%</td>
<td>1,67</td>
<td>0,51%</td>
</tr>
<tr>
<td>All</td>
<td>159,22</td>
<td>19,47%</td>
<td>327,9</td>
<td>40,09%</td>
</tr>
</tbody>
</table>
The “economic” value of informal care

Estimates of the value of unpaid informal care in EU Member States between 50 and 90% of the overall costs of “formal” LTC provision

Budgetary impact of progressive shift from informal to formal care by 2070 would mean an increase by 130% in share of GDP devoted to LTC on average for the EU

➔ No universal long-term care without informal carers!
Clear correlation between caring and:

- Work-life/care balance
- Social exclusion and poverty
- Health and well-being

“As a carer, you have no social life whatsoever. I have been an unpaid carer for 20 years. I do not feel part of society at all. I feel a complete outsider”
WHO Global Action Plan on Dementia 2017 - 2025

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation
Global target
75% of countries providing support and training for dementia carers by 2025.

Member States required to provide carers with access to:

- Evidence-based information, training, respite services and other resources tailored to their actual;
- Training programmes for care staff in order to help them identify carers and prevent carers' stress and burnout;
- Social protection and anti-discrimination measures (e.g. employment);
- Discussion regarding the planning of care (which ultimately affects them).
What do carers want?

Financial support: income based on a minimum wage

Employment: flexible working, paid and/or unpaid leave

Pension credits for care time

Regular breaks from caring

Information and Training

Caregiving is not the source of my stress and exhaustion, the constant battle for services is!
2014 - EC push for LTC coordination / Formal LTC as primary focus

2017 - Agreement on increased collaboration in social matters between EU MS (LTC and more)

2018 - Formal vs. informal care + Launch of Eurocarers proposal for an EU strategy on carers

2019 - Formal and informal LTC workers

Policy environment for work
The rationale for a European Strategy on Carers
STEP 1
Define and acknowledge Carers

STEP 2
Identify your Carers

STEP 3
Assess the needs of your Carers

STEP 4
Support multisectoral care partnerships for integrated and community-based care services

STEP 5
Facilitate carers’ access to information and advice about care, caring and care-life balance

STEP 6
Pay attention to carers’ health and prevent negative health outcomes

STEP 7
Give Carers a break

STEP 8
Provide Carers with access to training and recognise their skills

STEP 9
Prevent Carers’ poverty and allow them to maintain an active professional/educational life

STEP 10
Adopt the Carers’ perspective in all relevant policies
Thank you