

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)



The Situation of carers in Europe

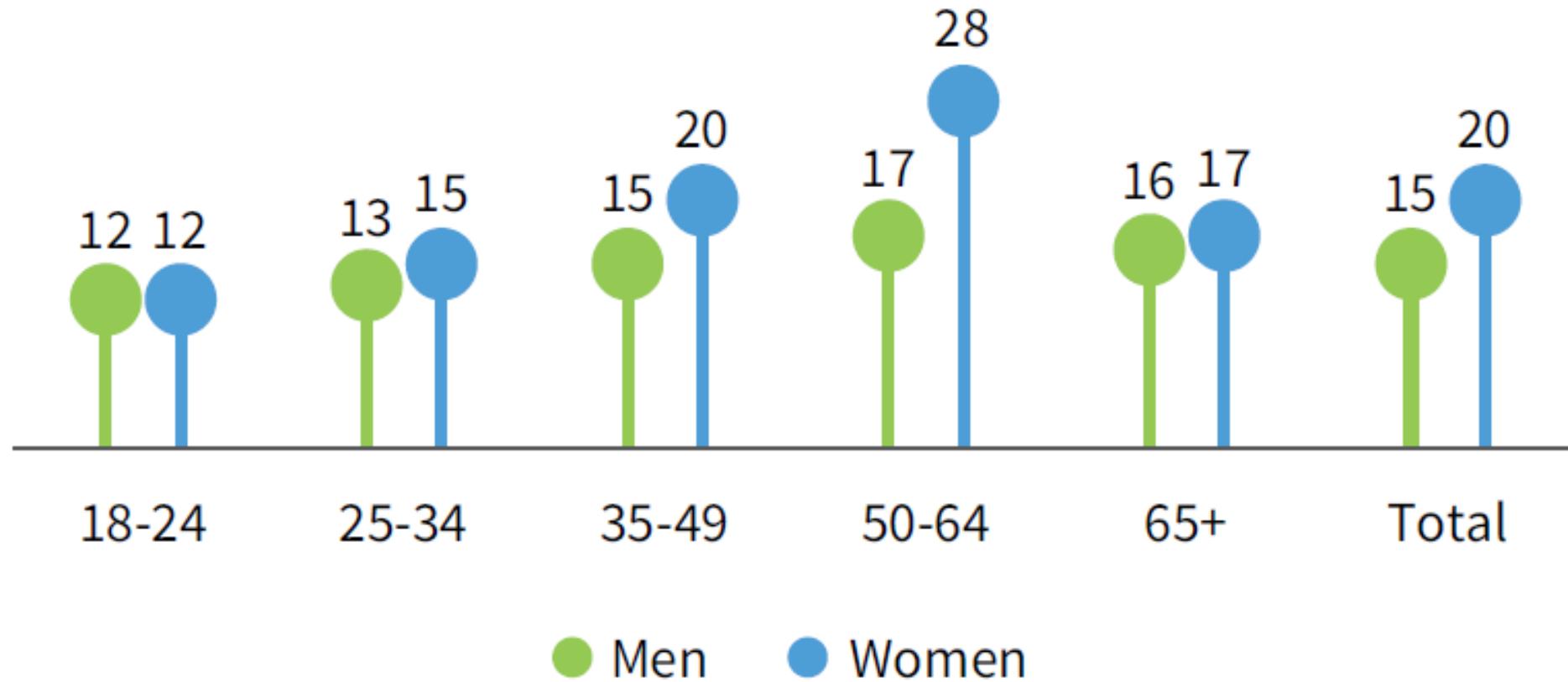


The Personal is Political

According to research:

- Informal carers are **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

WHO region	Direct medical costs		Social sector costs		Informal care costs		Total costs	
	bUS\$	Prop.	bUS\$	Prop.	bUS\$	Prop.	bUS\$	Prop.
Oceania	7,99	5,02%	63,49	19,36%	52,7	15,93%	124,18	15,18%
Asia	5,74	3,61%	11,97	3,65%	38,13	11,53%	55,84	6,83%
Europe	59,26	37,22%	120,89	36,87%	120,98	36,58%	301,13	36,82%
North America	61,08	38,36%	115,52	35,23%	92,32	27,91%	268,92	32,88%
Latin America	15,74	9,89%	14,36	4,38%	16,22	4,90%	46,32	5,66%
Africa	9,41	5,91%	1,67	0,51%	10,42	3,15%	21,5	2,63%
All	159,22	19,47%	327,9	40,09%	330,77	40,44%	817,89	100%

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

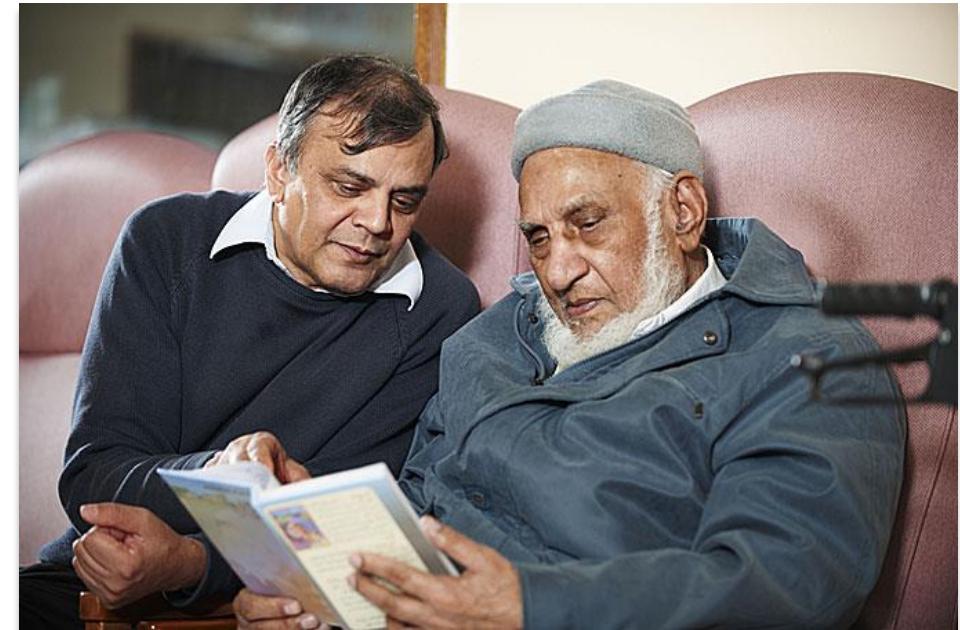
Budgetary impact of progressive shift from informal to formal care by 2070 would mean an increase by 130% in share of GDP devoted to LTC on average for the EU

→ No universal long-term care without informal carers !

Impact of caring

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



WHO Global Action Plan on Dementia 2017 - 2025



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

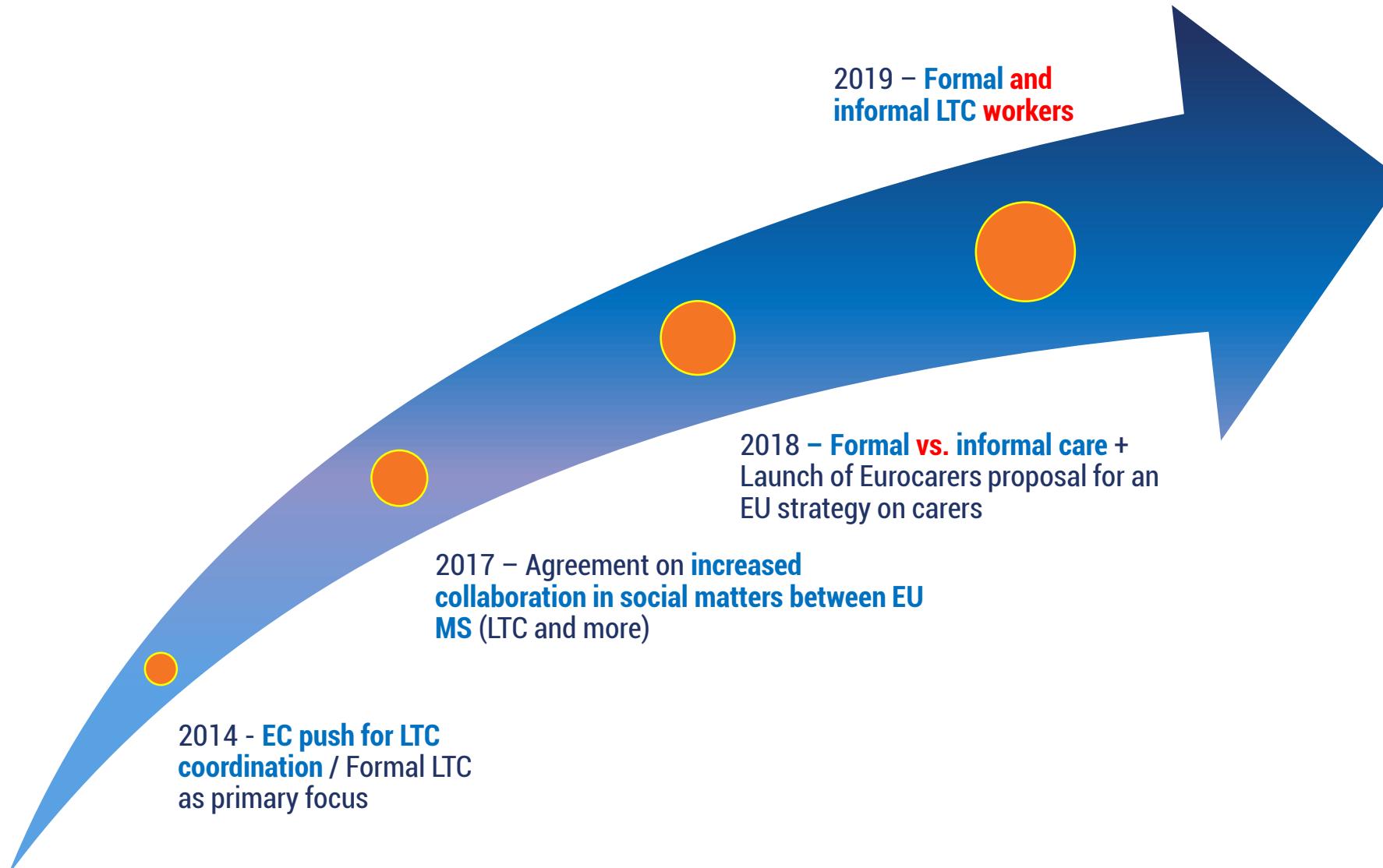
Pension credits for care time

Regular breaks from caring

Information and Training

Caregiving is not the source of my stress and exhaustion, the constant battle for services is!

Policy environment for work



The rationale for a European Strategy on Carers



Thank you