6° International Carers Conference - Gothenburg, 3-6 September 2015
Themed plenary P4: Technology-Enabled Care and Support

Setting standards in the provision of web-based support services for carers of older people in Europe: Eurocarers' new multilingual *InformCare* platform



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1: INRCA; 2: NKA; 3: EUROCARERS; 4: WirPflegen







Contents

- 1. Introduction: why InformCare?
- 2. How the InformCare platform was built
- 3. What is in InformCare: resources and services

4. Evaluation by users in three countries

5. Final remarks

1.Introduction:

why InformCare?

Support needs of informal carers in ageing societies

- Population ageing, a positive phenomenon in itself, leads often also to an increase in long-term care (LTC) needs
- As formal/professional care services are not able to meet (fully, but often not at all) this LTC demand, informal/family carers remain crucial in addressing (elder) care needs, thus relieving the pressure on public resources
- By doing this, however, carers often have to face many difficulties, e.g. health problems (depression, anxiety), lower work productivity (or even job loss), financial problems, family conflicts and social isolation
- To tackle such difficulties, in some countries different forms of support services for carers have been implemented

Support services for carers: the increasing role of the web

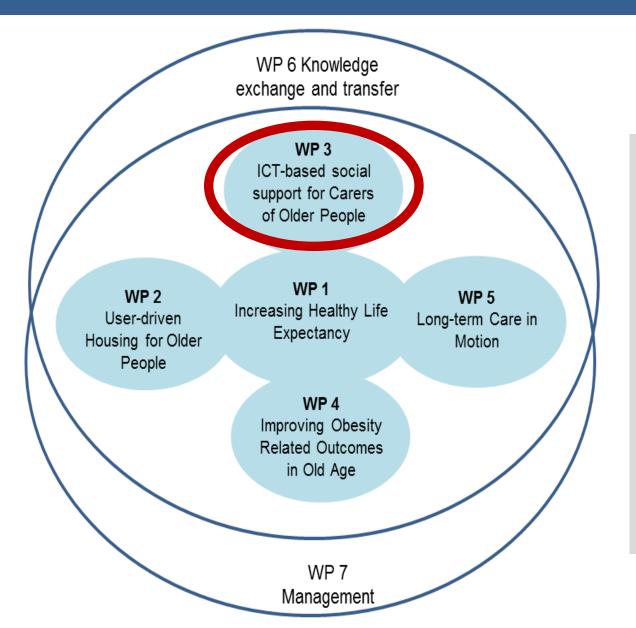
- An increasing number of support services for carers are being delivered via internet, in a static or interactive way, to provide the following:
- Information on different care-related aspects (static sites)
- individual counselling by health professionals to carers (via e-mail, audio or video communication)
- group support (structured: via video-conferencing group sessions with a moderator; unstructured: via on-line fora)
- social participation tools for interaction with other carers & significant others (via social networks etc.)

Gaps in the provision of web-based support services for carers in the EU

- Many web-based services for carers existing in the EU present substantial limitations (Schmidt et al 2011) as:
- many initiatives are small-scale and low-funded, with limited geographical coverage, so web-based services are available & accessible to few people only
- many countries in Europe experience (a) a low penetration of low-cost broadband internet connection and/or (b) a small (or even no) cultural and social recognition of carers' role (e.g. in Southern and Eastern Europe)

2. How the InformCare platform was built

The INNOVAGE project (WP3)



innovAge

SOCIAL INNOVATIONS PROMOTING ACTIVE
AND HEALTHY AGEING

Project Partners

- University of Sheffield, UK (Coordinator)
- 2. Lund University, SE
- 3. Heidelberg University, DE
- 4. Newcastle University, UK
- National Institute of Health and Science on Ageing (INRCA), IT
- 6. Age Platform Europe, BE
- 7. Eurocarers, LU
- 8. Sheffield Hallam University, UK
- Latvian Council of Science, LT

Goals of INNOVAGE-WP3: a multilingual platform for carers in the EU

- Overall goal: contribute to improving quality of life of informal carers of frail older people in Europe, by developing an integrated set of web-based, multilingual support services, to more effectively address carers' needs.
- Specific objectives: (1) to <u>develop</u>, (2) <u>test</u> (3) <u>implement</u> and (4) <u>disseminate</u> in the EU-27 the web platform with an integrated package of basic services.
- Two main types of services: information resources and interactive services

Three target groups

- Primary target group: Informal carers (all countries)
- Secondary target groups:

Care professionals (10 countries): health care workers, psychologists, psychotherapists, social workers, adult educators etc., who directly interact with informal carers (e.g. to promote integration of formal and informal care, provide direct support etc)

Employers (10 countries): Owners, CEOs & HRMs organisations interested in addressing the potentia difficulties (also on the workplace) experienced by the (growing number of) employees who provide informal care

Three target groups

COMMON NATIONAL CONTENTS FOR CONTENTS FOR INFORMAL INFORMAL CARERS **CARERS** ALL 27 EU ALL 27 EU **MEMBER MEMBER** STATES STATES

NATIONAL CONTENTS FOR CARE PROFESSIONALS 10 countries: Austria Belgium Czech Rep. Finland Germany Luxembourg Malta Slovakia Sweden

UK

NATIONAL CONTENTS FOR EMPLOYERS

10 countries: Bulgaria Germany Estonia France Lithuania Latvia Netherlands **Portugal** Sweden UK

Design and development

- A user-centred approach was adopted to design the platform and develop the services offered through it, based on:
- a wide mix of user representatives: almost 200 endusers/experts and 32 stakeholders (mainly user organisations & research centres), including an Advisory Board of 15 experts
- a series of user-centred development activities:
 - review of most successful web-based services tested and implemented in Europe & beyond (≅ 100 services reviewed)
 - surveys involving 58 selected experts, users and stakeholders, to get feedback on platform's main features
 - preliminary round of user tests to receive immediate feedback on prototypes of the platform
 - pilot test with 118 users in three countries (Germany, Italy & Sweden) for a more in-depth feedback and evaluation

Implementation and dissemination tasks carried out by national organisations

1. Contents for Informal Carers:

- a.revision of translations of common contents
- b.development and uploading of national

contents

2. Contents for Care Professionals and Employers:

- a. translation of common contents
- b. development of national contents

Implementation and dissemination: a EU-wide joint effort / 1

COUNTRY	ORGANISATION
Austria	European Centre for Social Welfare Policy and Research
Belgium	Thomas More Kempen vzw
Bulgaria	Alzheimer Association in Bulgaria
Cyprus	Cyprus Alzheimer Association
Czech	Centre of Expertise in Longevity and Long-term Care / DIACONIA?/ 50plus?
Republic	Certife of Expertise in Longevity and Long-term Care / DIACONIA! / Sopius!
Denmark	Carers Denmark
Estonia	Estonian Carers
Finland	The Central Association of Carers in Finland /Folkhälsans förbund
France	Association Francaise des Aidants
Germany	wir pflegen
Greece	Athens Association of Alzheimer's Disease and Related Disorders
Hungary	Magyar Máltai Szeretetszolgálat Egyesület - Hungarian Maltese Charity Service (MMSZ)
Ireland	Care Alliance Ireland
Italy	INRCA - Italian National Institute on Health and Science of Ageing

Implementation and dissemination: a EU-wide joint effort / 2

Italy Anziani e non solo

Latvia Apvienība "Apeirons"

Lithuania Lithuanian Multiple Sclerosis Union

Luxembourg RBS-Center fir Altersfroen (RBS)

Malta SoS Malta

Netherlands VILANS

Poland European Care Foundation (EFO)

Portugal Jose Alves

Romania Ana Aslan National Institute of Gerontology and Geriatrics

Civic Association for Sustainable development of Regions in Slovakia

(CASDRDS)

Slovenia Slovenian Federation of pensioners' organisations (ZDUS)

Spain FUNDACIÓ JOAN COSTA ROCA (Group Consorci Sanitari de Terrassa)

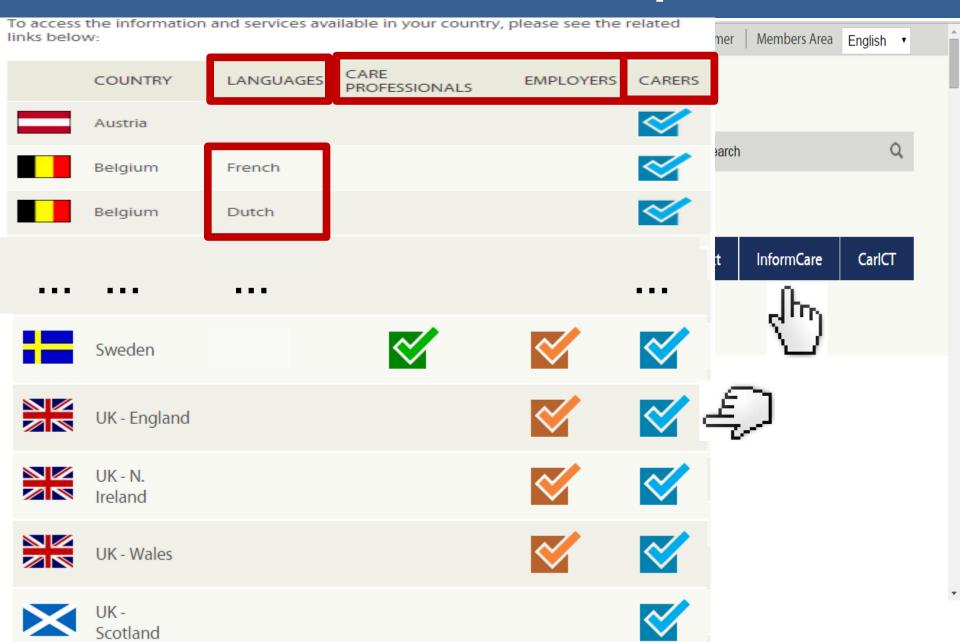
Sweden National Family Care Competence Centre (NKA)

UK CARERS UK

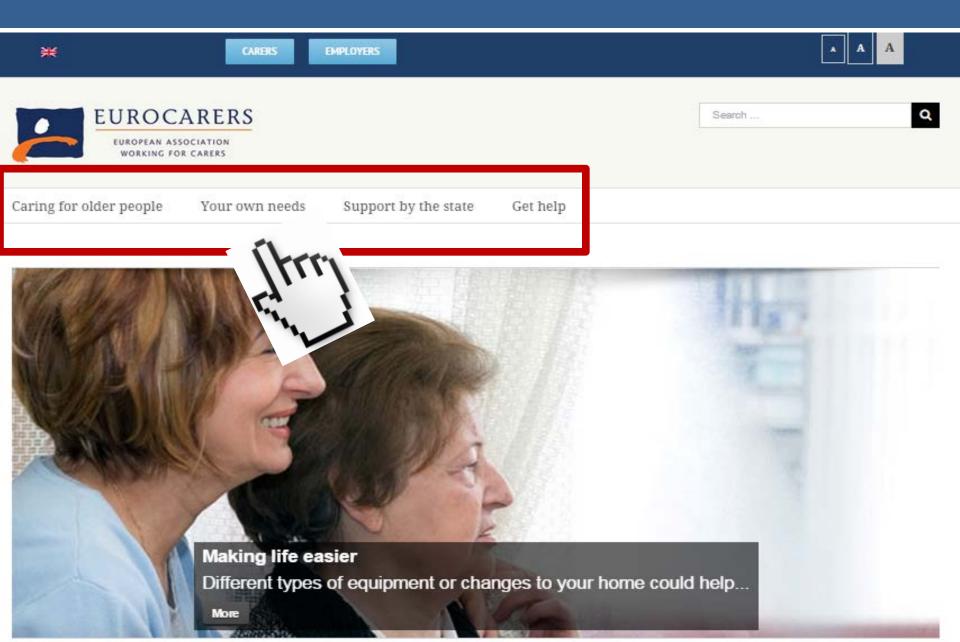
UK - Scotland VOCAL

3. What is in InformCare: information resources & interactive services

Where is the InformCare platform?



InformCare: section for carers



Example of Level 1 for 'Your own needs'











Caring for older people

Your own needs

Support by the state

Get help

Your own needs

Home / Carers / Your own needs

Carers Caring for older people > Site map Video Tutorial Your own needs > Coping with Caregiving > Family reconciliation > Work reconciliation > Physical exercise - Staying Active

Support by the state >



As a carer you may experience the psychosocial, physical and financial burden of caregiving. Help yourself section presents 4 main topics to help you cope with caring:

Search...

Coping with caring Family and Care Reconciliation Work and Care Reconciliation Physical Exercise - Staying Active

Stress, depression, family relationships, balancing between care and work and tips to stay active are discussed in above sections.

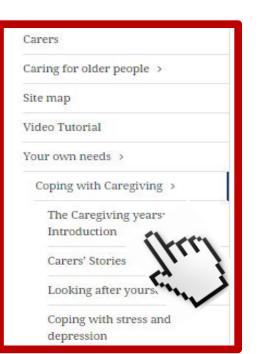
Remember, looking after yourself improves your quality of life and care!

Example of Level 2 information



Coping with Caregiving

Home / Carers / Your own needs / Coping with Caregiving





The Caregiving years: An introduction

When you expect a child, the community (your family, friends, co-workers) rally around you and your spouse.

More >



Carers' stories

I am exhausted and extremely tired but I have not had a good night's sleep since we moved. Everyone tells me to stop worrying, things will work out, etc, etc.

More >

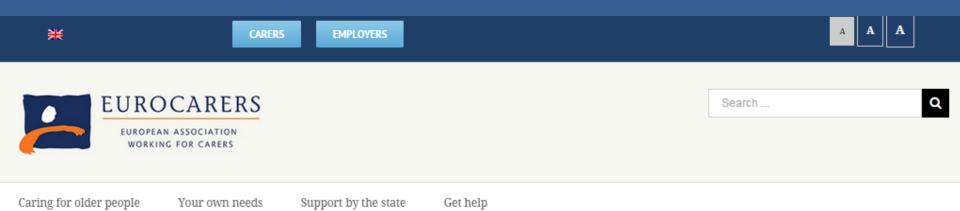


Looking after yourself

Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing as the disease progresses and looking after yourself takes usually last place on a long list of heavy duties.

More >

Example of Level 3 information



The Caregiving years: an Introduction

Home / Carers / Your own needs / Coping with Caregiving /
The Caregiving years: an Introduction

You have a growing concern that, within the near future, your family member or friend will.

Carers	
Caring for older people >	
Site map	
Video Tutorial	
Your own needs >	
Coping with Caregiving >	
The Caregiving years: an Introduction	
C1 04!	

The Caregiving
Years

I May Help

Stage 1

Stage 2

Stage 3

Stage 4

Stage 5

Stage 6

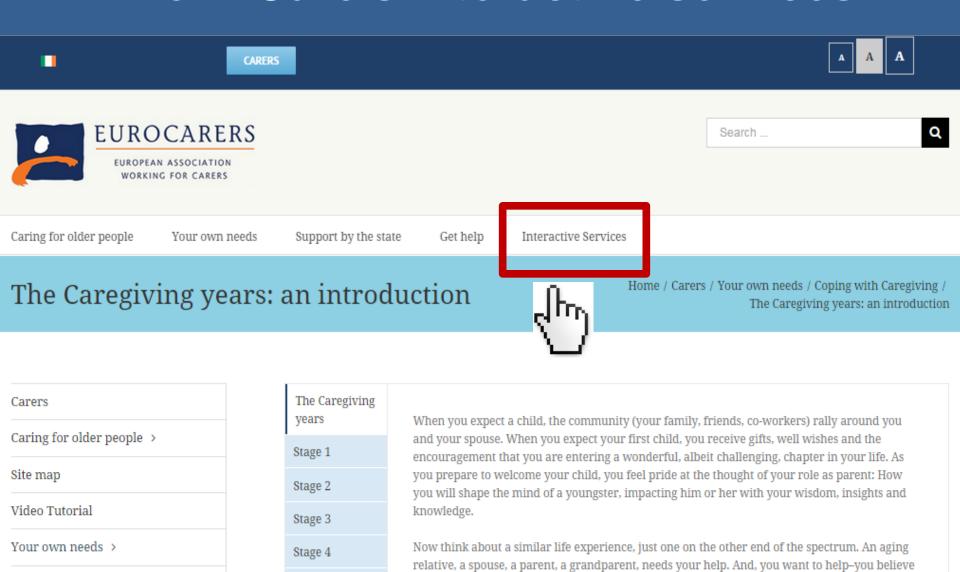
Who are you?

Summary of static information for carers

Caring for Information on illnesses and care management an older Available care and support services person **Psychological support- consultation** Your own Information on taking care of yourself needs as a Work and care reconciliation carer Family and care reconciliation Legal aspects Support by the state **Financial aspects Good Practices** How to get practical help

Emergency services

InformCare's interactive services



in making the most of the years you have left together. But, when you tell your friends, your

colleagues, even other family members, the comments you may hear are a far cry from well-

wishes. "I could never do that! Why do you?" Or, the more common response: "Why don't you just put your mother (or your wife, or your grandfather) in a nursing home? That way you won't

Coping with Caregiving >

introduction

The Caregiving years: an

Stage5

Stage 6

Social network



Servizi Interattivi

. Inpostazioni X Esci

Cerca

<< Torna alla homepage

Social Network

Messaggi Chat

Video Chat

Forum

Ciao Giovanni Lamural





Forum



Servizi Interattivi

Social Network

Messaggi

Video Chat

Chat

Forum



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♣ 0 Notifiche Profilo Impostazioni Esci





Messages

Video Chat

Forum

♥ 0 Notifiche (1) Profilo 🙀 Impostazioni 🗶 Esci



<< Torna alla homepage

Servizi Interattivi



I Miei Messaggi

Messaggi Ricevuti

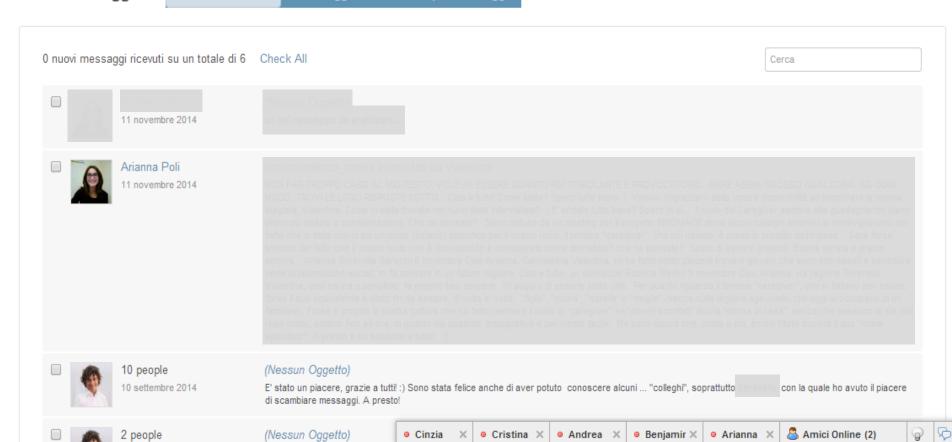
Social Network

Messaggi Inviati

Messaggi

Componi Messaggio

Chat



Chat

July O Updates (My Profile Settings Exit



Interactive Services





X Cristina Lancioni X Andrea

Cinzia Giuli



X A Friends Online (2)

Videochat

♣ 0 Updates My Profile Settings Exit



Interactive Services

<< Back to main site

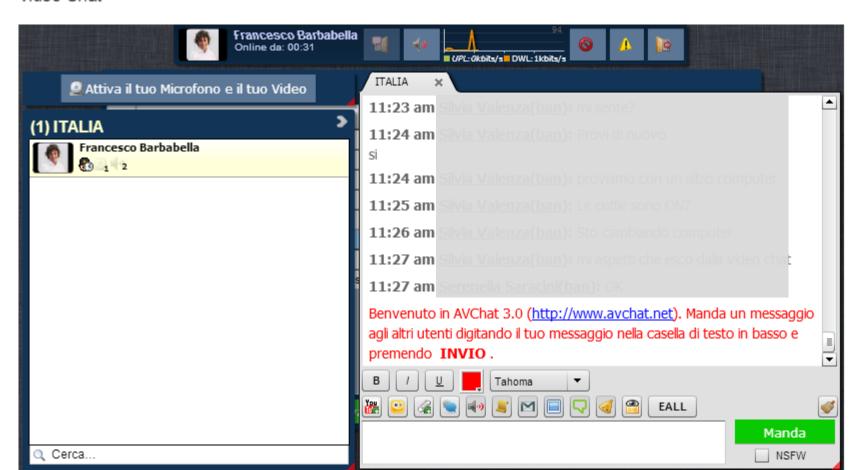
Social Network

Messages

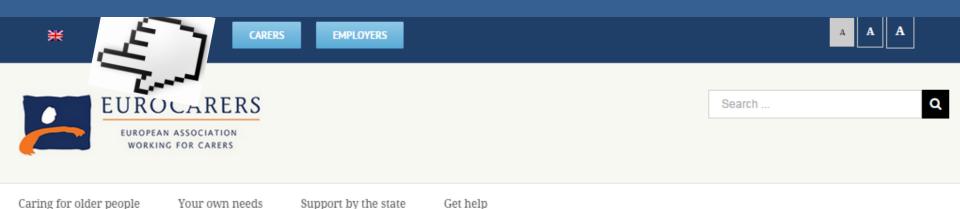
Chat

Video Chat

Video Chat



Changing language...



The Caregiving years: an Introduction

Home / Carers / Your own needs / Coping with Caregiving /
The Caregiving years: an Introduction

You have a growing concern that, within the near future, your family member or friend will

Carers	
Caring for older people >	
Site map	
Video Tutorial	
Your own needs >	
Coping with Caregiving >	
The Caregiving years: an Introduction	
C	

The Caregiving
Years

I May Help

Stage 1

Stage 2: The Expectant Carer

Stage 3

In the near future, I may help a family member or friend.

Stage 4

Stage 5

Stage 6

Who are you?

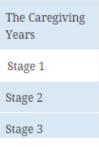
Changing language...



The Caregiving years: an Introduction

Home / Carers / Your own needs / Coping with Caregiving / The Caregiving years: an Introduction





I May Help

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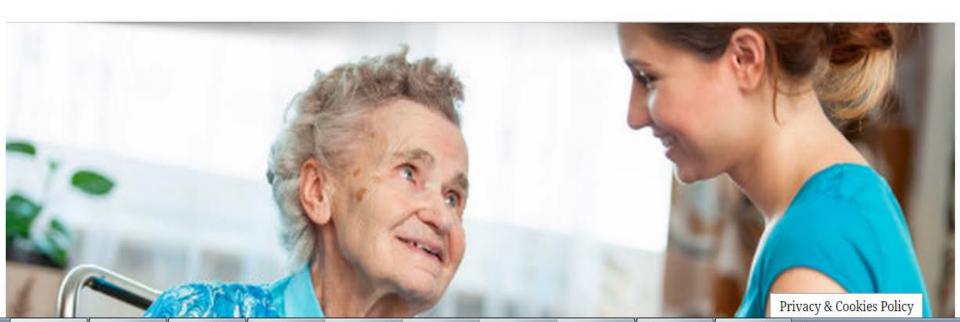
Stage 1: The Expectant Carer



In the near future, I may help a family member or friend.

Changing language... to Swedish





InformCare for care professionals

				•		
links below:						
		COUNTRY	LANGUAGES	CARE PROFESSIONALS	EMPLOYERS	CARERS
		Austria				
		Belgium	French			
		Belgium	Dutch			
					•	
		Sweden	Ē			
		UK - England		ζ _{[μν})		
		UK - N. Ireland				
		UK - Wales				
		UK -				

InformCare for care professionals



Professionella

Home / Professionella

Betydelsen av anhörigomsorg

Anhöriga kan definieras på många olika sätt utifrån olika variabler såsom relationen till den närstående, ålder, kön, etnicitet och den närståendes behov. Eurocarers definierar en anhörig som en person som ger obetald vård, hjälp och stöd till någon med en kronisk sjukdom, funktionsnedsättning eller annat långvarigt hälso- eller vård- och omsorgsbehov, utanför en professionell eller formell ram.

Juridiska aspekter för professionella som möter anhöriga i sitt arbete

Den rättsliga ställningen för den som är i behov av vård och omsorg regleras genom lagstiftning. För personal som arbetar inom vård och omsorg och socialt arbete finns det flera olika lagar som styr och påverkar arbetet. För personal som möter både enskilda och anhöriga är det naturligtvis viktigt att

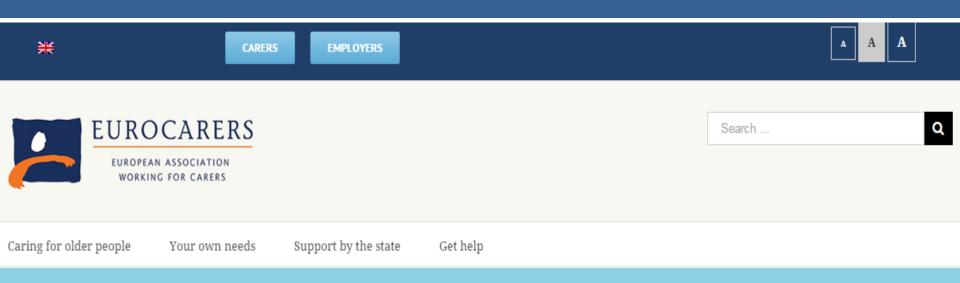
Att hantera vård- och omsorgspersonals belastning i arbetet

"Jag har arbetat som socialarbetare på en dagverksamhet för personer med demens i fem år nu. Förra året vaknade jag en morgon och kände mig på väldigt dåligt humör och ville inte gå till jobbet. Så fort jag kom till jobbet kände jag mig utmattad och energilös, som om jag redan hade arbetat i flera

InformCare for Employers

links below:						
	COUNTRY	LANGUAGES	CARE PROFESSIONALS	EMPLOYERS	CARERS	
	Austria					
	Belgium	French				
	Belgium	Dutch				
			• • •			
	Sweden	=				
	UK - England					
	UK - N. Ireland		(F			
	UK - Wales		~			
	UK -					

InformCare for Employers



Employers

Home / Employers

Your business and informal care

If not currently caring for someone ourselves, we probably all know somebody (a relative, a friend, a colleague) who is responsible for looking after a dependent person, such as an older parent. The experience of providing informal care to our loved ones can be satisfying but it is also a challenging

Legal framework

Carers' legal rights have changed over recent years and it is important for employers to ensure that they are complying with the law. This section highlights the key legislation affecting carers in employment and the issues of which employers should be aware...

Action run by employers

Apart from the legal framework, employers can implement different measures for supporting working carers, thereby both benefitting and getting benefit from them...

More >

More >

4. EVALUATION BY USERS IN 3 COUNTRIES

Evaluation methodology

- Design: one-group pre-test/post-test study (pilot)
- Duration: 12-17 weeks (Apr-Jul 2014)
- Countries involved: Italy, Germany, Sweden
- Sampling: convenience sample approach (exception in Italy: all patients approaching an Alzheimer Assessment Unit)
- Sample size: 118 carers
- Measures: structured questionnaire (with validated scales & ad-hoc items) & focus groups in each country

Who are informal carers (in need)?					
	Total	Italy	Germany	Sweden	
Carer					
Gender: woman	70.8%	69.6%	60.0%	77.3%	
Age	58.5 (11.5)	53.1 (10.2)	60.6 (9.0)	64.7 (10.8)	
Relationship with elderly:					

3.5%

84.2%

12.3%

78.6%

22.8%

28,1%

56,1%

15,8%

62.5%

26.3%

57.9%

15.8%

65.0%

20.0%

15,8%

26,3%

57,9%

31.6%

66.7%

33.3%

0.0%

81.8%

59.1%

6,8%

18,2%

75,0%

47.7%

30.6%

61.2%

8.3%

77.5%

35.5%

18,3%

37,5%

44,2%

52.1%

Other

Education

Low

High

education)

Employment: yes

school)

Children: yes

Spouse/Partner

Grandchildren: yes

Children/Children-in-law

to

lower

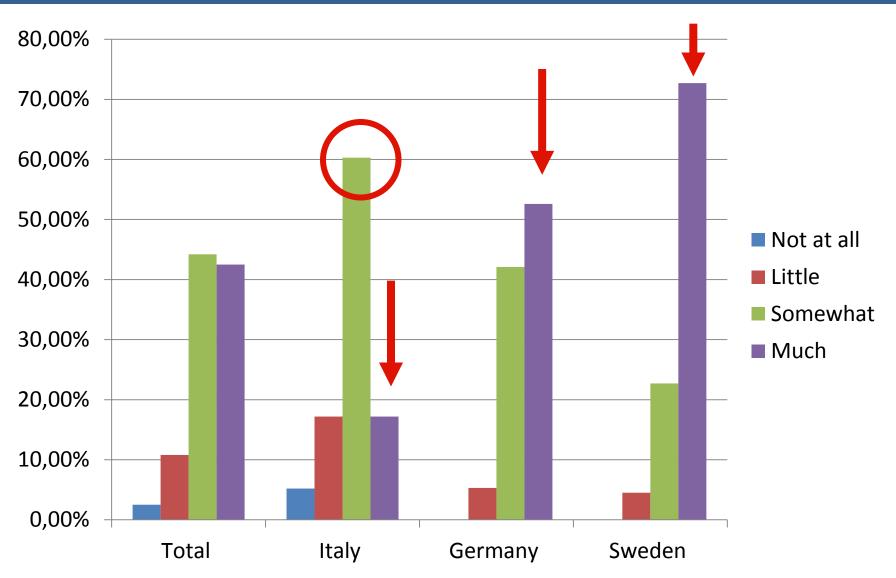
Medium (upper secondary school)

(post-secondary,

secondary

tertiary

Carers' confidence with internet



Usage of the platform

- Average days of visits varied from 5 in Italy to 23 in Germany, and average time spent surfing in the platform from 3 hours in Italy to over 7 hours in Germany and Sweden
- Most users preferred a passive use of services
- Among interactive services, the most successful was the social network, followed by the forum
- Private messages were a major communication channel in Sweden (over 70% of users sent/replied to messages) and used also in Italy and Germany
- Chat and videochat were the least used

Adequateness, usability and barriers

- Carers in all three countries appreciated the adequateness and usefulness of information provided from project staff through the platform
- Some passive users reported that even simply to know they could get any time support via the interactive services of the platform was a positive, reassuring feeling
- Overall scores of global usability were satisfactorily, albeit some Swedish carers were concerned about helpfulness and efficiency of the platform
- This was to a large extent related to **technical problems** during the pilot phase, affecting especially Swedish and Italian users (25% and 20% of cases, respectively)

5. Final remarks

Main achievements of InformCare...

- A set of both common and country-specific support services for carers, available for free via internet in 32 versions, 27 EU countries and 23 languages
- Contents' quality and user-centeredness has been ensured via a systematic involvement of final users and stakeholders through countless contacts (e-mails, skype and phone calls) over 2 years, and a 3-month field phase
- More than 2,500 web pages of contents specifically produced to address informal carers' needs & over 300 web pages for care professionals and employers
- For some countries, this kind of web-based support is available in local/national language for the first time!

InformCare's potential for the future

- Additional versions, countries and languages can be added at any time via Eurocarers
- Adaptation and update of contents in each version can occur according to national/local needs
- Wide choice of what interactive services to provide
- Possibility to become a national information hub for carers, employers and care professionals
- Potential for strengthening a Europe-wide network of stakeholders active and interested in supporting, lobbying and advocating for carers
- A powerful tool to promote the adoption of EU-wide policy measures to better support carers!

Thank you!

