

6th international  
**carers**  
conference

**3-6 september 2015**  
**Gothenburg, Sweden**  
**[www.anhoriga.se](http://www.anhoriga.se)**

**Care and Caring**  
Future proofing the new demographics

**Nka** anhoriga.se

**carersUK**

**ANHÖRIGAS  
RIKSFÖRBUND**



## Nationellt kompetenscentrum anhöriga

The Swedish Family Care Competence Centre (SFCCC) was established in January 2008, commissioned by the National Board of Health and Welfare via the Ministry of Health and Social Affairs to explore and collect existing research and development work in the area of informal (family) care; disseminate research results and examples of best practice, and support development work and knowledge transfer within municipalities, health care sector, business community and civil society organisations. We act as a link between practice, decision-makers, the voluntary sector and research to support evidence based practice, policy and research in the field of carers, care and caring. Our goal is to contribute towards a carer-friendly society, an improved work-life balance and a more effective health and social care for all. We create easily accessible sources of knowledge and engage in knowledge dissemination and consultation, blended learning networks, collaborative projects and international networks. In order to reach out to the entire country, we make use of video-conferencing technology, web-education, online information, use of social media as well as traditional media. The SFCCC is an active member of Eurocarers and the International Association of Caregiver Organisations (IACO).

## Carers UK

Carers UK is the only national membership organisation of carers, bringing together Carers Scotland, Carers Wales and Carers Northern Ireland. As well as our individual members of carers, we also have around 350 local affiliated organisations and hundreds of volunteers supporting our work to make life better for carers. 2015 sees our 50th birthday, celebrating our foundation in 1965 by the Reverend Mary Webster, who had to give up work in order to care for both her parents, despite her own significant health issues. Over those 50 years, we have been campaigning for change for carers, winning many different new rights and entitlements. Research, experience from carers, and strong evidence is at the heart of what we do to demonstrate the need for change and why it is important. Whether we're working in partnership with universities, our colleagues across the globe, with employers or using direct experience from carers, our mission is to make life better for carers. Our core work also includes providing advice and information to carers, reaching around 800,000 carers annually through our website and around 19,000 queries regarding carers from our advice experts. We raise awareness of carers and use the media frequently with around 200 million opportunities to hear about caring. We continue to innovate around solutions which fit better with carers lives and move with the times offering new opportunities to support, help and adviser carers through technology and other means. We work closely with decision-makers, politicians, local and national government employers, service providers, training hundreds of professionals every year to understand how they can support carers better. We are a founder member of Eurocarers, IACO and we are delighted to be co-hosting the 6th international conference on carers.

## Anhörigas Riksförbund

Carers Sweden was formed in 1996 by a local group in Stockholm led by representatives from the Red Cross. It comprises the national umbrella organisation in Sweden for unpaid carers who look after family members, relatives, friends, neighbours or work colleagues. Currently there are over sixty local associations across Sweden. Core activities include an Annual Carer Conference, established in 1999 that attracts over 800 delegates comprising carers, representatives from civil society organisations, practitioners, decision makers and members from the business community. It commonly attracts MPs from the major political parties. Its core work includes advocacy work for carers, lobby work at local, regional and national levels together with committee work in the municipalities, member of governmental reference groups, awareness raising and education and the running of a telephone helpline, newsletter and website. Carers Sweden is a founding partner of the Swedish Family Care Competence Centre and is an active member of Eurocarers, having hosted Eurocarers' AGM and conference in 2008 and 2012.

# Welcome to the 6th International Carers Conference

The world is facing major challenges, with demographic change set to affect societies across the globe. Advances in health care and technology means that we are living longer, and living longer with disability. This is a good news story, but it has an impact. The bulk of care is, and has always been, provided by families, with 75 per cent of all care in Sweden carried out by family, and 80 per cent in Europe. Carers – people who care, unpaid, for a relative friend or neighbour – will be critical in supporting our ageing and disabled population and how we support them needs to be at the heart of public policy and political debate, nationally and internationally. This three day conference will cover key topics in the caring debate, bringing together a distinguished global audience of policy and decision makers, researchers, health and social care professionals, carers organisations and representatives from civil society.

Focusing on four key themes – Health, Social Care and Wellbeing, Combining Work and Care, Paying for Care and Technology Enabled Care and Support – it will hear contributions from over 250 plenary and seminar sessions, opening up a lively and informed debate.

We are honoured that Her Majesty Queen Silvia will formally open the conference, and delighted too that Minister for Children, Older People and Gender Equality Ms Asa Regner will join us as a keynote speaker.

This 6th International Carers Conference is the first to be held in a non-English speaking country, and we are pleased to welcome you to Sweden. We wish you a successful and productive conference!



Lennart Magnusson  
Verksamhetschef, Nationellt  
kompetenscentrum anhöriga



Heléna Herklots  
CEO, Carers UK



Ann-Marie Högberg  
Ordförande,  
Anhörigas Riksförbund





## Thursday 3rd September

- 17.00 Registration and Exhibition Opening  
Informal Networking
- 18.00–19.30 Welcome Reception – Care and Caring

## Friday 4th September

- 08.30–10.00 Registration, Exhibition, Refreshments and Networking

- 10.00–11.15 **F4/F5** Opening Plenary  
(Simultaneous Swedish translation)    
Swedish Government welcome address  
Chair: Professor Elizabeth Hanson, Swedish Family Care  
Competence Centre, Linnaeus University, Sweden  
H.M. Queen Silvia  
Åsa Regnér, Minister for Children, Older People and  
Gender Equality, Government Offices of Sweden  
Baroness Pitkeathley OBE, House of Lords, UK



H.M. Queen Silvia

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Minister Åsa Regnér

Foto: Kristian Pohl/ Regeringskansliet



- 11.15–11.45 Exhibition, Refreshments and Networking

- 11.45–13.15 1. Themed Seminars (delegates should choose one). Page 8

1. Health, Social Care and Well-being (Simultaneous Swedish translation)  
2. Combining Work and Care
3. Paying for Care
4. Technology-Enabled Care and Support
5. Young Carers Symposium

- 13.15–14.15 Buffet Lunch and Exhibition

- 14.15–15.45 2. Themed Seminars (delegates should choose one). Page 12

1. Health, Social Care and Well-being (Simultaneous Swedish translation)  
2. Combining Work and Care
3. Paying for Care
4. Technology-Enabled Care and Support
5. Young Carers Symposium

- 15.45–16.15 Exhibition, Refreshments and Networking

16.15–17.45 Themed Plenaries (delegates should choose one)

**F4/F5**

**P1. Health, Social Care and Well-being** (Simultaneous Swedish translation)



Chair: Gail Gibson Hunt, President & CEO, National Alliance for Caregiving

Steven Zarit, Distinguished Professor, Department of Human Development and Family Studies, Penn State University, USA

Stecy Yghemonos, Director, Eurocarers

Tim Moore, Senior Research Fellow, Institute of Child Protection Studies, Australian Catholic University

Lennarth Johansson, Associate Professor, National Board of Health and Welfare and Aging Research Center (ARC)/Karolinska Institute

**F3**

**P2. Combining Work and Care**

Chair: Nadine Henningsen; President Canadian Caregiver Coalition

Ian Peters, Director, Customer Facing Strategy, Centrica, UK

Ara Cresswell, CEO, Carers Australia

Janet Fast, Professor and Co-Director on Aging Policies and Practice, University of Alberta, Canada

Sue Yeandle, Professor of Sociology, University of Leeds, UK

**F2**

**P3. Paying for Care**

Chair: Liam O'Sullivan, Executive Director, Care Alliance, Ireland

Jules Constantinou, Gen Re Life UK Limited

Aurélie Decker, Director, European Federation for Services to Individuals (EFSI), Belgium

Werner Eichhorst, Director of Labor Policy Europe, IZA Institute for the Study of Labor

Ralf Jacob, Head of Unit, Social Protection and Activation Systems, DG Employment, Social Affairs and Inclusion, European Commission

**F1**

**P4. Technology-Enabled Care and Support**

Chair: Madeleine Starr MBE, Director of Business Development and Innovation, Carers UK

Kathleen Frisbee, Co-Director, Connected Health, US Department of Veterans Affairs, USA

Giovanni Lamura, Head of Centre for Socio-Economic Research on Ageing, National Institute of Health and Science on Ageing, Italy

Susanne Iwarsson, Professor of Gerontology and Care for Older People, University of Lund, Sweden

Paul Thomas, Enterprise Strategist and Architect, Microsoft (STC) Corporation

18.00–19.30



Civic Reception hosted by Gothenburg City





**Göteborgs  
Stad**



## Saturday 5th September

- 8.30–09.30 Registration (for newly arrived attendees), Exhibition and Networking
- 9.30–11.00 **F4/F5** **Opening Plenary** (Simultaneous Swedish translation)    
 Chair: David Grayson CBE, Chair of Carers UK and Professor of Corporate Responsibility at the Cranfield School of Management, UK  
 Video address by the Hon Tony Abbott MP, Prime Minister of Australia  
 Lord Filkin, Chair, Centre for Ageing Better, UK  
 Bruce Bonyhady AM, Chairman, National Disability Insurance Agency, Australia  
 Anil Patil, Founder/Executive Director, Carers Worldwide

- 11.00–11.30 Exhibition, Refreshments and Networking

- 11.30–13.00 **3. Themed Seminars (delegates should choose one). Page 16**    
 1. Health, Social Care and Well-being (Simultaneous Swedish translation)  
 2. Combining Work and Care  
 3. Paying for Care  
 4. Technology-Enabled Care and Support  
 5. Young Carers Symposium

- 13.00–14.00 Buffet Lunch and Exhibition

- 14.00–15.30 **4. Themed Seminars (delegates should choose one). Page 20**  
 1. Health, Social Care and Well-being (Simultaneous Swedish translation)  
 2. Combining Work and Care  
 3. Paying for Care  
 4. Technology-Enabled Care and Support  
 5. Young Carers Symposium

- 15.30–16.00 Exhibition, Refreshments and Networking

- 16.00–17.30 **F4/F5** **Themed Plenaries (delegates should choose one)**    
**P5. Health, Social Care and Well-being** (Simultaneous Swedish translation)  
 Chair: Rick Greene, International Alliance of Carer Organizations  
 Mike Nolan, Professor of Gerontological Nursing, University of Sheffield, UK  
 Inger Ekman, Professor of Nursing, Sahlgrenska University Hospital, Gothenburg  
 Dame Philippa Russell DBE, Chari Emeritus, Standing Commission on Carers, UK  
 John Dunne, President, Eurocarers
- F3** **P6. Combining Work and Care**  
 Chair: Ara Cresswell, CEO, Carers Australia  
 Robert Anderson, Head of Unit, Living Conditions and Quality of Life, European Foundation for the Improvement of Living and Working Conditions (Eurofound)  
 Katherine Wilson, Strategic Manager, Employers for Carers, UK  
 Elizabeth Hanson, Professor of Health Care Sciences, Linnaeus University and Swedish Family Care Competence Centre, Sweden  
 Shingou Ikeda, Vice-Senior Researcher, Japan Institute of Labour Policy and Training

The exhibition will be open to the public on this day



**F2**

## P7. Paying for Care

Chair: Sue Yeandle, Professor of Sociology, University of Leeds, UK  
Lars Sandman, Professor of Caring Ethics, University of Borås, Sweden  
Allen Hager, Executive Chairman, Right at Home USA  
Dawid Konotey-Ahulu, Co-Chief Executive, Redington Ltd, UK  
Lennart Magnusson, Swedish Family Care Competence Centre, Sweden

**F1**

## P8. Technology-Enabled Care and Support

Chair: Helena Herklots, Chief Executive, Carers UK  
Karin Lind-Mörnsten, CEO, Swedish Care International  
Madeleine Starr MBE, Director of Business Development and Innovation, Carers UK  
Josep Roca, Professor of Medicine, University of Barcelona, Spain  
Gail Gibson Hunt, President & CEO, National Alliance for Caregiving, USA

17.30–19.00 Exhibition and Networking

19.00 Conference Dinner

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## Sunday 6th September

08.15–09.00 Registration (for newly arrived attendees), Exhibition, Refreshments and Networking

9.00–10.30 5. Themed Seminars (delegates should choose one). Page 23

1. Health, Social Care and Well-being (Simultaneous Swedish translation)
2. Combining Work and Care
3. Paying for Care
4. Technology-Enabled Care and Support
5. Young Carers Symposium



10.30–11.00 Exhibition, Refreshments and Networking

11.00–12.30 Closing Plenary (Simultaneous Swedish translation)



**F4/F5**

Chair: Lennart Magnusson, Director, Swedish Family Care Competence Centre and Associate Professor, Linnaeus University

Heléna Herklots, Chief Executive, Carers UK

Dr Susan C. Reinhard, AARP Public Policy Institute, USA

Dr Alexandre Kalache, Co-President, International Longevity Centre (ILC) Global Alliance; President, ILC Brazil

*Concluding comments:*

Gail Gibson Hunt, Secretariat for IACO and President and CEO, National Alliance for Caregiving, USA

John Dunne, President, Eurocarers and Chief Executive, The Carers Association, Ireland

12.30 Lunch and Networking

13.20 Exhibition closes

# Themed Seminars – Friday 4th september

## 11.45–13.15

*(delegates should choose one)*

### 1.1 Health, Social Care and Wellbeing

#### **R13** 1.1 Health, Social Care and Wellbeing

Chair: Ann-Kristin Ölund, Swedish Family Care Competence Centre

Aileen Bergström, Swedish Family Care Competence Centre, Karolinska Institute, Sweden and Gunilla Eriksson, Karolinska Institute: Participation in everyday life and life satisfaction in the stroke-caregiver dyad

Eva Månsson Lexell, Department of Health Sciences, Lund University, Sweden and Elizabeth Hanson, Swedish Family Care Competence Centre: Interventions for stroke family caregivers - a systematic review of the literature

Nan Greenwood, Faculty of Health, Social Care and Education, St George's University of London and Kingston University, UK: The human dimensions of post-stroke home care: Experiences of older carers from diverse ethnic groups in the United Kingdom

Josefine Persson, Institute of Neuroscience and Physiology, the Sahlgrenska Academy, University of Gothenburg, Sweden: Quantity of support given by spouses to stroke survivors and consequences on HRQoL in the long term perspective

#### **R11/12** 1.1.2 Health, Social Care and Wellbeing

Chair: Gunilla Lindqvist, Swedish Family Care Competence Centre

Yue Wang, School of Nursing, Tianjin Medical University, Tianjin, China and Mike Nolan, University of Sheffield, UK: Working with family carers following acute stroke in China: 'Hiding' as a barrier to partnerships between older people, family carers and professionals

Tamar Abzhandadze and Gunilla Forsberg-Wärleby, Institute of Neuroscience and Physiology, the Sahlgrenska Academy, Gothenburg/ Department of Occupational Therapy, Sahlgrenska University Hospital, Gothenburg, Sweden: Life satisfaction in spouses of stroke patients before the age of 70, seven years after the stroke.

Eva Joanna Alexjuk, University of Edinburgh, Scotland: The Journey from Dementia Diagnosis to Final Bereavement: An exploration of anticipatory grief, loss and bereavement experienced by carers of people with dementia

Susanna Ågren and Bodil Ivarsson, Thorax Vascular Clinic, Linköping University Hospital, Sweden: Psycho-social impact in family members before and up to two years after heart or lung transplantation

#### **R22/23** 1.1.3 Health, Social Care and Wellbeing

Chair: Madeleine Starr MBE, Carers UK

Tim Anfilogoff and David Evans, Herts Valleys Clinical Commissioning Group (NHS), UK: Opening the can of worms: why putting carers at the centre of the public health and integration agendas is critical to the sustainability of the health and social care system, with examples from Hertfordshire's carers' strategy

K.R. Gangadharan, Heritage Eldercare Services, Hyderabad, India: Are Caregivers burdened? Recognize, respect and address their needs

Beate Bestmann and Frank Verheyen, Techniker Krankenkasse, Germany: Home Care in Germany – Between Strain and Strength

Beth Dahlrup, Skånes University Hospital, Region Skåne and the Dept. of Health Sciences, University of Lund, Sweden: Coping as a family caregiver: A question of strain and its consequences on life satisfaction and health-related quality of life



# Themed Seminars – Friday 4th september

11.45–13.15

*(delegates should choose one)*

## **R24/25** 1.1.4 Health, Social Care and Wellbeing

Chair: Rick Greene, National Alliance for Caregiving USA

Leah Mc Laughlin, Centre for Applied Research in Inclusive Arts and Design, CARIAD, Cardiff Metropolitan University, Wales, UK: Breaking Bread: Share, Cook, Eat, Learn, a new intergenerational service connecting marginalising communities

Gavin McGregor: Social action: using volunteer networks to build carer friendly communities

Lena Tynnmek and Charlotta Karlsdotter, Swedish Red Cross: Red Cross volunteer support for family carers

Sven Turnhout and Frans Zoest, Vilans, Netherlands: Do it ourselves. How Dutch citizens take the initiative to arrange social care and well-being activities locally

## **F4/F5** 1.1.5 Health, Social Care and Wellbeing

Chair: Anil Patil, Founder and Executive Director of Carers Worldwide

Stecy Yghemonos and Elizabeth Hanson, Eurocarers: Eurocarers: carer organisations and research organisations working together to ensure evidence-based policy making at EU level

Emily Holzhausen OBE, Carers UK: the growth and impact of awareness weeks and days

Liam O'Sullivan, Care Alliance Ireland: 10 years of National Carers Week in Ireland - A reflection

Jen Kenward, NHS England, UK: NHS England's Commitment to Carers

## **R15** 1.1.6 Hälsa, omsorg och välbefinnande

Moderator: Birgitta Olofsson, Nationellt kompetenscentrum anhöriga

Anhörigstöd i utveckling. Gunilla Karlsson och Britt Eriksson, anhörigkonsulenter Norrköpings kommun

Har du förlorat någon som tagit sitt liv? Det finns en anhörig/efterlevande grupp för dig. Maria Schnelzer, anhörigkonsulent, Karlstad kommun och Kathy Blomqvist, diakon, Svenska kyrkan

Anhörigas delaktighet vid mötet för samordnad vårdplanering. Elisabeth Schwind Johansson, anhörigkonsulent Lunds kommun



## **R31** 1.1.7 Hälsa, omsorg och välbefinnande

Moderator: Mats Ewertzon, Nationellt kompetenscentrum anhöriga

Hälsorelaterad livskvalitet hos mammor och pappor till vuxet barn med långvarig psykisk sjukdom. Anita Johansson, Klinisk lektor, Skaraborgs sjukhus

Anhöriga till vuxna personer med psykisk ohälsa: En kunskapsöversikt om betydelsen av stöd.

Mats Ewertzon, möjliggörare/forskare Nka lektor Ersta Sköndal högskola

Hur mår anhöriga till personer med psykisk ohälsa/funktionsnedsättning?

Ingrid Lindholm, projektledare Nationell Samverkan för Psykisk Hälsa och Ulla Elfving Ekström, vice förbundsordförande Schizofreniförbundet

Så här kan kontakterna med anhöriga utvecklas inom psykiatrin. Ann-Kristin Sandberg, Samordnare, Nationell Samverkan för Psykisk Hälsa



# Themed Seminars – Friday 4th september

## 11.45–13.15

*(delegates should choose one)*

### 1.2. Combining Work and Care

**F3**

#### 1.2 Combining Work and Care

Chair: Robert Anderson, European Foundation for the Improvement of Living and Working Conditions (Eurofound)

Paul Coates, Carers Western Australia: An understanding boss and workmates: The key to balancing work and caring responsibilities

Paul O'Mahoney and Diarmaid O'Sullivan, The Carers Association, Ireland: Entitlements Facilitating Carer's Work-Life Balance in Ireland: Progress and Problems

Ann-Britt Sand, Swedish Family Care Competence Centre and Stockholm University, Sweden: How to combine caring responsibilities and gainful employment in Sweden: A population based study of middle age family caregivers

Alison Jarvis, NHS Lothian, Scotland: Juggling responsibilities: supporting staff to keep all the balls in the air

**R21**

#### 1.2.2 Combining Work and Care

Chair: Dame Philippa Russell DBE, Chair Emeritus, Standing Commission on Carers, UK

Victoria Wass and Melanie Jones, Cardiff Business School, Wales: Informal Carers at Work: Workplace-related Factors Associated with their Employment and Perceived Wellbeing

Tracey-Lee Dalton, University of Auckland, New Zealand: New Zealand perspective of combining work and care.

Shingou Ikeda, The Japan Institute for Labour Policy and Training: Carer Fatigue and Work: A Hidden Problem for Companies in Japan

Katherine Wilson, Carers UK: The value of workplace carer networks

### 1.3. Paying for care

**F2**

#### 1.3.1 Paying for Care

Chair: Chloe Wright, Carers UK

Natalia Marska-Dzioba, University of Szczecin, Poland: Contracting Involvement: The Impact of Care Commodification on Long-Term Care Policy in Poland

Nan Joo Yang, Department of Social Welfare, Daegu University, South Korea: The new form of 'routed wages': family care workers in Korean long term care

Jo Moriarty, Research Fellow, King's College London, UK: Working with carers - 90 per cent job satisfaction; zero per cent job security

### 1.4. Technology-Enabled Care and Support

**F1**

#### 1.4 Technology-Enabled Care and Support

Chair: Stefan Andersson, Swedish Family Care Competence Centre

Carol E. Smith, University of Kansas School of Nursing, USA: Family Caregivers Evaluation of Nurse Caring via Internet and iPad

Licia Boccaletti, Anziani e Non Solo Societa Cooperativa, Italy: Textiles for an Ageing Society (TAGS) Project

Cathrine Gamble and Jacqueline Sin, South West London & St George's Mental Health NHS Trust, UK: E-Sibling Project: Internet-based information and support for siblings of people with psychosis

Martha Mackay, ACCEPLAN, Spain: Care Respite

# Themed Seminars – Friday 4th september

## 11.45–13.15

*(delegates should choose one)*

**R26**

### 1.4.2 Teknik, vård och omsorg.

Moderator: Lena Gustavsson, Nationellt kompetenscentrum anhöriga

IKT-teknik, äldre och anhöriga - till nytta eller "onytta"? Ann-Christine Larsson, projektledare testmiljö, Norrköpings kommun

Kommunsamverkan kring ny teknik gör det möjligt för fler anhöriga att få stöd och kontakt med andra anhöriga. Annika Nilsson Lill, anhörig, Marlène Lund Kopparklint, Kommunalråd (M), Ordförande Vård- och Omsorgsnämnden i Karlstads kommun och Christina Pamies Jensen, Enhetschef förebyggande arbete vid Vård- och Omsorgsförvaltningen i Helsingborg

Användarna är nyckelspelarna när kommunen inför välfärdsteknologi. Maria Gill, Myndigheten för delaktighet och Mats Rundkvist, Västerås stad

Social media som verktyg för att nå ut till "de osynliga barnen". Olivia Trygg, generalsekreterare Trygga barnen och Carolina Björkman, handläggare Sveriges Kommuner och Landsting



## 1.5. Young Carers Symposium

**R14**

### 1.5 Young Carers Symposium

Chair: Ulrika Järkestig Berggren, Swedish Family Care Competence Centre and Linnaeus University

Ylva Nilsagard, Centre for Health Care Services and Katrin Boström, Healthcare Strategy, Department of Health and Medical Services, Region Örebro County, Sweden: Informing the children when Mum or Dad is diagnosed as having multiple sclerosis

Rosemary Warmington AM, Carers Association of South Australia: Study, work and care – the conflicting views and demands on young carers in Australia and future models of care

Daniel Phelps, Carers Trust: Protecting the health, wellbeing and life chances of young carers through a whole school approach

Feylyn Lewis, University of Birmingham: From Child to Adult Carer: Identities and Transitions

**R3**

### 1.5.2 Barn som anhöriga

Moderator: Eva Nordqvist, Nationellt kompetenscentrum anhöriga

Frågar man inget – får man inget veta. Therese Eriksson, utvecklingschef och Lisa Dahlgren, projektledare barnrättsfrågor, Maskrosbarn

Systematisk uppföljning. Pauline Johansson, Nationellt kompetenscentrum anhöriga och Linnéuniversitetet

Barn som anhöriga – Ett samverkansarbete med systematisk uppföljning. Christina Ramnfors, Västra Götalandsregionen, Malin Elbing, Uddevalla kommun och Kajsa Svanevi, Nationellt kompetenscentrum anhöriga och Linnéuniversitetet

Kan virtuella patienter hjälpa oss att förbättra anhörigomsorg? Solveig Ekblad och Charlotte Oja, Karolinska institutet



# Themed Seminars – Friday 4th september

## 14.15–15.45

*(delegates should choose one)*

### 2.1. Health, Social Care and Wellbeing

#### **R11/12** 2.1 Health, Social Care and Wellbeing

Chair: Liam O’Sullivan Care Alliance, Ireland

Ann-Marie Högberg, Carers Sweden: Carers Sweden: a voice and resource for carers in Sweden

Grace Whiting, Director of Strategic Partnerships, National Alliance for Caregiving USA: From Caring to Carer Advocate: How to Start and Sustain a Carer Organization

Catherine Suridjan and Nadine Henningsen, Canadian Caregiver Coalition: Canadian Caregiver Coalition: Championing the well-being of family caregivers in Canada

Alisoun Milne, University of Kent, UK: Knowledge generation about care-giving in the UK: a critical review of research paradigms

#### **R13** 2.1.2 Health, Social Care and Wellbeing

Chair: Mats Ewertzon, Swedish Family Care Competence Centre

Susanna Ågren and Bodil Ivarsson, Thorax Vascular Clinic, Linköping University Hospital, Sweden: The Unsteady Mainstay of the Family: Adult Children’s Retrospective View on Social Support in Relation to Their Parent’s Heart Transplantation

Catherine Gamble and Jacqueline Sin, South West London & St George’s Mental Health NHS Trust, UK: A whole-system recovery programme for families of people with mental illness - evaluating its impact on family members’ caregiving experience

Nan Greenwood, Faculty of Health, Social Care and Education, St George’s University of London and Kingston University, UK: Experiences of health and social care services amongst older Black and minority ethnic and White British carers of stroke survivors in the United Kingdom: focus group findings

#### **R15** 2.1.3 Health, Social Care and Wellbeing

Chair: Frida Andreasson, Swedish Family Care Competence Centre

Herawati Nowak and Malin Broberg, Department of Psychology, Gothenburg University, Sweden: Do children with disability and their parents participate in planning, decision-making, and evaluation of support?

Zoe Hughes, Care Alliance Ireland: Whose life is it anyway? The challenges of advocating for both people with intellectual disability and their family carers.

Anna Karin Axelsson, Jönköping University, Sweden: The Role of External Personal Assistants for Children with Profound Intellectual and Multiple Disabilities Working in Children’s Homes

Lisbeth Nilsson, Swedish Family Care Competence Centre: Children and youth with multiple and complex disabilities: A review of resources that provide opportunities for activity and participation

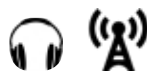
# Themed Seminars – Friday 4th september

## 14.15–15.45

*(delegates should choose one)*

**F4/F5**

### 2.1.4 Health, Social Care and Wellbeing



Chair: Pauline Johansson, Swedish Family Care Competence Centre

Maja Holm, Karolinska Institute, Sweden: Delivering and participating in a psycho-educational intervention: perspectives of health professionals and family caregivers

Kate Hall, Nutricia Advanced Medical Nutrition and Emily Holzhausen OBE, Carers UK: Food for thought and for action: Caring and nutrition

Ingrid Hellström and Jonas Sandberg, Ersta Sköndal University College and Swedish Family Care Competence Centre, Sweden: Support for palliative family carers: a review

Jonas Sandberg, University of Jönköping, Sweden: Chores and sense of self: Gendered understandings of voices of older married women with dementia

**R22/23**

### 2.1.5 Hälsa, omsorg och välbefinnande

Moderator: Lena Gustavsson, Nationellt kompetenscentrum anhöriga

Brukare- patient- och närståendemedverkan - strategi och länsgemensam modell.

Anna Olheden, utvecklingsstrateg, Kalmar läns landsting

Samverkan kring anhörigstöd - från akuten till hemmet. Pernilla Eidenberg, processledare anhörigstöd, Danderyds sjukhus och Catharine Berglund, Danderyds kommun

Patient och närståendebildning enligt Akermodellen. Margareta Tauberman, samordnare patient- och närståendebildningen, Centralsjukhuset Karlstad

Ett lyckat ledarskap i äldreomsorgen en trygghet för de anhöriga. Kerstin Wennberg och Lotta Henriksson, universitetsadjunkter Stockholms universitet



**R31**

### 2.1.6 Systematisk uppföljning och utvärdering. WORKSHOP

Målgrupp: Anhörigkonsulenter och motsvarande yrkesgrupper

Marianne Winqvist, möjliggörare/forskare och Jan-Olof Svensson, möjliggörare/praktiker, Nka



## 2.2. Combining Work and Care

**F3**

### 2.2. Combining Work and Care

Chair: Professor David Grayson CBE, Carers UK

Helen McFarlane, New South Wales Department of Family & Community Services, Australia: The NSW Carers Strategy: co-design with carers

Rachel Ledany, Caregivers Israel and Achinoam Ben Akiva-Maliniak, ESHEL-JDC ISRAEL: A Mapping Tool (Survey) as a Way to construct Organizational Policy toward Family Caregivers

Maria Wolmesjö, Linköping University, Sweden: The “mixed or blended caregiving situation” – How to support family caregivers with different ethnic backgrounds in Sweden

Beth Zikronah Rosen, The World Bank: The Role of Informal Childcare and Eldercare in Aging Societies in Eastern Europe and Central Asia

# Themed Seminars – Friday 4th september

## 14.15–15.45

*(delegates should choose one)*

### 2.3. Paying for Care

**F2**

#### 2.3. Paying for Care

Chair: Chloe Wright, Carers UK

Diarmaid O’Sullivan, The Carers Association, Ireland: The Nursing Homes Support Scheme Act in Ireland: Responding to Challenges

Rik Smet and Renate Barbaix, University of Antwerp, Belgium: Legal and fiscal aspects of intra-family care

Anne Corden, Social Policy Research Unit, University of York, UK: Economic implications for bereaved carers: the unacknowledged costs of care

### 2.4. Technology-Enabled Care and Support

**F1**

#### 2.4. Technology-Enabled Care and Support

Chair: Gail Gibson Hunt, National Alliance for Caregiving, USA

Allen Hager, Right at Home, USA: Technology Supporting Carers in the Home

Stefan Andersson, Linnaeus University/Swedish Family Care Competence Centre (Nka), Sweden): The use of web-based support services to support working carers of older family members

Sue Yeandle, University of Leeds, UK: Technological support in everyday life for frail older people and their caring networks

Janet Fast, Research on Aging, Policies and Practice, University of Alberta, Canada: Assistive Technology that Cares for the Caregiver

#### **R24/25** 2.4.2 Technology-Enabled Care and Support

Chair: Gavin MacGregor, Carers UK

Sofi Fristedt, School of Health Sciences, Jönköping University and Karl G. Rosen Neoventor AB, Sweden: Landräddningen- structuring human support and volunteers the app way

Cornelia Schneider, Salzburg Research Forschungsgesellschaft mbH, and Birgit Trukeschitz, Senior Researcher, WU Vienna University of Economics and Business, Research Institute for Economics of Aging, Austria: “Let users have their say” - experiences of user involvement from the AAL Pilot Region Salzburg, Austria

Mats Rundkvist, City of Vasteras and Maria Gill, Swedish Agency for Participation, Sweden: Users are the key players when a municipality implements welfare technologies

Madeleine Starr MBE, Carers UK: Engaging carers in technology: from perception to product



# Themed Seminars – Friday 4th september

## 14.15–15.45

*(delegates should choose one)*

### 2.5. Young Carers Symposium

#### **R14** 2.5. Young Carers Symposium

Chair: Elizabeth Hanson, Swedish Family Care Competence Centre and Linnaeus University

Ulrika Järketstig Berggren and Elizabeth Hanson, Swedish Family Care Competence Centre/

Linnaeus University, Sweden: Support for children, and their families when a parent is seriously ill

Susanne Knutsson, School of Health Sciences, Jonkoping University, Sweden: Health care professionals' approaches to children as next of kin to a sick parent

Ann-Sofie Bergman and Elizabeth Hanson, Swedish Family Care Competence Centre and Linnaeus University, Sweden: Bereavement for children when a parent dies

Lisa Dahlgren and Therese Eriksson, Maskrosbarn (Dandelion Children), Sweden: If you don't ask – you won't know

#### **R21** 2.5.2 Barn som anhöriga

Moderator: Christoffer Eliasson, Nationellt kompetenscentrum anhöriga

Kartläggning av unga omsorgsgivare i Sverige. Monica Nordenfors, lektor och Charlotte Melander, lektor, Göteborgs universitet

Trygga och förebygga – barnets rätt som närstående i palliativ vård. En process som gått från lärande till praktiskt vardagsarbete. Monica Gustafsson-Wallin, strateg för barnrättsfrågor och Jennie Nimborg, projektledare, Landstinget i Sörmlands län

Att betrakta barnen som anhöriga inom socialtjänsten – Exemplet kontaktfamilj. Lotta Berg Eklundh, forskare, FoU Nordost



#### **R26** 2.5.3 Barn Som anhöriga. WORKSHOP

Linda Frank, möjliggörare/praktiker och Eva Nordqvist, möjliggörare/praktiker, Nka



# Themed Seminars – Saturday 5th september

## 11.30–13.00

*(delegates should choose one)*

### 3.1. Health, Social Care and Wellbeing

**F4/F5**

#### 3.1 Health, Social Care and Wellbeing

Chair: Eva Gustafson, Swedish Family Care Competence Centre

Valentina Hlebec, Faculty of Health Sciences, University of Ljubljana, Andrej Szakar and Boris Majecin, Institute for Economic Research, Slovenia: Care arrangements for older people in Eastern European Countries

Aviad Tur-Sinai, Ph.D and Max Stern Yezreel Valley College, Israel; Israel Gerontological Data Center, The Hebrew University of Jerusalem, Israel: Social Companionship and Isolation among Old-Age People in European Countries

Mai Yamaguchi, Japan Lutheran College, Japan: Supporting Carers in the super-aged Japanese society: Marginalized agenda in the long-term care system

Deborah Cristina de Olivera, School of Health Sciences, University of Nottingham, UK: Who is the carer and who needs care? The impact of the caring role on older family carers

**R11/12**

#### 3.1.2 Health, Social Care and Wellbeing

Chair: Aileen Bergström, Swedish Family Care Competence Centre

Maria João Bárrios and Ana Alexandre Fernandes, ISCSP-Universidade de Lisboa; CICS.NOVA-FCSH/Universidade Nova de Lisboa; FCT Fundacao para a Ciencia e a Tecnologia, Portugal: Building a Model for Aging Local Policies Analysis According to Active Aging Perspective

Veerle Baert, Association for Flemish cities and municipalities (VVSG), Belgium: The Flemish dementia-meter: a way to assess Flemish communities for being dementia-friendly

Jane McKeown, Sheffield Health and Social Care NHS Foundation Trust, UK and Jo Cook, NIHR, CLAHRC, Yorkshire and Humber, UK: Person-centred care: The perspectives of family carers of people living with dementia in the UK

Åsa Sandvide, Swedish Family Care Competence Centre, Linnaeus University, Department of Health and Caring Sciences, Sweden: Experiences of Advanced Dementia and Family Caring: an integrative literature review within the Erasmus funded PALLIARE project

**R22/23**

#### 3.1.3 Health, Social Care and Wellbeing

Chair: Tim Anfilogoff, Herts Valleys Clinical Commissioning Group, UK

Deborah McKay, United States Navy (retired), Veterans National Caregiver Training Program, USA: Heroes on the Homefront: Serving and Supporting United States Military & Veteran Caregivers

Cecilia Wong-Cornall, University of Auckland, New Zealand: Applying Cultural Familial Beliefs to Understand the Informal Family Caregiving Experiences of Maori and Chinese Carers in New Zealand

Elena Katrakis, Carers New South Wales, Australia: Carers who need care

Gerdt Sundström, Institute of Gerontology, School of Health Sciences, Jönköping, Sweden: Demographic change: not always for the worse: Partner carers in Spain and Sweden

# Themed Seminars – Saturday 5th september

11.30–13.00

*(delegates should choose one)*

## **R24/25** 3.1.4 Health, Social Care and Wellbeing

Chair: Grace Whiting, National Alliance for Caregiving, USA

Ara Cresswell, Carers Australia: Demographic pressures on the supply of family and friend carers in Australia: turning challenges into opportunities

Jolanda Elferink, Movisie, Netherlands: Decentralisation and transformation in the social domain in the Netherlands: an overview of current developments and opportunities for the future in the Dutch informal help and care sector

Jed Johnson, Easter Seals, USA: Many Faces of Caregiving: Millennials and Generation X – Current and Future Caregivers

Emily Holzhausen OBE, Carers UK: Carers and Equalities - taking a diverse approach

## **R31** 3.1.5 Health, Social Care and Wellbeing

Chair: Stefan Andersson, Swedish Family Care Competence Centre

Martina Summer Meranius and Karin Josefsson, Mälardalen University, Sweden: Health and social care management of older people with multimorbidity: a holistic approach

Klara Lorenz, London School of Economics and Political Science, UK: The growing importance of unpaid carers aged 65 and above : a literature review

Linda Högsnes, Mid-university Östersund and Christina Melin-Johansson, Mid-university Östersund/Sahlgrenska academy, Gothenburg, Sweden: The existential life situation of spouses and adult children to persons with dementia

Kim Grosvenor, Elizabeth Gill and Emma Costello, High Weald Lewes Havens Clinical Commissioning Group, UK: The Dementia 'Golden Ticket': An Emerging New Model of Care

## **R13** 3.1.6 Hälsa, omsorg och välbefinnande

Moderator: Ritva Gough, Nationellt kompetenscentrum anhöriga

Hälsofrämjande hembesök – ett sätt att utveckla anhörigstödet i Jönköpings kommun.

Marie Ernst Bravell, lektor, Institutet för gerontologi och äldrestrateg, Jönköpings kommun och Eva Telander, anhörigkonsulent, Jönköpings kommun

Frivilliga – en resurs inom anhörigstöd! Lena Tynnemark och Charlotta Karlsdotter, Nationella rådgivare Sociala verksamheter, Röda korset

Anhörigstöd från kartläggning till utveckling och implementering i samverkan med anhöriga.

Anna Koskinen, anhörigsamordnare Nybro kommun och Raija Heiding, anhörigombud, Kalmar kommun

Anhörigdialog som underlag till förbättring av anhörigstödet. Gunilla Johansson, Äldre- och omsorgsnämndens ordförande och Sara Rahm Pernold, Kvalitets- och utvecklingsstrateg, Sigtuna kommun



## **R15** 3.1.7 Release av Webbutbildning om anhörigfrågor. Workshop

Gunilla Matheny, anhörigpedagog och Paul Svensson, projektledare, Nka



# Themed Seminars – Saturday 5th september

## 11.30–13.00

*(delegates should choose one)*

### 3.2. Combining Work and Care

**F3**

#### 3.2 Combining Work and Care

Chair: Katherine Wilson, Carers UK

Mary Chiu Ph.D and Virginia Wesson, The Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training; Mount Sinai Hospital, Toronto, Canada: An evidence-based group psychotherapy program for informal dementia caregivers who are concurrently employed in the Canadian workforce

Marie Lilja Jensen, Dane Age, Ældre Sagen, Denmark: The challenge of combining work and care for grown up children of frail elderly people in the Danish welfare state

Ann-Britt Sand, Swedish Family Care Competence Centre and Stockholm University and Els-Marie Anbäcken, Ph.D/senior lecturer, Mälardalens University, Sweden: An international comparative study of Japan and Sweden: different perspectives but similar consequences

Jacquie Eales and Janet Fast, University of Alberta, Canada: At the Intersection of Work and Care: Conversations with Caregivers and Employers

**R3**

#### 3.2.2 Combining Work and Care

Chair: Sue McLintock, Carers Scotland

Fiona Carmichael and Marco Ercolani, University of Birmingham, UK: Caring and employment over time: Different pathways, divergent outcomes and the role of social attitudes

Herawati Nowak and Mikaela Starke, Department of Psychology, Gothenburg University, Sweden: Trapped in transition from youth into adulthood: An issue of impairment, insufficient support, or lack of possibilities?

Agnes Leu, Careum Research / Kalaidos University of Applied Sciences, Department of Health Sciences, Switzerland: Employing family caregivers in home care agencies: Fostering an innovative model or blurring boundaries?

### 3.3. Paying for Care

**F2**

#### 3.3 Paying for Care

Chair: Chloe Wright, Carers UK

Frederik Swennen, University of Antwerp, Belgium: The Care Shift from State to Families: the case of the Low Countries

Jean Gieste, Carers ACT, Australia: Australia's National Disability Insurance Scheme: the Impact on Informal Care

Diana Nevzorova and Elizaveta Bakunina, Hospice No.1, Moscow, Russia: Economic aspects of running a hospice under conditions of financial instability

# Themed Seminars – Saturday 5th september

## 11.30–13.00

*(delegates should choose one)*

### 3.4. Technology-Enabled Care and Support

**R21**

#### 3.4 Technology-Enabled Care and Support

Chair: Frida Andreasson, Swedish Family Care Competence Centre

Madeleine Blusi, Research and Development Centre, Västernorrland, Sweden: Technology-based support services beneficial for family carers in rural areas

Gavin McGregor, Carers UK: Online forum and Connect: breaking isolation

Sharon Tentye, Carers NT, Australia: Working collaboratively in remote Australia

**F1**

#### 3.4.2 Technology-Enabled Care and Support

Chair: Elizabeth Hanson, Swedish Family Care Competence Centre

Madeleine Starr MBE, Carers UK: The Jointly app: using smart technologies to support 'circles of care'

Olivia Trygg, Trygga Barnen Foundation (Safe Children) and Carolina Björkman, Swedish Association of Local Authorities and Regions, Sweden: Using social media to reach out to 'invisible children'

Lilas Ali, Gothenburg University, Sweden: Web-based support intervention for young informal carers of people with mental illness

### 3.5. Young Carers Symposium

**R14**

#### 3.5 Young Carers Symposium

Chair: Ann-Sofie Bergman, Swedish Family Care Competence Centre and Linnaeus University

Linda Frank, Swedish Family Care Competence Centre, Sweden: Supporting children in families with illness, abuse or unexpected death - to take advantage of local activities in a nationwide improvement programme

Elisabet Näsman and Karin Alexanderson, Department of Sociology, Uppsala University, Sweden: Everyday life when a parent has addiction problems

Kristin Humerfelt, Associate Professor, University of Stavanger, Norway: From inability to ability to act: Identifying care conditions of parents with mental and/or drug/alcohol-related problems

**R26**

#### 3.5.2 Barn som anhöriga

Moderator: Eva Nordqvist, Nationellt kompetenscentrum anhöriga

Hälsoekonomisk studie av barn och vuxna med fetalt alkoholsyndrom (FAS). Lisa Ericson och Lennart Magnusson, Nationellt kompetenscentrum anhöriga och Linnéuniversitetet

Barn som anhöriga en hälsoekonomisk studie av samhällets långsiktiga kostnader. Bo Hovstadius, Nationellt kompetenscentrum anhöriga och Linnéuniversitetet

Att betrakta barnen som anhöriga inom socialtjänsten – Exemplet kontaktfamilj. Lotta Berg Eklundh, FoU Nordost

Childrens Program – en presentation av en preventionsmetod för barn i missbruksfamiljer med fokus på mindre barn och deras föräldrar. Lars Lewerth and Helen Olsson, Childrens Program Sverige, Hela Människan, Uppsala län



# Themed Seminars – Saturday 5th september

## 14.00–15.30

*(delegates should choose one)*

### 4.1. Health, Social Care and Wellbeing

#### **R11/12** 4.1 Health, Social Care and Wellbeing

Chair: Emily Holzhausen OBE, Carers UK

Daniel Molinuevo, European Foundation for the Improvement of Living and Working Conditions, Ireland: Workforce recruitment and retention initiatives in Europe

Steffen Zoller, Care.com Europe GmbH, Germany: Meeting the Needs of Migrating Nurses to Secure Constant High-quality Support of The German Care Sector

Chen-Fen Chen, Chinese Culture University, and Yuan Hui-Wen, Associate Professor, Chairperson, Chinese Culture University, Taiwan Association of Family Caregivers: Management or Exploitation? The Survival Strategy of Employers of Family Foreign Care Workers

Thomas Edes, US Department of Veterans Affairs, USA: Medical Foster Home: Where Heroes Meet Angels

#### **R13** 4.1.2 Health, Social Care and Wellbeing

Chair: Pauline Johansson, Swedish Family Care Competence Centre

Mats Ewertzon and Elisabeth Winnberg, Ersta Sköndal University College and Swedish Family Care Competence Centre: Family members' experiences of the healthcare professionals' approach and feeling of alienation in different health care areas: a methodological and empirical study

Aino Homann Nielsen and Anne Kofod, Capital Region of Copenhagen, Denmark: A palette for palliation - Competency of basic staff in hospital, municipality and general practice

Karen Watchman and Debbie Tolson, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland, UK: Palliare: equipping the registered dementia workforce to support advanced dementia care and family caring

John Pender, Institute of Technology, Sligo, Ireland: Futuring social care practice teaching and learning: the insights and experiences of final year honours degree undergraduates

#### **F4/F5**

#### 4.1.3 Health, Social Care and Wellbeing

Chair: Bo Hovstadius, Swedish Family Care Competence Centre

Stacey Rand, Juliette Malley, Julien Forder and Ann Netten, Personal Social Services Research Unit (PSSRU), University of Kent, UK: Measuring carers' quality of life outcomes

Margareta Adolfsson, Swedish Family Care Competence Centre and CHILD, School of Education and Communication, Jönköping University, Sweden: WHO health classification ICF- see why it is a treat

Emma Miller, University of Strathclyde, Scotland: Understanding and evidencing what matters to carers: focusing on personal outcomes

Anne Vibeke Jacobsen, Statistics Denmark: Register-based Study of Citizens living in Nursing Homes

#### **R22/23** 4.1.4 Health, Social Care and Wellbeing

Chair: Jenny Wilder, Swedish Family Care Competence Centre

Liz Lloyd and Randall Smith, School for Policy Studies, University of Bristol, UK: Assessing older carers' needs for support: changing policy and continuing themes in England

Katarina Harström and Maria Blad, Bräcke deaconry, Sweden: Parents of grown-up children with disabilities – an unknown group of carers

Carol-Ann Howson, Brunel University, UK: Examining the Quality of Life of Older Parent Carers of Adults with Learning Disabilities: A UK study

Kristina Ziegert and Margaretha Pejner, Halmstad University, Sweden: When both of them are in need of support - an action research project



# Themed Seminars – Saturday 5th september

## 14.00–15.30

*(delegates should choose one)*

**R15**

### 4.1.5 Hälsa, omsorg och välbefinnande

Moderator: Ritva Gough, Nationellt kompetenscentrum anhöriga

Barn och unga med flerfunktionsnedsättning: En översikt av medel som ger möjligheter till aktivitet och delaktighet. Lisbeth Nilsson, forskare, Nka

Anhörigskap och funktionsnedsättning hela livet. Ritva Gough, forskare, Nka

Ekonomiskt nytänkande inom personlig assistans. Per Lundkvist, ägare och Anna Nyberg samordnare, L&S assistans



**R21**

### 4.1.6 Hälsa, omsorg och välbefinnande

Moderator: Carin Wallman, Nationellt kompetenscentrum anhöriga

Anhörigstöd – allas angelägenhet. Birgitta Nygren, anhörigsamordnare och Eva Karlsson, utvärderare, Botkyrka kommun

Superanhörig. Hur kan samhället motverka att föräldrar till barn med autism sjukskrivs med utmattningssyndrom? Cecilia Brusewitz och Kerstin Alm, Attention

När sjukdom skadar samlivet för anhörigvårdare och vårdtagare behövs stöd till båda i paret. Birgitta Hulter, SESAM Consult i Uppsala AB

Anhörigperspektiv i socialt arbete. Kerstin Wennberg och Ann-Britt Sand, Nka och Stockholms universitet



**R31**

### 4.1.7 Systematisk uppföljning och utvärdering. Workshop

Målgrupp: Anhörigkonsulenter och motsvarande grupper.

Marianne Winqvist, möjliggörare/forskare och Jan-Olof Svensson, möjliggörare/praktiker Nka



## 4.2. Combining Work and Care

**F3**

### 4.2 Combining Work and Care

Chair: Sue Yeandle, University of Leeds, UK

Katherine Wilson, Carers UK: Older workers, working carers?

Elena Katrakis, Carers New South Wales, Australia: Carer friendly employment practices and associated outcomes

Delia Sinclair Frigault, Ontario Caregivers Coalition, Canada: Using policy to support Ontario caregivers/ carers in the workplace: An example from Ontario, Canada

Jenny Read, Centre for International Research on Care, Labour and Equalities (CIRCLE), University of Leeds, UK: Co-production in the design and implementation of voluntary sector employment support for carers

# Themed Seminars – Saturday 5th september

## 14.00–15.30

*(delegates should choose one)*

### 4.3. Paying for Care

**F2**

#### 4.3 Paying for Care

Chair: Gavin MacGregor, Carers UK

Sophie Cès, Université Catholique de Louvain, Belgium: How to measure informal care?

Chloe Wright, Carers UK: The shaping of a market in care and support services

Kate Johnsson, Carers Victoria: Building Capacity for Family Carers in Self-Management

### 4.4. Technology-Enabled Care and Support

**F1**

#### 4.4 Technology-Enabled Care and Support

Chair: Madeleine Starr MBE, Carers UK

Lillemor Broling, Kalmar County Council, Sweden and Frida Andreasson, Swedish Family Care Competence Centre, Linnaeus University, Sweden: Enhanced participation, safety and security for older people and their carers with health supportive e-services

Verina Waights, The Open University, UK: Developing carers' digital skills to improve the everyday lives of carers and cared-for older people

Brechtje Walburgh Schmidt, Movisie, Netherlands: eHealth in a caring society

Anna Jackson, The Carers' Resource, UK: Independence, Reassurance, Innovation

### 4.5. Young Carers Symposium

**R14**

#### 4.5 Young Carers Symposium

Chair: Tim Moore, Institute of Child Protection Studies, Australia Catholic University

Agnes Leu, Careum Research, Kalaidos University of Applied Sciences, Department of Health, Zurich, Switzerland and Saul Becker, Pro Vice Chancellor and Head of the College of Social Sciences, University of Birmingham, UK: Country's Awareness and Policy Responses to Young Carers: a Matter of Choice

Feylyn Lewis, University of Birmingham, UK: What about us? Young caring in New Zealand and the US

Michele Stokes, Carers In Hertfordshire, UK: Should societies accept that today's young carers will be tomorrow's paid Care Workers? Juggling working and caring does not mean being paid for caring

#### **R24/25** 4.5.2 Barn som anhöriga – Antologi release

Att se barn som anhöriga – Om relationer, interventioner och omsorgsansvar.

Eva Olofsson, ordförande i SKL:s Beredning för primärvård och äldreomsorg och oppositionsråd i Västra Götaland inleder

Ulrika Järkestig-Berggren, Lennart Magnusson, Elizabeth Hanson och författare presenterar antologin



# Themed Seminars – Sunday 6th september

9.00–10.30

*(delegates should choose one)*

## 5.1. Health, Social Care and Wellbeing

### **R11/12** 5.1 Health, Social Care and Wellbeing

Chair: Åsa Sandvide, Swedish Family Care Competence Centre

Mats Ewertzon and Eva Gustafson, Swedish Family Care Competence Centre, Linnaeus University, Sweden: Blended Learning Networks: An intervention for developing support for family caregivers of people with mental illness - implementation and evaluation in a Swedish context

Marie Persson, Swedish Family Care Competence Centre and Institute of Gerontology, School of Health Sciences, Jönköping University, Sweden: Family caregivers of elderly people with mental illness (not dementia) - who are they?

Marie Ernsth Bravell and Eva Telander, Jönköping University and Municipality of Jönköping: Health Promoting Visits - a way to improve family support

Stephen Gallagher, University of Limerick, Ireland: Building Resources in Caregivers: A Randomised Controlled Trial for Benefit Finding

### **R13** 5.1.2 Health, Social Care and Wellbeing

Chair: Aileen Bergström, Swedish Family Care Competence Centre

Gunilla Lindqvist, Swedish Family Care Competence Centre and Department of Health and Caring Sciences Linnaeus University, Sweden: Female informal caregivers' daily life with a spouse having chronic obstructive pulmonary disease

Elaina Smith, NHS Greater Glasgow and Clyde, Scotland, UK: Empowering carers through conversation in acute hospital setting

Jennifer Wingham, Royal Cornwall Hospitals NHS Trust, UK and Julia Frost, University of Exeter Medical School: Supporting carers in heart failure management: A qualitative study to identify carer needs

Joyce Cavaye, The Open University, UK: Health and Wellbeing in the Post-Caregiving Period

### **F4/F5**

### 5.1.3 Health, Social Care and Wellbeing

Chair: Emily Holzhausen OBE, Carers UK

May Yeok Koo, Nanyang Polytechnic, Singapore, John Keady and Helen Pusey, University of Manchester, UK: Finding new directions: Intergenerational care

Maria Liljeroos and Anna Strömberg, Linköping University: Long term follow up of factors influencing caregiver burden in partners of patients with heart failure

Mao Saito and Masatoshi Tsudome, Faculty of Social Sciences, Ritsumeikan University, Japan: Male carers in Japan: Difficulties and the need for gender sensitive support programs

Mary Larkin, The Open University, UK: Making room for former carers

### **R22/23** 5.1.4 Health, Social Care and Wellbeing

Chair: Gavin MacGregor, Carers UK

Jane Say, University of Hertfordshire, UK: Convoys of Care: How do Carers Shape, Adapt and Utilise their Networks for Caring?

Anna Olheden, Kalmar County Council in Sweden: User- patient- and family member involvement – strategy and county-wide model

Per Johan Ekelöf, Carers Association, Gothenburg, Sweden: Empowering Carers in the Local Community – Gothenburg one Example

Anne Helferty, Chief Housing Welfare Officer, Dublin City Council, Ireland: Dublin Age-friendly City – Strategy to Implementation

# Themed Seminars – Sunday 6th september

9.00–10.30

*(delegates should choose one)*

## **R24/25** 5.1.5 Health, Social Care and Wellbeing

Chair: Stefan Andersson, Swedish Family Care Competence Centre

Aina Granath and Nina Nordin, Mölndals Relatives Association, Sweden: It is never too late - Effects of physical training in an 86 year old man, diagnosed with Alzheimer's disease 10 years ago

Kristina Ziegert and Margaretha Pejner, University Halmstad, Sweden: When both of them are in need of support- an action research project

Eva Gustafson, Swedish Family Care Competence Centre, Sweden: I am just a visitor: Blended Learning Networks focusing on family carers' experiences and need for support in a residential or nursing home context

Ann-Kristin Ölund, Swedish Family Care Competence Centre, Sweden: Skilled nursing care in everyday life - recorded lectures online

## **R15** 5.1.6 Hälsa, omsorg och välbefinnande. Svenskt seminiarium

Moderator: Jan-Olof Svensson, Nationellt kompetenscentrum anhöriga

Någon att tala med. Blandade lärande nätverk, BLN, en modell att öka kunskapen och förståelsen får samtalets betydelse som stöd till anhöriga. Jan-Olof Svensson, möjliggörare/praktiker Nka och anhängkonsulent Växjö kommun

Vad är det vi pratar om? - Om orden vi använder och behovet av att definiera begrepp inom anhörigstödsområdet. Marianne Winqvist, möjliggörare/forskare Nka

Socialt hållbar utveckling- det obetalda omsorgsarbetet. Martina Takter, närståendekoordinator och doktorand och Magdalena Andersson, FoU-koordinator, Malmö stad

Anhörigas Riksförbund, en röst och en resurs för anhöriga. Ann-Marie Högberg, ordförande Anhörigas Riksförbund



## **R31** 5.1.7 Webbutbildning om anhängfrågor. WORKSHOP

Gunilla Matheny, anhängpedagog och Paul Svensson, projektledare, Nka



## 5.2. Combining Work and Care

### **F3** 5.2 Combining Work and Care

Chair: Katherine Wilson, Carers UK

Elena Katrakis, Carers New South Wales, Australia: Stopping work to care - what happens when employment gives way to care?

Linda Pickard and Derek King Personal Social Services Research Unit, London School of Economics and Political Science, UK: Does "replacement care" help unpaid carers remain in employment? A study based in England

Gail Gibson Hunt, President and CEO, National Alliance for Caregiving, and Dr Susan C. Reinhard, Senior Vice President and Director, AARP Public Policy Institute, USA: Caregiving in the US: Who are America's caregivers

Anne Norheim and Heidi Dombestein, University of Stavanger, Norway: Always on Guard! Informal Carer Roles as Resources When Family Members Develop Dementia

# Themed Seminars – Sunday 6th september

9.00–10.30

*(delegates should choose one)*

## **R21** 5.2.2 Combining Work and Care

Chair: Ann-Britt Sand, Swedish Family Care Competence Centre

Sue McIntock, Carers Scotland: Carer Positive: supporting working Carers in Scotland

Sue Yeandle, University of Leeds: Carers and the 'right to request flexible working': an international perspective on the origins, impact and trajectories of an employment policy change

Sarah Janssens and Herlinde Dely, Howest University of Applied Sciences, West Flanders, Belgium: The Importance of a Human Resource Strategy for Working Informal Carers

Noor Seghers, Parenting and Special Education Research Unit, KU Leuven, Belgium: The Magenta project: Effectiveness of an intervention on managerial skills for parents with a young child with disabilities

## 5.3. Paying for Care

### **F2** 5.3 Paying for Care

Chair: Chloe Wright, Carers UK

Kate Johnson, Carers Victoria, Australia: Building Capacity for Family Carers in Self-Management

Myra Lewinter, Department of Sociology, University of Copenhagen, Denmark: Thinking care in the long term: The changing role of state, civil society and market

Karen Duncan and Shahin Shooshtari, Kirsten Roger and Janet Fast, University of Manitoba, Canada: Care-Related Out-of-Pocket Expenditures: Avenues for Financial Support of Canadian Caregivers

## 5.4. Technology-Enabled Care and Support

### **R26** 5.4 Technology-Enabled Care and Support

Chair: Paul Thomas, Microsoft (STC) Corporation

Jenny Wilder, Swedish Family Care Competence Centre and Mälardalen University, Sweden: Professionals' and Parents' Shared Learning in Blended Learning Networks related to Communication and Augmentative and Alternative Communication for People with Severe Disabilities

Bitte Rydeman, Certec, Department of Design Sciences, Lund University and Swedish Family Care Competence Centre, Sweden: Communication technology for children and adolescents with severe and multiple disabilities: a guide for parents

Judith Timoney, ALA research foundation /The Swedish National Association for Persons with Intellectual Disability (FUB), Sweden and Kerstin Gatu, Mora People's College, Sweden: Becoming a citizen of the digital world through assistive technologies

Pauline Johansson, Swedish Family Care Competence Centre and Linnaeus University, Sweden: Tablet computers as a means to support patients undergoing radiotherapy

# Themed Seminars – Sunday 6th september

9.00–10.30

*(delegates should choose one)*

## **F1** 5.4.2 Technology-Enabled Care and Support INNOVAGE SEMINAR

Chair: Hanneli Döhner, Eurocarers

Francesco Barbabella, National Institute of Health and Science on Aging, Italy and Areti Efthymiou, Eurocarers: The impact of web-based services in supporting family carers of older people: results from a multicentre pilot study

Benjamin Salzmann, Wir Pflegen e.V., Germany: Pilot study of the German innovAge internet platform for carers: discussing usefulness and virtual social support

Frida Andreasson and Elizabeth Hanson, Swedish Family Care Competence Centre: Online support for carers. Using a social forum and social network as a means of developing the role of informal caregiving

Arianna Poli, National Institute of Health and Science on Aging, Italy: The Innovage-Eurocarers web platform supporting family carers of older people with dementia: results from an Italian pilot study

## 5.5. Young Carers Symposium

### **R14** 5.5 Young Carers Symposium

Chair: Ulrika Järkestig Berggren, Swedish Family Care Competence Centre and Linnaeus University

Ylva Nilsagård, Centre for Health Care Services, Region Örebro County: Informing the children when Mum or Dad is diagnosed as having Multiple Sclerosis

Katrin Boström, Department of Health and Medical Services, Region Örebro County: Multiple Sclerosis – a family matter

Katrin Bartfai Jansson, MD, and Agneta Anderza Carlsson, Associate Professor, University Hospital Örebro, Sweden: Teenagers: perspectives on living with a parent's cancer; a unique and personal experience

Bo Hovstadius, Research fellow, Swedish Family Care Competence Centre, Linnaeus University, Department of Medicine and Optometry: Societal costs in Sweden of adults who have grown up with parents with mental illness, addiction to alcohol or drugs

### **R3** 5.5.2 Barn som anhöriga. WORKSHOP

Linda Frank, möjliggörare/praktiker och Eva Nordqvist, möjliggörare/praktiker, Nka





## Main Speakers



H.M. Queen Silvia

In addition to her official duties as Queen of Sweden, Her Majesty has several other engagements. The Queen initiated the founding of the World Childhood Foundation - a non-profit working to prevent abuse and exploitation of children. It support and implements over 100 projects worldwide, assisting children who are at risk of or are victims of abuse, children who are in alternative care, street children, and families at risk. She is the founder and Honorary Member of the International Mentor Foundation and actively works on behalf of the disabled and hearing impaired. The Queen also initiated the founding of Stiftelsen Silviahemmet - a non-profit foundation devoted to improving the quality of life for persons affected by dementia and their families after her mother Alice Sommerlath was diagnosed with dementia. The Queen still chairs and actively works with Stiftelsen Silviahemmet to develop and improve care for people with dementia and to help relatives and caregivers of people with dementia. In addition to caring for people with dementia Stiftelsen Silviahemmet now train nurses, nursing assistants and doctors in dementia care together with Sophiahemmet and Karolinska Institutet. Queen Silvia is the patron of Dementia Forum X – the world's first global digital platform for relatives, nursing staff and caregivers.

<http://dementiaforumx.org>



Åsa Regnér, Sweden's Minister for Children, the Elderly and Gender Equality:

Åsa Regnér is a Swedish official and politician of the Social Democratic party. She holds a Bachelor of Arts (German, Spanish and history of art) from Stockholm University, a Master in democratic development from Uppsala University and has also studied political science, sociology and German literature at the Friedrich-Alexander Universität in Erlangen, Germany.

Regnér has extensive experience working with both politics and non-governmental organisations. She has previously worked as Country Director for UN Women in Bolivia, Secretary-General for RFSU, Director of Planning for the ministry of justice, and has worked as a political advisor at the Prime Minister's office and on several occasions.

She has served as the Minister for Children, the Elderly and Gender Equality since October 2014.



Baroness Pitkeathley OBE

Baroness Pitkeathley has worked in health and social care throughout her career and directly on carers' issues since 1986 when she became Chief Executive of the National Council for Carers, which later became Carers UK. She is a Vice-President of Carers UK.

Alongside her work as Peer and Deputy Speaker of the House of Lords, she is Chair of the Professionals Standards Authority for Health and Social Care and a Chair of the Big Society Trust. She has also been Chair of the Children and Family Court Advisory and Support Service and the New Opportunities Fund.



The Hon Tony Abbott MP, Prime Minister of Australia

Tony Abbott was sworn in as the 28th Prime Minister of Australia on 18 September 2013. Prior to the election of the Coalition Government, Mr Abbott had been Leader of the Opposition. During the Howard Government, he served as a Parliamentary Secretary, Minister, Cabinet Minister, and Leader of the House of Representatives.

With a ministerial responsibilities covering: Employment Services; Employment and Workplace Relations and Health and Aging, Mr Abbott oversaw the development of the Job Network and a major expansion of Work for the Dole; managed the establishment of the Cole Royal Commission and handled the expansion of Medicare rebates to allied health professionals along with introducing the Strengthening Medicare.

Prior to entering parliament, Mr Abbott was a journalist with The Australian and The Bulletin. He was press secretary and political adviser to the Leader of the Opposition, Dr John Hewson, before becoming Executive Director of Australians for Constitutional Monarchy.



Bruce Bonyhady AM, Chairman, National Disability Insurance Agency, Australia

Mr Bruce Bonyhady was formerly the President of Philanthropy Australia and also formerly the Convenor of the Independent Panel appointed to advise the Productivity Commission and Government during the Inquiry into long-term care and support for Australians with disability. He is a Member of the Disability Investment Group and the Reference Group for the Pension Review. He was Deputy Chair of the National Disability Insurance Scheme Advisory Group to the Council of Australian Governments and former Chairman of Yooralla.

Mr Bonyhady has also held a number of senior positions in the funds management industry and insurance industry in Australia and internationally. He is Chairman of Acadian Asset Management Australia Limited and a Director of Dexu Wholesale Property Limited. His former roles include senior positions in the funds management industry, including Managing Director of ANZ Investments and Executive Vice President at BT Funds Management. His earlier career was as an economist and econometrician in the private sector and the Commonwealth Treasury.

He is the father of three adult sons two of whom have disabilities. Mr Bonyhady was appointed as a member of the Order of Australia in 2010 for services to people with disabilities, their families and carers and to the community.



John Dunne

John is currently Chief Executive of The Carers Association, Ireland and President of Eurocarers. He has held a variety of senior public and voluntary sector positions in Ireland over the past 40 years as well as lecturing and consulting on management, strategy and policy analysis. He currently chairs Irish organisations dealing with early childhood development and community law and mediation



Lord Filkin CBE

Geoffrey Filkin's career has spanned public policy and service improvement as a Chief Executive, policy maker, Government Minister and member of the House Lords. He has worked across public, private and voluntary sectors, founding and chairing several charities and think-tanks.

He was a senior manager in housing associations and local government before becoming a local authority Chief Executive. Leading the Association of District Councils, he promoted the foundation of the Local Government Authority, creating Best Value - the policy for sourcing in local government. In 1997 he was appointed CBE and in 2000 he led the Prime Minister's Review of local government before being appointed a government Minister for four years.

He is an active member of the House of Lords and chaired the Lords Select Committee on Public Services and Demographic Change. Currently a trustee of several charities, he is also the founder Chair of the new Centre for Ageing Better, a What Works Centre supported with funding by the Big Lottery. He now sits on the cross-benches in the House of Lords.



Gail Gibson Hunt is President and Chief Executive Officer of the National Alliance for Caregiving, a non-profit coalition dedicated to conducting research and developing national programs for family caregivers and the professionals who serve them. She previously conducted corporate eldercare research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association. Ms. Hunt served on the Policy Committee for the 2005 White House Conference on Aging, as well as on the Centres for Medicaid and Medicaid Services Advisory Panel on Medicare Education. She was the chair of the National Center on Senior Transportation. Ms. Hunt is a commissioner for the Center for Aging Services Technology (CAST) and on the Board of the Long-Term Quality Alliance. Ms. Hunt is a member of the Multiple Chronic Conditions Workforce Technical Expert Workgroup. She co-chairs the National Quality Forum MAP Person and Family-Centered Care task force. Additionally, Ms. Hunt is on the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI). <http://www.caregiving.org/about/our-team/>



Prof. David Grayson CBE became director of the new Doughty Centre for Corporate Responsibility at Cranfield University School of Management in 2007, after a thirty year career as a social entrepreneur and campaigner for responsible business, diversity, and small business. This included chairmanship of the UK's National Disability Council and several other government bodies, & joint managing-director of Business in the Community. His 5 books include: "Corporate Responsibility Coalitions" – winner Academy of Management Social Issues in Management Best Book Award 2015 - & "Social Intrapreneurism and all that Jazz." David currently chairs Carers UK. The Guardian named David as one of the top ten global tweeters on Sustainability Leadership alongside Al Gore, & Apple CEO Tim Cook. Twitter: @DoughtyDavidG.



#### Elizabeth Hanson

Elizabeth is Scientific Leader of 'Nationellt kompetenscentrum anhöriga' (The Swedish Family Care Competence Centre-SFCCC), a national centre of excellence in the field of informal care and a Professor in Health Care Sciences at the Linnaeus University, Kalmar in the south-east of Sweden. She is also Visiting Reader at the University of Sheffield, School of Nursing in the UK. Elizabeth is currently Vice-President of Eurocarers, representing the research organisations. She co-ordinates the recently established Eurocarers Research Working Group, which has worked together to define current research priorities concerning carers, care and caring in the EU, to influence public policy makers and EU institutions of the need for research to help inform policy and evidence based practice in the area. She also acts as the SFCCC's contact person in IACO. She was previously a steering board member of 'Anhörigas riksförbund (Carers Sweden). Elizabeth is a nurse by background with long-standing interests in carer support services and interventions, quality of life of older people with advanced long-standing chronic conditions and their families and empowerment in research and practice.



#### Heléna Herklots, Chief Executive, Carers UK

Heléna is responsible for leading the organisation — working with the Board of Trustees to ensure that Carers UK meets its charitable objectives and improves the lives of carers. A key part of Heléna's role is to ensure that the needs of carers are brought to the attention of policy-makers, the statutory, private and voluntary sectors, the media and the general public. Helena co-chairs the Department of Health Care and Support Transformation Group, and represents Carers UK at the Carers Strategy Cross-Government Board, as well as serving on a number of other advisory groups covering policy, research and practice.



Dr Kalache has been a leading specialist and pioneer in age-related issues for close to forty years. Concurrently, Dr Kalache serves as Global Ambassador of HelpAge International, Senior Advisor at the New York Academy of Medicine and sits on a multitude of boards ranging from the World Economic Forum to the Gulbenkian Foundation. He acts as world-wide adviser on ageing issues to national, state and municipal governments, civil society organisations and the private sector and is actively involved in the process toward the adoption of a United Nation Convention for the Rights of Older Persons. Dr Kalache held research and teaching positions at both the Universities of Oxford and London for almost twenty years. During this time he founded the Epidemiology of Ageing Unit at the London School of Hygiene and Tropical Medicine (1983) and created the first European Masters degree in Health Promotion (1991). From 1995-2008 he directed the World Health Organisation's global Ageing and Life Course Programme from its Geneva headquarters. During his thirteen years at WHO he launched the Active Ageing Policy Framework and the global movement on Age-Friendly Cities among many other enduring initiatives. In addition of his position of being the President of the International Longevity Centre Brazil in 2014 Dr Kalache was elected Co-President of the Global Alliance of International Longevity Centres together with Baroness Sally Greengross, President of the ILC-UK.



Dr. Lennart Magnusson is Director of 'Nationellt kompetenscentrum anhöriga', (the Swedish National Family Care Competence Centre) where he actively works with influencing evidence based policy making and practice in the field of carers, care and caring. He is an Associate Professor at the Department of Health and Caring Sciences at Linnaeus University in the south-east of Sweden. He is an engineer and specialist nurse by background. Lennart has worked with research, development and education in the area of older people, carers and use of ICT for the last 20 years. He headed up the EU-project ACTION (Assisting Carers using Telematics Interventions to meet Older People's Needs) in 1997-2000. Together with business and municipality partners he implemented ACTION as an integrated service in the service delivery chain of Borås, West Sweden. ACTION is cited as an example of best practice in the field of e-health at EU level and at national level it is recognised as a catalyst for other municipalities to start working with the use of ICT in health and care, such as Västerås municipality (Stockholm) with e-home-help services for older people.



Dr. Susan C. Reinhard is a Senior Vice President at AARP, directing its Public Policy Institute, the focal point for public policy research and analysis at the state, federal and international levels. She also serves as the Chief Strategist for the Center to Champion Nursing in America, a national resource center created to ensure America has the nurses it needs to provide care in the future. Dr. Reinhard is a nationally recognized expert in health and long-term care policy, with extensive experience in conducting, directing and translating research to promote policy change. Previously, she served as Professor and Co-Director of Rutgers Center for State Health Policy, directing several national initiatives with states to help people with disabilities of all ages live in their communities. As Deputy Commissioner of the New Jersey Department of Health and Senior Services, she led the development of policies and nationally recognized programs for family caregiving, consumer choice and community-based care options. She is a former faculty member at the Rutgers College of Nursing, an American Academy of Nursing fellow and a National Academy of Social Insurance member. She holds many governance positions, including Chair of the Center for Health Policy Development/National Academy for State Health Policy. She holds a master's degree in nursing from the University of Cincinnati and a Ph.D. in Sociology from Rutgers University.



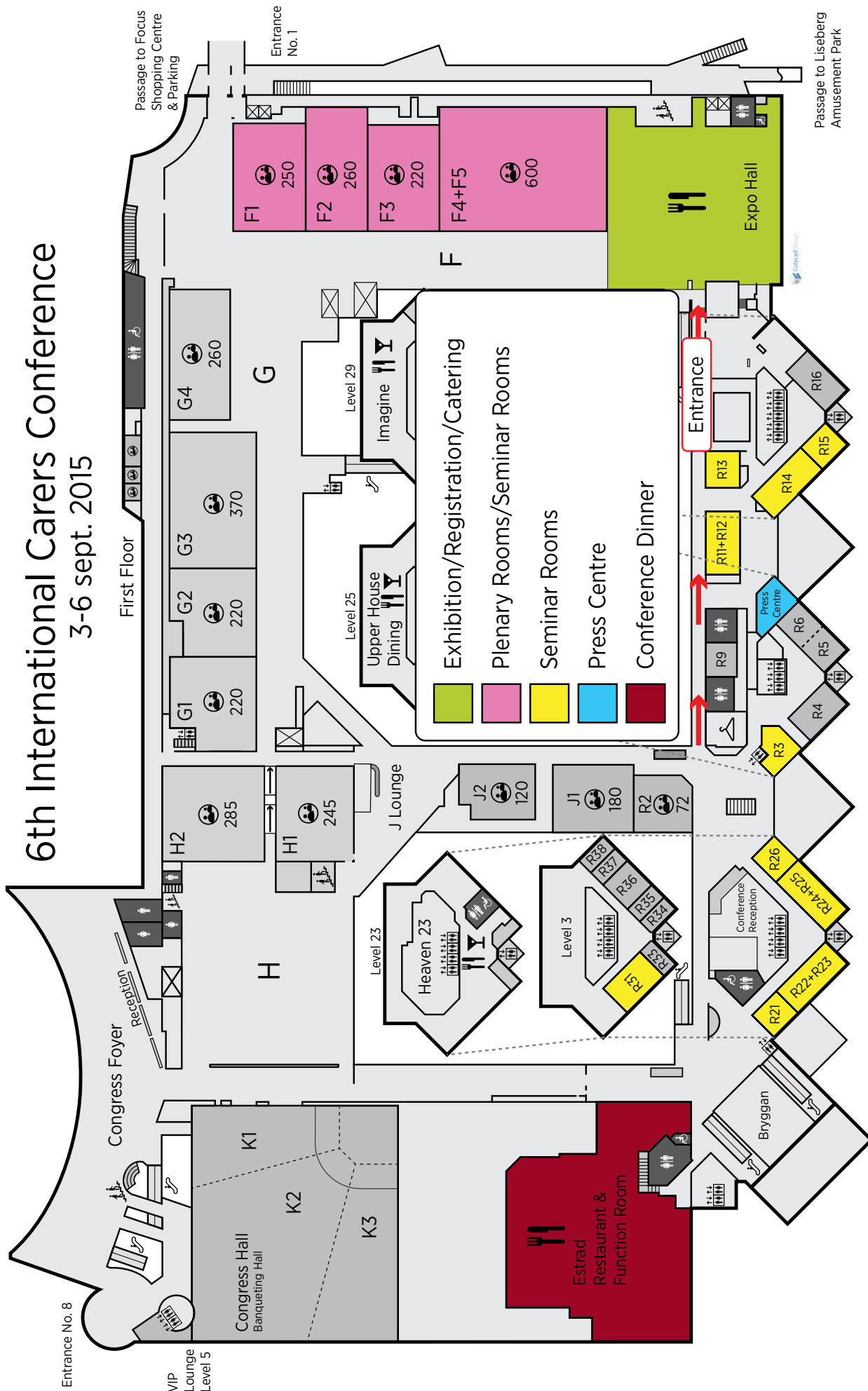
Anil Patil, Founder/Executive Director, Carers Worldwide

Anil founded Carers Worldwide with the aim of sensitizing local organisations, NGOs – both national and international – and governments to the needs of carers in the developing world. Anil has over 17 years of experience in the international development sector as a development worker and grant maker and Trustee. He has extensive experience in delivering positive change for the public benefit in the fields of community mental health, disability and farmed animal welfare as well as community based interventions in developing countries.



# 6th International Carers Conference

## 3-6 sept. 2015



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