

# Supporting the Family in Palliative Care

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on End of Life Care**

# Family caregivers at home



# Questions to be addressed:

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- Who are family carers?
  - Why should family carers be offered support?
  - How can family support needs be assessed?
  - What are the best types of support to offer family carers?
  - What are the challenges in delivering support services?

# Who are family carers?

# Definition of family carers

*Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management.*

(NICE , 2004; p.155)

## Assumptions

- Single 'primary' carer, cohabiting, willing and able to provide care, female, provides virtually all care
- Alternatives - Caring network involving family, friends and community neighbours, may or may not be co-ordinated.

# Social and emotional context of family caregiving in palliative care

- Complex nature of disease process
- Multiple losses
- Provide care over a prolonged period
- Changing roles and relationships
- Awareness of approaching death and bereavement
- Potential financial impact
- Uncertainty



# What do family carers do?

- Physical care
- Nursing care
- Manage medications
- Domestic care
- Emotional care
- Social care
- Information provider
- Liaison person
- Anticipatory care
- Preventative care



# Experts in care

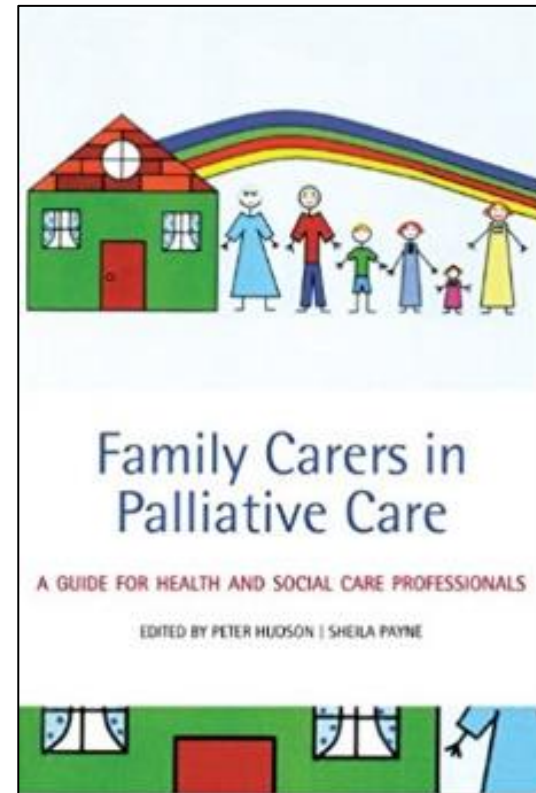
Family carers are likely to be experts in their role and in the care of the person living with a life threatening condition (Seymour 2013)





# Three theoretical positions

- Burden model
- Stress and coping model
- Social relationship model



Hudson P and Payne S (ed). *Family Carers in Palliative Care* Oxford University Press, Oxford, 2008.

# What are the ways to conceptualise support needs of family carers?

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## Burden model

- Psychological framework
- Assumes family carers are overburden, measures

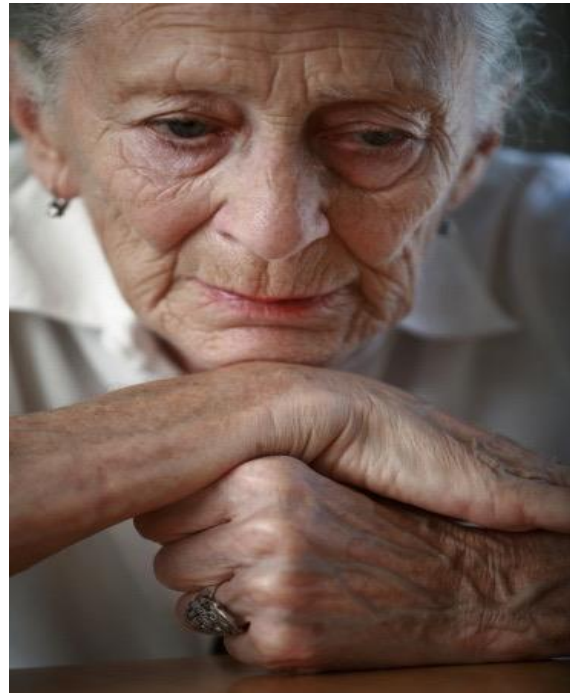
## Stress and coping model

- Focuses on individual appraisal of stress and coping
- Measures emotion focused and problem focused coping
- Support in 'fixing' problems and promoting coping

## Social relationship model

- Focuses on caregiving in the context of social relationships
- Examines relationship demands and expectations

# What is the evidence of family carers needs?

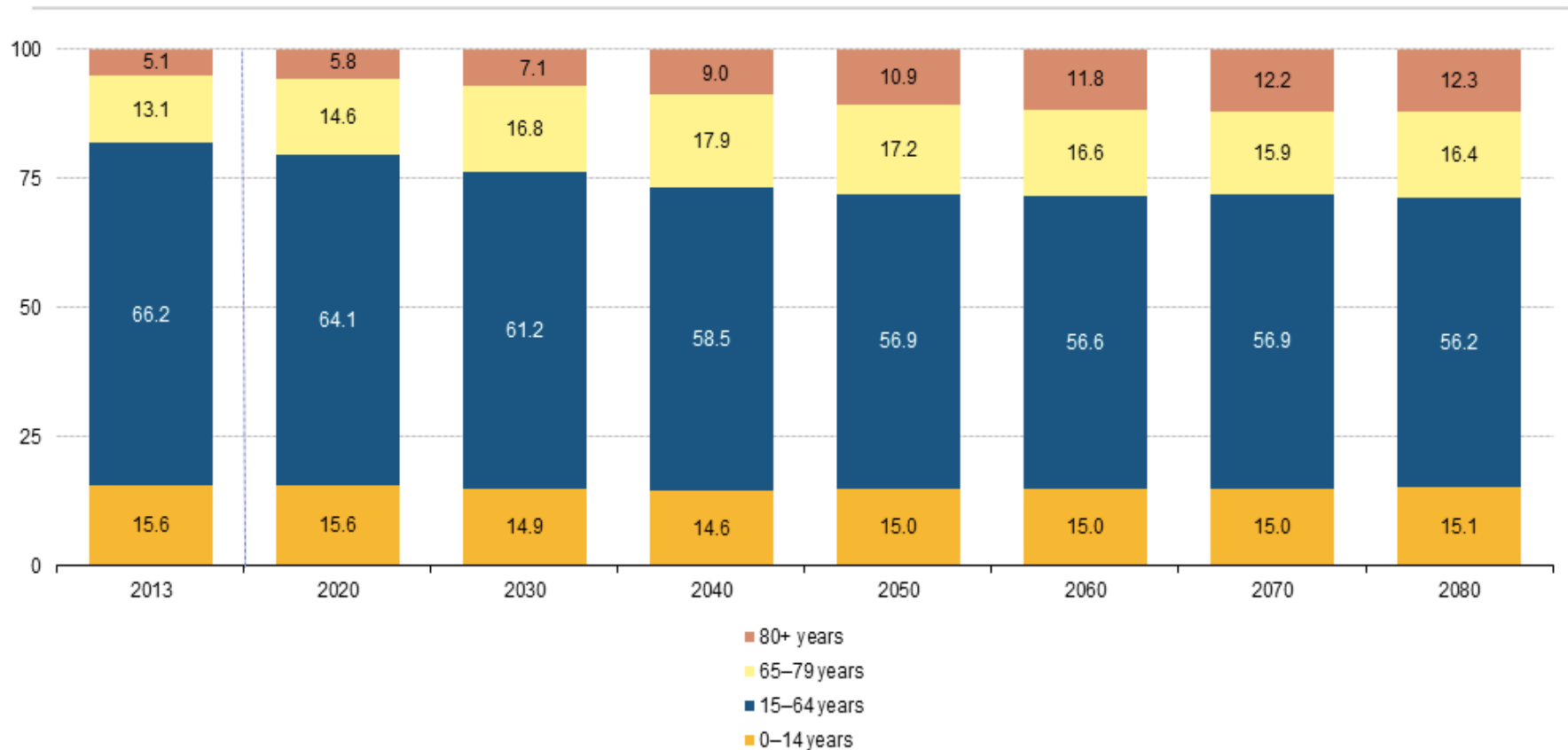


# Changing demographic and social patterns in Europe

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- Increasing longevity – especially the increasing numbers of people over 85 years.
- Women’s role in society – increasingly employed outside the home, later childbearing, fewer children.
- Marital relationship patterns - single parenting, step parenting.
- Employment patterns - geographical mobility, more part-time working
- Caregiving is more prevalent in later life, the peak age of caregiving is 55-64 years (18%) and then declines to 13% among those 75 years and over (in the UK).
- Half of carers over 65 years are women, but among the oldest old carers more men than women carers (2001 Census data, ONS UK).

# Changing population profiles in Europe

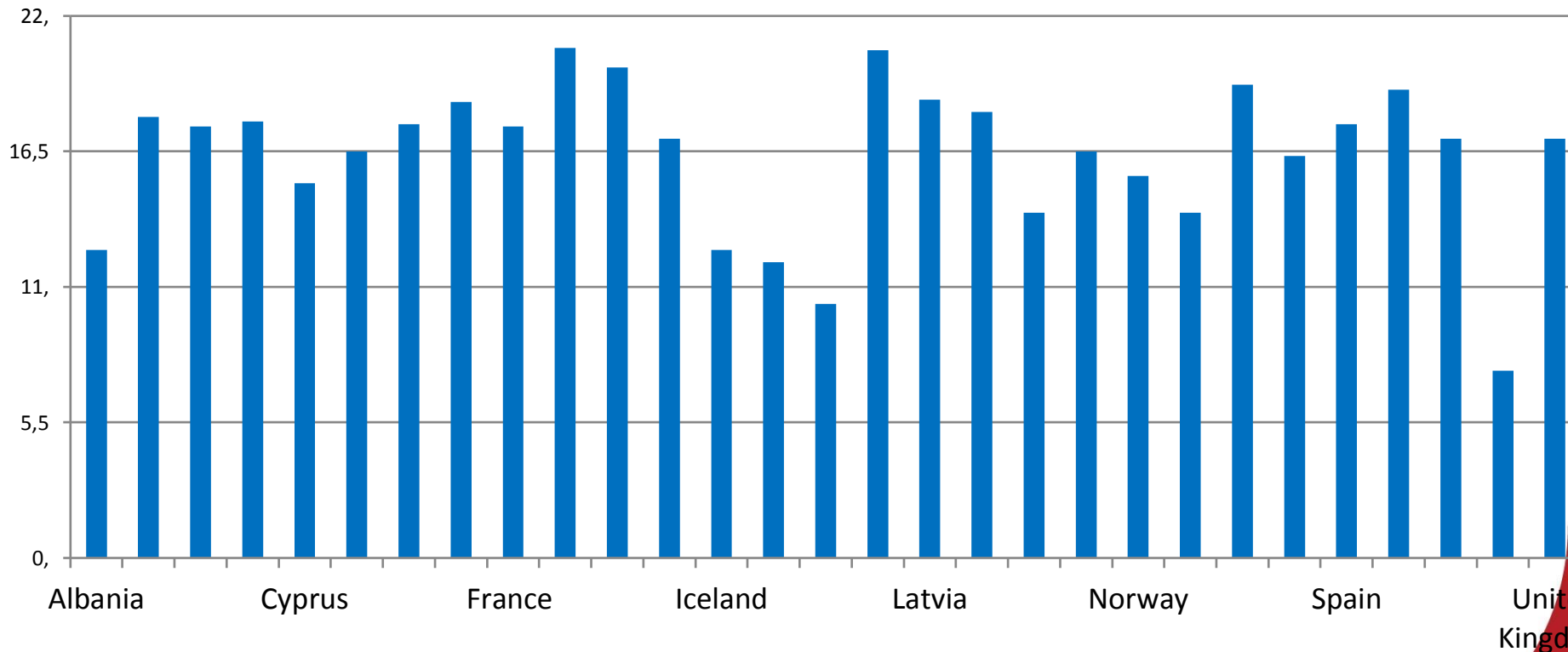


(<sup>1</sup>) 2020–80: projections (EUROPOP2013).

Source: Eurostat (online data codes: demo\_pjangroup and proj\_13npms)

# How many older people in the population of each country?

Proportion of population 65 years and older  
 Range: **7.6%** in Turkey to **20%** in Italy and Germany.  
 (%)



# Family carers are both *care providers* and *care receivers*

- An ageing carer population has significant health needs.
- Carers and their family members can often have multiple morbidities and mutual, fluctuating care giving and/or receiving needs.

*Anna has cared for her husband Bill who has dementia, for approximately 2 years. Prior to this Anna was cared for by Bill following a stroke. Anna was recently diagnosed with cancer and requires hospital inpatient treatment. Bill has a planned nursing home respite stay arranged for the duration of her hospital admission and her recuperation afterwards.*

# Family caregivers experience:

- Family carers may experience considerable physical, psychological, social and financial challenges which they are largely unprepared for.
- Little evidence of family carers choice in decision making.
- Family carers increasingly have to combine paid employment with care giving.
- Little is known about the real economic costs to individuals.

A study of out-of-pocket costs of healthcare in the last year of life in 13 European countries showed that costs varied between 2-25% of median household income. (Penders et al (2017) *Palliative Medicine* 31 (1) 42-52)



*Well my mum and dad moved in to live with us, because my dad had peripheral neuropathy, and he was going gradually downhill and obviously my mum was getting older and finding it harder to look after him.*

*(Daughter aged 64 and her husband aged 66 caring for her father aged 90; mother with dementia also being cared for at home).  
Payne et al, (2013) 'Unpacking the home': family carers' reflections on dying at home.*

# How can family support needs be assessed?

# Health professionals often feel unprepared to assess and support family carers

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- There is a lack of understanding of the needs of patients and carers who do not have cancer, especially those with dementia.
- More skills needed in undertaking family carers' assessments.
- Transitions between places of care (hospitals, hospices and nursing homes) with home are often poorly managed.
- Most staff are intrinsically motivated to help carers but systems and patterns of working create barriers.

Hanratty B, Addington-Hall J, Arthur A, Cooper L, Grande G, Payne S and Seymour J. What is different about living alone with cancer in older age? A qualitative study of experiences and preferences for care. *BMC Family Practice*, 2013, 14: 22.

# Structured Assessment

Undertake regular and repeated assessment of family carers needs.

Downloaded from <http://spcare.bmj.com/> on February 16, 2018 - Published by [group.bmj.com](http://group.bmj.com)

## Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial

Gunn Eli Grande,<sup>1</sup> Lynn Austin,<sup>1</sup> Gail Ewing,<sup>2</sup> Neil O'Leary,<sup>3</sup>  
Chris Roberts<sup>3</sup>



# What interventions are available to support family carers?

## Information, training and education

- Strategies for safe moving and handling of the patient.
- Information resources on disease process, trajectory and prognosis.
- Information on how to provide specific care tasks, equipment and medication.
- Information about the dying process and symptom management in a timely way.
- Access to welfare or benefits advice.

## Supportive activities

- 'Drop in' centre/ Coffee mornings/ lunch clubs.
- Self-help groups, virtual or face-to-face.
- Walking, exercise or activity groups.
- Volunteers visiting or befriending.
- Art making or creative groups.

## Therapeutic activities

- One-to-one or group counselling.
- Therapeutic support groups.
- Drama, music or art therapy.
- Relaxation, meditation, Mindfulness or yoga classes.
- Complementary therapies.
- Psychotherapy.

# Evidence on interventions

- Overall little robust evidence on which interventions are best (Harding et al, 2012).
- A menu of options might be best.
- The window of opportunity for family carers to access appropriate information and support is often brief.
- Preparedness for caregiving intervention (Hudson et al 2013).
- All interventions should be **timely, accessible, affordable and appropriate.**

# New challenges

- The diseases from which people die are likely to change – more with chronic and multiple conditions, including dementia.
- Where family carers exist, they are likely to be providing care for longer and face more complex care situations.
- Family carers may be older and have health needs themselves.
- Family carers are likely to be experts in their role and really *know* the person they provide care for.
- Family carers may wish to have a central role in caring for the person, and continue to give care even when the person is in hospital, hospice or nursing home.



# Reflections

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- Remember that not all family carers need ‘support services’
  - Some family carers may draw upon other resources in times of stress
  - Consider the benefits of ‘social prescribing’ – helping family doctors and others to make non-clinical referrals eg: physical activities (exercise classes, walking groups, yoga), art classes, gardening, lunch clubs, welfare advice
  - Draw upon the strengths of community organisations eg volunteers, faith groups, women’s groups, men’s groups

# Implications and recommendations

- Family carers need **respectful and compassionate** care.
- Family carers are **experts** in relation to their carer-for person.
- Family carers require **information** and access to up-dated knowledge about how to provide care.
- Family carers should be offered **regular assessment** of their needs.
- Family carers should be offered a **menu of support services** which are **timely, accessible, affordable and appropriate**.

# Implications and recommendations

- There may be a greater role for volunteers in supporting family carers (Walshe et al 2017 ELSA wait-list trial).
- Staff need training in understanding different cultures, norms and expectations of families, especially when they are migrants or do not share a common language.
- Consideration for the special needs of family carers of those with dementia or more prolonged caregiving periods.
- Regular assessment of family carers needs should be embedded in practice and not just a response to a ‘crisis’.
- Improve transitions between care settings to reduce disruption and distress for patients and family carers.

# Supporting Families

Families, including children, close friends and neighbours, also experience a range of problems during palliative care. They play a crucial role and have needs of their own before, during and after the person's death: these too must be addressed.

# Family Carer's Report



# Resources:

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## International Palliative Care Family Carers Research Collaboration

[centrepalliativecare@svha.org.au](mailto:centrepalliativecare@svha.org.au)

### EAPC Task Force on Family Carers

- Payne S. EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 1. *European Journal of Palliative Care* 2010, 17 (5): 238-245.
- Payne S. EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 2. *European Journal of Palliative Care* 2010, 17 (6): 286-290.

# 10<sup>th</sup> World Research Congress of the European Association for Palliative Care



**24-26 May 2018, Bern, Switzerland**

*[www.eapcnet.eu/research2018](http://www.eapcnet.eu/research2018)*



Thank you for your attention

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