



Overview Report – Caring and Post Caring in Europe - *September 2010*

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Introduction

This report has its origins in a pan-European post-caring project called Life After Care. (www.lifeaftercare.eu)

This partnership of 5 non-governmental organisations brings together groups involved in training, support and advocacy of family carers to address the issues faced by such carers after they have ceased in their caring roles.

The partnership aims to exchange ideas, experiences, good practices and tools in order to learn from each other. It aims to strengthen local and national strategies concerning informal training of former family carers to help their reintegration into society after they have ceased in their caring roles.

One of the specific agreed outputs of this project is to produce an overview report on caring and post caring in Europe.

Background

As the population of Europe gets older, the cost and resources needed to provide long-term care in the years ahead will increase. family members, friends, neighbours and other informal carers provide most of the care to ill, frail and disabled people of all ages. These informal carers are not paid for the work they do, but they enable people with care needs to stay at home and in their local community, which saves the government having to pay for that care. There is a real danger that informal care is being forced to compensate for the inadequacies in state support. Despite their contribution, the needs of carers are often not considered. Many carers experience serious financial, health and social consequences.

In this overview of caring and post-caring in European countries, we acknowledge the kind permission of Eurocarers¹ and Vilans² to reproduce large sections of their reports.

An ageing Europe

Europe's society is ageing due to three factors: people are living longer, having fewer children, and those born during the post-war population boom (so-called 'baby-boomers') are reaching retirement age.³ Latest population projections estimate that the population of the 27 EU countries (EU27) will rise to a high of 521 million people in 2035, then begin falling to about 506 million by 2060.⁴ However, these changes will not be distributed equally across the Member States.

One thing is constant across Europe: in general Europeans are living longer, expected to gain an extra five years in life expectancy by the year 2050.⁵ It is estimated that the number of people aged 65+ will increase by three-quarters between now and 2050. In the same period, the old age dependency ratio is expected to double.⁶ The proportion of the population over the age of 65 will almost double over the next 40 years, from 17% in 2005 to nearly 30% by 2050.⁷ The 'very old' (people over 80 years of age) in the EU will rise from 4.1% of the population in 2005 to 6.3% in 2025 and 11.4% in 2050.⁸

The working age population is shrinking, which will affect the tax base for funding public services and numbers of people able to provide formal and informal care.⁹ While there are currently four people of working age (between 15 and 64 years) for every one person aged over 65, by 2060 this ratio will have declined to only two to one, putting greater pressure on public finances.¹⁰ Although advanced age does not necessarily lead to a need for care, looking at the age profile of the population can help us to predict the future demand for long term care.¹¹

What is a carer?

Historically, care by family and friends has provided the bulk of home care and this is still the case. The central place of the family and extended networks in delivering support to older and disabled people is a consistent across all European countries. In the late 19th century, state involvement in health and social welfare began to augment, but not replace, this form of provision.¹²

There is no consistent definition of 'informal and family carers' used by governments and researchers in different countries.¹³ Informal care-giving activities are a part of long-standing family and other relationships.¹⁴

An informal carer has been defined by Eurocarers as 'a carer that looks after family, partners, friends or neighbours in need of help because they are ill, frail or have a disability; the care they provide is unpaid'.¹⁵

How many carers are there?

Estimates of the numbers of carers in the EU may vary due to a number of factors, such as different definitions of a carer and the methods used to identify carers. The most recent source of EU-wide data concerning carers is the second European Quality of Life Survey (EQLS).¹⁶ While the EQLS does not provide data on the actual number of carers in Europe, it gives a picture of the activities of a significant number of the adult population.¹⁷ In the EU27, 3% of people state that they care for an elderly or disabled relative several times a week, 4% do it once or twice a week and 8% do so less than once a week. Altogether, a quarter of people report being involved in caring for an elderly or disabled relative; amounting to 125 million carers in Europe.

Who are the carers?

It is clear from the available data that more women than men provide care. In all countries, women are more likely to be carers and are also more likely to provide more physically intimate, emotionally demanding and longer-term care.¹⁸ Of those reporting that they care for an older person every day, most carers are in the 50-64 age group (9%), followed by the 35-49 age group (7%). Overall women in the middle years of life may be faced with care responsibilities for both elderly dependents and children, as well as possible paid employment.¹⁹ The concentration of carers in the 50-64 age group reflects the prevalence of older people as the recipients of care and the role of adult children in providing that care.²⁰ Using data from England and Austria, it is estimated that between 2% and 4% of all children and young people have care responsibilities, usually as a result of the chronic illness or disability of a parent.²¹

There is a growing concern that the reliance on family care across Europe is too high and will not be sustainable in the years ahead, without measures to improve support to carers.

What do carers do?

Carer activities can be measured in a number of ways, such as hours per week, types of activities, or duration of the care period. The average caring period across Europe has been

found to last 60 months. Over 27% of family carers report having stopped caring after one year.²²

Recent European data from the SHARE²³ study has found that informal care provided by adult children is an effective substitute for long-term formal care as long as the needs of the elderly are relatively low and require everyday skills such as shopping for groceries or cleaning the house.²⁴ However, as the complexity or level of disability increases, the burden of care may become so heavy that it tends to require both formal and informal care.

The contribution of carers to society

Economic data illustrates the contribution of carers across Europe:

- The estimated value of care-giving in six EU member states exceeds public expenditure on formal care and care allowances²⁵
- In England, the value of the care provided by family carers is estimated to exceed the budget of the National Health Services for the whole UK²⁶
- There are estimated to be over one million professional nurses across the EU, compared with the 9.6 million family carers providing 35 plus hours of care per week²⁷

While the contributions of carers are rarely included in calculations of the costs of long-term care systems, this does not mean that these contributions are budget neutral.²⁸ Indeed, carers face a number of significant costs including lost earnings and leisure time, displaced household expenditure, poor health, relationship breakdown, and a redistribution of employment, health and future opportunities for wellbeing between women and men.²⁹

The impacts of caring

A range of factors will shape the carers' experience and the impact of providing care on their wellbeing and socio-economic circumstance. These include: the age and gender of the carer and care recipient, the family and generational relationship between carer and care recipient, the health and prognosis of the care recipient, the socio-economic and labour market status of the carer and the availability and access to formal health and long-term care services.³⁰

The concept of burden can be termed multi-dimensional as there are many aspects which interact with or vary from each other. Someone with an apparently heavy care burden, in terms of hours per week spent caring, the tasks involved or the duration of the caring, may not necessarily feel burdened. In contrast, carers with relatively light responsibilities may feel overburdened. Reasons for these apparent differences may include the quality of the relationship with the person they care for; their reasons for and experiences from caring; and other commitments such as paid work.³¹

The risks of carer burden have been found to increase in a number of instances: where carers own health was poor; where they provided high levels of care; when the care recipient had behavioral problems; and when the carer did not feel supported by social services.³²

Health impact

The physical and emotional health of the carer is of vital importance if they are to continue to provide care in the home. There is evidence to suggest that carers are at risk of becoming 'patients' themselves.³³ In general, the more intensive and demanding the caring role is, the more likely that carers will experience adverse physical and psychological effects.³⁴ Carers have been found to be three times more likely to report ill-health than the non-carer population.³⁵ Negative health effects on carers are more common where they provide care of greater intensity in the type or quantity.³⁶

Irish research found that carers presented a considerably less positive picture of their quality of life in comparison to the general population.³⁷ Carers reported high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. A key factor in this appears to be the limits on leisure and recreation time imposed by caring.³⁸ A more recent Irish study has found that carers face a series of challenges in their role and these may have an effect on their mental and physical health.³⁹

In the Eurofamcare study, the highest quality of life was reported by carers in the UK and Sweden (65% and 67% respectively). In contrast, the lowest quality of life was reported by carers in the Mediterranean regions (Greece 50%, Italy 51%). It was concluded that quality of life may reflect the level of support services and policies related to carers.⁴⁰

Carers in the Eurofamcare study frequently reported physical health problems as a result of their demanding care activities. Other complaints reported included loss of energy, sleep deprivation, stress or panic attacks, pain, depression, headaches or weight changes. Carers also reported psychological problems such as poor concentration; feelings of anxiety, guilt, insecurity and depression.

Carers' health has been shown to worsen the longer they are providing care, with physical health found to decline after the first year of caring.⁴¹ Low incomes and lack of breaks from caring are other factors which contribute to poor health among carers.⁴² Religious belief has been found to alleviate feelings of depression for carers in some European countries.⁴³

Social impact

Carers may experience isolation, poverty and barriers to participation in wider society as a result of their role. Half of carers of older people across Europe who took part in the Eurofamcare study reported feeling 'trapped' in the care situation.⁴⁴

Financial impact

Research in the UK found that 72% of carers were financially worse off as a result of their role.⁴⁵ The reasons given included: the additional costs of disability, giving up paid employment to provide care, the inadequacy of current benefits and charges for services. Family carers may face higher bills than the non-carer population, such as extra heating, laundry and transport costs.⁴⁶ Carers have reported various financial problems caused by caring for an elderly person: the cost of medicines, extra travel, telephone, heating, (out of pocket) payments for health care, and loss of income if carers could not combine work and care.⁴⁷

Combining work and care

There has been a rise in interest in supporting carers to combine care with paid employment, both as part of the wider work/family balance framework, and also to achieve higher employment levels, to which all EU governments have committed themselves.⁴⁸

As part of the Eurofamcare study, it was found that carers in Eastern Europe and some Southern European countries had far fewer opportunities to reduce working hours compared to Nordic and Western-European countries.⁴⁹ Working carers have reported finding it difficult to plan for retirement, partly because of the many unknown factors related to their caring situation.⁵⁰

Carers need support to combine paid employment with providing care in terms of time, cash and services.⁵¹ Both respite care and systems of longer-term leave enable carers to undertake paid employment.⁵² A key requirement for this is flexibility in the workplace, as well as flexible services.⁵³

Carers who are unable to combine paid work and informal care are less likely to re-enter the workforce once they stop caring. In addition, any break from paid employment affects carers' pensions, savings and financial independence when they reach old age.⁵⁴ The short-term costs of reduced work hours or career breaks are compounded by lower pension entitlements in later life.⁵⁵

Care cultures across Europe

The balance between informal and formal care differs substantially from country to country. It also changes over time within countries due to political, economic, demographic and cultural factors.⁵⁶ Some point to a North-South divide in European 'care cultures'.⁵⁷

Although there may be different levels of formal service provision, generally higher in the north, and different paid care solutions, for example the extensive use of migrant labour outside the formal economy in the south (and in particular in Italy); there are still immense pressures on informal carers throughout Europe - physical, financial and emotional.

Support to carers across the EU

A variety of supportive measures for carers exist across Europe. In general, the measures adopted reflect 'fundamental differences in societal attitudes to uncertainty, inequality, transparency, citizenship and the role of unpaid care' in addition to the constitutional and fiscal arrangements that influence the development of social policy in each country.

Assessment of the needs and situation of individual carers has emerged as an important measure among some member states in ensuring they receive flexible and quality support services. It appears that such carer assessments are most developed in the UK, however undertaking of a carer assessment and identifying needs does not necessarily lead to the provision of supports to meet such needs. Such assessments continue therefore to be less effective than they might be. Some other EU states make formal attempts at identifying the needs of carers but only in the context of assessing the needs of the dependent person.

The importance of continued education and training of carers has become part of the wider EU Lifelong Learning Programme. An innovative research project – CARERS (Content Materials to Raise Employability and Reinforce Skills of Carers) is currently taking place across six EU countries. Its overall objective is to design a programme of education and training specifically aimed at informal carers, providing answers to meet their real needs in their caring role as well as for their own emotional wellbeing. It is also working with the 'ECL European Care License', which is designing a basic entry certificate in the care sector that could become a recognised and accepted certificate across Europe.⁵⁸

Another growing trend among several member states has been the introduction of personal budgets in order to support carers and promote choice and flexibility in long-term care. This is known in some countries as 'self-directed support'. The older or disabled person can purchase their own care, either from a nursing or care agency or by directly employing a personal assistant. The funds for such care often come from the local social services though may be from a wide range of sources including health and disability budgets and may be in voucher format.

The Caring Context – Gruntvig Project Partner Countries

Italy

It is estimated that between 3 and 3.5 million people in Italy provide care to a dependent relative.⁵⁹ United Nations data ranks Italy second in the list of countries with the oldest populations in terms of median age, just behind Japan. This clearly has implications for dependency ratios and care provision.

Support for carers

There are currently no national carers organisations in Italy, but several national and regional organisations do offer specific supports to Family Carers. In recent years some regions have introduced financial supports for Family Carers but there is no national structure for this. Some dependent people get a care allowance payment, again in some regions only, which they can use to pay someone to provide care for them. Since 2008, several Italian regions have used Regional Funds to provide economic resources for services to help disabled people.

Compared with some North Western European countries, there is relatively little published research on Family Carers in Italy. However, the findings of some significant reports are outlined below. We also list other reports in the footnote⁶⁰.

Eurofamcare – Report for Italy

This report represents the most comprehensive overview of the relationship between informal and Family Care and the provision of social supports for dependent people in Italy. However no reference is made to post-caring.⁶¹

CENSIS Report

This research was carried out by the Italian Institute of Socio-economic Research (2007), based on 401 interviews throughout Italy on the social and economic costs of Alzheimer's Disease.⁶²

Main findings

- Alzheimer's can be called a "family disease" because the care burden on other family members may be so heavy that they might also get sick. Support from appropriate community services may not be available.

- Most carers felt that the best place to care for the patient is at home.
- Carers suggested that their situation could be improved through the provision of a wide range of integrated services. According to carers, an ideal support system would mean economic support, tax relief, community services (day care, home care), the availability of a 'one stop shop' for diagnosis, therapy and social support.
- Those carers who reported a significant improvement of their situation were more likely to have access to an integrated system of services, where the carer is supported by community services such as day care or home assistance.
- Compared to 1999 data, the services available are slightly improved but still very limited and with significant regional differences.
- The main difference with the previous research is the phenomenon of 'badanti' (migrant live-in caregivers) who provide support to at least 700,000 families in Italy. Family carers considered badanti as supports only, not a replacement for their care.
- Carers noted the economic burden of care. Most of them agreed with the idea of a dedicated public fund to cover the risk of not being self-sufficient, financed by general taxation.

Private assistance

Compared to other countries in Europe, Italy is characterised by widespread recourse to privately hired caregivers – 'badanti' – often migrant women who live-in with the cared-for person. This context of informality, lack of a proper job contract, of training and supervision paid carers, who may be frail themselves, can cause problems.

- 40.9% of families interviewed employ a 'badante'.
- In most cases the badante lived in the same household as the cared-for person.
- These workers are mostly migrant (only 8.2% were Italian), female (95.1%) and without a professional qualification in the care field (89%).
- The cost of this service is borne entirely by families – 82.3% are paid for by the patient or their spouse.
- 63% of patients receive the 'mobility allowance', provided to people who are considered to be in need of constant care to provide their daily needs.

Care burden

- Family carers provide an average of six hours a day of direct assistance (personal care, meals, therapies) and seven hours of companionship (they stay with the patient while doing other activities). The amount of hours of care required is directly proportional to the stage of the illness. The employment of 'badanti' allow carers to decrease the number of hours of care, but not significantly.
- 52.4% of carers are helped by other members of the family to provide care, while 16.5% claim to be absolutely alone in taking care of their ill relative. Help from other members of the family is higher in southern Italy (60.7%) while in the north the percentage of lone carers is higher (20.7%).

Health

Caring can contribute to both physical and psychological fatigue which can have a negative impact on carers' health:

- 21.9% report they get ill more often
- 20% claim to have taken medication for illnesses related to care work, such as anti-depression and anti-anxiety drugs
- 87.3% reported feeling tired because of care work
- 53.6% said they don't get enough sleep
- 31.9% have experienced weight loss or gain.

Family relationships

- The majority (85%) of carers reported that their social life had been totally or partially affected by care work.
- 56.2% reported that care duties had created tension in the household, especially with the closest relatives. More than 50% regretted an incident of aggressive behaviour toward the assisted elderly. Nevertheless, 96.5% claimed that the feeling of being useful balanced out the difficulties.
- Carers were motivated by a strong feeling of responsibility towards the elderly and the moral obligation to provide care. 87% of carers considered care to be proof of family bonds and depth of feelings.
- 61.1% believed that care work had helped them to re-set their life priorities.

- 70.3% of interviewed refused respite care services and 87.5% strongly refused to take advantage of nursing home services.

Working and caring in Italy

The findings below are taken from a 2006 transnational report:⁶³

- 17% of economically inactive women of working age and 13% of retired women in Italy consider that caring has had a significant negative impact on their professional status, resulting in failure to access the labour market, giving up work to care, or early retirement.
- Working women face significant difficulties in combining work and care, with more than half reducing their working hours.
- One in four non-working women carers would consider part-time work as a means of combining work and care.
- 23% of women working in the private sector would like to work part-time in order to combine work and care.

The 2007 CENSIS report also reviewed the impact of caring on work.⁶⁴ It found that among those who reported having made changes in their working life:

- 33.9% had changed their role within the same workplace
- 32.1% had asked for part-time work
- 16.1% had to leave their job as they could not balance work and care
- 3.6% had lost their job
- 48.7% felt more tired carrying out their usual activities
- 28.9% reported frustration at not being able to perform as usual.
- 19.7% experienced problems in the workplace because of frequent absences
- 13.2% had given up chances for promotion or career progression
- 40% had in the past month stayed home from work to carry out care duties – with an average of 14.2 hours per month lost.
- In the past year, carers lost an average of 107.3 hours (equal to 13 workdays).
- Only one third of the sample had taken advantage of work permits under law 104/92 (for those who assist relatives with serious disabilities).

The UK

Facts about carers⁶⁵

- The most recent national figures on carers in the UK come from the 2001 Census. This showed that there are nearly 6 million carers in the UK. This is 10% of the total population, or approximately 12% of the adult population.
- Of the UK's 6 million carers, 58% are women, 42% are men
- Nearly 80% - 4.4 million – are of working age
- The peak age range for caring is 45-64
- 3 million people juggle paid work with care, 2 million full-time, 1 million part-time

Financial impacts of caring

- 72% of people are worse off as result of caring because of:
 - Costs of disability
 - Loss of income
 - Costs of paying for care
 - Inadequate benefits
- Two thirds of people spend their own income or savings to pay for care

Health impacts of caring

- People caring for more than 50 hours a week are twice as likely to be in poor health (three times more likely in the 18-25 age range)
- People's physical and mental health declines the longer they care
- People caring for more than 20 hours a week are twice as likely to be in poor mental health
- Carers report they are unable to look after their own health because of a lack of alternative care and emergency planning

Social impacts of caring

- Carers can become isolated even within families and communities because of:
 - Lack of services and support
 - Lack of access to social and leisure activity
- Carers who give up work to care are out of work for on average up to 10 years, and face considerable barriers to returning

- Carers can be forced to take early retirement to care – an average of eight years

A comprehensive briefing on carers in the UK, Facts About Carers, can be downloaded at:

www.carersuk.org/Professionals/ResourcesandBriefings/Policybriefings

Carers organisations in the UK

Carers UK is a campaigning and advocacy organisation, and provider of information and training to carers and professionals working with carers. Its mission is to improve carers' lives by: campaigning for change, providing information and advice, building an evidence base, mobilising supporters and transforming understanding of caring. It has 12,000 individual members, over 100 local groups and an affiliate membership of over 700 organisations working with carers.

Other national carers organisations include the Princess Royal Trust for Carers (PRTC) and Crossroads Care. PRTC is an umbrella for over 120 local carers organisations and Crossroads Care provides a range of sitting and respite services to families providing care. Carer support is also provided locally by age and condition-specific organisations such as Age UK, the Alzheimer's Society, Mencap, Scope, the Parkinson's Disease Society and others. Many of these organisations also have a campaigning role and are committed to raising awareness of the needs of their members and their carers, and improving their support.

Statutory services in the UK

Local authorities in the UK have a duty of care to people in their communities who are old, ill or disabled. Each person is entitled to a Community Care Assessment to determine their needs, and statutory services are provided within a Fair Access to Care eligibility framework. The criteria for eligibility are: critical, substantial, moderate or low levels of need. In practice, most local authorities only provide for critical and substantial needs. Services are means tested and can be charged for.

Local authorities also have a number of legal obligations towards carers through three key pieces of legislation:

- The Carers (Recognition and Services) Act 1995 gives carers the right to ask for an assessment of their own needs when a Community Care Assessment is being carried out for the person they care for.

- The Carers and Disabled Children Act 2000 gives carers the right to an assessment separate from a Community Care Assessment of the needs of the person they care for. It also enables carers to get Direct Payment for services in their own right.
- The Carers (Equal Opportunities) Act 2004 places a duty on local authorities to inform carers of their right to an assessment, and requires that assessment take account of a carer's wish to access work, learning and leisure.

Local authorities provide some services 'in-house' but many more now commission services externally, from the private or voluntary sectors. These services are still subject to eligibility criteria, and can still be charged for. Services can also be delivered through Direct Payments or Individual Budgets (budgets which draw on a number of statutory sources of support) which can be used to purchase services directly, or to pay for a personal assistant. This is seen as a way of providing more personalised services

Services provided by the National Health Service (NHS) are free at the point of delivery. These now include respite for carers following new funding made available through the National Carers Strategy. There is dedicated hospital discharge legislation that requires medical staff to involve carers in hospital discharge decisions about the person they are caring for. Community health services such as occupational therapy and stroke rehabilitation can provide valuable support for families and families. These are free of charge as part of the NHS's Continuing Care commitment.

There are a range of welfare benefits and payments which carers can apply for. These include: Carers Allowance, Income Support, Pension Credit and Housing and Council Tax Benefit. Carers Allowance has an earnings limit (and is the lowest benefit of its type) and the other benefits are means tested. They therefore only support carers on very low incomes.

National Carers Strategy⁶⁶

Launched in 2008, following extensive consultation and involvement with NGOs, the Strategy contains a bold vision which the report says is a shared vision and responsibility between central and local government, the NHS, voluntary sector, families and communities. The Strategy says that by 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;

- carers will be able to have a life of their own alongside their caring role;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity;
- children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

There are specific commitments in the areas of social care services, information for carers, carer support services, health, carers and employment, young carers and carer identification.

For a full report go to:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

For a summary and policy digest go to:

<http://www.carersuk.org/Professionals/ResourcesandBriefings/Policybriefings>

As of August 2010, a consultation has been launched by the UK's Coalition Government to 'refresh' the Strategy in the context of the Coalition Agreement. However, a commitment has been made to retain the vision as published in 2008.

Working and caring in the UK

There are 6 million carers in the UK, and 3 million combine work and care. Of these 1.4 million are men and 1.7 million are women. It is now recognised in the UK that caring can have a significant impact on labour market participation. The National Carers Strategy makes provisions for support into learning and work for carers, specifically:

For working carers:

- An awareness raising campaign to ensure carers and employers are aware that carers have the right to request flexible working.
- Government to work with business to produce a good practice guide for all employers on the benefits of recruiting carers. It will include case studies and focus on the business case for employing carers.
- A review the definition of carer in the flexible working regulations to consider

extending it to the 20% of carers who currently miss out.

For carers seeking to enter or re-enter work:

- A Care Partnership Manager in every Jobcentre Plus (employment service) district. These will be aware of care services that are available in the local area so can ensure that carers are offered appropriate support.
- Improvements in training for Jobcentre Plus advisers.
- Funding for replacement care for carers participating in approved training.
- Jobcentre Plus to investigate the feasibility of providing return to work support through voluntary sector organisations
- Government to encourage more flexible learning opportunities to be made available to carers.

There is also legislation which supports and protects carers in the workplace:

- The Employment Relations Act 1999 gives carers the right to emergency leave to make arrangements for a disabled child or adult dependant.
- The Work and Families Act 2006 gives carers of an adult dependant the right to request flexible working.
- The Equality Act 2010 protects carers from discrimination by association with disability and age at work and in the provision of goods and services.

The most significant activity and research in the area of carers and work was commissioned through the Action for Carers and Employment (ACE National) partnership, funded by the ESF's EQUAL Community Initiative Programme from 2002-2007 and led by Carers UK. The research was undertaken by the Centre for International Research into Care, Labour and Equalities (CIRCLE) at the University of Leeds.

The full report and other reports relating to the ACE partnership and carers and employment are available at;

www.carersuk.org/Professionals/ResearchLibrary/Employmentandcaring

Ireland

The latest data indicates that there are in the region of 274,000 Family Carers, with in the region of 53,000 full-time Family Carers.⁶⁷ Family Carers are currently registered in relevant statistics as economically inactive. However, they provide vital care to family members in the home, thus saving the economy considerable amounts of money. It is estimated that Family Carers contribute over €5 billion to the economy every year which would otherwise have to be spent in the health service. It is also estimated that every week 3.7 million hours are worked by Family Carers across Ireland.⁶⁸

A comprehensive overview of Caring in Ireland has recently been completed (August 2010) and is available at: www.carealliance.ie/Family%20Caring%20in%20IrelandAugust2010

Carer support services in Ireland

There are currently two national carers organisations, The Carers Association and Caring for Carers. There is also one umbrella organisation, Care Alliance Ireland, which brings together more than 75 not-for-profit organisations currently involved in delivering carer support services. The state supports Family Carers in a number of ways. For a full list of the supports offered to carers see:

[www.carealliance.ie/pdfs/Services%20directlyforortoassistcarersDSFANovember2009\[1\].pdf](http://www.carealliance.ie/pdfs/Services%20directlyforortoassistcarersDSFANovember2009[1].pdf)

Many full-time Family Carers receive a weekly payment – either The Carers Allowance or Carers Benefit. However as the Carers Allowance payment is means tested, many Family Carers do not receive financial support. In many regions some carer support services such as telephone support, outreach, training, carer support groups and home or residential respite are contracted out to voluntary organisations, most of whom are members of Care Alliance Ireland. In other areas home care support and respite care are delivered by state organisations. In addition, in some areas a co-ordinator is employed by the state to oversee carer support services.

Health impact

The most extensive piece of Irish research to date examining the health status of Family Carers found that, in comparison to the general population, those Family Carers who responded to the survey (n=1,411) were less likely to report themselves in excellent or very good health.⁶⁹ Family

Carers presented a considerably less positive picture of quality of life in comparison to the general population. Family Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. A key factor in this appears to be the limits on leisure and recreation time imposed by caring.⁷⁰

In a 2009 study of Family Carers, 71% reported their health as 'quite good' or 'very good' but well over half experienced being mentally or physically 'drained' by their role. Heavy caring tasks such as dealing with verbal or emotional abuse, coping with bizarre or inconsistent behaviour and getting up in the night were most often linked to poor health. Over half reported having a medical problem, the most frequent being back injury, and over half reported a significant mental health problem, the most frequent being anxiety disorder. Most carers worried how the person they cared-for would cope if they could not care any longer due to illness or death. They were also concerned that they had no time for themselves due to caring.⁷¹ Qualitative research was undertaken in 2009 which explored the health and wellbeing of Family Carers of people with Parkinson's disease. It found that the role of Family Carer is both physically and emotionally demanding, particularly as the cared for person's condition deteriorates and caring needs intensify.⁷² High blood pressure, tiredness, lack of physical energy, back problems and arthritis were all seen as consequences of caring. Carers expressed feelings of loneliness, anxiety and depression as a result of the physical demands of caring.⁷³

Young carers

A recent (2009) report on young carers found that the majority of respondents were providing care for someone with an intellectual disability.⁷⁴ A significant number of those interviewed were the primary carer for a family member. Their caring roles included intimate and emotional care as well as domestic and child care. Respondents looked for more information, advice and home help to support them in their caring.

The report considers the impact of caring and concludes that any policy response designed to support and assist young carers should be guided by the principles of:

- Protection of children's rights
- A family support approach
- Multi-agency and multi-departmental response

Working and caring In Ireland

In the 2006 Census, 90,544 Family Carers reported to be also in paid employment. This represents 56.27% of the overall Carer population identified. 55% of working Carers are female, while 45% are male. Of those working, 16% (14,068 people) were also providing full-time care to a loved one. Male Carers are more likely to report full-time caring as well as being in paid employment. 54% of male Carers who reported providing full-time care also reported being in paid employment. This compares with 31% of female full-time Carers.⁷⁵ On average, Family Carers who work outside of the home provide 19 hours of unpaid care per week.⁷⁶

Key policy documents

Issues relating to Family Carers in Ireland are visible in several recent national policy documents. The National Partnership Agreement **Towards 2016**⁷⁷ contained a commitment to develop a National Carers Strategy. This was to set out the Government's vision for Family Carers and establish a set of goals and actions in areas such as income support, health care and services, housing, transport, information services, labour market issues, programmes of training, social inclusion and research and technology development. However, the Government took the decision in March 2009 that the long-promised strategy would not be published, citing the economic situation which they claimed "makes it difficult to commit to major advances in services for carers".⁷⁸ In 2009 The Carers Association of Ireland compiled a comprehensive, mostly quantitative report entitled **Carers in Ireland – A Statistical and Geographical Overview**. It is recommended reading and is available to download at:

www.carersireland.com/library_census.php

Greece

The family continues to be very important in Greek society. Informal care is a common phenomenon in Greece, with a large number of informal carers. However there is no national data on the number of informal carers in Greece.

Research on family care in Greece

The 2006 Eurofamcare study⁷⁹ provides an overview of available data: “One of the first qualitative reports on family care in Greece,⁸⁰ described the role of family care, while a later report by the same author and others, evaluating the ‘Help-at-Home’ programme, provides a cost benefit analysis of the service, comparing this to the costs of residential care, though this was not focused on the benefits to family carers.⁸¹ Triantafillou and Mestheneos in a qualitative study and in a number of articles on family care and services supporting older people and family carers have reviewed the support given to family carers and the private arrangements they are forced into making, such as the use of migrant care workers. Since this original study there have been no further studies on family care though data from the European Household Survey and the EuroBarometer study provide some information on the probabilities of older people living near their families with some data on attitudes, patterns of help and support etc.⁸² European research studies, such as PROCARE, provide descriptions of the services available for older people in Greece, together with some reflections on their use by family carers and whether or not family carers are “integrated” into the work of care teams.⁸³ Aspects of Greek public policy to support older dependent people are reviewed in the OECD and WHO reports”.

EUROFAMCARE is the latest survey where 1029 Greek carers were interviewed. The main aim of the EUROFAMCARE project was to evaluate the situation of family carers of older dependent people in Europe.

Eurofamcare results – report for Greece

According to Eurofamcare results for Greece, nearly two thirds (64.5%) of the dependent older people were women.

- About half the older people being cared for (49.8%) were aged 65-79 years and the rest (50.2%) were over 80 years of age.
- The great majority of those cared for (98.7%) lived at home. Those in residential care represent only 1-2% of the elderly population.

- As might be expected, the main reason for care reported by family carers was physical illness and disability (30.6%), followed by mobility problems (24.4%) and the non-specific category of age-related decline (15.9%). When all reasons for care (2nd, 3rd and 4th reasons) are added, these figures rise to 55.7%, 57.6% and 29.3% respectively.
- 35.8% of those cared for were reported to have memory problems and in a further 23.8% behavioural problems were noted, giving an indication of the higher levels of stress likely to be experienced by carers dealing particularly with the latter type of problem.
- Interestingly, mental health issues such as depression were reported as the main reason for care in only 1.9% of the sample, although their total contribution to the need for care rose to 9.9%. These types of disorder are also a significant cause of behaviour problems and attempts to improve their recognition and treatment at an early stage should help to improve quality of life for both older people and their carers.

Facts about Greek carers

- The average age of Greek family carers was 51.7 years, though the actual range of carers age was from 18 - 95 years. Women were overwhelmingly the main providers of care, representing 80.9% of family carers.
- The marital status of family carers: 76.4% of the sample were married or cohabiting; 6% were widowed; 5.7% divorced or separated and 12% were single.
- 17.1% were spouse carers, and many of the male family carers were in this category. A further 1.8% were siblings of the cared-for older person.
- 55.4% of carers were adult children of the cared for person and 13.9% were daughters-in-law or sons-in-law. 4.4% were grandchildren, 4.2% were nephews or nieces and 3.2% fell into other categories such as other relatives, close friends, neighbours and volunteers.
- The educational level of carers was relatively low: 37.4% had a low level of education; 40.6% an intermediate (typically those who had finished High School / Lykeio) and 22.1% had a high level of education.
- 47.2% of family carers were also in paid work.
- The findings showed that in 50.7% of the sample family carers and the dependent older person shared the same house. The mean number of hours of care given to the main cared for person was 51 hours per week.

When Caring Ends

There are few published reports on the post-caring period, but there is strong evidence to show that the psychological, social and physical health consequences of caring may leave some family carers poorly equipped for life after care.⁸⁴

Looking after a loved one may have taken up a massive part of many carers' lives, with the needs of the cared for person taking priority. When this caring ends – due to the death of the cared for person, moving into long-term residential care or because they no longer need care – many carers find it difficult to deal with this significant change to their life circumstances. It is vital that former carers are adequately supported in the period immediately after caring ends, through bereavement and counselling services, return to work, training and education programmes, and social inclusion programmes.

Some key reports on post caring include:

- McLaughlin, E. and J. Ritchie (1994) *Legacies of caring: the experiences and circumstances of ex-carers. Health and Social Care*, 2 (4): 241-253.
- Larkin, M. (2009) *Life after caring: The post caring experiences of former carers. British Journal of Social Work*. 1-17

Both reports are available in full. See www.lifeaftercare.eu/resources.php

Larkin (2009) identifies two core categories which emerged that related to both caring and post-caring experiences. With reference to post-caring, integrating the categories led to the development of two new concepts – 'the post-caring trajectory' and the 'serial carer'.

Larkin's study established that;

*“post-caring life for those interviewed had an identifiable trajectory with three phases, each of which involved a distinct set of experiences. These were the **post-caring void**, **closing down ‘the caring time’** and **constructing life post-caring**. As the cessation of caring coincided with the death of a close relative for all but one of the former carers interviewed, bereavement influenced this trajectory. In the exploration of the three phases that follows, the findings about the interviewees' lives when caring that emerged from the study are used to identify those post-caring experiences that were associated with caring and its cessation. Hence, distinctions are*

made between those experiences that relate to post-caring life and those that are influenced by bereavement."

The post-caring void

The initial phase in the trajectory involved specific emotional experiences, such as feelings of a loss of purpose, disequilibrium and loneliness. The second phase involved a different set of experiences.

Closing down 'the caring time'

The first few months of post-caring life were described as the 'wind-down period' because it involved winding down life as a carer. During this transitional period, routines changed and carers undertook closure activities. The final type of closure activity associated with this phase was undertaking domestic tasks that had been left undone during caring because of lack of time, particularly in the later stages of caring.

As these transitions were made, carers gradually reconstructed life post-caring in different ways. This process took place in the third phase of the post-caring experience.

Constructing life post-caring

This involved carers getting 'life together' again, and 'coming up to the surface'. Although factors such as being well integrated into a local community, good physical and mental health, and an adequate income all helped; it was families, interests, friends, paid work and further caring activities that played the most important roles in the reconstruction of life post-caring. The concept of the 'serial carer' was developed to reflect the phenomenon of serial caring that had emerged.

Larkin makes three specific recommendations(in a specifically UK context):

- **Adoption of a more holistic approach to carers' needs:** The study indicates that the focus on carers' needs during caring should be broader and include post-caring needs. One way forward is to use the resources available to carers as a result of the 2004 Carers (Equal Opportunities) Act, not only to support them during caring, but also to address their post-caring needs. When working with carers, social workers can encourage them to think about life post-caring and what they need in order to achieve

their goals when they have ceased caring. Some of the resources within their care package can then be allocated to helping them plan for their post-caring lives while still caring. For example, they could use their vouchers or cash payments to obtain respite care or short break services for their dependant so they can spend time maintaining their interests, developing their skills and undertaking any relevant education and training. A further suggestion is that local authorities redesign and extend carers' assessments to identify serial carers and address needs that arise during caring and post-caring for this group.

- **Increased recognition of former carers by professionals:** Those working in health and social care who have had contact with carers during caring should not automatically close cases when caring ends. Follow-up visits could be introduced during which former carers can discuss any challenges they may face in their post-caring lives as well as sources of support, such as carers groups.
- **Use of voluntary provision:** Social workers working with those in the voluntary sector organisations who support carers, such as carers centres and carers groups, should encourage them to provide post-caring support that is responsive to the possible demands on former carers.

Larkin concludes that more research about former carers is required in order to ensure policy and practice improves the lives of post-carers.

“Whilst the paucity of up-to-date research into this neglected area needs to be addressed, the two original concepts produced as a result of this study require additional exploration in particular; there is need for a more comprehensive understanding of the phases within the post-caring trajectory that can then be used to guide the future planning of post-caring support. Further research into the concept of the serial carer would contribute to greater recognition of the frequency of serial caring, its implications for the lives of those concerned, and enable more constructive ways of meeting serial carers' needs to be devised.”

McGartland-Rubio argue that the well-being of some carers after the death of the person they care for is enhanced by their caregiving experience. However longitudinal studies have also documented complicated grief for about 20% of carers, including aspects of disbelief, anger and bitterness, preoccupation and recurrent painful emotions, and avoidance of situations and

activities that are reminders of the loss, often leading to depression⁸⁵ There are other findings that pre-existing depression in carers persists after the death of the cared for and more recent bereavement is associated with higher depression scores⁸⁶. However, there are also findings that death of the cared for person reduces carer depression, and carers often return to normal levels of functioning within a year.⁸⁷

Current Research on Post / Transition Caring

Breen's literature review has detailed the three types of post-caring transitions identified previously.⁸⁸ These are:

Nursing home placement transition

Significant findings from the literature included; negative stereotype of nursing homes – carer guilt, reconstructing relationships with relative, lack of privacy or intimacy, carers trying to maintain identity of loved one, personalising their space in the care facility, advocacy and case manager role, continuing with caring tasks such as feeding, brushing hair, going for walks, shopping, and negotiation of staff/informal carer relations.

Hospice transition

Significant findings from the literature included; mutual understanding, awareness, acceptance, clear communication with carers – focus now is on quality of life rather than hope of cure, carer reluctance to enrol in hospice – impending role transition from carer to bereaved, carers view dynamic period of hospice – time for powerful emotions and meaningful interactions with loved one, former carers rate hospice more favourably than hospital care – better communication with family and more dignity, professional bereavement interventions very helpful.

Death transition

Significant findings from the literature included; preparation for loss enhances carer well-being outcome, bereavement support (mostly based on talking), few support services – if not linked to hospice, mixture of relief and grief, range of carer reactions – depends on exposure to stressors and access to resources.

In summary, Breen found that there appears to be a larger literature on nursing home placement than either hospice or death transition. The majority of the literature focuses on carers for those who are elderly (dementia, Alzheimer's, frail) or people who have cancer. She reports a dearth of research examining carers of children, adults with learning or physical disability or mental illness.

Despite the various backgrounds of the former family carers interviewed, the initial findings of Breens qualitative research (July 2010) are suggesting commonalities across the group interviewed (n=26). Similar emotional reactions to postcaring, as well as shared needs for health, training and financial supports are emerging from the data. It is envisaged that the report will be completed by year end 2010.⁸⁹

Supports for former carers

The UK has taken the lead in the EU in this area, with a tailor made online training for ex-carers. **Learning for Living** is an online learning programme designed specifically for unpaid carers. Over one and a half million people in the UK have given up their jobs to look after sick, disabled or frail relatives. These people often do not think of themselves as carers, but view caring responsibilities as part of their daily lives. See www.learning-for-living.co.uk

More recently, as part of the commitments made in the 2008 National Strategy state-funded job centres have worked closely with carers organisations to ensure that ex-carers are given particular supports to enable them to return to the workforce. Carers UK also have a dedicated web-page outlining the various options for those whose caring has ended. See <http://www.carersuk.org/Information/Whencaringends/Lifeaftercaring>

We are not aware of any specific projects or state initiative within other partner countries which support ex-carers. This is something which we hope will change in time.

Who speaks for carers in Europe?

A **European Parliament Interest Group** was launched in June 2007. The Group has been active and proved to be an invaluable tool in supporting awareness raising and influencing current and future EU health and social policy development. Following the European Elections in June 2009, the group was re-established in February 2010 with the support of Eurocarers and Marian Harkin, MEP. Currently there are 30 MEPs who are members of the group. The Interest Group has the potential to provide an effective platform for concrete contributions to EU policy initiatives.

Many of the current EU policy initiatives have a bearing on care provision and carers, and include the following:

- the upcoming post-Lisbon consultation
- future Communication on long-term care provision
- the European Employment Strategy
- Equal Opportunities initiatives
- Open Method of Coordination in health and long term care
- EU Health Programme and Health Strategy
- Alzheimer initiatives
- European Mental Health Pact
- Framework Programme (FP)7 and FP8
- the PROGRESS programme
- upcoming European Years – Social Exclusion 2010, Volunteering 2011 and Active Ageing 2012

Eurocarers, the European association working for carers, was also launched in 2007.

Eurocarers is a non-government organisation (NGO) which aims to represent and act on behalf of all informal carers, irrespective of their age or the particular health need of the person they are caring for. Eurocarers brings together organisations representing carers and those involved in research and development. Among its principal aims are:

- Contributing to policy development at national as well as European level supported by evidence-based research: by acting as a voice for informal carers and issues relevant to carers and by translating relevant EU policy developments to members operating at national and regional level.

- The exchange, gathering and dissemination of experience, expertise and good practice, as well as innovations.

Eurocarers also aims to collaborate with other interest and advocacy groups at national and EU level – including organisations representing disabled people and their families, women’s organisations, organisations campaigning against social exclusion and poverty – in order to promote recognition of carers and carers’ interests and shape a policy environment that is more favourable to carers. Other organisations such as AGE, Coface and Alzheimer Europe also have a keen interest in carers’ issues, often acting as advocates for carers at a European level.

For further information see www.eurocarers.org

Footnotes

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- ⁸⁸ We acknowledge early access to Dr Marianne Breen's literature review in her ongoing (2010) research on post caring. This research, based in the School of Nursing and Midwifery in Trinity College Dublin is exploring the needs and experiences of former at-home carers whose loved ones have recently died or moved to either a nursing home or hospice.
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