

CARERS AND SOCIAL EXCLUSION

Claire Cairns - The Coalition of Carers in Scotland



“You lose yourself in being a carer – although it’s a label, it actually becomes who you are. You are the carer, and that is what actually defines you.”

The Personal is Political

- Across Europe, unpaid family carers and friends are the largest providers of health and social care support
- As demographic change increases demand, the ‘balance of care’ increasingly shifts to informal care
- Women are disproportionately affected and are more likely to give up employment to care



*“There is nothing else we can cut back on.
The boiler is broken so we are freezing cold.
I buy reduced or unhealthy cheap food from the shops.”*

Impact of Caring on Finances

- Out of the 23 countries in Europe which offer any type of **financial support**, only 9 offer direct support in the form of a **carer allowance**
- Carers face **77%** higher utility bills and **67%** higher transport costs (UK)
- A third of carers are **in debt** (UK)



"I broke down and only now do social services listen to me and assess us."

Inadequate Support

- **Respite care** services are provided in 21 European countries. They are the most common type of services provided to carers in Europe.
- **Training and information** are provided in 17 countries, counselling in 12 countries
- **How accessible?** 1 in 5 carers in the UK receive no practical support with caring



*“As a carer, you have no social life whatsoever.
I have been an unpaid carer for 20 years. I do not
feel part of society at all. I feel a complete outsider”*

Social Exclusion: isolation, loneliness and the impact of caring on relationships

- 83% of carers have felt **lonely or socially isolated** as a result of their caring responsibilities (UK)
- 75% of carers said it was hard to maintain **relationships and social networks** because people do not understand the impact that caring has (UK)
- 57% **lost touch** with friends or family. (UK)



“I know: by the time we qualify for support I will have been forced to give up my job and be caring 24/7 – I’ve been told as much by social service”

Employment and Gender

- Across Europe, **2/3 of carers are women**
- Women are more likely to be **sandwich carers**
- Women are more likely to give up work to care
- **1 in 5 carers had to give up their jobs** because they were in crisis (UK)
- **Half of working age carers** live in a household where no-one is in paid work (UK)
- Support for carers in employment varies across Europe



“63% of carers from an ethnic minority have not had break from caring. Of those who accessed a break only 29% used formal services (Scotland)”

Isolated Groups

- Carers from an **ethnic minority**
- **Young Carers** / Young Adult Carers
- Carers from **rural and island communities**
- Carers from **LGBT** communities
- Carers looking after someone with **mental health** issues or **drug/alcohol misuse** issues



*"I had a heart attack
from the stress and
worry of it all."*

Physical Health

- 50% suffered a **physical injury** or seen a deterioration in their health (UK)
- 75% said they could not get a good nights **sleep** (UK)
- 46% said they had fallen ill but had **no choice but to continue to care** (UK)



*“One day I couldn’t take any more.
I was just crying uncontrollably and couldn’t function.
My family stepped in to look after mum
so I could just rest and pull myself together”*

Mental Health

- 63% of carers had suffered from **depression** as a result of caring (UK)
- 20% higher **prevalence of mental health problems** in the caring population (European study)
- More anxious and depressed carers report more **incidents of abuse**



*“My doctor described it as ‘burnout’ –
the next step after chronic fatigue.”*

Breaking Point

- 6 in 10 carers have been pushed to **breaking point** (UK)
- 1 in 4 of these required **medical treatment** as a result (UK)
- 1 in 8 required **emergency care**, were rushed to hospital, or social services had to step in to provide replacement care (UK)





*“Always, always a duty!
If left to government
guidance it will never
happen”*

From Recognition to Rights

*“Carers rights should not be seen as a party political issue,
but a human issue, a community concern, a common
responsibility which does and will affect all of us at some
time in our lives”*



“At all levels carers need to experience a constancy of purpose, a clarity of policy and a consistency of practice.

This can only be achieved when carers have a legal entitlement to support and are recognised, respected and rightfully seen as equal and expert partners.’

Scotland’s 2015 New Year Resolution

To give carers the right to the support they need to sustain them in their caring role, based on a National Framework that ensures this right is implemented consistently across Scotland.



“There needs to be equality across the board – everyone assessed using the same eligibility critieria with the same entitlements to support and resources.”

Policy focus: rights and entitlements

- **Financial support:** income based on a minimum wage
- **Employment:** flexible working, paid leave, unpaid leave
- **Regular breaks from caring:** minimum entitlement for those with substantial caring roles
- **European Carers Strategy** and strengthening carer focus in other EU workstreams



*“Unpaid carers are providers of services, not users.
Investment in carer support brings huge economic
and financial returns to every society.”*

Eurocarers Motion – Helsinki 2014

- A ‘**new social contract**’ for carers?
- **National and regional carer strategies** in each member state and municipality by 2020, addressing caring and poverty?
- More research on carers and economic well-being?
- Cut link of carer payment from employment related benefits?
- Carer Action Day on 17 November to combat poverty in caring?



We **SAVE**
Scotland
£7.6 Billion
INVEST
in carers

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Voice of Carers Across Lothian

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CARERS
NEED
REAL CHANGE
NOT
SHORT
CHANGE

HUMAN RIGHTS
ARE FOR
DISABLED PEOPLE
TOO

Thank you!

Information sources

- **Carers at breaking point**, Carers UK, 2014
- **Caring and family finances inquiry**, Carers UK, 2014
- **State of Caring**, Carers UK, 2014
- **Mapping support policies for informal carers across the European Union**, Emilie Courtin, Nadia Jemiai, Elias Mossialos, July 2014
- **Rest assured**, a study of unpaid carers' experience of short breaks, Shared Care Scotland, COCIS, IRISS, MECOPP, 2012
- **Help Wanted? Providing and Paying for long-term care**, OECD, 2011

