

AGENDA

10.30 Refreshments and Welcome

11.00 Paying the Price: The Hidden Impacts of Caring.
Dr Nikki Dunne (Family Carers Ireland)

11.20 Findings in Context: David Maher, Family Carer

11.30 The Impact of Caring: Analysis of Research Findings
Dr John Hillery, President, College of Psychiatrists of Ireland

11.55 Discussion/Q&A

12.15 The Burden of Wounds: The Role of the Family Carer in Wound Care – Focus Group
Findings, Fiona Rafferty, Nutricia

12.15 Discussion/Q&A

12.30 ***Lunch***

1.30 How Family Carers can Advocate Effectively, Jillian Garvey, Carr Communications

2.50 Closing Conference Address, John Dunne, CEO,, Family Carers Ireland



PAYING THE PRICE

THE HIDDEN IMPACTS OF CARING

This study was a collaboration between Family Carers Ireland, the College of Psychiatrists of Ireland and UCD School of Nursing, Midwifery & Health Systems



**College of Psychiatrists
of Ireland**

Wisdom • Learning • Compassion



**UCD School of
Nursing, Midwifery
and Health Systems**

This is the second report in a series examining the health and wellbeing of family carers.

About the Research

- ▶ Survey of the membership and network reach of Family Carers Ireland
- ▶ Repeat wave of a similar study conducted in 2009
- ▶ Combination of online and postal distribution
- ▶ Achieved sample of 1102 family carers
 - ▶ All counties in Ireland represented
 - ▶ 95% CI of +/- 3%



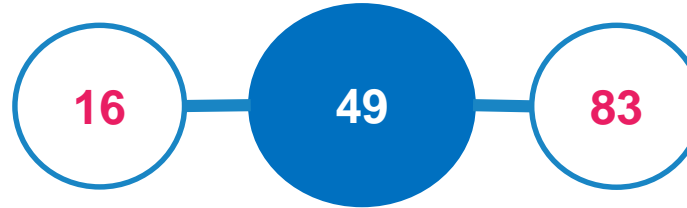
Overview of Respondents (N=1102)



90% were women



Average Age = 49 years



47% of carers were providing care to a child (under 18)



31% of carers were providing care to an older adult (over 65)

21.3% were in paid work

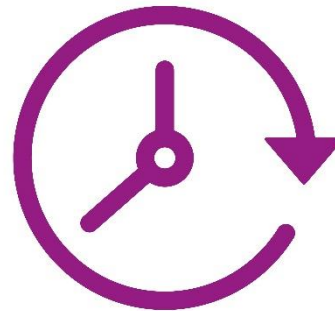
70% part-time and **30%** full-time

70% full-time carers

42% of respondents have been caring for 10 years or more

61% of carers are provide 100 hours or more care per week

22% of carers are provide 50-99 hours care per week



Family Carers' Health



67% of carers reported that they were diagnosed or treated for a physical health condition

40% diagnosed with **back injury** (compared to 33% in 2009)

26% diagnosed with **high blood pressure**



48% of carers reported that they were diagnosed or treated for a mental health condition

35% diagnosed with **depression** (compared to 20% in 2009)

39% diagnosed with **anxiety**

68% of carers reported that they quite frequently or nearly always felt that their health had suffered because of their caring role



88%

**felt
stressed**

Almost 9 in 10 (88%) carers
felt stressed trying to balance
caring with other family and
work responsibilities.



Which of these tasks do you do on a regular basis for the person you care for? Tick ✓ all that apply to you.

- Shopping for food, prescriptions and clothes
- Preparing meals
- Doing housework and routine jobs around home
- Doing laundry and ironing
- Giving medicines
- Washing and dressing
- Assisting with getting in and out of bed
- Assisting with toileting
- Assisting with cutting up and eating food
- Assisting with recommended exercises, activities or therapies
- Supporting with applications for benefits/advice they might be entitled to
- Transporting to shops and appointments
- Transferring and positioning
- Dealing with physical aggression/violence**
- Dealing with verbal/emotional abuse**
- Coping with inconsistent/bizarre behaviour
- Getting up in the night
- Supporting them to manage their finances/money
- Other (please specify) _____

Family carers experiencing abuse



44% of family carers regularly experience abuse as part of their caring role



57% diagnosed with mental ill health



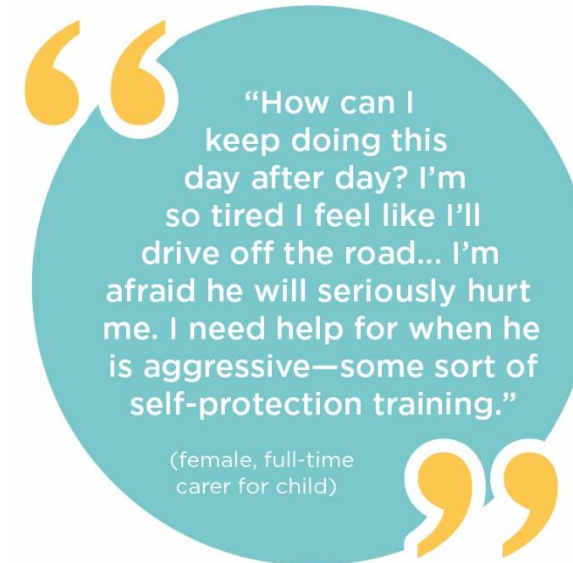
72% diagnosed with physical ill health



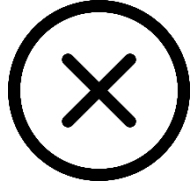
80% have received no training for their role



70% do not have access to appropriate respite



1. Unavailable & Inadequate



49% said services were unavailable



76% of care recipients did not receive any home care hours



16% of children received home support hours where their carer couldn't leave the home



“Living with a child with a severe disability both intellectually and physically has profound effects on the parents and the siblings, there are NO support services for them. Family life is not ‘normal’ and can never be, it leaves a mental scar on us all. Nobody understands what it’s like until you live in it.”

(female, full-time carer for child)



2. Inconsistent



83% of care recipients had no access to suitable respite



Inconsistency of provision and availability of respite across the country

“I’ve cancelled a medical procedure for myself three times this year because I can’t get my son minded for the 24 hours I need to be in hospital. My own health suffers a lot and I’ve no back up so I can’t take care of myself. I was diagnosed with depression... nobody minds me or knows how bad it is.”

(female, full-time carer for adult child)

“I’m sick of doing multiple different assessments to go on a waiting list to be told they have to be redone when the service actually becomes available.”

(female, full-time carer for elderly parents)

“There’s no appropriate respite for my Mum with Alzheimer’s who is a fall risk. An appropriate service is available but it’s not in our catchment area. So we don’t get any respite. We can’t afford to pay privately.”

(female, full-time carer for elderly parents)

“We’re not in a catchment area for appropriate intellectual disability services.”

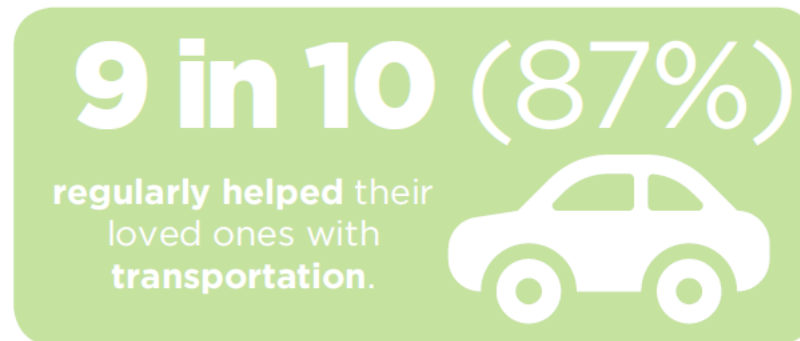
(female, full-time carer for child)

3. Inaccessible

22% reported that supports and services, when available, were too far away

14% said they could not access supports due to a lack in transport

22% requested assistance with transport.



“I travel non-stop to numerous appointments, clocking up 500km per week. Yet there’s no travel allowance or car maintenance subsidy for family carers.”
(female, full-time carer for two children)

“I’ve had huge problems getting to appointments in SVUH due to a lack of disabled spaces, set down areas and assistance in getting him out of the car and into the clinic.”
(female, full-time carer for spouse)

4. Unsuitable & Poor Quality

“My Dad needs more local day care with quality stimulation activities and better quality meals. He needs more than bingo!”

(female, full-time carer for elderly parent)

“Many supports and groups are well intentioned but they end up calling us to manage issues and behaviours, even the day services.”

(female, full-time carer for an adult and young child)

43% said supports and services were not disability, condition and/or age appropriate

37% said quality was poor

28% said staff needed more training

5. Unaffordable

“Payments to carers are too low to sustain a family, especially with the rising rental prices. DCA is getting used for living expenses in order to survive which means the child isn't able to get private therapy, which the payment is meant for.”

(female, full-time carer for child)

73% of carers were worried about money

79% of carers looking after children said they did not have enough money to take care of their loved one and meet other expenses

“Housing is a major worry. How will we cope if we lose our home of 20 years? This is a real possibility as the mortgage is now being prepared for sale to a vulture fund.”

(male, full-time carer for two children)

Recommendations to support and safeguard carers



Recognise carers as at risk of abuse



Practical approaches to protecting carers at risk of harm include:

- Healthcare professionals trained to identify and support carers
- Training for carers
- Emergency respite care services, available at short notice
- Involve all agencies who play a role in safeguarding adults and children

Recommendations to support and safeguard carers



Urgently address the home care crisis and postcode lottery



Immediate abolishment of the *in loco parentis* rule.



Address the transport needs of carers