



# Caring for the Carers Balancing the rights of Carers and the Cared for Person in Ireland: Implications for Policy and Practice

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# Context for Family Caregiving

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- 80% of all long-term care is provided by family carers (Eurocarers, 2025),
- Since the 1980s, responsibility for providing care has shifted almost completely away from formal services onto families (Fraser, 2016).
- Key drivers of demand - globally - include the ageing profile of the population alongside growing numbers of children & working age adults with long-term health conditions (Milne & Larkin, 2023)
- Care demands are also more time-consuming & complex:
- Carers are supporting more people with challenging conditions & multi-morbidities (e.g. dementia)
- Carers are doing more care tasks and more complex tasks too
- Is it right and/or safe that family carers do these tasks?
- Carers are now expected to care in almost all circumstances
- The 'ageing of caring' is also relevant: a third of all UK carers are older



# Family Caring in Ireland

## 2025

### Who is a Family Carer?

Someone who provides regular unpaid personal help or support to a family member, neighbour or friend with a long-term illness, health issue, an issue related to old age or disability (CSO, 2022a)



### Who Cares?

**14%** or **611, 828**

of the population aged 15 and over are providing family care (CSO, 2022b & Healthy Ireland, 2024)

### What About Gender?

61% of family carers are women, and 39 % are men. (CSO 2022)



29% of women aged 45-54 identify as a carer (Healthy Ireland, 2024)



**€244** per week

is the additional cost of caring for an adolescent with additional needs (MacMahon, Boylan & Thornton, 2022)

**101,426**

carers receive the Carers Allowance

**137,000**

carers receive the Carer Support Grant

(DSP, 2025)

### What is the Financial Contribution of Family Carers?

**€ 20bn per year**  
(FCI, 2021)

### How Many Home Support Hours Are Provided Each Year?

**23.4m** in 2024

(HSE 2024; excludes PA & Home Support Hours delivered through Disability Services)

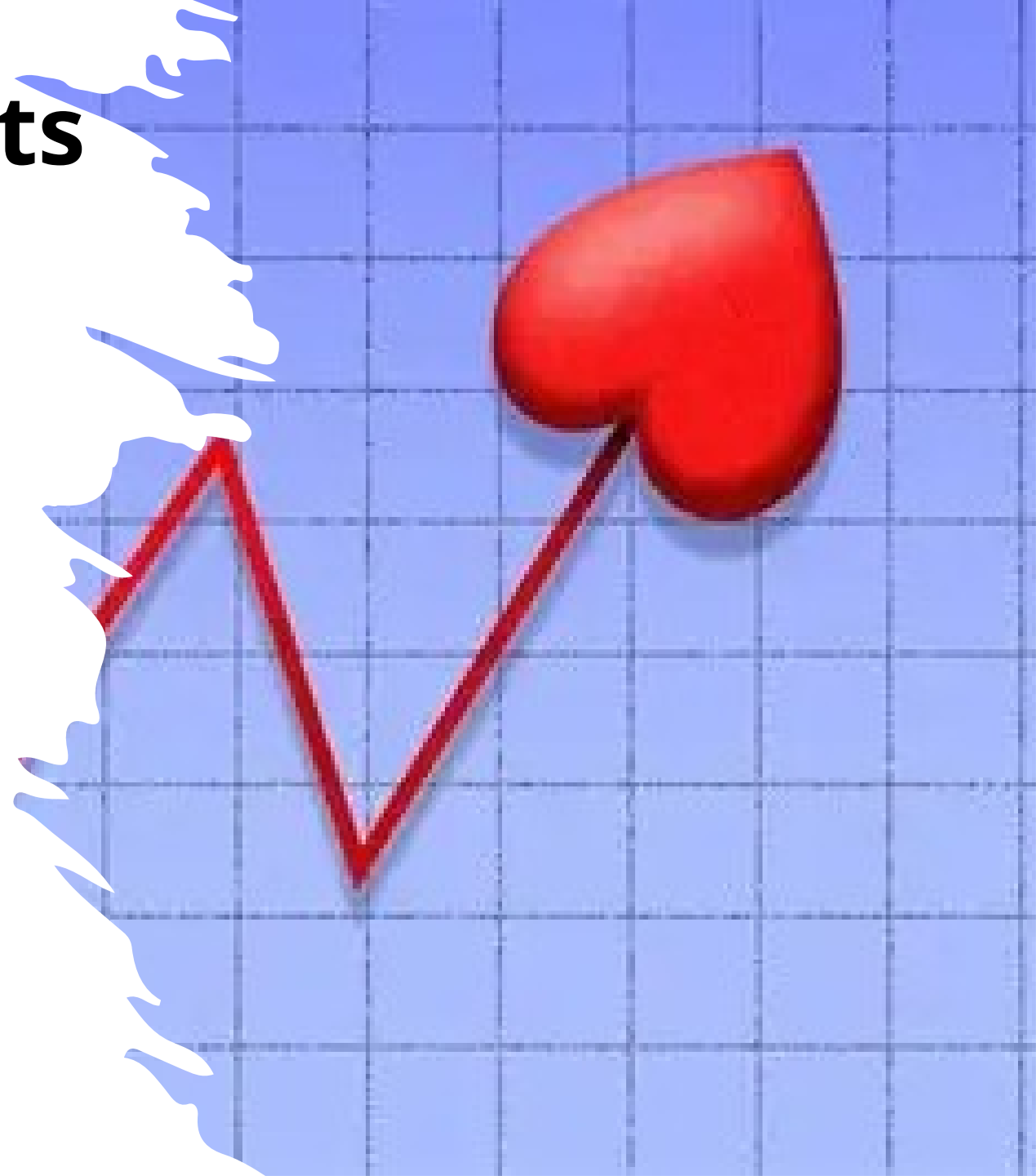


**160,000**

overnight respite stays are provided for people with a disability (HSE, 2024)

# Economic Impacts

- Current policy is underpinned by a utilitarian logic that frames family carers primarily as an unpaid economic resource.
- Centre for Care calculated the value of care in the whole of the UK at £184 billion; 29.3% increase over the past decade.
- Increase in the number of hours of care provided by unpaid carers has led to an increase in the economic cost of care.
- 29% providing care for 43 hours or more per week in Ireland (Census, 2022)
- If unpaid carers stopped providing care overnight, the health and social care systems in the UK would collapse (Petrillo et al. 2024).







**6% of family carers are LGBTQ+**

*(FCI, 2024)*

**11%**

of family carers report an ethnicity other than White Irish

*(CSO Request, 2024)*

**67,000**

children aged 10-17 provide regular unpaid care

*(FCI, 2023)*



## What are some impacts of caring?

**48%**

of family carers report severe loneliness

*(FCI, 2024)*



**41%**

of family carers also have a long-term health condition

*(Healthy Ireland, 2024)*

**69%**

find it hard to make ends meet

*FCI, 2024*

Family carers have a **38%** higher probability of experiencing depression than the average population

*(Gallagher & Wetherell, 2020)*

## Sources of Information

CSO (2022a) Census 2022, Household Form. Question 23

CSO (2022b) Census 2022, Summary Results.

CSO Request (2024) Private request through CSO using 2022 Census Data

Department of Social Protection (DSP) (2025) Numbers published at DSP Annual Carers Forum, May 2025

Family Carers Ireland (FCI) (2021) 2022 Pre-Budget Submission

Family Carers Ireland (FCI) (2023) Sharing The Caring: Young Carers' Experiences and Access to Supports in Ireland

Family Carers Ireland (FCI) (2024) The State of Caring 2024

Gallagher, S., & Wetherell, M. (2020) Risk of depression in family caregivers: Unintended consequences of COV-19. BJPsych Open 6(6) E119

Healthy Ireland (2024) Healthy Ireland Survey 2024. Summary Report

HSE (2024) HSE National Service Plan 2025

MacMahon, B., Boylan, H. & Thornton, R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of living for a household caring for an adolescent with a profound intellectual disability.



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# (Indirect) Impact of Caring

- The care demands of someone - especially if they have complex needs & caring is long term - are intensive; it is associated with a range of adverse outcomes:
  - 42% of parent carers of a disabled/chronically ill child have 'experienced suicidal thoughts' (O'Dwyer et al., 2024)
  - Increased risk of impaired physical & mental health, insecure employment, social isolation & poverty
  - Two-fifths of carers struggle to afford 'essentials including food', 80% of carers report 'feeling isolated' (Carmichael & Ercolani, 2016)
- Risk of carer 'lashing out' at the person they are supporting is heightened in challenging circumstances: recognition of *abuse of the cared for person* (Momtaz et al., 2013)





## What is (direct) Carer Harm?

- No accepted definition
- *Towards* defining carer harm:
  1. 'Carer harm' is when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological and/or sexual harm' (Isham et al., 2020)
  2. The behaviour may be caused *intentionally* or *unintentionally* by the person with care needs
  3. Incidents or patterns of harmful behaviour may pre-date the need for care: the behaviour may also start, or be exacerbated by, the onset or worsening of an illness or by the caring role (Milne, 2023; Wydall et al., 2018)
- Most work on 'harm' tends to be on the 'impact of caring' i.e. *indirect harm* such as stress rather than *direct harm* by the cared for person - carers are rarely conceptualised as *victims* of harmful behaviour



# Carer Harm: emerging evidence

Limited evidence about the nature & prevalence

- **Prevalence:**

- 44% of carers “regularly experienced” either physical aggression or verbal/emotional abuse from their relative (Family Carers Ireland, College of Psychiatrists and University College Dublin, 2019).

- **Patterns:**

- Wide range of types of abuse reported: shouting & screaming, damage & destruction of personal possessions/family home, significant levels of physical violence & psychological distress
  - Most victims are women: more parent carers are mothers, intimate care tends to be done by female relatives
- Carers at risk of harm tend to be embedded in a dyadic intimate relationship &/or a demanding care context: they are also isolated, have few resources & little contact with services (Donnelly & O’Brien, 2022)





# Why do we know so little about it?

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- ▢ Many carers do not define themselves as carers
- ▢ 'Carer harm' is not a term recognised/accepted by carers or professionals
- ▢ Perceived as taboo and/or a sensitive topic: carers feel guilty, embarrassed, or disloyal to the cared for person
  - ▢ Private 'hidden' nature of abusive or harmful behaviour: it takes place behind closed doors
  - ▢ Concerns re contravening familial or cultural norms &/or disrupting domestic patterns (Isham et al., 2021)
  - ▢ It may be hard to disentangle harm from (inter)dependency & the relational nature of care
- ▢ Fear of the consequences of disclosure

## Isham (2020;2021)

*“I think that for me... It’s about recognising that a lot of people are suffering as I did... How can you be critical of someone who is ill? It’s not the illness but it is the effect that it has on you, and I think that we need a word to describe the effect on the person, on the caregiver, rather than the service user being an ‘abuser’. That’s what I would like to try and find”.*

(Mary, caring for her husband)





# Impact on Family Carer and Siblings

(Donnelly and  
O'Brien, 2023)

'When D was about nine years of age, I was home on my own, my husband was in work and D came back from school and had a tremendous meltdown. He pulled my hair even though he doesn't usually do that, but that day he did. He was only eight or nine and he pulled me with such force that he pulled me to the ground, and I hit my head and I was there for a few seconds. And then my eldest child came from school, so imagine D was nine so my eldest was eleven, can you imagine what it's like for an 11 year old child to restrain his brother on the sofa to give me the chance to get up. I remember this day to the day I die... My eldest was crying, he was saying Mammy, I don't know how long more I can restrain him.'

(Lana, Family Carer)



# The Harmful Role of the 'Care System'

The role played by welfare policy & services which *'can create and aggravate the stresses within (care) relationships and responses to these'* (Sherwood-Johnson et al. 2023, p5)

- Carers who seek help face an opaque & complex care system in the British Isles
  - Who do they turn to? Very limited recognition of the issue
- Carers report having to 'fight' and 'beg for help' in order to stay safe: they are made to feel that 'it's their problem to resolve'
- Unrealistic & unhelpful expectations placed on carers are constantly reinforced - carers are simply 'expected to cope'
  - Rather than offering relief practitioners offer 'more training' for carers or 'behavioural interventions' for the cared for person
  - 'Rule of optimism' is common (Wydall et al., 2018)
- The fact that there are few, and (often) inadequate services, contributes to carers reluctance to report harm (Donnelly et al., 2025)
- May be a case for arguing that system related harm is a type of 'social harm' (Carr et al., 2023)



# Unrealistic Expectations

(Donnelly and O'Brien, 2023)

*This perception that "You're getting Carer's Allowance, so you've signed your life away."  
And exactly, exactly what does it mean to be a family carer? And you know, I think of parents of children with additional needs, who are really good at vocalising this-my child needs 24/7 care. It's amplifying those voices and kind of saying it, you know, nobody can do twenty-four-seven care, and it's not that you're paid to work 24 hours a day, 7 days a week, you know.'*

(FCI Senior Manager)



# Unhelpful Responses

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*'There was an incident where a carer was hurt so, so it was just the two carers in the room at the time so, you know, obviously we weren't there to see what happened... A carer got injured... And then the next day at four o'clock in the afternoon, I got a phone call from the Manager of Older Persons Services, advising me that care had been withdrawn with immediate effect, from my Dad. She advised that there was a physical assault within the home, that he needed a psychiatric assessment, and it wasn't safe for her employees to be coming into the home and that we could expect a call from the Gardaí.'*

*(Mairead, Dementia Family Carer)*



# Terminological & conceptual issues (Five Nations Carer Harm Working Group 2025)

Carer harm challenges a number of dominant narratives that underpin policy & practice relating to carers & their relatives:

- Constraining binary discourse about who can *legitimately* be regarded as a 'victim' or 'perpetrator' of abuse (Isham et al., 2020): Care Act guidance only identifies the '*person with care & support needs*' as being 'at risk' of abuse *not* the carer
- It unsettles the persistent framing of family caring as 'virtuous & natural' & care relationships as positive (Manthorpe and Liffé, 2016)

The organising focus of *intentionality* is also an issue: it can obscure the complexity of caring & act as a barrier to help-seeking:

- Most carers are reluctant to describe the person with care and support needs as *abusive* especially if they view it as *unintentional* e.g. arising from a health condition such as dementia (Donnelly et al., 2025)



# Hidden Harm: Utilising the Ethics of Care for Theory Development using the Trace Method (Sevenhuijsen 2004)

- England, Ireland, and Northern Ireland: focus on discourse of duty and familial responsibility.
- Wales and Scotland have moved somewhat toward rights-based, recognition-oriented framings.
- Unpaid care remains largely established as a family responsibility, with the most demanding, unequal, and emotionally complex aspects remaining largely unacknowledged.
- Care relationships are presented implicitly as almost entirely positive, with carers portrayed as virtuous and heroic.
- No 'choice' about being a carer
- Interdependancy and harm are not explicitly recognised

## *Five Nations Working Group*

*Assoc. Professor Sarah Donnelly, University College Dublin, Ireland*

*Dr Louise Isham, University of Birmingham, England*

*Dr Kathryn Mackay, University of Stirling, Scotland*

*Emeritus Professor Alisoun Milne, University of Kent, England*

*Professor Lorna Montgomery, Queens University, Belfast, Northern Ireland*

*Dr Fiona Sherwood-Johnson, University of Stirling, Scotland*

*Profes:  
Swans*



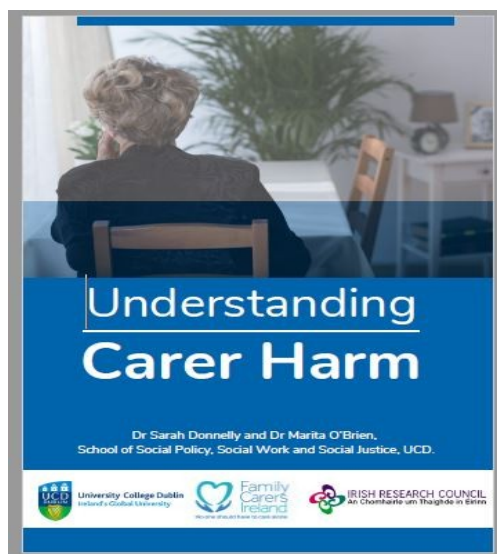
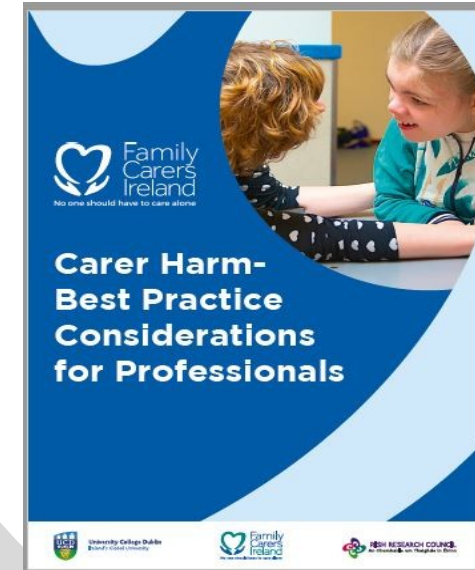
THE ETHICS OF CARE



# Policy Issues: what may help...

- A range of intersecting enforceable legal rights would help to ensure that carers were better protected:
  - A *statutory entitlement* to services for *both* the carer and the person with care & support needs
  - Legal *right* for carers to be protected from harm: paid carers *are* protected
  - *No meaningful limit* on demands on carers, including what they are expected to tolerate in terms of harm
- Consider 'carer harm' as of equivalent importance to other 'types' of harm & violence such as domestic abuse: *social justice* issue as well as a *welfare* issue
- Family care is currently a 'privatised risk'- families bear all of the costs & responsibilities for care:
  - Case for treating care as a *social risk* ie. a risk that is shared with wider society & the state: offer social protections to carers such as rights to care services, welfare payments, right to remain in work (Morgan, 2018)





# Understanding Carer Harm Study Outputs





# Key Considerations: Going Forward

- ▮ Need to accord family carers rights to be protected from harm (Anka & Penhale, 2024)
  - ▮ Competing rights of the carer and caree for person
- ▮ Family care is currently a privatised risk - families bear all of the costs and responsibilities for care:
- ▮ Carer harm is also likely to increase:
- ▮ '.... abuse of unpaid family carers can flourish where the demand for care is great & where there are complexities in relation to the needs of the cared for person' (Anka & Penhale, 2024, p8)
  - ▮ The lack of a legislative underpinning and a statutory entitlement to home care/outcome of disability assessments, and family carers' right to a standardised assessment of need is critical.
  - ▮ Need to consider the more sophisticated concept of 'human interdependence' (Tronto, 1993) and the interdependent nature of everyday living and caregiving.



# Exploring unintentional ‘carer harm’—Insights from family carers and professionals: An Irish case study

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# Carer harm: a challenge for practitioners, services and research

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Sarah Donnelly, Louise Isham, Kathryn Mackay, Alisoun Milne, Lorna Montgomery, Fiona Sherwood-Johnson and Sarah Wydall

## **Abstract**

**Purpose** – *The purpose of this study is to consider how carer harm is understood, surfaced and responded to in contemporary policy, practice and research.*

**Design/methodology/approach** – *This paper offers a reflective commentary on the current “state of play” relating to carer harm drawing on existing research and related literature. This study focuses on how we define carer harm and what we know about its impact; lessons from, and for, practice and service provision; and (some) considerations for policy development and future research.*

**Findings** – *The authors highlight the importance of engaging with the gendered dimensions (and inequalities) that lie at the intersection of experience of care and violence and the need to move beyond binary conceptions of power (lessness) in family and intimate relationships over the life course. They suggest that changing how we think and talk about carer harm may support practitioners to better recognise the impact of direct and indirect forms of carer harm on carers without stigmatising or blaming people with care needs. The findings of this study also consider how carer harm is “hidden in plain sight” on two accounts. The issue falls through the gaps between broadly domestic abuse and adult and child*

(Information about the authors can be found at the end of this article.)



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*Many thanks for  
listening and  
happy to answer  
any questions.*

