



# 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



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Nursing, Midwifery  
and Health Systems**

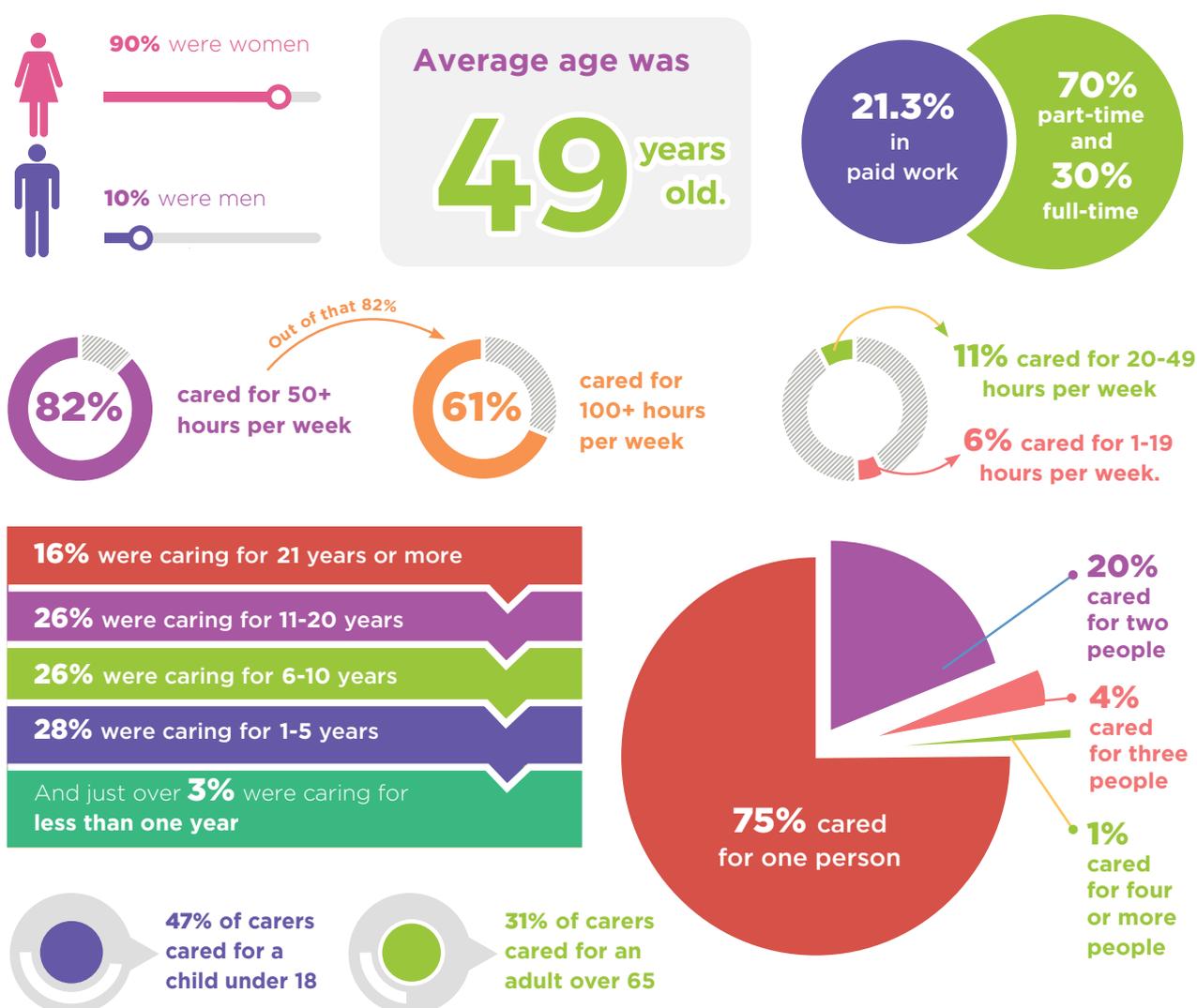
This is the second report in a series examining the health and wellbeing of family carers.

## ABOUT THE RESEARCH

This second report sets out the findings of a national Family Carer Health and Wellbeing Survey undertaken between November 2018 and January 2019 by Family Carers Ireland, the College of Psychiatrists of Ireland and UCD School of Nursing, Midwifery and Health Systems. The survey was completed by 1,102 current family carers who are members or part of the network reach of Family Carers Ireland. The survey is a repeat wave of a similar survey undertaken in 2009 and allows us to track changes in the health, wellbeing and burden of carers ten years later.

This is the second in a series of reports which examines the health and wellbeing of carers. While *Paying the Price: The Physical, Mental and Psychological Impact of Caring*<sup>1</sup> focuses on carers' general health and wellbeing and how carer wellbeing has changed during the ten year period 2009 -2019, this second report examines carers' access to supports and services and how this can affect their health. It also considers the daily challenges faced by family carers including their exposure to abusive behaviours.

## PROFILE OF RESPONDENTS



As not all respondents completed every question in the survey, a number of the figures given in this report are based on responses from fewer than 1,102 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

<sup>1</sup>Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) *Paying the Price: The Physical, Mental and Psychological Impact of Caring*, Ireland: Family Carers Ireland. <https://familycarers.ie/wp-content/uploads/2019/05/Paying-the-Price-The-Physical-Mental-and-Psychological-Impact-of-Caring.pdf>

## INTRODUCTION

Care is part of the human condition<sup>2</sup>– it touches every family in Ireland and will come to us all one day. Yet despite the centrality of care to our everyday lives and the enormity of family carers' unpaid contribution, this report demonstrates that carers are paying the price for inadequacies in public systems of support. The research shows that many family carers are experiencing physical and emotional abuse on a regular basis, yet are doing so without any emotional support or training on how to deal with challenging behaviour. The impacts of care and abuse on their physical and mental health are clear, yet they continue to care in potentially harmful environments, largely unsupported.

As well as their safety being put at risk, many carers find that their needs are overlooked and they have to fight to get support for their loved ones including respite, home care and therapies. Even when services and supports are available, they are often inconsistent, insufficient, inadequate, inaccessible and poor quality.

**Carers are expected to fill the significant and substantial service gaps in the health and social care system, regardless of the health, social or financial costs to them.**

Within the next ten years, demand for care at home will increase dramatically due to a rising ageing population, the shift away from institutional care for people with disabilities and the increased emphasis on home-based care. As a society, we need to think differently about how care is provided and about how we support families who decide to provide that care, unpaid. A starting point is to recognise our duty of care, not just to patients, but to family carers who are providing the bulk of care in the community, sometimes in harmful situations. Investment in dependable, consistent, good quality services not only promotes the independence of older, disabled and chronically ill people; it can make a real difference to carers' lives too. The introduction of new safeguarding policies, the Assisted Decision-Making (Capacity) Act, the forthcoming Statutory Home Support Scheme and the ongoing reorganisation of the health service provides an opportunity to support and sustain safe family care now and in the future. These opportunities must not be missed.

# 355,000

**family carers in Ireland**  
(that's **1** in every **10** adults)



# FAMILY CARERS

save the State  
**€10 BILLION**  
per annum

## By 2030

**1 in 5 people**  
will be a carer



<sup>2</sup>Tronto, J. (2013) *Caring Democracy: Markets, Equality and Justice*. New York: New York University Press

## KEY FINDINGS

Key findings from the current report, *Paying the Price: The Hidden Impacts of Caring*.

**44%**

of carers surveyed regularly deal with abusive behaviour

**70%**

of carers experiencing abuse as part of their caring role said their loved one did not have access to suitable respite

**76%**

of care recipients did not receive any home support hours

**74%**

of care recipients requiring 100+ hours of care per week had no access to home support hours

**49%**

of carers said that no supports and services were available

**79%**

of carers supporting children with care needs found it difficult to make ends meet

**25%**

of carers could not access supports and services due to distance and/or transport issues

**43%**

of carers said that supports and services were not disability, condition and/or age appropriate

Key findings from our first report *Paying the Price: The Physical, Mental and Psychological Impact of Caring*.

**48%**

of carers said they were diagnosed with mental ill health

**67%**

of carers reported they suffered with physical ill health

**68%**

of carers felt that their health had suffered as a result of caring

**83%**

of carers' loved ones did not have access to suitable respite

## MANY FAMILY CARERS REGULARLY EXPERIENCE ABUSE<sup>3</sup>

Although there is a growing body of research on the health outcomes of caring, little is known about the abuse experienced by carers, both physical and emotional, at the hands of the person for whom they care. In this survey, **almost half (44%) of carers reported that they regularly experienced either physical aggression or verbal/emotional abuse as part of their caring role.** This figure shines a light on a hidden aspect of caregiving that is seldom discussed. While the risk of deterioration in carers' health and wellbeing as a consequence of caring is evident in an emerging body of research, there is clear evidence of the significant, long-term negative impact on the health of those who experience abuse. Consideration must be given to the consequences on a person's health when caring and abuse are combined.

- **35% of carers regularly dealt with verbal and emotional abuse.**
- **32% of carers regularly dealt with physical aggression and violence.**

Caring for a person whose behaviour is challenging can put family carers under great pressure. Unsurprisingly, carers regularly dealing with abusive behaviour were more likely to report poor health outcomes than those who didn't. **57% of those experiencing physical and verbal abuse were diagnosed with anxiety and/or depression**—significantly higher than the 48% of carers in the overall survey sample diagnosed with mental illness. **72% of carers dealing with physically abusive behaviour reported a physical ill health diagnosis**—higher than the 67% in the overall sample being treated for poor physical health. Abusive behaviour exhibited by care recipients was also associated with higher levels of carer stress and burden than that experienced by carers not dealing with such behaviours. Despite this, **70% of carers at risk of abuse were not able to take a break because their loved one did not have access to suitable respite**, creating a dangerous and unsustainable situation for family carers.

**57% of those experiencing physical and verbal abuse were diagnosed with anxiety and/or depression.**

Despite the risks of abuse, **80% of those dealing with physical and/or verbal abuse had received no training for their role.** Yet training for managing challenging and aggressive behaviour was a common training need identified by many carers.

“How can I keep doing this day after day? I'm so tired I feel like I'll drive off the road... I'm afraid he will seriously hurt me. I need help for when he is aggressive—some sort of self-protection training.”  
(female, full-time carer for child)

“We've been waiting 18 weeks for an urgent psychology assessment for my son who is often verbally and physically abusive to me, his dad and young siblings. This is after we waited over four years for an ADHD diagnosis.”  
(female, full-time carer for child)

“I need training on how to protect myself from getting hurt during my child's violent behaviour and how to prevent the person you are caring for hurting themselves during a violent outburst.”  
(female, full-time carer for child)

“I would love to learn about managing challenging behaviours as my daughter can be quite aggressive and violent and she is only six. My mother who has dementia can be quite aggressive too.”  
(female, full-time carer for elderly parents and child)

<sup>3</sup> Although we use the terms 'abuse' and 'abusive behaviour', we are not suggesting that the person with care needs intended to abuse the carer.

# UNAVAILABLE, INACCESSIBLE AND INADEQUATE SUPPORTS AND SERVICES

## Half of carers said supports and services were unavailable for their loved ones.

Supports and services should enable family carers to carry out their caring role and allow them to have a life of their own alongside caring. However, **1 in 2 (49%) carers said that services were not available for their loved ones** despite almost 2 in 3 (61%) caring for 100+ hours per week, over 1 in 5 (21%) continuing to work alongside caring and almost 2 in 3 (62%) regularly experiencing broken sleep due to night-time caregiving<sup>4</sup>.

- 49% of carers said supports and services were unavailable for their loved ones.

- 62% of carers regularly get up in the night to care.



“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)



“Child mental health services are non-existent and our self-harming depressed child was not severe enough for CAMHS. We paid privately for a counsellor because there are no appropriate services available to deal with that level of mental health issue.”

(female, full-time carer for child)



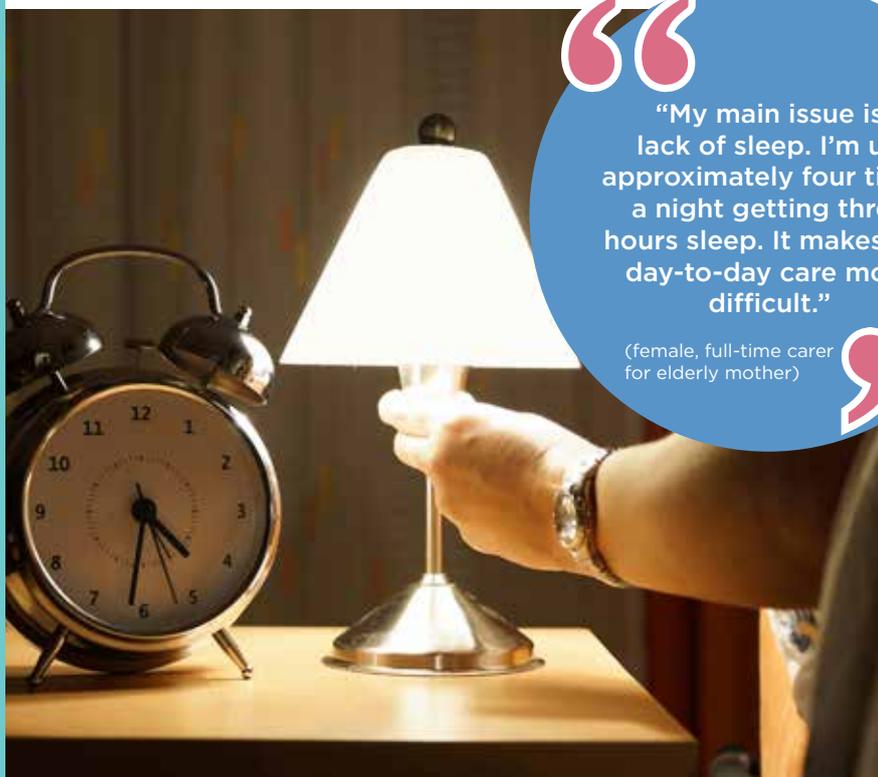
“My main issue is lack of sleep. I’m up approximately four times a night getting three hours sleep. It makes the day-to-day care more difficult.”

(female, full-time carer for elderly mother)



“I get no support as my son’s condition is not considered profound enough, even though he has no other supports and cannot function alone.”

(female, full-time carer for adult child)



<sup>4</sup> Research shows that poor sleep quality and short sleep duration have profound adverse consequences for both physical and mental health. See Arber, S. & Venn, S. (2011) Caregiving at night: Understanding the impact on carers. *Journal of Aging Studies*, 25, 155-165

## Three quarters of people requiring care did not receive any home support hours.

Our findings illustrate the country's ongoing home care crisis, with many carers reporting that they receive no support or only limited support in the home. **Three quarters (76%) of people requiring care did not receive any home support hours<sup>5</sup>**, despite over half (52%) of carers reporting that they needed help with personal care and household tasks. Even when family carers were providing constant, round the clock care, they were still expected to carry on caring without adequate supports in place. **Three quarters (74%) of care recipients that needed substantial care (100 hours or more) had no access to home support that allowed their carer to leave the home.** Almost 2 in 3 (60%) carers who spent 100+ hours per week caring for their loved one requested support in the home. This suggests high levels of unmet need in home care, where only a minority of those reporting that they need home support are able to access it.

## No right to leave.

Access to home support hours does not automatically equate to a break for carers. **Over 1 in 7 (16%) of care recipients under 18 received home support hours where carers were not allowed leave the home during this time.** This suggests that the HSE's *in loco parentis* rule, which requires the parent/guardian of a sick or disabled child to be present with home care staff at all times, has impacted on carers and is further contributing to an environment where parents feel trapped in their own home.



"I have most of my mother's personal care done before the allocated time for the care workers call. I feel they want to come and go before the hour is up and it's not enough time for me to go to town for groceries."

(female, full-time carer for elderly mother)

"...the system treats myself and my parents as a burden. It's a system that forces people into nursing homes due to the lack of supports despite the fact that it costs the state less to support people to stay in their own homes. We have had to fight for every support we have at every turn and this is exhausting and frustrating."

(female, full-time carer for elderly parents)



"I have to stay in the home with my child when home support is here...instead of the system offering support it adds extra stress on the household. But if I withdraw from the service, I'm fearful that when my child becomes older, I'll get nothing."

(female, full-time carer for two children)



<sup>5</sup>This is a combination of home support hours that allowed the carer to leave the home and hours that required the carer to remain in the home.

# FACTORS AFFECTING ACCESS TO SUPPORTS AND SERVICES

1 in 4 carers experienced difficulties accessing supports and services due to inadequate transport and/or length distances from home.

Carers are often reliant on reliable and affordable transport to help their loved one get to the places they need to be, such as hospital appointments, schools or shops. Yet this survey shows:

- **Over 1 in 5 (22%) carers reported that supports and services, when available, were too far away.**
- **One in 7 (14%) said that they could not access supports and services due to a lack of transport.**
- **Over 1 in 5 (22%) requested assistance with transportation.**

“I counted once, it took 16 phone calls to organise assisted wheelchair transport for a hospital appointment!”  
(female, full-time carer for elderly parents)

Many carers said that driving long distances to drop off and collect those they care for is exhausting and expensive. The issue of services not being located in a carer's locality was compounded when carers did not have appropriate transport. In the absence of affordable transport and with available services too far away from home, participation in critical activities such as healthcare and education was difficult, if not impossible, for many carers.

**9 in 10 (87%)**  
regularly helped their loved ones with transportation.



## A postcode lottery in respite provision.

Our earlier report on carer health and wellbeing, *Paying the Price: The Physical, Mental and Psychological Impact of Caring*, showed that **83% of care recipients did not have access to suitable respite**. Further analysis shows that even when respite was available, **there was significant variation across the country in relation to access**. Although our survey drew on a convenience sample and is not representative of the population of family carers across all counties, our findings support recent research which indicated the existence of a postcode lottery in respite provision across Ireland<sup>6</sup>.

“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 travel hundreds of miles per week for school and this will increase in September if we get the specific school for our little guy...it's extremely costly.”  
(male, full-time carer for two children)

“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)

<sup>6</sup> Economic and Social Research Institute (ESRI). (2019) *Geographic profile of healthcare needs and non-acute health-care supply in Ireland*. Dublin: ESRI

## Almost half of carers were concerned about the quality of supports and services.

It is not only access to services that is important for carers—the quality of these services is also crucial. If services are to be effective, then carers must be confident that their loved one is in safe hands and receiving quality care from appropriately trained staff. Worryingly, many carers in this survey expressed concern about the quality and suitability of available services. **Two in 5 (43%) carers said that services were not disability, condition and/or age appropriate. One in 3 (37%) said that the quality was poor and over a quarter (28%) reported that staff needed more training.** If services are poor quality or unsuitable to meet the needs of their loved one, carers may find it difficult to rely on such services. In this context, it is unsurprising that **75% of carers were worried about a lack of appropriate supports or services** for their loved one.

## 45% of carers were concerned about quality in supports and services and staff training.

“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)

## Family carers paying the price of financially subsidising services.

Unsurprisingly, the impact of going without practical support spilled over into other areas of life for family carers. Our previous report showed that three quarters (73%) of carers said they do not have enough money to take care of their loved one and meet their other expenses. This was even worse for carers supporting a child with care needs, with almost **4 in 5 (79%) carers of children reporting that they found it difficult to make ends meet.** Comments from these carers frequently focused on the difficulties in securing assessments and subsequent therapies for their children due to excessively long waiting lists. Many felt they were left with no choice but to pay privately, whilst others said it was simply unaffordable. Comments suggest that those who felt forced into paying privately for treatment risked impoverishment, which had clear impacts on their mental wellbeing. Indeed, **carers caring for a child were significantly more likely to be diagnosed with mental ill health than those caring for adults.**

“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)

“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)

“There should be reimbursement for those who had to go private because of HSE waiting lists. I'm so worried about my finances, I'm managing the whole family as a single parent. It's very, very difficult.”  
(female, full-time carer for child)

# RECOMMENDATIONS TO SUPPORT AND SAFEGUARD CARERS

Despite Government policy to support care in the home, this survey has shown that practice and policy remain at odds. If Government truly values carers and respects them as the bedrock of the health and social care system, then they must develop and commit to policies to better support carers including enforceable rights, accessible and dependable services and a comprehensive safeguarding framework.



## RECOGNISE CARERS AS VICTIMS OF ABUSE:

The impact of physical and verbal abuse on family carers remains hidden and under-researched. Further research and public discussion on this hitherto hidden aspect of the caring experience is key to recognising carers as victims of abuse and developing effective interventions to allow them to care safely.



## URGENTLY ADDRESS THE HOME CARE CRISIS AND POSTCODE LOTTERY:

Whilst the Department of Health's plans to establish a Statutory Home Support Scheme by 2021 is a welcome step in appropriately supporting care in the home, families cannot wait until then for home care services to improve. The consistent underfunding of home care needs to be urgently tackled to address the needs of the thousands of patients stuck in hospitals or forced into nursing homes when they could return home if appropriate care was provided. This underfunding also places enormous pressure on carers to care for their loved one(s) without adequate or appropriate supports in place. Despite being consistent with Government policy and the clear advantages of caring for people in their own homes, funding for carers has not reflected this priority nor are essential supports offered consistently across the country. Urgent additional funding of €3.2 million per annum is required to support family carers and ensure that they are guaranteed access to a basket of supports and services regardless of where they live.



## FINDING YOUR WAY - ADDRESSING THE TRANSPORT NEEDS OF CARERS:

Travelling to and from services poses a significant challenge to many carers, involving significant fuel costs and a great deal of time. This is compounded when suitable services are not available in a carer's locality. Replacing the Mobility Allowance and Motorised Transport Grant Schemes, withdrawn in 2013, with the long awaited Transport Support Scheme and widening the criteria of the Disabled Drivers and Passengers Scheme to include people with intellectual or cognitive impairments would allow carers to help their loved ones without incurring significant costs.



## **ABOLISH THE *IN LOCO PARENTIS* RULE WHICH IS UNDERMINING SERVICES AND PLACING FAMILIES UNDER EVEN GREATER PRESSURE:**

Organisations involved in supporting children and families are united in their call to end the *in loco parentis* rule and the unfair restrictions it places on the families of Ireland's most vulnerable children.



## **PRACTICAL APPROACHES TO PROTECTING CARERS AT RISK OF HARM:**

The deterioration in carers' wellbeing as a consequence of their caring responsibilities is increasingly recognised. For some this is accepted as something that comes with the territory—the price of caring. There is a point, however, where the behaviour of the person being cared for, whether intentional or not, can fall into the category of abuse. Recognising, reporting and responding to carers at risk of harm will not always be easy as the situation may be complicated by carer denial, guilt, or a sense of loyalty to their loved one—but it is critical. Practical approaches to how we can support carers at risk of or experiencing abuse include:

- **Healthcare professionals trained to identify and support carers** vulnerable to harm at the outset of the caring journey may help prevent carers reaching crisis point. To do this, healthcare professionals could offer carers an assessment of their own needs, including an assessment of safeguarding needs.
- **Offer carers training** which can help them to understand and manage harmful behaviours and difficult situations, as well as building their capacity to protect both themselves and the person requiring care.
- **Emergency respite care services, available at short notice**, are important for all family carers who may face crisis situations that prevent them from carrying out their caring role. Without access to emergency respite, carers at risk of abuse may have to stay unwillingly in situations which are unsafe.
- **Involve all agencies who play a role in safeguarding** adults and children including the HSE, Tusla and An Garda Síochána.



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## FIND OUT MORE

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