



Family
Carers
Ireland

No one should have to care alone

Are you experiencing Carer Harm?

If you are a family carer, ask yourself:

Does the person I care for behave in a way that causes me physical injury, emotional pain, or other kind of harm?

In my engagement with professionals and organisations, is my coping capacity and need for support recognized and responded to?

This leaflet may be useful to carers of people living with dementia



University College Dublin
Ireland's Global University



No one should have to care alone



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn



FAMILY CARERS IRELAND

Family Carers Ireland is in a unique position to support carers experiencing carer harm, recognising that the needs of family carers exist on a continuum of severity and that family carers have strengths as well as needs. With this in mind, supports for carers experiencing harm include:

- A focus on the full spectrum of carer well-being.
- A willingness to act as an advocate for any carer who feels they need it.
- Support for any family carer in a situation where the state is engaging to 'take over' their caring role.
- Help with development of a safety plan through the Free Emergency Scheme – joining the scheme ensures that the person you care for will continue to receive the support they need during a time of crisis and from people you trust. See: <https://familycarers.ie/carer-supports/help-guidance/emergency-care-scheme>
- If there are other children or family members who are 'young carers' who are also affected, Family Carers Ireland has a dedicated young carer support team who can be contacted in confidence at youngcarers@familycarers.ie or their Freephone Careline 1800 24 07 24.
- All of these supports are free of charge and can be accessed directly.

UNDERSTANDING CARER HARM - DEMENTIA

Dementia is an umbrella term for a range of conditions that cause damage to the brain. This damage can affect memory, thinking, language, the ability to plan and carry out everyday tasks. Dementia may also cause hallucinations and changes to personality and behaviour.

The areas of the brain in which the changes occur determine the type of dementia and this can range from Alzheimer's Disease, Vascular Dementia, Frontotemporal Dementia, Lewy Body and mixed dementia. Symptoms vary from person to person and everyone's experience with the disease is unique. For the person living with dementia, the loss of these abilities can make them fearful, angry, anxious, and frustrated at not being able to communicate their feelings or pain. This may cause them to behave in a way that is harmful to themselves or to others.

What is 'Carer Harm'?

Carer Harm is where a family carer experiences intentional or unintentional harm from the person living with dementia they are trying to support. Harmful behaviours experienced can include:

- Psychological (e.g., emotional abuse, bullying, threats, humiliation, mocking, controlling, intimidation, coercion, refusing to allow the carer to leave the house, verbal abuse).
- Physical (e.g., slapping, hitting, pushing, kicking).
- Financial (e.g., refusing to pay towards household costs or other goods and services).
- Sexual (e.g., inappropriate sexual comments, unwanted touching, or sexual acts without consent).

Other types of Carer Harm

Family carers can also experience harm from the professionals and organisations they are in contact with. Harm can be experienced because of the attitudes or unrealistic expectations of professionals you can come into contact with. It can also be as a result of:

- Discrimination (e.g., Making rules around accessing services without a valid reason such as age requirements, or being humiliated and distressed by discussions that suggest by meeting your needs, and those of the person you care for, will deprive others seen as more needy of support).
- Institutional (e.g., where organisations disregard a person's rights or provide inadequate responses to complex needs. For example, not being listened to, having to 'beg' for support, or being sent from agency to agency as part of disagreements between service providers or professionals about responsibilities and funding).

Prevention and Protection

Sometimes family carers do not understand or are not aware of what is, and is not, acceptable behaviour. This may leave you believing that being subjected to intentional or unintentional harmful behaviour from the person living with dementia you are trying to support is the 'norm', the price for caring. Being aware of harmful behaviours and recognising the risks associated with these behaviours is vital to help prevent carer harm and protect you as a family carer.

It is not uncommon that you might want to keep your experiences of harm a secret due to a sense of shame that the person you are caring for has injured you. You might feel guilty that you are 'telling tales' on them. You may also be worried about possible consequences such as unwanted care alternatives or interventions.

While changes in behaviours may be part of the disease and not part of the person, if it results in harm to you, the family carer, it needs to be recognised and addressed in order to support and protect you. In some relationships, family carers may also harm or be abusive towards the person living with dementia they are caring for. This may be a result of carer stress or burnout. It may be related to the family carer trying to protect themselves from the harm they are experiencing.

Stigma and shame associated with harm experienced within the context of the care giving relationship makes it very difficult for family carers to share their experiences of harm. You might find it difficult to disclose that you have been harmed because you feel guilty, ashamed, or disloyal.

Potential situations where carer harm is more likely

- When there are unrealistic expectations and demands placed on you as their family carer in relation to the levels of care you are providing which leads to stress and caregiver burnout.
- When a professional gives the diagnosis of dementia to a spouse/ family member, but not to the person living with dementia or communicates it in a way that they cannot understand what the diagnosis means for their care needs.
- The person living with dementia can feel excluded from decision-making if their diagnosis has not been properly explained to them. This may damage trust between you, the person you are caring for and professionals and can cause strain on relationships and lead to conflict. For example, if professionals advise that they are no longer safe to drive, you try to make sure this doesn't happen, but they are angry and frustrated as they haven't been properly educated about how dementia is affecting them.
- If a health professional communicates a diagnosis of dementia and does not arrange a follow-up phone call or meeting it can leave you and the person living with dementia feeling isolated. The person living with dementia will not know where to go for advice and support on how to live well with dementia. They may also not be aware of the behavioural changes associated with dementia. For example, some people living with dementia may feel frustrated as their memory loss gets worse, and they may experience paranoia or delusions. A person living with a type of dementia called Frontal Temporal Dementia may have mood swings and act in an uninhibited way.
- If a person living with dementia is diagnosed at an early stage, they may not require any care or support. However, you or another family member accompanying them may be automatically referred to as their 'carer'. This immediately changes the relationship between spouses/other family members and doesn't take account of how you work as a couple/family unit.
- The person you support and care for has health and care needs that you cannot meet, particularly if this arrangement continues over a long period of time.
- The person living with dementia does not have insight or understanding of your capacity to meet and provide the level of care they require. They may refuse to wash or dress and when you are trying to deal with this, it can lead to conflict both physical and emotional. Personal care can also be physically demanding and that can lead to strain and injury.
- They may refuse to accept support from outside agencies, including respite opportunities which would give you an opportunity to focus on your own needs.
- The person you are supporting is angry about their situation. This might lead to abusive, aggressive, or frightening behaviors.
- The person you are supporting has a history of substance misuse and/or domestic violence.
- Providing personal care to a spouse or parent living with dementia can be a trigger for harmful behaviours.



- Caring for a person living with dementia who is in distressed, agitated, anxious or hostile for a prolonged period while waiting to access expert input or help.
- When services or supports are not available, for example, respite care or home support hours.

How can I help prevent or reduce the risk of experiencing carer harm?

- Talk through your situation with a professional or a support organisation like Family Carers Ireland and get advice, direction, and peer support. Family Carers Ireland National Freephone Careline 1800 24 07 24
- When speaking to service providers, be clear about your ability to care as a family carer. It is also important to keep up your own interests and hobbies as much as possible as this will help you to manage any stress you are experiencing.
- Seek early intervention and concrete supports such as home care or respite.
- If this is not available or if you are encountering barriers to accessing services and supports for the person living with dementia and supports necessary to keep you safe, seek help from a professional or advocacy organisation who can assist you to advocate for what you need. Some useful services are:
 - Alzheimer's National Helpline 1800 341 341
 - Family Carers Ireland National Freephone Careline 1800 24 07 24
 - National Advocacy Service for People with Disabilities 0818 07 3000
 - SAGE Advocacy 01 5367330
- Seeking advice at an early stage from an expert can help you work out what is causing the behaviour and how it can be addressed. For example, from an Alzheimer Society of Ireland Dementia Adviser: Dementia Advisers' contact details can be found here: <https://alzheimer.ie/service/dementia-adviser/>),
- A Dementia Nurse Specialist or OT attached to memory clinic or technology resource room can also provide advice and help. See <https://www.understandtogether.ie/get-support/service-finder>
- Engage in free education and training opportunities for understanding and guidance on communication, responsive behaviours, and triggers such as those run by:
 - Family Carers Ireland <https://familycarers.ie/courses/dementia-care/index.html#/>,
 - The Alzheimer Society of Ireland <https://alzheimer.ie/?s=training>
 - The Dementia Services and Information Centre <https://dementia.ie/>
- Consider and discuss with a professional if the person you are caring for would benefit from referral to other services or supports.
- Access counselling services if your experience of harmful behaviour has left you feeling in despair or not sleeping (<https://familycarers.ie/carers-supports/help-guidance/counselling>). Your GP can also refer you.

I am experiencing intentional or unintentional harm from the child/adult I support, what can I do?

In the first instance, speak to someone about your experience – contact your GP, Public Health Nurse, Social Worker, school or service provider or Family Carers Ireland National Freephone Careline 1800 24 07 24

Other steps you can take

- Connect with other family carers via peer support or carer support groups. These can provide a space to share and validate your experiences, voice concerns, and learn about entitlements, services, and supports.
- Family Carers Ireland, check for a group in your area: <https://familycarers.ie/carers-supports/carers-support-groups>

- The Alzheimer Society of Ireland, check for a group in your area <https://alzheimer.ie/>.
- Online Family Support groups can also provide support if it is difficult for you to leave the house, see:
- Family Carers Ireland Online Family Support Group <https://forum.familycarers.ie/>
- Care Alliance Online Family Carer Support Group <https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>.
- Get help with development of a safety plan for you and other family members through Family Carers Ireland Free Emergency Scheme – joining the scheme ensures that the person you care for will continue to receive the support they need during a time of crisis and from people you trust. See: <https://familycarers.ie/carer-supports/help-guidance/emergency-care-scheme>
- As part of your safety planning, contact your local Community Garda and brief them on your situation, ask them to call to meet your family so that if there is a crisis, they will be familiar to you, the person you are caring for and other family members.
- If you or a family member are in immediate danger, call 999 or 112 and ask for an immediate Garda response.

(These supports are also free of charge and can be accessed directly)

Remember, if you are experiencing carer harm, public sector bodies have a duty to protect your human rights

Human rights reflect the minimum standards necessary for people to live with dignity. Legislation enacting the European Convention on Human Rights (ECHR) places a statutory obligation on public sector bodies to protect human rights in carrying out their function and in how it provides services.

These rights include protection from abuse or being treated in a degrading way, respect for family life and protection of physical integrity.

Public bodies such as the Health Service Executive, Disability Networks and health and social care providers have a duty towards adults and children at risk to take reasonable steps to prevent ill-treatment or harm. Professionals working in these organisations must treat you with **fairness, equality, dignity, and respect**.

If you feel you or the adult you care for have been unfairly treated by a public service provider such as the HSE, care provider or any publicly funded service, contact the Office of the Ombudsman 1890223030, www.ombudsman.ie

The information and guidance in this document is based on a small research project that involved interviews with 9 family carers who have experienced carer harm as well as interviews and focus groups with a range of professionals. This document was co-designed using a World Café methodology and by drawing on the emerging research findings. The information does not relate to the experiences of all family carers. For further information on this project, please contact Dr Sarah Donnelly, Assistant Professor of Social Work, School of Social Policy, Social Work and Social Justice, UCD: sarah.donnelly@ucd.ie



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