Family Carers Ireland
No one should have to care alone

Carer Harm-Best Practice Considerations for Professionals

University College Dublin
Ireland's Global University

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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 though 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.

What is ‘Carer Harm’?

Carer Harm is where a family carer experiences intentional or unintentional harm from the child/adult they are trying to support or from professionals and organisations they are in contact with. Harm can also be experienced because of the attitudes or unrealistic expectations of professionals or service providers. Harmful behaviour experienced can include:

- Psychological (e.g., emotional abuse, bullying, threats, humiliation, mocking, controlling, intimidation, coercion, refusing to allow the carer to leave the house, insisting the carer provide all of the care, verbal abuse, sleep deprivation)
- Physical (e.g., slapping, hitting, pushing, kicking)
- Financial and material (e.g., stealing, destruction of goods in the family home)
- Sexual (e.g., inappropriate sexual comments, unwanted touching, or sexual acts without consent.)
- Discrimination (e.g., imposition of an arbitrary age to access services or be-ing 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 or 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

Issues relating to understanding and awareness of what is, and is not, acceptable behaviour leaves some family carers believing that being subjected to intentional or unintentional harmful behaviour from the child/adult they are trying to support is the ‘norm’, the price for caring. Addressing normalisation of harmful behaviours in caring relationships and supporting carers to understand and recognise risks associated with these behaviours is vital.

It is not uncommon for a family carer to want to keep their experiences of harm a secret due to sense of shame that their own child/ relative has injured them. Family carers may also feel guilty that they are ‘telling tales’ on the cared for person. They may also fear the consequences such as triggering unwanted interventions for example, residential care, homeless and/or have Gardai get involved and their loved one become ‘criminalised’.

The stigma associated with carer harm means that carers are rarely asked questions about this. This can mean they don’t get an opportunity for disclosure, and it can be difficult to know who to tell. Even when family carers have shared experiences of carer harm or raised concerns, professionals do not always seem to grasp the seriousness of the harmful behaviour. Professional responses often focus on education and training with the expectation that this will enable the family carer to manage to provide the necessary care, even to those with very complex needs.

Potential situations where carer harm is more likely

- A family carer is isolated and has no one to talk to or to give them advice. They are not getting any practical and/or emotional support from professionals or formal care givers or they receive unhelpful advice which imposes a professional agenda (i.e., only focusing on physical safety).
- The person they support has health and care needs that the family carer cannot meet, particularly if this arrangement continues over a long period of time.
- The person being supported does not have insight or understanding of the capacity of the family carer to meet their level of care. They may refuse to accept support from outside agencies, including respite opportunities which would give the family carer an opportunity to focus solely on their own needs.
- The person being supported is angry about their situation. This might lead to abusive, aggressive, or frightening behaviors.
- The person being supported has a history of substance misuse and/or domestic violence.
- Pressure on parent carers of adult “children” which increases as they both age. This can lead to difficulties in family relationships or inappropriate restrictions on the lives of older parents who are family carers.

Assessment

- There is a need for routine and proactive assessment of family carers support needs, coping capacity, and impact of caregiving on their physical and mental health. It is not unusual for carers to report dealing with difficult and harmful behaviours from the person they care for. This can include emotional harm, physical /sexual harm, controlling behaviour and violence. As part of this assessment family carers should be asked about carer harm.
- Routinely and proactively raise the issue and 'ask the question.'
- Include as part of standardised assessment processes.
- Understand that stigma plays a key role in stopping family carers from looking for help.
- Be aware that some family carers may not understand or perceive the behaviour to be harmful, or they may define their experiences differently.
- Be clear that this is not a normal aspect of caregiving.
- Name the behaviour as unacceptable. Try to 'Reduce the Shame' and 'Remove the Blame.'
- Be aware of gender considerations (men may find it more difficult to disclose) and the nature of caregiving relationships in terms of disclosure.
- Acknowledge the multidimensional and complex nature of carer harm.
- Support family carers to identify and make informed choices about how to manage potential risk of significant harm.
- Ensure responses to referrals are timely, proportionate, and protect from risk of harm.
- Have consideration of issues relating to communication.For example, language and literacy barriers. The family carer may not have the confidence or the words to express what is happening.
- Provide space for family carers to share their experience of carer harm.
- Take your lead from the family carer in terms of interventions and responses.
- Work from a partnership rather than an expert approach. Carer harm may occur in the context of relationship dynamics and limited supports. You need to address both. In terms of relationship dynamics: What change does the carer want/is willing to make? Encourage the carer to make space for them to reflect on the dynamics in the current relationship and what choices they wish to make – the carer may need time to reflect and may benefit from exploring these relationship questions in formal counselling – the carer should receive information on how to access supports to help them reflect on the relationship.
- Provide full information on formal supports, for both the carer and the person receiving support. Working in a partnership with the family carer, consider if the carer would like to trial or engage in some of the supports, talking through the positives and fears the carer may have in relation to service engagement.
- Be open and upfront with family carers that speaking up and reaching out doesn't necessarily mean they will get the supports they need to help keep them safe.
- The person receiving support may also decline interventions. This emphasises the importance of carer support around the relationship dynamic.

Therapy/Intervention

- Provide family therapy which focuses on the needs and impact of carer harm on the whole family unit. Give opportunities for each member of family to voice their worries/concerns and wishes.
- Provision of one-to-one counselling services for family carers to help manage their feelings of stigma, shame guilt, stress, and burnout. Counselling can also help family carers work on boundaries, in terms of carer well-being, and what they can reasonably expect of themselves; and how to hold boundaries in terms of others' expectations.
- Meítheal, a Tusla led early intervention model can be very helpful in situations where a child is displaying harmful behaviours towards their parent and/or other siblings. This brings together parents, schools, youth services, family resource centre staff, medical practitioners, Gardaí, and all

other parties with an interest in the child's life together. It has been found to be very beneficial in supporting the whole family unit.

Providing Support and Service Provision

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It is important to discuss how the family carer can be supported in their role and to explore protection and prevention strategies. This often involves putting in place supports and help both for the family carer, but also for the child/adult whom they are providing care for.

- Work with service users and family carers to ensure that no care package relies on an inappropriate level of caring responsibilities that is not sustainable, or is likely to impact adversely on the independence, rights and well-being of the family carer.
- Consider the need for and benefits of incorporating "keeping safe" plans within support planning. Where a parent/carer is at significant risk, have a process of safety planning- in some cases, this may also include discussion of legal protections such as protection orders, safety orders and barring orders.
- Explore how risk may be reduced. This may include, for example, the provision of training, information or other supports that minimise the stress and harmful behaviour experienced by the family carer.
- Encourage "whole family", joined up approaches to assessment and support planning that help to consider risks alongside benefits for the family carers and the person they support.

- Convene proactive and preventative case conferences/care planning meetings.
- Encourage and help to set up local peer support initiatives for family carers experiencing carer harm.
- Provide family carers with helpline numbers for organisations offering phone support and details of online support forums.

Specific considerations for family carers of children/adults with autism

- Early intervention is critical when family carers are experiencing carer harm. Assessment of the child/adult who is causing harm is important in order to identify triggers for example, for some children/adults with autism, emotional overload resulting in 'meltdowns' can inform strategies for responses. This may require input from a professional to observe the child in their own home and assisting parents to put in place a 'meltdown' response plan.
- Organise for a Behavioural Therapist to engage with the family in order to develop a behaviour management strategy beginning when the child is very young. The Behavoural Therapist can then develop a plan for school and home, and it is reviewed routinely as the child gets older.
- Strive to ensure that autistic adults who require high levels of care or support are part of service that is available 5 days a week.
- Seek support such as play therapy for siblings.

Specific considerations for family carers of people living with dementia (PLWD)

- Early intervention to support the person with dementia is crucial to preventing carer harm as it can bring the person living with dementia and family carers into the support system.
- Where there are ongoing issues around responsive behaviours, linking the person living with dementia to HSE Mental Health for Older Persons Services in a timely manner can help with managing some of the behaviour.
- Providing in-home respite provision. Moving a person living with dementia to a strange environment is very upsetting for the person and their family carer.
- Providing social care support workers for people living with dementia to enable them get out into the community and provide respite to allow the family carer to focus on his/her own needs.
- Provide one-to-one input with a professional expert – makes is easier to talk through concerns/ worries with a dementia knowledgeable person who knows the individual.

Advocacy

Advocacy is hugely important when supporting family carers. Make sure that family carers have access to practical representation and professional advocacy support when attending meetings with Education Providers, the HSE, Disability Managers or other service providers.

- Provide assistance with identifying power holders, who can deliver on what the family carer needs e.g., name and contact details of the Disability Manager, Manager of Services for Older Persons, names of local politicians.
- Provide help with writing letters/emails to stakeholders.
- Provide support with social media and interviews when engaging with the media.

Collectively advocate with other professionals and service providers in relation to putting services and supports in place for family carers experiencing carer harm. The collective advocacy group would include all stakeholders: family carers, Family Carers Ireland, Educators and service providers, professionals, and Gardaí.

Collaboration, building links at community level and signposting

Collaboration between organisations and service providers will enable resources to be pooled and avoid duplication. This can be achieved by joint working protocols between organisations and the setting up of referral pathways and services. Signposting between organizations and service providers is important. It can help family carers access some level of support such as peer support from local networks.

- Raise awareness about the harmful behaviour – take every opportunity, every encounter to ask about carer harm.
- Encourage discussion locally (for example between primary care teams and special education and dementia advisors, hospital multi-disciplinary teams) about how to help carers stay safe from harm.
- Explore opportunities for setting up informal care and support services to provide respite to alleviate pressure within families. For example, after school and youth clubs for autistic children; social groups for people living with dementia.
- Identify in your area carer and other advice organisations providing information, advice, peer or advocacy support, connect with them and set up signposting/referral pathways for family carers.
- Develop local strategies for preventing, recognising, reducing, and responding to stress-related risk experienced by family carers providing substantial care to another person.
- Develop local strategies for improving the recognition of and reductions in carer anxiety, depression, reshaping unhelpful care and support practices and encouraging awareness of appropriate coping mechanisms.
- Where links are made with Community Gardaí, their help and support should be utilized. They should be routinely involved in local area planning forums and invited to participate in case conference/care planning meetings.

Education and Training

Information and knowledge for the family carer and the child/adult they are caring for on the nature of the disability/condition(s) is essential for understanding and supporting the person.

Consider education and training opportunities in relation to:

- The inclusion of carer harm as a topic in current education and training courses for family carers
- At diagnosis when explaining the symptoms of a condition
- For wider community service providers including GPs, Public Health Nurses, Primary Care teams (occupational therapists, physiotherapists, speech and language therapists, social workers), Disability Networks, home care workers, Gardaí, Family Resource Centres, and for hospital professionals.

Useful Contacts

Family support organisations

Family Carers Ireland National Freephone Careline 1800 24 07 24; https://familycarers.ie/

Family Carers Ireland Online Family Support Group https://forum.familycarers.ie/

Care Alliance Online Family Carer Support Group https://www.carealliance.ie/OnlineFamilyCarerSupport Group

Dementia specific

The Alzheimer Society of Ireland National Helpline 1800 341 341; https://alzheimer.ie/

The Alzheimer Society of Ireland Dementia Advisors https://alzheimer.ie/service/dementia-adviser/

Autism specific

AsIAm Information Line 0818 234 234 https://asiam.ie/

Autism Supporting Diversity Information line 1800 71 88 65 https://www.asdireland.ie

Irish Association for Autism Helpline: 01 481 93 https://autism.ie/

Education and training resources

Family Carers Ireland https://familycarers.ie/courses/dementia-care/index.html#/

Care Alliance https://www.carealliance.ie/Training-For-Family-Carers

Equality and Human Rights in the Public Service Education to support and enable staff within public bodies to understand and meet their obligations under the Public Sector Equality and Human Rights Duty (Public Sector Duty) available from: https://www.ihrec.ie/elearning/

Dementia

The Alzheimer Society of Ireland: https://alzheimer.ie/?s=training.

Family Carers Ireland https://familycarers.ie/courses/dementia-care/index.html#/

The Dementia Services and Information Centre https://dementia.ie/

Autism

ASIAm https://asiam.ie/training-2/

Middletown Autism Centre https://www.middletownautism.com/

Non-Violent Resistance training www.nvrireland.ie

Advocacy Organisations

Family Carers Ireland, The Alzheimer Society of Ireland and AsIAm provide advo-cacy- their contact details are under ‘Family Support Organisations’ section.

National Advocacy Service for People with Disabilities 0818 07 3000; https://advocacy.ie/

Inclusion Ireland 01 8559891; https://inclusionireland.ie.

SAGE Advocacy 01 5367330, https://www.sageadvocacy.ie/

Human Rights and Equality Commission (IHREC) information line 1890 245545

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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