



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 autistic adults or children



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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/carers-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 - AUTISM

What is 'Carer Harm'?

Autism is a neurological difference in the nervous system, a form of neurodivergence. Autistic individuals may interact, think, and process things differently. For a small number of children/adults, they may find it difficult to cope with a situation, experience a build-up of emotions - fear, anger, anxiety, frustration, pain, and become overwhelmed resulting in a meltdown, which is not their choice or under their control. In many cases, the child/adult may also have mental health disorders or secondary neurodivergence.

Carer Harm is where parents or other family members supporting autistic children/adults experience intentional or unintentional harm when a child/adult cannot cope with their emotions and cannot communicate or understand why they feel this way. Harmful behaviours experienced by parents or siblings 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, choking)
- 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.)

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

You may not understand or be aware that the harmful behaviour that you are experiencing is not acceptable, and not a normal part of caregiving. Awareness of harmful behaviours and recognition of the risks associated with these behaviours is vital to the prevention of carer harm and protection of family carers.

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 autistic child/adult has injured them. You may feel guilty that you have failed the child/person you are caring for and that disclosure will mean labelling them or have them categorised as a person who could possibly inflict harm on others, which could limit their options.

The stigma associated with carer harm means that you may not feel comfortable asking questions about this issue, and you may be hesitant about raising your experience of carer harm because of fear of the consequences for the autistic child/adult and/or the family as whole.

It can also be difficult to know who to tell as your autistic child/adult, not the family, is often the focus of professional attention and service delivery so what happens to other family members is not the primary concern of service providers. When family carers have shared experiences of carer harm or raised concerns, professionals sometimes seem to not grasp the seriousness of the concern. Responses often focus on just generic parenting courses and training with the expectation that this will solve the issue of physical and emotional harm being experienced by family carers.

Potential situations where carer harm is more likely

- Your child or the adult you are caring for has not had early intervention due to delayed diagnosis because of waiting lists.
- Lack of availability of early education places appropriate to your autistic child's specific needs or therapies, such as speech and language therapy, to meet their communication needs. In these instances, for autistic children, the opportunity to develop communication skills, learn the 'right' behaviour and have boundaries and demands placed on them early in their life can be lost.
- You are isolated, have no one to talk to or to advise you. You are not getting any practical and/or emotional support from professionals on how to support the child/adult.
- Your child/adult is at home for long spells and has no daytime activities due to service providers or schools no longer being able to manage their behaviour. They have reached the cut-off point for a service and no appropriate services are available or where adult services such as supported employment or day centres are only available three or four days per week.
- At times of transition for your child/adult (for example, puberty, starting post primary school, entering training or day services at 18 years), the intensity of the harmful behaviours can increase.
- Dealing with a sense of loss e.g., death of a parent or family breakdown, can be overwhelming for an autistic child/adult.
- Pressure on parent carers of adult "children" which increases as you both age. This can lead to difficulties in family relationships or inappropriate restrictions on the lives of older parents who are family carers.
- The person you support and care for has care needs that you cannot meet, particularly if this arrangement continues over a long period of time.

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

- Autism is unique to every individual. Being open with the child/adult about their autism gives them an understanding of who they are. Understanding how your child feels and why they are behaving the way they are will help you identify triggers and strategies for managing these.
- Get support and talk through your situation with a professional or a support organisation like Family Carers Ireland to get advice, advocacy, direction and peer support. Family Carer 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 autistic child/adult which are necessary to keep you and your other children safe, seek help from a professional or advocacy organisation who can assist you to advocate for what you need. Some useful services are:

AsIAm 0818 234 234

Family Carer Ireland National Freephone Careline 1800 24 07 24

National Advocacy Service for People with Disabilities 0818 07 3000

- Identify and take part in education and training that might help you to understand and manage the harmful behaviours.
- Have a meltdown response plan that is easy to put in place and meets your child's needs e.g., give time to settle, show you understand, be empathetic and explore what caused the upset. Meltdowns shouldn't be punished or responded to negatively as this can undermine the child/adult's sense of safety of being able to express what they are feeling and their emotions around the person they feel safe. Do not be tempted to restrain the child/adult.
- Consider and discuss with a professional if the autistic child/adult would benefit from referral to other services or supports.
- Access counselling and seek out support for all of your family members affected, such as that offered by Family Carer Ireland: <https://familycarers.ie/carer-supports/help-guidance/counselling>

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 parents in your community through parent-run support groups like Parent Led Autistic Networks, for list see: <https://asiam.ie/support/>
- Join carer support groups, like those run by Family Carers Ireland, check for a group in your area: <https://familycarers.ie/carer-supports/carer-support-groups>
- Online Family Support groups can also provide support if it is difficult for you to leave the house:
Family Carers Ireland Online Family Support Group <https://forum.familycarers.ie/>
Care Alliance Online Family Carer Support Group <https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>.
- Other organisations with family support groups include national autism organisations such as:
AsIAm <https://asiam.ie/>
Autism Supporting Diversity <https://www.asdireland.ie/>
- Getting involved in these types of networks provides peer-support, opportunity for social activities, information on resources and access to education events. Many also provide support to siblings, which is essential for their wellbeing.
- 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.
- Resources that other parents have identified as helpful in identifying triggers include input from behavioural therapists and Middletown Autism Centre education resources <https://www.middletownautism.com/>.
- A useful training resource recommended by professionals is Non-Violent Resistance training - www.nvrireland.ie

- 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 your child and other children.
- If you or your children 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 child/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 for Children 1800 20 20 40; www.oco.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

