



**Family carers and
being a 'hero'**

1. Introduction

There is no doubt that family carers provide a considerable level of care in families across Ireland. Many make significant personal and professional sacrifices to enable them to provide care and support to family members with extra support needs. These family members include those with disabilities, long-term and chronic illnesses, mental health conditions, and substance abuse problems, as well as those who are growing old in the community. Ireland's 500,000+ family carers provide upwards of €20 billion worth of care per annum¹. Many provide this care at considerable levels of intensity, without any form of payment or compensation from the State. If family carers do receive financial payments as part of their role, in Ireland these are designed and conceptualised in policy as anti-poverty measures rather than payment for support and care provided.

A dominant narrative applied to family carers across media, political discourse and to a certain extent the voluntary sector is that of the 'hero' or 'angel' – someone who sacrifices everything to do a job that nobody else could. Family carers are held up as examples of selflessness, of heroic undertaking and sacrifice that elevate them above others. There is no doubt that family carers can and do make sacrifices in their personal and professional lives, and in terms of their mental, physical and emotional health in order to provide that care. However, a blanket 'hero narrative' applied to family carers is not always appropriate, and can elicit feelings of frustration, anger and inadequacy from family carers, who feel uncomfortable with such labels. In addition, it can fuel a paternalistic view of those in receipt of care and support, as caring for them is positioned as a job nobody else could possibly want or successfully do. It can also mirror the heroic view of people with disabilities as inspirational figures simply for existing in their disabled bodies, without necessarily thinking about how those bodies and individuals are disabled by a society which insists on holding them to a different standard.



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¹ Family Carers Ireland, 'The State of Caring 2022' (Family Carers Ireland, 2022).



This discussion paper is not designed to dissuade any support professional from acknowledging the vital role of family carers in providing care to people who need it. Neither is it designed to position carers as not wanting to be acknowledged for the care they provide. Many family carers are happy for the work they do and the care they provide to be acknowledged. Our hope is that this paper will stimulate debate and discussion regarding the possible misuse or overuse of these narratives in public discourse.



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This is the 12th paper in the Care Alliance Ireland Discussion Paper Series. The papers in this series are not intended to present a definitive account of a particular topic, but to introduce a less-discussed, sensitive or perhaps controversial topic for discussion within the wider community of practitioners, policy makers, researchers and other interested parties. This often takes the form of a literature review (where possible), along with a discussion of views which have been shared with the Care Alliance team, either by our member organisations or by family carers themselves. In some cases, the topic will be one which has been raised and shared in the media or social spaces online.

What is a hero?

Anyone working or volunteering in the family carer 'space' has likely used – or at least heard – the phrase 'family carers are the unsung heroes' or similar. But what exactly is a 'hero'? When you think of the word 'hero', what do you picture?

Perhaps someone like Batman, Supergirl, Thor or the X-Men; someone given powers to do extraordinary things, save lives – to beat the 'bad guy'. Maybe you think of more 'everyday' heroes like firefighters, nurses or mountain rescue crews. Regular people who, in the course of their work, save lives and make significant contributions to society. In that way, family carers could of course be classified as heroes. Every day, family carers keep those they care for safe, well and happy. They often provide the most intimate care, and complex medical care, as well as companionship, practical help and emotional support.

Bravery and virtue seem the most likely descriptors applied to the concept of a 'hero' – from ancient Greece to modern day². Bravery to do the things 'mere mortals' cannot, and virtue for knowing how to always do 'the right thing'. For many, the idea of a hero is motivating, demonstrating 'encouragement, motivation, character-building models of behaviour, or visions of an ideal personal self'³.

If we do position family carers as such 'heroes', what kind of picture are we painting of them? It is impossible to live up to the label of hero on a long-term basis, even if the care being provided is of high quality, empathetic and consistent. By holding family carers to these standards, are we creating a world whereby a mistake in care, a bad day, or the realisation that the family member can no longer provide the best care means that family carers fall from the high pedestal on which the hero narrative places them?



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² Sara Staats et al., 'The Hero Concept: Self, Family, and Friends Who Are Brave, Honest, and Hopeful', *Psychological Reports* 104, no. 3 (June 2009): 820–32.

³ Staats et al.



Just as importantly, what kind of narrative are we creating of those they care for? The 'hero' typically needs someone to 'save'; someone incapable of saving themselves. Our understanding of disability, illness and frailty has changed over time from the paternalistic view that those with any kind of extra support needs should be removed from public life for their own safety, to one where the needs and rights of the individual are placed at the centre of care. Viewing family members as heroes for providing care risks perpetuating the view that people with disabilities are in need of saving, or at best some kind of burden on their loved ones.

'Inspiration Porn' and family care

The disability activist Stella Young has been widely credited with bringing the idea of 'inspiration porn' to the masses, most particularly through her work in a 2014 TedTalk titled "*I am not your inspiration, thank you very much*"⁴. In it, she speaks about how her mere existence in the world, doing the most basic things, the same as anyone else, is seen as 'inspiring' or 'extraordinary':

"When I was 15, a member of my local community approached my parents and wanted to nominate me for a community achievement award. And my parents said, "Hm, that's really nice, but there's kind of one glaring problem with that. She hasn't actually achieved anything." And they were right, you know... I wasn't doing anything that could be considered an achievement if you took disability out of the equation."

She speaks about the motivational-type images that are so often shared on social media, with taglines such as 'the only disability in life is a bad attitude', etc. As images are used so often as part of this messaging, she uses the phrase 'porn' very deliberately:

"I use the term porn deliberately, because they objectify one group of people for the benefit of another group of people. So, in this case, we're objectifying disabled people for the benefit of nondisabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, 'Well, however bad my life is, it could be worse. I could be that person.'"

Without attempting to appropriate the use of this term away from disabled people, in many ways 'inspiration porn' could be a useful way of viewing how family carers are

⁴ https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/transcript?language=en

thought of or held up as a heroic example to society. Casting them as the hero or hailing them as inspirational objectifies them and the work they do.



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That is not to be confused with attempts to acknowledge the significant contributions of family carers both to their loved ones and to society at large. Nor is it comparable to sharing the experiences of family carers to enable greater understanding of both the challenges and the positive impacts of caring. Sharing their experiences is a key component in advocating for more supports and services both for the family carer and the person they care for. There is no doubt that as supports for disabled people and those with long-term conditions improve, the family carer benefits. They are less likely to spend so much time advocating for their loved one, and can begin to spend some of that time and energy on themselves and their own mental, physical and emotional health.

Some readers will wonder why using the term 'hero' or similar could be seen as negative. Given the often very significant tasks that a family carer does on a daily basis, why would we wish to downplay them or risk trivialising them? After all, the family caring we are talking about in this paper is by definition above and beyond, for example, the usual level of care expected in caring for a child. The difficulty is that applying the overarching narrative of the hero to family care leads to incredibly high expectations of family carers.

Many family carers will not view what they do as extraordinary, but simply as part of the fabric of everyday life. It is seen by many carers as part and parcel of being a member of a family, whatever form that takes. Previous research conducted by Care Alliance Ireland investigated the label or title that family carers prefer to use to refer to themselves; in general, the preferred label pertained more to the relationship between the individuals (e.g., 'mother', 'father', 'husband', etc.) than to the more



intensive 'care' relationship⁵. These carers think of themselves as simply being a caring family member, and, just as with the concept of 'inspiration porn' discussed above, this should not necessarily be seen as extraordinary.

It has long been documented that providing family care can be very challenging and lead to significant negative impacts, particularly when there is minimal or inappropriate support given to carers or those they care for. Carers often identify their significant challenges as inadequate support in terms of the resources needed for care, financial difficulties, and personal negative health impacts. It is arguable that these impacts would be mitigated with appropriate and timely support from health and social care professionals, along with policy and legislative supports.

No room for mistakes

When the dominant narrative regarding family carers is that of a hero, it becomes very difficult for some family carers to feel comfortable in venting their frustrations, in particular if those frustrations concern the person they are caring for. In a previous paper in this series we discussed the issue of family carers navigating difficult relationships⁶. There can be significant stigma around caring for a person you just don't like but have to continue to care for due to feelings of guilt or familial responsibility⁷. If carers are constantly viewed as heroes, as all-sacrificing, as extraordinary, then there is little room for perceived 'error' or 'failure' in the role.



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It is not, of course, a failure for a family carer to conclude that perhaps the role is best suited to another member of the family or paid care workers, or indeed that the best and most appropriate care is not in the home but in long-term care, such as a nursing home. Neither is it a failure for a family carer to prioritise their own mental, physical and emotional health. Irish research has found that 1 in 3 family carers

⁵ Zoe Hughes and Liam O'Sullivan, 'Defining and Profiling Family Carers: Reflections from Ireland', *International Journal of Care and Caring* 1, no. 3 (2017): 421–27.

⁶ Care Alliance Ireland, 'Difficult Relationships and Family Care', 2018.

⁷ Care Alliance Ireland, 'We Need to Talk About It' – *Stigma and Family Care*, 2016.

have a diagnosis of depression, almost 40% experience anxiety, and 40% have a back injury⁸. Clearly, the impacts of caring are significant.

But 'heroes' don't make mistakes. 'Heroes' keep going through difficult times. 'Heroes' make sacrifices for their role that others cannot. For some family carers, however, this is having significant impact on their health.

Of course, some family carers have no choice but to care. There are not enough services to support their needs, or they may be caring for someone who refuses to access their own supports outside of the home, even if they are available. They may be caring for children with exceptionally high support needs, and of course many parents want to be the ones caring for their children. This is completely natural.

Often it is these carers particularly who are labelled as heroes, with all the accompanying narrative of going above and beyond for their loved ones.

Certainly, this paper is not advocating a dismissal of the significant difficulties and challenges these families face. Nor are we dismissing the positives of caring for family members through difficult experiences. However, positioning carers as heroes can act as an unconscious boost to the argument for providing less support. After all, heroes are extraordinary, and don't need the help of anyone else.

Hero or nothing

According to the most recent census, there are 195,000 family carers in Ireland. However, the estimated number of carers varies greatly depending on the source. Data from the 2019 Irish Health Survey, as briefly mentioned earlier, indicates that close to 500,000 people provide family care⁹. The reasons for this apparent disparity in numbers have been discussed in publications by ourselves in Care Alliance Ireland and colleagues across the sector. What is clear is that many family carers do not identify as carers. They prefer different labels, or indeed don't see what they are providing to loved ones as anything extraordinary.

This is where the narrative of heroism can be unhelpful. Taking on the identity and label of 'family carer' is 'the gateway through which supports are accessed' in Ireland¹⁰. A reluctance to assume this identity can affect the support they receive in their role as carer. If the main narrative around family carers a person sees in the media, across support organisations and in the public eye is 'hero' or similar, then the assumption is that you must be doing something extraordinary to be a family

⁸ Family Carers Ireland, College of Psychiatrists of Ireland and UCD, *'Paying the Price: The Physical, Mental and Psychological Impact of Caring'* (Family Carers Ireland, 2019).

⁹ Care Alliance Ireland, *'Estimates for Numbers of Family Carers in Ireland'* (Care Alliance Ireland, 2019); Family Carers Ireland, *'Counting Carers: Carer Prevalence in Ireland - Working Paper 1'* (Family Carers Ireland, 2021).

¹⁰ Victoria Molyneaux et al., *'Reconsidering the Term "Carer": A Critique of the Universal Adoption of the Term "Carer"'*, *Ageing and Society* 31, no. 3 (2011): 422–37.



carer. It follows that only doing something ‘extraordinary’ permits you to receive support in that role – whether financial, emotional or practical. This can render those who are providing less intensive – but no less important – care invisible both to society at large but also to family carers who are intensively caring.

According to research undertaken by Knowles et al., carers for people with less intensive care needs or those supporting a loved one in a long-term care facility are often reluctant to see themselves as a carer:

“the nature and extent of caring work undertaken are the key attributes [that are] compared, with the work of emotionally supporting relatively independent people with long-term conditions unfavourably compared to the stereotypical ‘hero’ who ‘puts their life on hold’”¹¹.

Occasionally you will hear those caring at intensive levels repeat this, most likely completely unconsciously. The hero narrative creates a level of normalcy around intensive caring, as though that is the only type of caring that is valid. This is not fair or accurate, and may compound the isolation felt by family carers if their own peers and those around them are dismissive of their caring. Doing so risks creating a hierarchy of caring, rather than addressing the hierarchy of caring needs.



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Providing validation

It would be irresponsible to assume that all family carers dislike the idea of being called a hero, or that its use is only negative. As many family carers relinquish other roles when their caring begins – such as the role of employee – then it can be validating to have the identity of family carer valued and respected, and the ‘hero’ descriptor applied. The term can and does encapsulate many of the attributes that family carers would use to describe themselves: caring, responsible, hard-working and dedicated.

¹¹ Sarah Knowles et al., ‘Hidden Caring, Hidden Carers? Exploring the Experience of Carers for People with Long-term Conditions’, Health & Social Care in the Community 24, no. 2.

Rhetoric in place of action

A distinct critique of the points raised in this paper may be that the language used to describe family carers does not matter so long as the right services and supports are in place. Indeed, there is a definite truth to that.

However, in looking at the mental, physical, emotional and financial impacts that family carers experience it is clear that the right services and supports are not in place in Ireland at the current time.

The Family Carers Ireland State of Caring 2022 report¹² makes this starkly clear. Some of the key findings from that research are:

- 13% of carers are in arrears with their rent or mortgage payments (compared to 7% of the general population)
- 68% are experiencing financial distress
- 70% report difficulties in accessing services for those they care for
- 88% feel that what they do is not recognised by society.

Yet, the rhetoric used by politicians, policy makers and, at times, family carer advocacy organisations includes variations on the theme of heroism: carers are the ‘backbone of society’, the ‘unsung heroes’ and other similar terms. Yet, even as this language is used, the services and supports provided are clearly ineffective. Using this type of language yet failing to make concrete changes that would directly benefit family carers and those they care for is clearly contradictory. Many family carers report being sick of hearing that they are the backbone of society, or a hero. They would prefer to be able to access timely diagnostic support for their disabled child, consistent and reliable respite for their ageing mother, or specialised and sufficient home care for their father with dementia.



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¹² Family Carers Ireland, ‘The State of Caring 2022’.



Policy and service responses

So, what can health and social care professionals, along with policy makers, do with the information presented in this paper?

Consider language use when discussing family care

The paper should not be taken as advocating not acknowledging the significant contribution that family carers make. As stated, on a purely economic basis, carers provide upwards of €20 billion worth of care per year¹³. On top of that, they contribute hugely to ensuring that those with disabilities, mental health difficulties and other long-term conditions can, with support, remain living in their own homes and communities.

It is worth stopping and considering the language we use to describe family carers and their work. By creating a hero narrative around family care, we risk creating an image of the undefeatable carer, one who can triumph over adversity by sheer will. This is not what is meant by those using the term, of course. What is often intended is to acknowledge that family carers frequently do go above what they expect of themselves, and develop skills and abilities they may never have known about. However, if we consistently use only this type of language we risk undermining the need for adequate and appropriate support that must be provided to family carers to mitigate some of the negative consequences of care.



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Challenge the media assumptions and dominant narrative of heroic caring

In reconsidering our language, we should also challenge the media, who are key to perpetuating this hero narrative around family care. This can be difficult. The health and social care sector – particular the voluntary sector organisations who are funded to provide supports in the area of family care – depend on the media to raise issues of policy and practice, and to create awareness of the challenges faced by family carers and those they care for.

¹³Family Carers Ireland, 'The State of Caring 2022'.

But by consistently allowing these messages to go unchallenged, we risk making the issue of 'inspiration porn', as discussed above, worse. We risk adding to the assumption that those in need of care and support are a burden, that only a certain type of person could possibly care for a loved one, or that family carers are inspirational just because they are caring for someone. All family carers are worthy of acknowledgment, and worthy of support for themselves.

Understand that some family carers enjoy the hero narrative

Not all family carers dislike the idea of being called a hero. This paper was in no way designed to say that carers who embrace that label are wrong to do so. Being acknowledged visibly can be very validating for a group often ignored, and who often do what they do without expecting praise.

Conclusion

This paper has examined the use of the hero narrative as it is applied to family carers. It is clear that the idea of a 'hero' can both be appreciated by family carers and seen as problematic. However, by continuing to support such a narrative without question, there is a risk that such praise and accolades are simply a way to 'pay lip service' to the considerable support needs of family carers in terms of their own physical, emotional, mental and financial health.



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Guiding support for family carers

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