



Guiding support for family carers

**Discussion
Paper 11**

**Defining Carers:
Update June 2022**



1. Introduction

The word ‘carer’ is used across many sectors, and to describe many different groups of people. However, the word ‘carer’ – and in particular the term ‘family carer’ – is often very consciously *not* used in certain sectors and circumstances. Language evolves, and has different meanings and connotations depending on the speaker, the listener and the context. This is why we feel it is important to review the language used around caring and family carers, and to understand the impact that language use has. This updated paper will briefly review the term ‘carer’ with regard to general usage and how it is understood by society.

The purpose of this paper is less to answer questions than to ask them, and less to define ‘carers’ than to understand who they are. In particular, its purpose is to ask why the label ‘family carer’ may be rejected by some of them, or by particular groups who were traditionally thought of as needing such care from family members. In contrast, many family carers find solace and support in claiming the identity of ‘family carer’. The acceptance or rejection of the term itself can have a huge impact on whether the supports available to family carers in Ireland are in fact available to all those providing care, or just to those who accept the term as a descriptor of their situation.

This paper is an update to the first in this Discussion Paper Series, first published in 2015. Given that there have been two Censuses since the original paper was published, along with significant other research and discussion (both national and international) into the definition of ‘family care’, we felt this paper was particularly timely. In addition, the current work of the Joint Oireachtas Committee on Gender Equality¹ has a particular interest in this issue, and we hope this paper will be of value. Of course, the experience of Covid-19 has also forced many to re-evaluate their concept of care, of being cared for, and of how we, as a society, position that care moving forward in the 21st century.



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¹ Currently convened and expected to produce their report by December 2022.

2. The Term ‘Family Carer’ – And Who It Refers to

In order to begin exploring these issues, with particular regard to the Irish context, it would be remiss not to clarify who this paper refers to, particularly when using the term ‘family carer’.

The most recent Census of Population of Ireland defines a ‘carer’ as someone who

‘provide[s] regular unpaid personal help or support to a family member, neighbour or friend with a long-term illness, health issue, an issue related to old age or disability’ (Census 2022)

There was a delay in the administration of Census 2021 due to the Covid-19 pandemic, and so that census took place in April 2022.

This wording used in 2022 is noticeably different to the previous definition used by the Central Statistics Office (CSO) in census forms:

‘... provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems which are due to old age). Personal help includes help with basic tasks such as feeding and dressing.’ (Censuses 2011 and 2016)

The most up-to-date census data we have in relation to family carers is based on the 2016 data, which used the previous wording of the question. However, as part of the updating and rewording of the latest census form, two versions of the question on care were tested/piloted in 2020. The experience from this pilot is that the revisions to the question appear to have contributed to significant increases in the reported level of caring. The questions in both versions of the pilot form were significantly reworded as shown above, with the addition of explicit reference to provision of ‘support’, ‘caring for a neighbour’ and ‘caring for persons with issues related to old age’. Both versions of the question tested in the pilot caused increases in the number of persons reporting as carers. In 2016, 4.1% of the population in the areas of Ireland used in piloting reported as carers; this increased to 5.6% in testing of Form A and 5.7% in testing of Form B. This shows just how important the wording of any definition of family care is to our understanding of the quantum of care being provided.



Broadly speaking, this paper focuses on those individuals who provide care and/or support to a family member, friend or neighbour in that person's own home on a regular basis, regardless of time spent doing so. Those needing this care and/or support include older people with general ageing concerns; people with dementia and memory loss; people with intellectual, physical, sensory and neurological disabilities; and people with life-limiting conditions and/or terminal illnesses. These individuals may be children or adults – and those caring may also be children or adults. They also do not need to be a relative (either by blood or by marriage) of the person being cared for. The concept of 'chosen family' is one which was originally conceptualised in relation to the LGBTQIA+ community in the early 1990s² and has since spread beyond that community to be of relevance across society in general.



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Internationally, numerous phrases are used to describe the cohort of people providing care as described above. In the UK³ and Australia⁴, the prevailing descriptive term seems to be 'carer', with no 'family' designation⁵; this is a more inclusive term, but is it too inclusive or too wide a definition? Could it be interpreted widely as also referring to those who provide paid care and support? In an Irish context, a 'carer' generally refers to a paid care worker. Indeed, the carer movement in Ireland explicitly uses the term 'family carer' to differentiate between carers who are family members or friends, and others in caring roles, such as paid home care support workers, nurses, and indeed those working in the wider so-called 'caring professions'. In the US⁶, the terms 'caregiver' or 'family caregiver' prevail, with the term 'caregiver' in particular being used interchangeably to describe both paid home care workers and family members. In some countries, there is no particular word or phrase to capture the work done by family carers, while in others, specific words have evolved to describe certain facets of care work, for example, the word *badante*⁷ in Italian. In addition, Eurocarers, the European membership organisation for community groups across the EU supporting family carers, uses

² Kay Weston, *Families We Choose: Lesbians, Gays, Kinship* (New York: Columbia University Press, 1991).

³ See for example www.carersuk.org.

⁴ See for example www.carersaustralia.com.au.

⁵ This is based on a review of previous documents published by these groups, and their usage on their respective websites.

⁶ See for example www.caregiving.org.

⁷ Meaning 'carer' or 'care worker'.

the term ‘informal carers’ – which many family carers disagree with; they argue that there is nothing ‘informal’ about the care they provide. Such care is regular, significant, and often completely equivalent to care provision in a nursing home or hospital environment. We in Care Alliance contend that the term ‘informal carer’ risks trivialising the work of family carers who provide significant levels of high-quality care. It may not be paid, but that does not mean it is not of sound quality and contributing significantly to the health and well-being of hundreds of thousands of people with various health conditions around the country⁸.



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While these are minor differences across national boundaries, the nuances highlight the difficulties inherent in categorising those who provide care on a regular, unpaid basis to friends or family. In Ireland, how is the term ‘family carer’ received both by those it refers to directly (those providing care) and indirectly (those receiving that care)?

Broadly speaking, when asked to imagine a typical ‘family carer’, much of society imagines a woman in her 40s or 50s, caring for her ageing parents. While the cohort of people most likely to be carers is indeed women in that age range, those receiving care are not as easily identifiable. The National Quarterly Household Survey in 2009⁹ indicated that 40% of carers looked after a parent or parent-in-law, and one-third of carers were caring for a person who required that care due to old age. This leaves 60% of carers caring for someone other than a parent, and two-thirds of carers providing care for reasons other than ageing. We acknowledge that these figures are significantly outdated; however, this does serve to highlight just how little we understand about who is being cared for in Ireland.

In order to update this data somewhat, a survey was undertaken by Care Alliance Ireland in preparation for the first version of this paper (2015), and a considerable

⁸ Care Alliance Ireland, “The Right Not to Be Called an Informal Carer. Care Alliance Ireland: Position Statement on Language Use” (Care Alliance Ireland, 2017).

⁹ Central Statistics Office, “Quarterly National Household Survey-Carers (Quarter 3 2009)” (Central Statistics Office, 2010)



47% of respondents indicated they were caring for a child, with 12% caring for a spouse, and 31% caring for a parent¹⁰. The majority (69%) of respondents were aged between 36 and 55. The reasons identified¹¹ as to why the person being cared for requires help were:

- Physical disability (34.18%)
- Long-term health condition (25.67%)
- Intellectual disability (25.54%)
- Dementia (21.60%)
- Needs that arise from being older (19.70%)
- An autism spectrum disorder (18.93%)
- A mental health condition (12.83%)
- A neurological condition (12.07%)
- Cancer (4.70%)
- Alcohol or substance abuse (1.52%)
- An eating disorder (1.27%)
- Other reason (10.80%).

What this serves to illustrate is that many assumptions about those who provide and receive care in a family setting are inaccurate.

Of course, the key aspect of these studies (the Census, the National Quarterly Household Survey, the Care Alliance Ireland study, etc.) is predicated on family carers identifying themselves as such. As discussed in the following sections, numerous factors call into question some carers' willingness and ability to self-identify as 'family carers'. Currently, for many, taking on the identity and label of 'family carer' is 'the gateway through which supports are accessed'¹². A reluctance to assume this identity can affect the support they themselves receive in their role as carer, a role which has of course been acknowledged to have many challenges for individuals in terms of finances, isolation, and physical and mental health¹³.

¹⁰ This survey was carried out online using Survey Monkey, with 789 respondents.

¹¹ Respondents could choose more than one.

¹² 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.

¹³ Liam O'Sullivan, "Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance" (Combat Poverty Agency, 2008); Ann Stokes, "The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of People with Parkinson's Disease," 2010; 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).

3. Self-Identity

Identity is a deeply personal thing, which impacts decisions, self-confidence and other key aspects of personality. In identifying as part of a particular social, economic or other group, one gains or loses prestige in accordance with that identity. In understanding what it means to identify or to be identified as a family carer, there are a number of issues to be considered.

Stigma

Although stigma is decreasing as awareness-raising campaigns become more successful, certain conditions which necessitate family members becoming involved in caring for loved ones are still viewed in negative terms by some of society. In particular, noticeable levels of stigma or misunderstanding still exist in the areas of mental health, intellectual disability, addiction and eating disorders. By identifying as family carers, family members may risk further stigmatising their loved ones, particularly those with conditions such as mentioned above. In some cases, assuming the identity of 'family carer' may in fact 'out' those being cared for, particularly if the condition necessitating care is hidden. Consequently, in these sectors, many family carers and those for whom they care reject the term, declining to identify either as a 'carer' or as someone being 'cared for'¹⁴. This of course has significant impacts on the services and supports that a family carer may feel they can access for their own mental health; carers are themselves more likely than the general population to experience a mental health difficulty such as anxiety, depression or insomnia¹⁵.



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¹⁴ J Henderson, "He's Not My Carer – He's My Husband': Personal and Policy Constructions of Care in Mental Health," *Journal of Social Work Practice* 15, no. 2 (2001): 149–59.

¹⁵ Stefanie Doebler et al., "Informal Care-Giving and Mental Ill-Health - Differential Relationships by Workload, Gender, Age and Area-Remoteness in a UK Region," *Health and Social Care in the Community* 25, no. 3 (2017); Family Carers Ireland, "Caring Through COVID: Life in Lockdown" (Family Carers Ireland, 2020); Jacqui O'Riordan and Carol Kelleher, "A Fine Balance: Mental Health and Family Caring," 2016.



Loss of previous identity

In identifying as a family carer, the label of ‘daughter’, ‘son’, ‘husband’, ‘wife’, etc. may be lost or at risk of being lost. Some researchers advise caution when labelling or identifying a person as a family carer, in particular if that signals an end to a previous relationship¹⁶.

While the large-scale Care Alliance study outlined above was not specifically designed to test the notion of identity and caring, responses highlighted the difficulties many parents in particular have with assuming the role of family carer:

‘Change the name carer. Some of us have no choice if we want to be a carer or not. A carer in my eyes is someone who wants that role. I want to be a mother.’

‘[I] feel like I’m everything else except a Mum.’

‘Sometimes [it’s hard] to be just the carer when other family members have careers.’

‘I am still a Mum.’

These comments show that navigating the world of a family carer can be stressful not simply because of the tasks which become part of daily life, but also because of the need to become reconciled to a new identity, an identity which may supplant a previous identity developed over decades prior to this life change. Parents, in particular, seem to have difficulty reconciling being a family carer with being a parent raising their children, and are not keen to relinquish the role and identity of parent for that of ‘carer’¹⁷.



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¹⁶ Henderson, “‘He’s Not My Carer- He’s My Husband’: Personal and Policy Constructions of Care in Mental Health.”

¹⁷ C Robinson and V Williams, “Carers of People with Learning Disabilities and Their Experience of the 1995 Carers Act,” *British Journal of Social Work* 32, no. 2 (2002): 169–83.

In some cases, the realisation that a person has assumed a new identity may not be resisted as a conscious decision – the nature of care and support can often mean that what began as dropping in some grocery shopping to Mum every few weeks developed to every other day, which itself has developed into daily visits to help with cooking and cleaning. Arguably this is part of the ‘natural’ way families, friends and neighbours create a community and a degree of reciprocity – however it can be difficult to pinpoint this change in needs and care provided over time when the development of increased care needs is gradual¹⁸.

What constitutes a ‘family’?

According to the Irish Constitution, the Family is ‘the natural primary and fundamental unit group of Society’. While the Constitution itself does not define ‘family’, it does commit to safeguarding the institution of marriage ‘on which the Family is founded’, thereby implying that a non-marital family is not a Family for the purposes of the Constitution¹⁹.

In 2021 the Citizens Assembly on Gender Equality made some key recommendations with regard to this definition of ‘family’ which are pertinent to this discussion of family care and self-identification. Twenty-first-century Ireland is a very different place from Ireland of 1937. As such, the idea of the family as being founded upon marriage between one man and one woman, resulting in children, is significantly outdated. In 2015 the definition of marriage was changed to reflect this, bringing marriage equality into the Constitution by popular vote. However, fundamentally this definition of family still excludes lone-parent families, blended families, multi-generational families and families of choice.

It would be easy to ask why this really matters in relation to family care; as illustrated earlier in this paper, care does not have to be provided to or by a member of a marital family in order to ‘count’ as care for the purposes of the Census, nor indeed for the purposes of accessing many of the supports available. However, as we primarily use the term ‘family carer’ in Ireland, some carers, care recipients and indeed policy makers may see this definition as exclusionary of the care provided by neighbours, friends, unmarried partners and others. We in Care Alliance are very supportive of the recommendation passed by 98.9% of the members of the Citizens Assembly in 2021 that the Constitution should ‘protect private and family life, including forms of family life beyond the marital family’²⁰.

¹⁸ Family Carers Ireland, “Counting Carers: Carer Prevalence in Ireland – Working Paper 1” (Family Carers Ireland, 2021).

¹⁹ G Whyte, “The Constitutional Status of the Unmarried Family and Its Constituent Members” (Treoir, 2017)

²⁰ Citizens Assembly on Gender Equality, “Report of the Citizen’s Assembly on Gender Equality,” 2021.



4. Paternalism

Within certain sectors, the use of the term ‘family carer’, while well-intentioned, is often not welcomed by those who receive the support and care of family members. The term is seen as paternalistic, and not in keeping with the dominant ideology of the social model of disability²¹. A 2001 study in the UK found that people with intellectual disabilities rejected the term ‘carer’, preferring the term ‘supporter’ instead²². Pilgrim²¹ advocates a shift away from the term ‘carer’ altogether, and a move towards situating the support according to specific roles, relationships and contexts.



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Even the fact of ‘having a carer’ can undermine the independence of individuals, and as the role of ‘carer’ may not change as individuals age, parental carers may find it difficult to accept their child’s adult identity, continuing to exert inappropriate levels of parental control²⁴. In an Irish context, this can muddy the waters of the parental relationship, in particular with regard to adults with intellectual disabilities. While the National Carers Strategy²⁵ is explicit in seeing a role for family carers as partners in care involved in the process of support to the greatest extent possible, the National Disability Inclusion Strategy 2017–2021 uses the word ‘family’ only twice, with no reference at all to ‘family carer’.

²¹ Dan Goodley, “‘Learning Difficulties’, the Social Model of Disability and Impairment: Challenging Epistemologies,” *Disability & Society* 16, no. 2 (2001): 207–31.

²² Robinson and Williams, “Carers of People with Learning Disabilities and Their Experience of the 1995 Carers Act.”

²³ D Pilgrim, “Who Cares?,” *Openmind* 98, no. 15 (1999).

²⁴ Robinson and Williams, “Carers of People with Learning Disabilities and Their Experience of the 1995 Carers Act.”

²⁵ Department of Health, “The National Carers’ Strategy” (Department of Health, 2012).

5. Gender

Traditionally, care work is often seen as ‘women’s work’ – indeed much of the modern ‘carers movement’ has developed from a push to have the value of the work of female family carers recognised²⁶. In contrast to this ‘traditional’ view of family carers, the percentage of male carers increased to 39.5% in Census 2016²⁷, from 38% in 2011. Male carers are the demographic group with the highest percentage increase in Ireland – a fact which creates its own challenges.

However, relatively few male carers seem to publicly identify as such, or to take part in carer support groups, etc. Just 11.6% of the followers of the National Carers Week Facebook page, for example, are male²⁸, while 7% of members of the Care Alliance Ireland-moderated Facebook group are male. This can be partially accounted for by the differing types of support which men, traditionally, prefer. While female carers enjoy speaking with others about challenges, and daily routines and tasks, many men prefer to share an activity unrelated to their caring role²⁹.

Ribeiro, Paul and Nogueira’s study indicated that men fail to identify with the term ‘carer’, seeing the tasks and status involved in caring duties as part of a relationship³⁰. In that study, participants integrated their ‘caring’ identity with their sense of masculinity, taking pride in that role. In other studies, male carers appear to have developed a vision of masculinity that not only de-emphasised certain traditionally ‘masculine’ elements (such as not revealing emotions etc.), but also emphasised others, such as taking charge, and ‘male-to-male’ bonding³¹. More recent work in Ireland has shown that male carers, when telling their personal



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²⁶ Molyneaux et al., “Reconsidering the Term ‘Carer’: A Critique of the Universal Adoption of the Term ‘Carer.’”

²⁷ Central Statistics Office, “Census 2016 Summary Results – Part 1” (Central Statistics Office, 2017).

²⁸ Care Alliance Ireland coordinates National Carers week each year, and established the Online Family Carers Support Group in response to Covid-19 – see <https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>.

²⁹ West Cork Carers, “Male Carers Ireland’s Unsung Heroes,” Irish Examiner, August 29, 2013, <http://www.irishexaminer.com/farming/life/male-carers-irelands-unsung-heroes-241296.html>.

³⁰ O Ribeiro, C Paul, and C Nogueira, “Real Men, Real Husbands: Caregiving and Masculinities in Later Life,” *Journal of Aging Studies* 21, no. 4 (2007): 302–13.

³¹ L Campbell and M Carroll, “The Incomplete Revolution: Theorizing Gender When Studying Men Who Provide Care to Aging Parents.,” *Men and Masculinities* 9, no. 4 (2007): 491–508.



stories, were resisting traditional discourses surrounding masculinity. For example, they expressed satisfaction in skills learnt as part of their caring role which are traditionally not associated with masculine behaviour, such as dealing with household tasks. The gentle and tender way in which men described their involvement with and responsibility for intimate personal care also de-emphasised hegemonic masculinity - that idea that men should always be tough and dominant over women³².

As will be outlined below, Irish male carers identify more strongly with the relationship than with the identity of 'family carer', which mirrors the findings of previous studies³³.

³² Ann Stokes, "A Never-Ending Love Story: A Narrative Exploration into the Experiences of Men Who Provide Care in the Context of Dementia" (Unpublished PhD Thesis, Dublin, University of Dublin, Trinity College Dublin, 2015).

³³ Molyneaux et al., "Reconsidering the Term 'Carer': A Critique of the Universal Adoption of the Term 'Carer'"; Ribeiro, Paul, and Nogueira, "Real Men, Real Husbands: Caregiving and Masculinities in Later Life."

6. Irish Family Carer Preferences

In a survey³⁴ undertaken by Care Alliance in which family carers were specifically asked about their preferred identity when it came to describing or ‘labelling’ themselves with regard to their caring role, it became clear how challenging the use of language is in this area. Respondents were asked to pick from a list of commonly used terms to describe themselves, and could pick more than one term.

The phrase/word most commonly chosen by respondents was ‘mother’ (45%), followed by ‘carer’ (39%) and ‘daughter’ (21%), which reflects the fact that 90% of responses came from female carers. For male carers, the top three responses were ‘son’ (57%), ‘husband’ (42%) and ‘family carer/family caregiver’ (both 28%). In both instances it is clear that those providing care to a family member prefer to identify themselves by their relationship to the person ‘cared for’ rather than by the tasks or duties of ‘caring’.

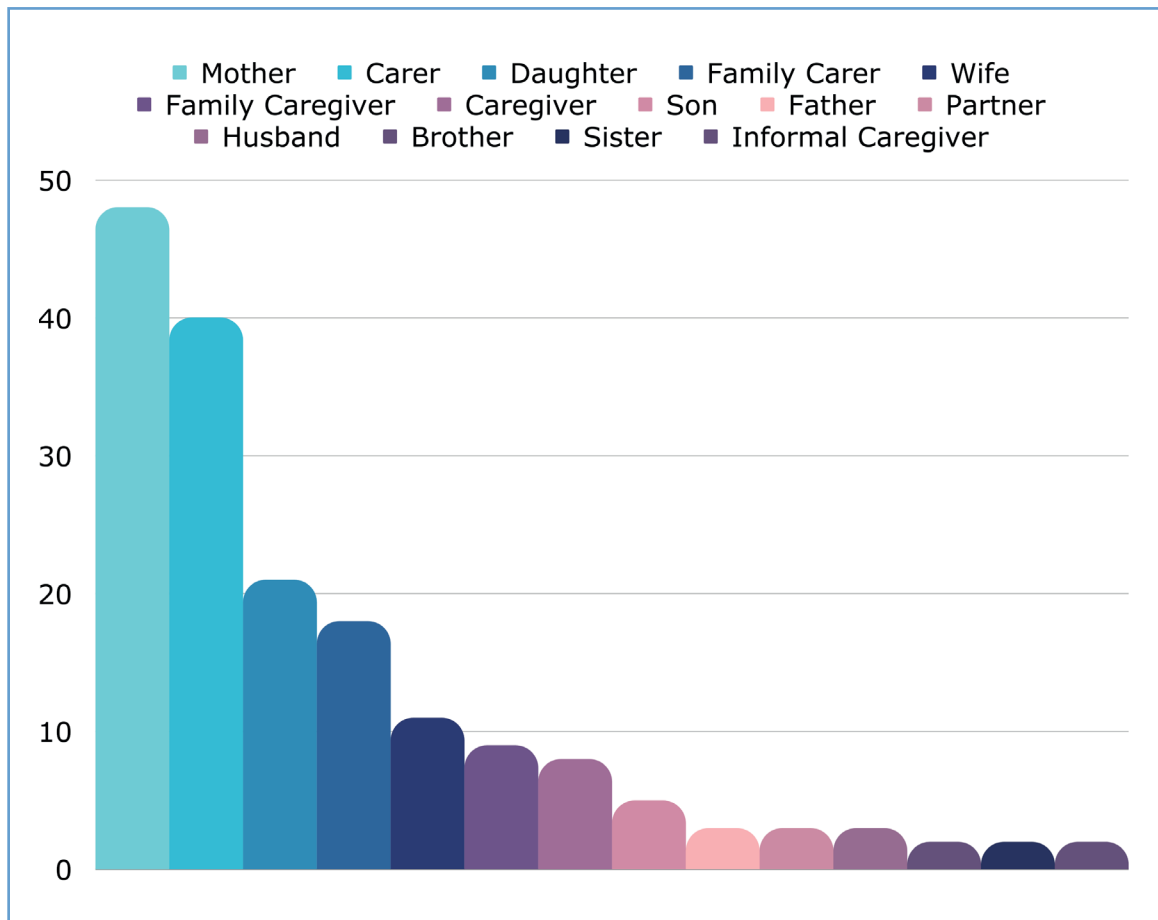


Fig. 1: Language preferences (all respondents)

³⁴ More information on this study available on request (info@carealliance.ie).



As discussed previously, it is important to understand the nature of the existing relationship. When those who care for a spouse or partner were asked this question, two terms were equally popular – ‘wife’ and ‘carer’ (38% each). This is somewhat surprising, given the desire of many partners and spouses to keep the original nature of that relationship to the fore, as discussed above.

Perhaps unsurprisingly, when those caring for a child were asked which term they preferred, the overwhelming majority chose ‘mother’, with 88% of respondents choosing this term. In addition, these respondents were most likely to reject other terms, by adding to their answers comments such as the samples below:

‘The word “carer” is ok when it’s not a family member. A mother is always a mother to all her children and I “care” for all my children.’

‘I prefer to be known as mammy before carer. I care for my son who ... is three years (old). Himself and his older sister know me as mammy and not as a carer.’

‘I think all mothers are family carers, I’m a mammy first, carer second.’

Only those caring for a person with a mental health difficulty identified the term ‘family carer’ as their preferred identifier, which contrasts with many of the comments emphasising the importance of the pre-existing relationship with the person receiving care. The general term ‘carer’ was one of the top two choices in all other areas (with the exception of cancer and alcohol and substance abuse situations).

When the respondents were given an opportunity to expand on their responses, a number of overarching themes emerged – in particular the feeling that some of the commonly used terms do not adequately describe them or the role they play in their loved ones’ lives:

‘I feel that the term “informal carer/caregiver” is rather dismissive, suggesting that care is second rate rather than primary and invaluable’

‘The formal carers in the HSE need a different title as everyone seems to think us family caregivers are the same as employee carers’

‘I am not totally happy with any of the terms as none adequately describes me; however I have not found a better alternative’

The personal preferences of those being ‘cared for’ also have an impact on the words family carers use to describe themselves, as they take into consideration the impact that identifying as a ‘carer’ has on how those they care for are viewed:

‘I know what I do is regarded as caring but my partner doesn’t like this term. He is well aware of what I do and appreciates what I do, but I think it makes him more aware of his illness/es, so I try not to refer to myself as his carer.’

‘Both persons [I care for] are sensitive about discussing the fact they need care’

Others reject the term ‘carer’ and other similar terms outright, citing the lack of understanding of what the terms really mean and how the role of carer has affected them:

‘Most people who are carers didn’t plan to be carers, it just happened, it’s our lot in life, so “family carer” implies we choose to be that, when in fact it was foisted on us.’

‘One-word labels do not communicate the scope of my caring role. Feel I always have to explain as people undervalue what I do.’

‘Personally I don’t like being called a Carer. Having to leave my job and salary behind and take on this new role has dented my confidence and my sense of self-worth and my standing in the community. I will probably get used to it in time but I hate using the Carer word.’

While we acknowledge the data in this survey may now be outdated we were unable to find more up-to-date data for this refreshed paper. This highlights just how little is known about the concept of self-identity and caring. Of particular interest is the difference the experience of Covid-19 may make to how we conceptualise care, caring and the receipt of care and support in Ireland.

Due to the restrictions and lockdowns, in particular during the first year of the pandemic, so many families had a glimpse into the everyday experiences of those with significant care responsibilities³⁵. Will this have an impact on individuals’ willingness to accept the identity of ‘carer’? Or will it in some way mark a turning point in how we define and conceptualise care and caring in the years ahead?

³⁵ Alzheimer Society of Ireland, “Caring and Coping with Dementia During Covid-19” (Alzheimer Society of Ireland, 2020); Carers NSW, “Covid-19 and Carers: A Review of the Evidence” (Carers NSW, 2020); Family Carers Ireland, “Caring Through COVID: Life in Lockdown.”



7. Conclusions and Recommendations

A unified definition of family care may be impossible

As this paper has shown, it may be impossible to create one unifying definition of care and caring that is accepted by all stakeholders. Some carers identify solely by the relationship they have to the person they care for; others take on the identity of a carer sometimes to their detriment where it subsumes their previous identities and roles and impacts their mental health. Those who receive care may disagree with the paternalistic nature of being defined as needing ‘care’ and/or ‘protection’. While policy makers, legislators and health and social care professionals may desire a single, unified definition to assist with data collection and service planning, this may simply not be an achievable goal. Other methods to ensure that all who provide care and who need support receive that support must be used in conjunction with raw data depending on self-identification. This could include offering Carer Assessments to those with significant caring responsibilities³⁶.



While policy makers, legislators and health and social care professionals may desire a single, unified definition to assist with data collection and service planning, this may simply not be an achievable goal

Acknowledge caring relationships outside of traditional family units

Caring cuts across ages, genders, socio-economic backgrounds, abilities and relationships. As such, care cannot be held to within the boundaries of a marital relationship. Supporting the Citizens Assembly recommendation to ‘protect private and family life, including forms of family life beyond the marital family’ will help to ensure that the diversity within care and caring relationships, along with the reciprocal nature of care, is acknowledged and supported.

³⁶ Care Alliance Ireland, “The Case for Carer Assessments,” 2012.

The purpose of this discussion paper was not to answer the question ‘what term should be used to describe those who care for family members’, but rather to acknowledge the challenges in attempting to use one or two unifying phrases to describe a diverse group of individuals, and to update this important topic in light of research and discussions which took place after first publication of this paper. There are clear differences in views between different ‘types’ of carers, as outlined in the above sections.

It is clear from research undertaken by Care Alliance that there is no unifying phrase or term which those who care for family members feel describes their role well. For some, having an identity as a ‘carer’ is important, allowing them to feel that they have a true role in their loved one’s life, as encapsulated in the comment of one respondent:

‘I think the word “carer” helps to acknowledge what I am doing ... Where as if it was just “daughter” it doesn’t acknowledge the changes made to my life to care for Mum.’

For others, the label of ‘carer’ overshadows their existing relationships, and they much prefer to be seen as a mother or husband first. The challenge for those supporting family carers is to acknowledge that there will be many individuals who are ‘family carers’ who refuse to see themselves in that light, and therefore who may be rejecting opportunities for accessing the vital supports (financial, social or health) available to them. The question is: how can supports be made available to those who do not wish to assume the identity which acts as the gateway to those supports?



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The final word can be left to a ‘family carer’:

‘Really the words used are unimportant. More real help and support is needed.’



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Care Alliance Ireland

CHY No: 14644

Charity Registration No: 20048303

Company No: 461315

Registered office:

Coleraine House, Coleraine Street,
Dublin 7, Ireland, D07 E8XF.

Telephone: +353 (0)1 874 7776

Email: info@carealliance.ie

Twitter: [@CareAllianceIrl](https://twitter.com/CareAllianceIrl)

www.carealliance.ie