Care Alliance Ireland

Guiding support for family carers

Discussion Paper 8

Difficult Relationships and Family Caring

March 2018

Care Alliance Ireland

1. Introduction

This is the eighth 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 a member of the Care Alliance team either by our member organisations or Family Carers themselves. In some cases this will be a topic which has been raised and shared in the media or social spaces online.

Caring for a "loved one" has long been acknowledged as having real implications for Family Carers' physical and mental health, along with economic, employment and other impacts.[1] Not all of these impacts, however, are negative. The positive impact of providing care – often significant levels of care – has been well researched.

However, much of this research presupposes that the person being cared for is, indeed, a "loved one". What happens when the person being cared for isn't particularly well-loved? How do Family Carers who perhaps do not even like the person they are providing care for deal with the effects of this negative, maybe even toxic, relationship?

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On the other hand, how do carers who are perhaps caring for someone they love deeply manage difficult relationships with other members of the family – who perhaps have very different opinions about how, where and when care should be provided?

[1] Care Alliance Ireland, 'Family Caring in Ireland', 2015.

This paper focuses on three particular "scenarios" in which Family Carers may need to manage difficult, negative and even toxic relationships while providing care to a family member or friend. These are:

- Caring for a family member (generally a parent) who abused or neglected them in childhood
- Caring for a spouse/partner where the relationship had significant difficulties prior to the care situation arising
- Conflict in family/sibling relationships where one party provides significant care and others do not.

This is not meant as an exhaustive list of possible scenarios in which Family Carers may find themselves. It is simply meant as an overview of issues Family Carers may face and which they may not feel are appropriate to discuss publicly or to discuss with health and social care professionals.

Following discussion of the scenarios outlined, this paper will outline a number of implications for policy makers and those providing services to Family Carers in Ireland. This includes organisations that focus on carer support, as well as those whose primary focus is the support of people with an illness, chronic condition, or mental health concern. These implications have relevance to health and social care professionals such as social workers, occupational therapists, nurses and allied health professionals. All of these groups have a responsibility to support Family Carers alongside their support of those being cared for, in keeping with the vision statement of the National Carers Strategy for Family Carers – for carers to be "respected as key care partners".[2]

[2] Department of Health, 'The National Carers' Strategy' (Department of Health, 2012).

2. Caring for a family member who abused or neglected the carer in childhood

Childhood neglect and abuse is not uncommon in Ireland. Research in 2002 found that over 20% of Irish women and 16% of Irish men had experienced contact sexual abuse in childhood.[3] This is significant when current estimates suggest that 10% of the population, or approximately 360,000 people, are currently providing care to a friend or family member.[4] It is likely, therefore that many Family Carers are providing care to a person who abused or neglected them in childhood.

In a US context, research with carers caring for one or both parents suggests that nearly 20% of caregivers experienced some kind of parental abuse as children, with a further 10% having experienced neglect as a child.[5] The effects on a caregiver of providing care to a person who previously abused or neglected them include more frequent depressive symptoms, along with a decreased ability to use appropriate coping strategies for the stresses which often occur in a carer–caree relationship.[6] There is some evidence that abuse of the carer in the past by the current care recipient is part of a mutually abusive relationship – that past abuse is a predictor for instances of elder abuse by caregivers themselves.[7]

A 2013 US study[8] found that carers providing care for a parent who abused them in childhood had significantly more frequent depressive symptoms than carers who had not experienced such abuse and/or neglect. In addition, many individuals who have survived childhood abuse and/or neglect have difficulties in later life in using coping mechanisms in difficult emotional periods, along with difficulties forming relationships with intimate and romantic partners. This in turn makes it more likely that Family Carers abused in childhood may have a reduced social support system at the outset of caring. It is documented that Family Carers can feel lonely and isolated as their caring journey develops, with friendships and intimate relationships becoming more difficult to maintain as caring responsibilities increase.[9]

[3] Hannah McGee et al., *'The SAVI Report: Sexual Abuse and Violence in Ireland'* (The Liffey Press, 2002).
[4] Central Statistics Office, *'CSO Releases Irish Health Survey Results'*, 16 November 2016, http://cso.ie/en/media/csoie/newsevents/documents/pressreleases/IHS2015.pdf.
[5] Jooyoung Kong and Sara Moorman, *'Caring for My Abuser: Childhood Maltreatment and Caregiver Depression'*, The Gerontologist 55, no. 4 (2015): 656–66.
[6] Kong and Moorman, *'Caring for My Abuser'*.
[7] Judith Wuest et al., *'The Effects of Past Relationship and Obligation on Health and Health Promotion in Women Caregivers of Adult Family Members'*, Advances in Nursing Science 30, no. 3 (2007): 206–20.
[8] Kong and Moorman, *'Caring for My Abuser'*.
[9] Care Alliance Ireland, *'Romancing the Carer – Intimate Relationships and Family Caring'* (Care Alliance Ireland, 2017); Care Alliance Ireland, *'Family Caring in Ireland'*.

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The situation where the person receiving care is still in a position to cause harm to the person caring for them must also be considered. While there is a common narrative of the “helpless” care recipient, this will not always be the case. Although stigmatising certain conditions should be avoided, there may well be instances when a Family Carer may be at risk of significant physical and emotional harm throughout their caring role, such as some mental health conditions and behaviour change attributable to brain injury or dementia.

3. Caring for a spouse/partner where the relationship had significant difficulties prior to the care situation arising

While it is tempting to believe that all those caring for a romantic partner are doing so in the context of a happy relationship, this is simply not always true. It is safe to say that many, if not all, relationships go through difficult periods, regardless of other circumstances involved. While there are no easily verifiable statistics to be found on exact numbers of individuals who carry out affairs, estimates start at 10%+ of partners being unfaithful within a long-term relationship. Again, this makes it not necessarily likely but entirely possible that some spousal carers are providing care where there is a history of infidelity. In researching this paper, relatively few studies or articles about this issue from an organisational or academic perspective were found; however, there are quite a few carers' stories online, in forums and blogs, which discuss it. One Family Carer describes her experience below:

"He was cheating on me when his spine was crushed in a car accident.
I have no idea where he was going that afternoon. He was supposed to be at work. It could have been a work meeting, a lunch time errand, whatever.
But obviously I'm going to believe it was to meet her.

I had just found out, but hadn't let him know I knew yet.
I was deciding what to do; deciding if I should leave him or not.

It's just assumed that I'll take care of him. No one asked." [10]

It has been difficult to source material from professional and support organisations but relatively easy to find carers speaking about this topic online, often with the safety of the anonymity which the internet provides. This indicates that this is a topic that support organisations and health and social care professionals need to be aware of.

Dealing with the effects of an affair is tumultuous for all involved, with grief, anger, anxiety and a multitude of other emotions present for both partners, in particular the partner whose spouse was unfaithful. If a diagnosis of illness or sudden onset of disability coincides with the recent discovery of infidelity, the emotions raised by the affair will be compounded by the emotions which many Family Carers feel when faced with the life-altering news that their relative requires ongoing care.

[10] Anonymous, 'I Don't Want to Be My Husband's Caregiver', The Caregiver Space (blog), January 2017, https://thecaregiverspace.org/i-dont-want-to-be-my-husbands-caregiver/.

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While infidelity is one reason for poor relationships, there are other reasons for difficulties in relationships. Domestic violence, controlling behaviour, jealousy and other behaviours also have an impact on partners and family members who find themselves providing care. There has been some work conducted on the effect that the quality of the pre-existing relationship has on carer health and wellbeing throughout the caring journey, but relatively little empirical work on the effects of caring for an individual who has abused the carer in the past.[11] What work has been done indicates that where the existing relationship was characterised by love, affection and respect, Family Carers have more satisfaction and fewer negative health outcomes than those caring within relationships which had previously been characterised by abuse, neglect and strain. This is particularly so where the overriding reason for providing care was not love, but obligation.[12]

[11] Wuest et al., *'The Effects of Past Relationship and Obligation on Health and Health Promotion in Women Caregivers of Adult Family Members'*.
[12] Judith Wuest, *'Precarious Ordering: Toward a Formal Theory of Women's Caring'*, Research in Nursing & Health 21 (1998): 39–49.

4. Conflict in family/sibling relationships where one party provides significant care and others do not

It is easy, at times, to forget that often a Family Carer is not acting in isolation from the rest of the family – there may be a network of family members who have an interest in the care being provided. Sometimes, the family works together to divide the necessary workload of caring between siblings, with perhaps each taking charge of the facet of caregiving which best suits them. Some people are naturally better at the administrative tasks which accompany care, such as liaising with medical and social care staff, dealing with legal matters such as powers of attorney, or ensuring that bills and expenses are taken care of on time. Others may not be in a position to spend time providing direct support in this manner, but can contribute in other ways, such as making contributions to the costs of caring. Others again are more suited to providing the intimate one-to-one care which we tend to picture first in relation to family care.

Family Carers so often talk about feeling isolated, alone and anxious due to the significant responsibility of their role.[13] This suggests that while there are many situations where care is organised within families in an equitable manner, the reality that many carers experience is that, for various reasons, caring will be taken on by a particular member of the family. There is an unspoken assumption in many societies that the youngest member of the family, or indeed an unmarried female, will take on these responsibilities, as they are less likely to have other responsibilities of their own, such as an established family, career, etc.[14]

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[13] Care Alliance Ireland, *'Family Caring in Ireland'*.
[14] Orla Parslow and Peter Hegarty, *'Who Cares? UK Lesbian Caregivers in a Heterosexual World'*, Women's Studies International Forum 40 (2013): 78–86.

Many Family Carers have discussed with us the desire for family members to assist in some way with the caring responsibilities, in particular, for help from adult siblings where one person in particular provides the majority (or all) of the care for an ageing parent. Carers describe feelings of frustration due to a lack of understanding from siblings about the actual level of care provided. Communication is key; however, such conversations are difficult to begin and difficult to maintain throughout the entire care journey, which may continue for many years. Some carers report that a simple act of gratitude and acknowledgment from other family members would go a long way towards creating a feeling of appreciation. A 2013 US study highlighted this, noting that expressions of gratitude and understanding from the siblings of primary caregivers were much appreciated, even when they were infrequent and perhaps peppered into a sibling relationship which was at times in conflict due to the difficulties experienced during the caring period.[15]

[15] L. Amaro and K. Miller, *'Discussion of Care, Contribution and Perceived (In)gratitude in the Family Caregiver and Sibling Relationship'*, Personal Relationships 23 (2016): 98–110.

5. Policy and service provider implications

As the focus of this series is to stimulate discussion and create greater visibility about under-discussed issues facing Family Carers, it would be remiss of us not to include some of the implications of this topic for support organisations, and some recommendations for practice. While the number of Family Carers accessing support who have been affected by the above issues may not be high, it is important that support organisations and health and social care providers are aware of the issues.

5.1 Acknowledgement of the issues by support organisations and health care professionals

As with many of the issues raised as part of this Discussion Paper series, the first and foremost recommendation for support organisations and allied health professionals is simply to acknowledge and understand that many Family Carers struggle with difficult, even negative, relationships, which may be exacerbated by the responsibilities of providing family care.

Family Carers may struggle with feeling that they have to appear "happy" at all times, in particular when dealing with health professionals. In contrast, many feel that they are simply not listened to if and when they do speak about relationship difficulties. This extends to Family Carers attempting to manage difficult relationships with family members who are not directly involved in the day-to-day care. It is awkward to bring up the notion of relationship conflict, as we have previously discussed in this series.[16] However, by simply acknowledging these difficulties both in support and education group settings and indeed in the narrative of family caring in the media, conversations can begin and the negative impacts of navigating these difficult relationships can be addressed.

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[16] Care Alliance Ireland, 2017. *'Romancing the Carer - Intimate relationships and Family Caring'.*

5.2 Break down assumptions of "love" as the overriding emotion within Family Carer situations

While the majority of Family Carers undertake their caring role out of deep love and affection for those they care for, this is not the case for everyone. There is no shame in this, and stigmatising Family Carers who continue to care while acknowledging their dislike of the person they care for is deeply unhelpful. Some Family Carers have voiced their frustration that the media and health and social care professionals constantly relate care only to love. Sometimes, carer-caree relationships are built solely on a sense of obligation, of having no choice but to provide care. The narrative that emphasises love as the basis of care can exacerbate the guilt which some Family Carers experience when they voice such feelings. This is not helpful for carers trying to navigate caring for someone they may not even like.

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5.3 Create spaces for Family Carers to talk openly about their relationships – negatively and positively

There are many spaces where Family Carers can talk about the love and affection they feel for the person they are caring for. Health and social care professionals often encourage these discussions as a way to promote positive feelings about what can be a difficult role.

However, it is clear that caring for someone who you do not love or indeed like can be incredibly difficult. As one carer said online:

> *"Caring for others is very hard – hard when you love them, hard when you only 'like' them, and I'd say pretty damn impossible when you neither love nor like them!"* [17]

[17] See http://bit.ly/2BeSAU0 (post available when accessed 06/02/2018).

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Many Family Carers we have spoken to simply do not talk with health and social care professionals about their dislike of the person they provide care for, for many reasons. While sometimes these negative emotions can be attributed to the natural ups and downs of any relationship, in other cases this dislike and difficulty in the relationship has its roots farther back in time, and is harder to unpick and deal with. In these cases, it is important to allow carers to have the time and space to talk about their relationships – the positive and the negative.

Online there are numerous blog posts and peer support forums where this is already happening. Carers UK in particular has a very open and supportive online peer community of Family Carers, with a number of discussion threads on this very topic. While online peer support is a vital outlet and source of support for many Family Carers,[18] it is not always accessible or even desired by others.

We recommend that support organisations, along with health and social care professionals, act, practice and intervene in a way that facilitates the creation of an atmosphere where Family Carers are free to speak openly and honestly, without fear of stigmatisation, about their relationship with the person they provide care for.[19]

5.4 Inclusion of relationship management skills in training and education programmes for Family Carers

There are a number of Family Carer support and education programmes available across Ireland, delivered in both online and face-to-face format. Many of these courses focus on skills to make caring tasks easier, safer, and more positive for both the carer and the person being cared for. Others focus on skills for looking after the carer's own wellbeing, such as mindfulness and self-care. Some specifically tailored courses provide detailed information on particular conditions such as dementia, intellectual disability, autism, etc.

[18] Care Alliance Ireland, *'Online Supports for Family Carers – Options & Experiences'* (Care Alliance Ireland, 2016).
[19] Readers may find it useful to read a previous paper in this series, on the topic of stigma and family care: Care Alliance Ireland, *'"We Need to Talk About It" – Stigma and Family Care'*, 2016.

These training and educational opportunities are absolutely vital to the ongoing support of Family Carers. We recommend that support organisations that provide such training consider including modules on addressing familial conflict and coping with negative relationships as part of their online and offline offerings. We are sure that the topic is raised at support groups, and no doubt facilitated well in many instances; however, many Family Carers continue to struggle with these issues. One-to-one counselling or mediation is not always an option for Family Carers, so addressing these issues in a formal context that validates and normalises them would certainly benefit Family Carers for whom these are issues which affect their ability and desire to provide care to family members.

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6. Conclusion

As with all papers in this Discussion Paper series, there are no easy answers. To continue the overarching narrative that Family Carers care solely out of love is potentially damaging for them and the people they care for. While many Family Carers do share the sentiment that they are simply "paying back" the love that their parent or spouse has given them throughout these relationships, this is simply not always the case. Some Family Carers care out of a sense of obligation or necessity, and perhaps even fear based on past experiences. Likewise, many Family Carers struggle to provide care without significant understanding and support from siblings or other family members, leading to resentment, frustration and considerable negativity. All of these issues have impacts on Family Carers' self-esteem, mental health and indeed physical health.

This paper has outlined some of the instances in which Family Carers struggle to feel affection whether for the person they provide care for or for family members who are perhaps only peripherally involved in the caring relationship. Negative and even toxic relationships can of course develop within caring experiences. We hope that this paper is the start of a conversation on this uncomfortable but necessary topic.

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