





**Discussion  
Paper 7**



**Romancing the  
Carer - Intimate  
Relationships and  
Family Caring**

**November 2017**

## 1. Introduction

This is the seventh 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 academics, not-for-profit organisations and other interested parties.

The relative unavailability of studies specifically addressing the issue of the impact on intimate relationships of Family Carers is worth noting. The majority of studies that have been undertaken often focus exclusively on the impacts of the disability on the relationship, rather than the impact of caring on the partner/spouse providing care, or on the partner/spouse of a Family Carer. Consequently, this paper is exploratory in nature, and is based on discussions with professionals and Family Carers. Where reference material is available, it has been included; however, material was not available for all topics under discussion in this paper.



The majority of studies that have been undertaken often focus exclusively on the impacts of the disability on the relationship, rather than the impact of caring on the partner/spouse providing care, or on the partner/spouse of a Family Carer

The inspiration for the paper has been drawn from conversations with some of our member organisations and a number of Family Carers. These Family Carers have indicated that while this topic may not be of relevance to all Family Carers, it is a topic which those supporting carers must be aware of, and not be afraid to address if necessary.



## 2. Why is the issue of intimacy in relationships an important one?

Given the other significant challenges facing Family Carers – which can include lack of respite from caring, significant waiting lists for therapies for those they care for, and the increased likelihood of experiencing financial difficulties (amongst others) – it may seem unusual to focus on the impact of caring on intimate and romantic relationships. However, given the importance of support for Family Carers, and given that for many their first line of support remains a spouse or partner, the topic requires addressing in some form.

There are studies which focus on the stress and strain naturally present in spouses and partners of individuals who experience trauma and/or sudden illness or disability. For most studies, the evidence is clear that Family Carers who are spouses are more likely to experience elevated stress levels, less satisfaction with life as a carer, and higher likelihood of depression and anxiety<sup>1</sup> than are members of the general population. However, these studies appear to focus more on the expected psychosocial aspects of illness and management of conditions than on the effects of these conditions on the intimate and romantic life of the couple. The topic of sexuality and romantic intimacy is not an easy one for many to discuss; in particular it is often seen as secondary to the difficulties being faced in other aspects of life and in the relationship (as mentioned above).

Sexual and romantic intimacy is for many what differentiates spousal and partner relationships from friendship and other relationships which develop between families and friends. When a sudden and unexpected illness, disability or other trauma occurs within that relationship, this key aspect can be ignored or deprioritised, which in turn threatens the foundation of the relationship. Likewise when a person begins significant care for a person outside that intimate relationship (such as for a parent or other family member), time and priorities shift away from the intimate relationship. This is only natural at times of significant stress and role change – however, if not addressed or acknowledged, this can quickly become a source of tension within a relationship. It is understood that “communication” is the life-blood of relationships; sometimes couples do not have the language to communicate their feelings or vulnerabilities. When an intimate partner has a disability or illness, the capacity of some Family Carers to understand or even notice the role change in the relationship can be impaired. This forces a couple to renegotiate the relationship, which can be challenging when life is already so demanding in other areas.

<sup>1</sup> D Gillespie and F Campbell, ‘Effect of Stroke on Family Carers and Family Relationships’, *Nursing Standard* 26, no. 2 (2011): 39–46.

It should be stressed at this juncture that not all of the impacts of family caring on romantic and intimate relationships are negative – many couples acknowledge positive changes in relationships which force change in previously negative patterns of interaction, and enhanced levels of intimacy. An example of this might include a couple being forced to acknowledge a strain or challenge in the relationship, which in turn opens up communication and a greater sense of connection between the couple.



Not all of the impacts of family caring on romantic and intimate relationships are negative – many couples acknowledge positive changes in relationships which force change in previously negative patterns of interaction, and enhanced levels of intimacy

This paper proposes a number of impacts of different caring situations, with a specific focus on impacts to romantic and intimate relationships. Some of these may be obvious, and expected – however, some are impacts which may only be felt by a small number of carers in very specific circumstances. This is to highlight that every individual who is a Family Carer is balancing not just work and caring, but also multiple other relationships, and caring may need to be prioritised and reprioritised at different times across the “caring journey”. This section of the paper is organised under two main headings – caring for a spouse/partner and caring for an older relative. Similar impacts to those that occur in these situations can also occur in other caring situations – for example, for those caring for a child or adult with intellectual disabilities.

The final section of the paper proposes some organisational and policy responses to the issues. Due to the very personal nature of the issues raised in this paper, and the individual ways in which romantic and intimate relationships are approached by couples, there are no easy answers – no easy policy documents to be written, no easy workshops which can be offered by organisations.



## 3. Caring for spouse/partner

When caring for a spouse or partner, there are a number of salient issues which it may be helpful to address – key amongst these is, of course, the romantic and sexual nature of these relationships, differentiating them from friendships and other close relationships.

For some, the provision of significant care is not a “new” phenomenon. The parameters of their relationship have always included this type of care. Indeed, it must be noted that all intimate and romantic relationships will include providing intimate care at some point – for example, if a partner has a broken arm, illness, or other health concern – as part of the expected and anticipated experiences of living. Such intrinsic caring is to be expected as part of these relationships. However, for other people, significant care (for example, following a diagnosis of cancer, or an acquired brain injury) will be unexpected, and not something that was ever anticipated or planned for.

### 3.1 Role change

The first and foremost change and challenge facing spousal partners is that of role change – changing from wife, husband or partner to “Family Carer”. Many individual carers resist the language change, far preferring to claim their identity towards the cared-for person through their long-established partnership. This is clearly corroborated throughout numerous studies<sup>2</sup>.

Aside from language concerns, the role change involved in changing from spouse or partner to carer can be difficult to navigate, taking account of the needs of all concerned. For example, some people with an acquired disability or illness will not wish for anyone to know the extent of care required, due to the effects of stigma, which can be significant<sup>3</sup>. This in itself is difficult, and sensitive to manage. However, if those providing care cannot access any support outside the home, the pressure on the fabric of the relationship can be significant.

Related to this role change, and particularly pertinent for carers and supporters of partners with mental health difficulties, dementia-type conditions and acquired brain injury, to name a few, is the challenge of personality change which can occur with these conditions. Such change can be significant, and can lead to a situation where the person being supported feels like a “different person” to the person they were before the onset of their difficulties:

<sup>2</sup> Care Alliance Ireland, ‘Defining Carers’, 2015.

<sup>3</sup> Care Alliance Ireland, “We Need to Talk About It” – Stigma and Family Care’, 2016.



Particularly pertinent for carers and supporters of partners with mental health difficulties, dementia-type conditions and acquired brain injury, to name a few, is the challenge of personality change which can occur with these conditions.

*This is not the person I married 4 years ago . . .  
he is just a shadow of who he was, and that is sad*

– Family Carer of a person with depression<sup>4</sup>

Other Family Carers report feeling more like “care workers” than partners, with still others noting the impact of the role change from being an independent individual within a “team” to having more of a generational relationship:

*But I feel I am losing my life’s partner and companion.  
The relationship has changed in that my husband relies on me completely.  
I am now responsible for everything, including banking and business affairs,  
daily activities and arrangements. He does not want or expect to make  
decisions or organise what we do. So it’s more like a  
parent/child relationship now.*

– Woman caring for husband with dementia<sup>5</sup>

### 3.2 Intimate tasks

For many, the sudden onset of the need to provide intimate care<sup>6</sup> to a spouse or partner is a line in the sand that is difficult to cross, yet it can be simply unavoidable. While some spouses find ways to circumvent the need to provide intimate care tasks for a partner (by paying for additional supports privately, for example), for many that is not possible. That can lead to a situation whereby either (or both) the person requiring care, and the care giver, feel uncomfortable with tasks that are necessary every day, which can have an impact on the physical and emotional intimacy of a relationship.

<sup>4</sup> Nicole Highet et al., “How Much More Can We Lose?": Carer and Family Perspectives on Living with a Person with Depression', *Medical Journal of Australia* 181, no. 7 (2004).

<sup>5</sup> Alzheimer's Australia, 'Discussion Paper 19: Relationships and Dementia', 2017.

<sup>6</sup> Such as assistance with toileting and feeding, as well as dressing and other activities of daily living.



Some Family Carers may feel a sense of shame and guilt if they feel less attracted to their partners when in a situation of having to undertake intimate care tasks – it can change the dynamic of the relationship for many. For others, however, undertaking these intimate care tasks significantly contributes to an increased level of intimacy which positively impacts the relationship.



Some Family Carers may feel a sense of shame and guilt if they feel less attracted to their partners when in a situation of having to undertake intimate care tasks – it can change the dynamic of the relationship for many

### 3.3 Medication effects/physical ability

There has been much work undertaken to bust myths regarding the ability, capacity, and right of people with disabilities to enjoy a healthy sex-life and intimate relationships with loved ones. However, there is commonly a period of adjustment to this “new reality” when a disability develops within an established relationship. This can be complicated by side effects of treatment and/or medication<sup>7</sup>.

A study in 2004 which examined carers of people with depression<sup>8</sup> noted that depression as an illness, and the side effects of medication used to treat it, can have a negative impact on the physical side of relationships:

*Our love life used to be really good.  
She used to enjoy making love, she used to have orgasms . . .  
on medication it's all gone . . . she feels nothing.  
So we don't make love.*

– Family Carer of a person with depression

<sup>7</sup> Tanja Zimmermann, 'Intimate Relationships Affected by Breast Cancer: Interventions for Couples', *Breast Care* 10 (2015): 102–108.

<sup>8</sup> Hight et al., "How Much More Can We Lose?": Carer and Family Perspectives on Living with a Person with Depression'.

Some conditions which may necessitate care can also impact a person's physical ability in relation to certain types of physical intimacy, and their ability to communicate with their partners about the issue. For example, after stroke a person may be left with weakness on one side, depending on the nature of the stroke. This in turn may impact on the physicality of a sexual relationship. Sometimes after stroke a person may also have impaired cognition and speech difficulties, adding to complications in an intimate relationship. Indeed, the stroke itself may also impact libido, which means either an increase or decrease in sexual appetite.

### 3.4 Inappropriate behaviour

Much of the grey literature about sexuality and dementia, in particular, or in the context of an acquired brain injury, relates to the phenomenon of “inappropriate behaviour” – generally classed as sexualised behaviour which is outside the agreed norms of a relationship and conventional societal behaviour. Examples would include public masturbation and a person embarking upon sexual behaviour with people outside the established relationship. Seeing a spouse or partner of many years “forget” about their partner and express attraction for someone else can be a hurtful experience to process and understand – even if that carer understands that the very nature of the condition means that their loved one is not in control of these challenging behaviours.



Seeing a spouse or partner of many years “forget” about their partner and express attraction for someone else can be a hurtful experience to process and understand

### 3.5 Consent

Recent legislation has come into force in Ireland which goes some way towards clarifying the legal responsibilities which a spouse or partner of a person with decreased capacity has pertaining to sexual intimacy. Individuals within marriages are deemed to be consenting adults regarding sexual intimacy<sup>9</sup>. However, as Irish society is changing, many more couples are choosing not to enter into legally binding marriages. Likewise, given the relatively short timeframe since marriage was opened to same-sex couples in Ireland (November 2015), there may be couples for whom

<sup>9</sup> This does not include situations where consent was clearly not given (i.e. sexual assault and/or rape).





marriage was not a legal option, who are now living with, and caring for, partners who have developed dementia, or other conditions. This has legal ramifications for Family Carers and partners of adults with “reduced capacity” with regards to sexual expression.

In addition, some carers may need to establish personal “boundaries” when it comes to sexual intimacy with partners with advanced dementia. In this case, Family Carers have lost a large and often very important aspect of their lives together. Again, the loss of sexual intimacy in a relationship may not be the first thought in a Family Carer’s mind in caring for a spouse with dementia, but nevertheless it is likely to have some impact, upon the Family Carer in particular.

## 4. Caring for a parent

### 4.1 Practical arrangements & disruption (time and energy)

When the time comes to begin caring for a parent, often those assuming responsibility will be in their 30s or older – at a time in their lives when they are not only assuming responsibility for the care of a parent, but when they also have other burgeoning or established responsibilities towards partners, children and career. If the “reason” for care being needed is unexpected (i.e. sudden illness or trauma), caring can come crashing into one’s life, turning it upside down within a short space of time. A new world of home adaptations, negotiating with employers and/or leaving formal employment, organising hospital appointments and medication, can be thrust upon individuals with no prior experience of such tasks. This newly established “normal” will heavily impact the time and energy which individual carers have to dedicate to other responsibilities<sup>10</sup>. Often, some kind of equilibrium does re-establish itself; however, not without effort and time.

### 4.2 Caring for parent-in-law

While it may be “expected” that children assume some level of responsibility and care for their parents if and when needed, the same cannot be said for the parents of a spouse. However, many Family Carers – particularly female carers – assume such responsibility for the care of their parents-in-law, if to do so is the most practical arrangement available to the family (in particular if this can be coordinated in tandem with existing childcare responsibilities managed in the home).

<sup>10</sup> Emma Hayes, ‘Caring for Mam: “Putting Myself First Is Not an Option Even Though I Have the Most to Lose”’, *The Journal*, 13 August 2017, <http://www.thejournal.ie/readme/caring-for-mam-putting-myself-first-is-not-an-option-even-though-i-have-the-most-to-lose-3537840-Aug2017/>.

### 4.3 Disruption to existing and new relationships

Caring for a loved one, regardless of who that loved one is, is often time intensive. Figures indicate that Family Carers provide significant levels of caring, with many carers providing round the clock care – 24 hours a day, 7 days a week<sup>11</sup>. With these levels of caring commitments, in particular at the onset of caring, existing relationships are necessarily disrupted to account for increasing time needed to provide care.

In addition, caring for a parent with significant care needs may necessitate a change in living arrangements, with ageing parents often moving in with their children, or adult children spending significant time in the home of the person they provide care for. This lessens the time available for intimate relationships, and reduces the privacy of carers and their partners.

Dating as a Family Carer can be very challenging. Some carers have stated that they simply do not try to date when acting as a Family Carer because, much like attitudes towards single parents, Family Carers are seen as having a lot of “baggage” and extra responsibilities that many people looking for romantic relationships seek to avoid – certainly in the early stages of relationships.



Dating as a Family Carer can be very challenging. Some carers have stated that they simply do not try to date when acting as a Family Carer

### 4.4 LGBTQ Family Carers

An unrecognised sub-group of Family Carers with specific concerns and support needs are those who identify as members of the LGBTQ<sup>12</sup> community. Many members of that community move away from their home locations – at least traditionally – in particular where they have had negative experiences growing up in rural or overly traditional settings. However, for Family Carers who identify as members of the LGBTQ community, an added layer of needing to “return to the closet” may be experienced, adding strain to any romantic relationship they may be involved in. Likewise, LGBT Family Carers can sometimes feel unwelcome in their own home

<sup>11</sup> Central Statistics Office, ‘Census 2016 Summary Results - Part 2’ (Central Statistics Office, 2017).

<sup>12</sup> Lesbian, Gay, Bisexual, Transgender and Queer/Questioning



when caring for parents, in particular when dating a member of the same gender; relationships are conducted in hotel rooms and other locations<sup>13</sup>.



LGBT Family Carers can sometimes feel unwelcome in their own home when caring for parents, in particular when dating a member of the same gender; relationships are conducted in hotel rooms and other locations

## 5. Responses

As discussed in the introduction, there are no easy or “one-size-fits-all” policy responses, or easily delineated organisational responses which can be rolled out to address the many layers and complexities of this topic. Issues relating to intimate and romantic relationships are deeply personal, and very sensitive. Care Alliance Ireland do not purport to speak on behalf of all Family Carers – more research and work with Family Carers in different caring scenarios is needed to understand the impacts of caring on intimate relationships.

### 5.1 Acknowledgement

Even though not spoken about to a large extent, evidence (both in limited literature searches and through anecdotal discussions with organisations and Family Carers) indicates that family caring can and does impact significantly on the romantic and intimate relationships of a Family Carer. These impacts will be experienced to a greater or lesser degree depending on individual circumstance. The first step for many Family Carers and their partners is to understand that this sensitive topic is open for discussion with professionals who support them. This includes Family Carer organisations and condition-specific organisations, along with professionals such as counsellors, outreach workers, family support workers, etc. For many, difficulties within intimate romantic relationships often go unaddressed; when a health crisis hits a relationship, the chances of a fractured intimate relationship being addressed can be lower again.

<sup>13</sup> Orla Parslow and Peter Hegarty, 'Who Cares? UK Lesbian Caregivers in a Heterosexual World', *Women's Studies International Forum* 40 (2013): 78–86.

We appreciate that discussing these issues is easier said than done. Many of us do not wish to raise the topic of sex and intimacy outside of our own relationships, if at all. This is doubly true for Family Carers, who have many reasons for not discussing it: it is awkward, they do not want the person they are caring for to feel guilt, and often they may fear the reactions of others, who may think that they are putting their sex-life at a higher priority than the health and wellbeing of their loved one.



Family Carers may fear the reactions of others, who may think that they are putting their sex-life at a higher priority than the health and wellbeing of their loved one

## 5.2 Respite

The topic of “respite” is well researched and advocated for in Ireland and across the world. The need for respite for Family Carers is not a new or controversial topic – it is included in Family Carer policy<sup>14</sup> and practice, even if it can be difficult to access at optimum frequency for Family Carers<sup>15</sup>.

However, when a Family Carer is part of a couple, whether the person cares for a parent, a child/children or a spouse, the idea of needing respite as a couple is not necessarily explicitly stated. Perhaps, as part of an assessment of need for respite, the topic of “couple time” and improving romantic intimacy should be taken into account.

## 5.3 Sexuality and disability

Although work on the topic has been significant, there still exists the belief that people with disabilities and chronic conditions are not (or should not be) sexual beings. This includes those with chronic conditions, long-term illnesses, physical disabilities, and cognitive impairments. This attitude is not helpful for either the person with such a condition or their partner or spouse.

<sup>14</sup> Department of Health, ‘The National Carers’ Strategy’ (Department of Health, 2012).

<sup>15</sup> National Carers Strategy Monitoring Group, ‘Family Carers’ Scorecard – Assessing the Government’s Third National Carers’ Strategy Report from the Perspective of Family Carers’ (Family Carers Ireland, 2016).



## 6. Conclusion

Sexuality and intimacy are without doubt sensitive topics to discuss. These are personal issues, and for many Family Carers not something they wish to address or discuss, in particular when caring is new. However, those supporting Family Carers must become increasingly comfortable with doing so, when appropriate. In order to do so, it is important that professionals understand that such issues may well be impacting some Family Carers, and prepare themselves with the necessary information and skills to open lines of communication where possible.

**Note:** Many thanks to those who reviewed this paper before print, in particular to Ciaran Nolan (Headway) and members of the Care Alliance Ireland Research Sub-Committee.



Guiding support for family carers

**Care Alliance Ireland**

**CHY No:** 14644

**Charity Registration No:** 20048303

**Company No:** 461315

**Registered office:**

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

**Telephone:** +353 (0)1 874 7776

[info@carealliance.ie](mailto:info@carealliance.ie)

[www.carealliance.ie](http://www.carealliance.ie)

[@CareAllianceIreland](https://www.instagram.com/CareAllianceIreland)