Care Alliance Ireland

Guiding support for family carers

Discussion Paper 4

The Wisdom of Family Carers

October 2016

"You are just as important as the person you care for..."

1. Introduction

It is widely understood that Family Carers are more likely to experience poor health (O'Sullivan, 2008), economic hardship (OECD, 2011), anxiety, stress, loneliness and isolation than the general population. Much of the research conducted and written about Family Carers focusses on the negatives experienced by Family Carers, and on ways to overcome these challenges. Suddenly becoming responsible for the health and wellbeing of another person, often in a 24/7 capacity, can be overwhelming. Whilst there are a range of income and other supports available from the State (the latter often delivered by not-for-profit organisations), and there are many support organisations doing tremendous work supporting Family Carers, it is still, for many, a very challenging experience.

However, the experience of caring can be incredibly rewarding. It can highlight skills and traits an individual never knew they had – determination, patience, intelligence, tenacity and boundless love, to name but a few. Over time, a Family Carer builds up knowledge about practical matters related to caring and about the emotional and other impacts of caring. Peer-peer supports can be crucial to the wellbeing of Family Carers, and can afford experienced Family Carers the opportunity to pass on their considerable knowledge and skills to those at the start of their caring journey.

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In 2015, Care Alliance Ireland undertook a significant survey of Family Carers. The survey was designed to capture a "snapshot" of caring in Ireland, with questions on topics such as what current Family Carers view as the best and worst things about being a Family Carer; where Family Carers turn to for support; and what "advice" experienced Family Carers would seek to pass on to others in the same situation.[1] With over 800 responses, a wealth of information is available to help us understand the lived

[1] This survey was undertaken in March 2015, using SurveyMonkey.com to collect data. The survey was shared online, via Care Alliance member organisations, interested parties, and via the National Carers Week Facebook page, which is managed by Care Alliance Ireland and had over 11,000 followers at the time.

experience of being a Family Carer in Ireland in the 21st century. As part of the survey, we posed the question "What advice would you give to others in a similar role as yourself?" This discussion paper focusses on the responses to this question. It is clear that the Family Carers of Ireland have a wealth of knowledge that should be shared, not only with other Family Carers, but also with support organisations that can use the information to tailor their services appropriately.

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All responses to this question were coded and grouped into themes using broad thematic analysis (Braun & Clarke, 2006). Five main themes have been identified, and are discussed with examples in the following sections. These themes and examples are presented with limited comment. This paper is not intended to comment on the validity of these pieces of advice from Family Carers, but to present them in a way that highlights the vast learning which can be achieved by listening to the words of Family carers directly.

2. Themes

2.1) Seek help and support

"Take as much support as you can get. Don't wear yourself out – I did."

The positive impacts of the correct supports being in place for Family Carers are generally well known. These supports range from Home Care support and respite schemes to access to training and education. These supports are not confined to those provided by the State or indeed by the community and voluntary sector –support from family and friends can be equally important. However, some Family Carers are hesitant to access such supports – or in fact may not even be aware of the supports that are available to them. Of course, in many cases there simply is not enough access to these supports (Care Alliance Ireland, 2016; Donnelly, O'Brien, Begley & Brennan, 2016).

Across the board, Family Carers who have advice to give said they would encourage any Family Carer to actively look for – and take – any support they could. The sources of this support can include other family members, nursing and medical staff, State supports and support organisations across the not-for-profit sector.

"Seek out as much outside help [as is] available – you will need help."

Within this broad "seek and accept help" theme, a few specific comments stand out – in particular regarding accepting help and advice that, whilst well intentioned, may not be appropriate or beneficial for all Family Carers. This speaks to a later theme which emerged, which is that of developing self-confidence and trusting your own instincts as a Family Carer:

"Learn to smile at people who give you crap advice and say 'that's really interesting, I never thought about it that way' and forget the crap advice immediately"

Likewise, whilst most respondents were highly positive regarding the help available – in particular from support organisations and the HSE – others placed a caveat as regards information available for Family Carers:

"Don't believe everything you are told by health professionals. Do your own research. Be very careful what you commit to as you will be abandoned by the system as time goes on"

It is clear that some Family Carers are distinctly sceptical as regards the support available and the "lip service" which in some cases is paid to Family Carers on one hand, whilst on the other hand services are underfunded and in some cases cut completely

Perhaps this is indicative of the sometimes tenuous nature of funding for various supports and services in the past decade, as Ireland experienced a significant recession, which put considerable pressure on successive governments to make savings where possible, and led to reductions in various schemes which Family Carers and those they care for depend upon (Care Alliance Ireland, 2016; Care Alliance Ireland & Neurological Association of Ireland, 2014; Donnelly et al., 2016; National Carers Strategy Monitoring Group, 2016). Many schemes and funding are

returning to previous levels; however, the impacts of these cuts are still being felt across the country. It is clear that some Family Carers are distinctly sceptical as regards the support available and the "lip service" which in some cases is paid to Family Carers on one hand, whilst on the other hand services are underfunded and in some cases cut completely:

"Look for help and take the help offered. You will become anonymous, people will talk about the wonderful work we do . . . but don't give up trying to get the financial, physical and emotional support you need to do this work."

Of course, the advice to seek and accept help was not restricted to the support which may be available from organisations and the State – respondents encouraged new Family Carers to involve their family where possible:

"Involve ALL family. Don't try to do it all yourself, accept offers of help"

In some cases, Family Carers expressed a feeling that they should be able to do everything straight away, or that it is somehow weak and will reflect poorly on them to request help – experienced Family Carers are quick to disagree with such an idea:

"Don't be a martyr – ask for and take help"

"Get support for yourself too because caring can be tough and demanding, it's not weak to ask for help"

2.2) Stay positive

Multiple studies both nationally and internationally have highlighted the increased prevalence of poor mental health in Family Carers (Livingston et al., 2013; O'Sullivan, 2008; Social Policy Research Unit, York, Carers UK, & Carers Scotland, 2004; The Carers Association of Ireland & Royal College of Psychiatrists, 2009). Family Carers often report higher levels of anxiety, depression, emotional strain, loneliness and other mental health difficulties than those who do not have caring responsibilities. Current and recent research is attempting to further reflect on this dominant narrative regarding impacts on Family Carers (for example; Brand, Barry, & Gallagher, 2016; Gallagher & Care Alliance Ireland, 2015).

Respondents to our survey were clear in their articulation of the need for Family Carers to be mindful of and to address their own mental health needs, in addition to caring for their loved ones. A key theme which emerged from the data was that

of staying positive, which ties in with another emergent theme addressed later in this paper, that of self-care. The clear message is not to deny the possible negative consequences of family caring, nor the challenges which come with providing care, with varying levels of support, for a person with a serious illness or disability, but to understand that staying positive is a vital "buffer" against those negative consequences:

"Don't be disheartened, there will be good days and bad days, and days you feel you can't go on, but you do and it's always for the better"

"Commit to the whole experience so that you can feel the joy and not just focus on the challenges"

"It's not easy but chin up, it could be worse"

"Keep smiling, every day brings a new challenge. It's easier to get through with a smile"

Keeping a sense of humour along with positivity is something mentioned by a number of respondents. The link between humour and resilience in stressful situations has long been understood (Kuiper, 2012), with evidence available that those working in the healthcare sector (which intersects in relation to duties and responsibilities with Family Carers) use humour as a method of coping with illness and, in particular, death (King-Smith, 2104).

"Always blame the illness when you hit a bad patch. With a person with dementia you have to find a funny side to it or you wouldn't last a week"

2.3) Take time out/indulge in self-care

Along with the advice from many Family Carers in relation to asking for and accepting help, a separate theme emerged regarding the need for carers not merely to accept practical help with tasks, but to be "selfish". In this context, being "selfish" means accepting that self-care is vital, allowing Family Carers to remain in touch with friends, other family members and their own personality throughout the caring journey.

As previously discussed, Family Carers experience higher levels of mental ill-health than do non-carers (O'Sullivan, 2008; The Carers Association of Ireland & Royal College of Psychiatrists, 2009). Self-care includes positive steps which individuals can take to improve their mental health, and can take the form of time to themselves, relaxation techniques, healthy eating, and myriad other activities which have a positive impact on wellbeing and mental health.

Many Family Carers identified taking time for self-care and relaxation as a key piece of advice which they would pass on to new Family Carers.

"Make sure to self-care. Be relentless with this"

"Take it day by day and try give yourself some 'me time'. It's not good when you burn out"

"Get a hobby if you are unable to leave the house much, such as sewing, crocheting . . . and join online chat groups for chat that isn't related to your role as a carer"

"Try to get sleep. Don't end up with insomnia. Talk to your doctor about things"

Many Family Carers noted the guilt which can accompany taking time for self-care, certainly when caring is new and all consuming. Many carers note that it is not possible to keep up a high level of constant care without even a mental break – burnout will surely follow.

In this context, being "selfish" means accepting that self-care is vital, allowing Family Carers to remain in touch with friends, other family members and their own personality throughout the caring journey.

"Always try to think of yourself first – make sure you as an individual are well cared for and looked after. It may sound selfish but if you're not 100% then you can't offer 100% to the person you care for"

"Make sure you learn to take time off when needed and not to feel guilty about it. We all need time to do things for ourselves"

"Give yourself a break – physically and psychologically – as we beat ourselves up for not doing enough, even when we do it all"

This issue of guilt came up in a number of different ways, not only in relation to Family Carers not feeling guilty about taking time for themselves, but also not allowing themselves to feel guilty for wanting the situation to be different, or for being angry:

"There will be days you are resentful of the life you have no control over anymore, the choices you can no longer make . . . this is ok, you are not a monstrous human being if you feel this way. Carers are not saints. We are 'do-ers'"

2.4) Trust yourself

A Family Carer may interact with many health professionals on a regular basis – doctors, nurses, speech therapists, occupational therapists, social workers, psychiatrists, and many more. There is a tendency, when faced with so many "experts", for the Family Carer to downplay the innate knowledge they have about their loved one's behaviour and other aspects of their lives. Thrust into a new world which they may know little about, it is easy for the carer to begin to doubt knowledge that has built up over years spent with the individual now being cared for. Policy, including key actions in the National Carers Strategy (Department of Health, 2012), aims to encourage Family Carers to be seen and acknowledged as "key partners in care", with specific knowledge and abilities. However, Family Carers can be reticent about sharing knowledge and acknowledging themselves as experts. The experienced Family Carers who responded to the survey were keen to encourage all Family Carers to trust themselves, and to trust their experience and knowledge, whilst encouraging them to educate themselves in the situation at hand.

"Take control of the situation. Be the lead in the team of doctors. Be confident – you know your child the best"

"Believe in yourself, as you know your family member better than anyone else, and no one else will care for him the way you will. Always trust your instincts"

"Educate yourself and never doubt yourself. Get as much info as you can, but make your own decision suitable for all of your family"

Thrust into a new world which they may know little about, it is easy for the carer to begin to doubt knowledge that has built up over years spent with the individual now being cared for.

An aside to this theme was an undercurrent of belief that the current health system in Ireland was failing many patients, and that Family Carers needed to be confident in their ability to provide the best care for their loved one:

"Be tough with the HSE – don't accept everything they tell you. Question everyone and everything"

2.5) Don't do it

Whilst the majority of respondents were clear about the positives of accepting the role of Family Carer, albeit with some caveats (such as the need to self-care and educate oneself), a small number of respondents were clear that the key piece of advice they would give to new Family Carers is not to do it. Their advice would be not to take on the responsibility, and certainly not to do so without serious thought and consideration.

"Think long and hard before making a commitment"

"Don't do it. Walk away. Let the State do it"

The reasons for this are not clear. As this was an online survey, it is impossible to ask follow-up questions of these particular Family Carers. However, it should be noted that many Family Carers do not feel they have a choice about whether to take on the responsibility – and given the significant number of respondents who highlighted the difficulty in accessing supports (either financial or personal), it is understandable that Family Carers who felt unable to choose another path, or who feel unsupported in their role, will feel negative about their situation.

3. Conclusion

Family Carers remain the true experts in the challenges which they face every day, and are consequently best placed to offer advice to those new to the role. Given the opportunity to do so, Family Carers articulated clearly some of their key learning, which both Family Carers and support organisations can learn from. This brief discussion paper has identified five main themes which highlight some of the key practice and policy issues which concern Family Carers as the first National Carers Strategy comes to an end.

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Bibliography

Brand, C., Barry, L. & Gallagher, S. (2016).
Social support mediates the association between benefit finding and quality of life in caregivers. Journal of Health Psychology, 21, 1126–1136.

Braun, V. & Clarke, V. (2006).
Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77–101.

Care Alliance Ireland. (2016).
Analysis of Home Care Supports Funded by the HSE 2008-2016.
Care Alliance Ireland. Retrieved from http://carealliance.ie/userfiles/file/Briefing%20Paper%201%20%3B%20An%20Analysis%20of%20Home%20Care%20Supports%20Funded%20by%20the%20HSE%202008-2016%20June%202016.pdf

Care Alliance Ireland, & Neurological Association of Ireland. (2014).
Nationwide Survey of Neurological Carers Highlights Impact of Budget Cuts.
Retrieved from http://www.carealliance.ie/userfiles/file/National%20Survey%20Highlights%20Impact%20of%20Cutbacks%20on%20Family%20Carers%20Final%20120314.pdf

Department of Health. (2012).
The National Carers' Strategy. Department of Health.

Donnelly, S., O'Brien, M., Begley, E., & Brennan, J. (2016).
"I'd prefer to stay at home but I don't have a choice": Meeting Older People's Preference for Care: Policy, but what about Practice? University College Dublin.
Retrieved from https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf

Gallagher, S., & Care Alliance Ireland. (2015).
Trial of Benefit Finding in Caregivers: The Building Resources in Caregivers (BRiC) Study. Clinical Trials. Retrieved from https://clinicaltrials.gov/ct2/show/NCT02444312

King-Smith, L. (2104).
Whistling Through the Graveyard: A Study to Examine the Uses of Humor in Self-Care and Compassion Fatigue in Mental Healthcare Practitioners. University of West Virginia.

Kuiper, N. (2012).
Humor and Resiliency: Towards a Process Model of Coping and Growth. Europe's Journal of Psychology, 8(3), 475–491.

Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Cooper, C. (2013).
Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. The BMJ.

National Carers Strategy Monitoring Group. (2016).
Family Carers' Scorecard – Assessing the Government's third National Carers' Strategy report from the perspective of family carers. Family Carers Ireland.

OECD. (2011).
The Impact of Caring on Family Carers. In Help Wanted? Providing and Paying for Long-Term Care. OECD.

O'Sullivan, L. (2008).
Health and Well-being of Family Carers in Ireland: results of a survey of recipients of the Carer's Allowance. Combat Poverty Agency.

Social Policy Research Unit, York, Carers UK, & Carers Scotland. (2004).
Hearts & Minds: The health effects of caring. Carers UK. Retrieved from https://www.york.ac.uk/inst/spru/pubs/pdf/Hearts&Minds.pdf

The Carers Association of Ireland, & Royal College of Psychiatrists. (2009).
The Health of the Carer in Ireland. The Carers Association.

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