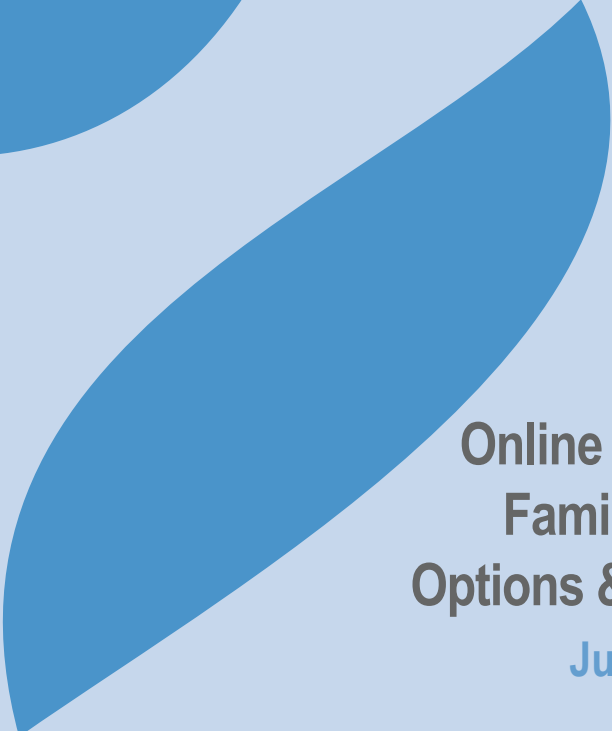


**Discussion
Paper 3**



**Online Support for
Family Carers:
Options & Experiences**
June 2016

1. Introduction

One of the key developments of the late 20th and early 21st centuries is the development of the internet as an everyday tool used by the majority of citizens. By 2015, 80% of the Irish population, across all age groups, had used the internet in some way in the three months preceding the survey (Central Statistics Office, 2016). Ninety-five percent of those aged between 16 and 29, and nearly half of those aged between 60 and 74, had done so. It is clear, therefore, that the internet is increasingly becoming a tool that must be understood and utilised as a viable way to increase supports for Family Carers.



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Continuing in the tradition of previous papers in this series, this paper details some of the key issues on this topic – introducing the various types of online supports for Family Carers currently available and in development, both nationally and internationally, and going on to outline some of the benefits and challenges facing organisations who provide such supports. The purpose of this paper is not to present an exhaustive piece of research, but to stimulate discussion.

2. Informational websites

Since the development of the internet, static “websites” have been a key feature, and these have developed into the basic “unit” of the internet. It is now expected that organisations, states and other groups have at least basic websites where information about their services is available to the public.

2.1) State information

In Ireland, the State is increasing its web presence, with several improvements in the accessibility and quantity of information available for Family Carers online. Several websites have information on carer entitlements, supports available and other information relevant to Family Carers¹. Within the National Carers Strategy there are

¹ Examples include www.citizensinformation.ie, www.hse.ie, www.yourmentalhealth.ie and www.welfare.ie



several policy points² dealing with development towards comprehensive and proactive use of technology.

2.2) Health information

Whilst it is important that the internet does not become the sole source of health information, Family Carers (along with the general public) can access more information than ever before about medical conditions and about health and well-being. This can include gathering information on existing conditions which affect those they care for – which can in turn increase their capacity to care for and advocate for their loved ones. There are also conditions which are the subject of new research, about which many GPs may know very little³.

Other initiatives support Family Carers in accessing health information relevant to their loved one, and indeed relevant to themselves as carers. These include condition-specific support organisation websites, national and international websites for Family Carers, information on HSE-mandated schemes such as the Treatment Abroad Scheme and other national and international fora⁴. Additional new projects are coming online across Europe, some with a focus on sharing health data across platforms, and between Family Carers, medical professionals and those in receipt of care (Broling & Andreasson, 2015). These initiatives have the potential to significantly alter the way Family Carers – in particular those who are caring in collaboration with other family members – provide care to their loved ones.

2.3) Organisational information

In Ireland, there are hundreds of organisations that work to improve the lives and the health of people with specific conditions and disabilities. The majority of these have comprehensive information on their websites, which, for many Family Carers looking to obtain information, is often the first port of call. Information on these websites includes basic information regarding the particular condition (including health and behavioural issues), policy and legislation which have an impact on the individual and family members involved in care, and contact details for obtaining further information and for accessing available supports.

² In particular, points regarding the supply of information to Family Carers (Points 1.3.1, 1.3.2, 1.3.4) and overarching National Goal 3 (Support Carers to care with confidence through the provision of adequate information, training, services and supports).

³ Many genetic and rare diseases are being discovered and researched every day. For more information please visit the Office of Rare Diseases website at <http://rarediseases.ie/>

⁴ For example, InformCare, the EU information hub on informal care (<http://eurocarers.org/InformCare>). Other examples include the Mayo Clinic website, IrishHealth.ie, etc.

2.4) International information

Having access to the latest information on international research and interventions has the potential to prompt patients and Family Carers to agitate for access to such supports at local level. Whilst it is not always helpful to compare countries, keeping up to date with international best practice has proven useful in the past in facilitating questions as to why certain therapies and services are unavailable in Ireland. Some groups of Family Carers have embraced such information and used it effectively, in particular parents of young children with disabilities.



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2.5) Training and education websites

Online education and distance learning has become more widely used in recent years, thanks in part to increasing technological ability among the public and increased availability of high-quality internet access. Massive Open Online Courses (MOOCs) are available across multiple disciplines, without charge in many cases. These courses are often developed by universities and contain material drawn from undergraduate and postgraduate courses. Many MOOCs are of interest to Family Carers, particularly in the fields of dementia, mental health and disability. Some specifically target Family Carers, for example, the Caring Counts programme available through the Open University⁵.

⁵ See <http://www.open.edu/openlearnworks/course/view.php?id=1688>.



3. Peer-to-peer supports

Peer support for Family Carers has long been established as a key method for creating supports for current and former Family Carers (Cuskelly & Higgins, 2015). Formats such as peer-led groups that bring together former and current carers to learn from each other have proven to be effective, not only in providing support and information to Family Carers who are just beginning their caring journey, but also in providing an environment for former Family Carers, who are adjusting to radically different lives after care, to pass on skills and knowledge earned throughout the process.

These peer-to-peer supports are no longer dependent on time or space constraints, as may have been the case in the past (for example, they may have depended on Family Carers being able to access transport, having someone to take over caring duties for a period of time, etc.). In addition, it would appear that Family Carers are increasingly going online to access the supports they need. In a study of Irish Family Carers in 2015⁶, a small number of respondents indicated that online activities were one of their three main sources of support in their role as Family Carers. These online peer-to-peer supports have developed in numerous forms, as outlined below.

3.1) Social media

Social media has seen a huge increase in usage in recent years. The term “social media” covers those websites and tools which allow internet users to create and share content; classic examples are Twitter and Facebook, but the term also covers blogging platforms and other online fora. As with many social groups drawn together because of a common interest, peer-to-peer supports for carers have sprung up in different social media formats. Some are supported (and moderated) by organisations and formal groups, with others existing as a result of one user deciding they wanted support, or to support others in similar situations, or to share knowledge.

3.1.1) Facebook

Originally developed for university students to connect with their friends, Facebook is by far the most used social network in Ireland. In 2015, 60% of Irish people had Facebook accounts, with three-quarters of users logging in and checking the site at least daily (RTÉ, 2015). Increasingly, individuals and organisations are setting up Facebook pages and groups for their own interests – including Family Carers and their advocates. Most charities and not-for-profit groups have a presence

⁶ This study was conducted online via SurveyMonkey.com in March 2015, with over 800 respondents. The survey was publicised through Care Alliance member organisations and the National Carers Week Facebook page.

on Facebook, with many Care Alliance member organisations having significant engagement with individual followers.

Individuals can set up their own Facebook groups for people with shared interests. A quick search of Facebook turns up thousands of groups across the world set up by individual carers to support themselves and others in similar situations. Some of these groups have thousands of members, most of whom have direct experience in caring. That is a huge level of peer-to-peer support at the fingertips of anyone with access to the internet.

In the 2015 study outlined above, a number of respondents indicated that Facebook was a huge source of support, in particular when talking about how to combat isolation and loneliness:

"I love the info on your [National Carers Week] Facebook page. When you're at home on your own with a loved one, social media can be your only means of entertainment and news updates"

When asked what advice would they would give to a Family Carer new to the role, a number indicated that setting up a Facebook group or joining an existing online network would be highly useful, in particular for younger Family Carers:

"Create and promote a closed group on Facebook to give carers safe space to chat about the challenges. Many carers are younger and may already spend a lot of time online, so there's a niche there to be exploited"

"Get in touch with people ... via social networks etc. who are in a similar situation. It can be very isolating if you can't get out of the house."



When you're at home on your own with a loved one, social media can be your only means of entertainment and news updates



3.1.2) Twitter

While Facebook, in general, is a private forum, Twitter, by its very nature, is public. Approximately 26% of Irish people have a Twitter account (RTÉ, 2015), with a higher proportion of business people, policy makers and broadcasters having accounts. While this means that the average Family Carer may not be active on this platform, Twitter involves a high level of engagement and advocacy on Family Carer issues by certain individuals. This advocacy includes the sharing of research, media and information about services, which makes it an interesting port of call for Family Carers and also for organisations which provide services to them.

3.1.3) Online fora

Aside from Facebook, there are many other “message board”-style fora which Family Carers are already using to connect with each other, and which are both national and international in remit.

There are a number of online fora and message boards specifically for Family Carers; a recent collaboration between members of Eurocarers (the European Association Working for Carers) has led to the development of InformCare, an informational website for Family Carers of older people, with additional interactive services in a number of the participating countries – these include a private Facebook-style social media hub, a private messaging service and an online forum (Barbabella et al., 2015; Efthymiou et al., 2015).

Boards.ie is an Irish national message board forum, with an average of 2.2 million monthly visitors, and over 800 new users signing up each week in 2015 (The Journal, 2015). There are dedicated fora for Family Carers, parents of children with intellectual disabilities and other related interest groups.

3.2) Blogging

Blogging, which can be understood as public journal writing, has seen large expansion in the last number of years. Easy-to-use website building software, along with increased free and paid hosting options, has led to many people now taking the time to write articles and personal opinion pieces which can then be shared publicly across the world. It would be impossible to list or acknowledge the thousands of blogs written by Family Carers; however, a simple internet search for “Family Carer Blog” yields 668,000 results⁸.

⁷ These services are not available for Irish Family Carers at the current time.

⁸ Search undertaken 30 May 2016 using www.google.ie. If search term is “Family Carer Blog Ireland” the results number 297,000.

There is a particularly strong level of blogging within the community of parents of young children with special needs – this likely reflects the younger profile of these Family Carers, who are at the beginning of their family life and who have grown up with technology as part of everyday life, in contrast perhaps with other Family Carers. Thousands of these Family Carers across the world are sharing their personal experiences and stories in a very public way, which in turn helps new (and more long-term) Family Carers to feel less isolated in their roles. Some of these bloggers gain national and international recognition for their work, with articles and posts being shared on widely read syndication news portals such as The Huffington Post, a website within the top 200 most-visited websites in the world⁹.

Not only does this help Family Carers to create a vibrant community within which to share valuable experience across county and country borders, it also serves the important purpose of bringing Family Carer issues to the attention of those who may have no knowledge or experience of them.

4. Challenges

While it is clear that the web and related technologies offer numerous benefits and exciting opportunities, there are some challenges to be overcome, and indeed it must be understood that the internet is not a perfect fit for all Family Carers. Given that the profile of Family Carers stretches across gender, age, employment status, education and a myriad other socio-economic factors, there are some individuals and sub-groups for which web supports are simply not appropriate. Below are some of the key challenges identified.

4.1) Connectivity

Web connectivity can be poor in certain areas of Ireland, particularly in rural areas. However, according to the most recent Eurostat figures, 85% of Irish households have some type of web connection (either through mobile phone, dial-up or broadband connection), which is higher than the EU27 average (83%) (Eurostat, 2016). This of course does not tell the whole story, as it is likely that the remaining 15% of the population are among the most geographically isolated. If, therefore, families in this group have caring responsibilities, they may be among the most isolated Family Carers in the country – which of course is the group most in need of the types of support that online initiatives could supply¹⁰.

⁹ Ranked no. 154 globally as of 1 April 2016 (as per metrics from Alexa.com).

¹⁰ For example in multiple studies, Family carers across the country reported feelings of social and geographical isolation due to their caring role (Carers Association Ireland, 2008; O'Sullivan, 2008)



4.2) Technical knowledge

While it is not true in all cases, technical knowledge tends to be lower with increased age. In a 2011 study of older people and older carers in Ireland, it was clear that older carers did not see the benefit of communication technology either for themselves or for those they care for. Whilst some did say they would use new technologies if they could, less than half were willing to undertake IT training to do so. Most of those involved in the study were either negative or ambivalent about the use and potential of technology, ranking it in importance behind increases in their Home Care package or other human interventions which would assist them in their caring role (Saunders, 2011). Thus, the internet may not be the most appropriate or desirable method of support for older carers.

Technology has become embedded in culture for younger citizens, including for young Family Carers. Many Family Carers, given their higher average age profile, are part of the group which has become known as “digital immigrants” (Prensky, 2001), that is, people who did not grow up with technology as an everyday part of their lives. They struggle with embedding technology into their normal routines, as it does not feel natural for them to do so. Conversely, younger carers (35 years and younger) tend to integrate technology and the use of the internet into everyday life without really thinking about it – they are “digital natives”. It is not surprising that a large number of blogs, Facebook groups and other web-based supports are focused on issues which particularly effect younger carers – for example, young children with intellectual disabilities.

This is of course an important issue for services wishing to develop online supports for Family Carers. If the target group either does not have access to an internet connection, the skills to take part in online supports, or the desire to develop the necessary skills, then such measures will encounter difficulties. Training in digital skills for Family Carers may be necessary. This of course is impacted by the level of resourcing available for training. It is likely that this time-poor cohort of Family Carers may in fact benefit the most from a flexible support system such as this, which can be accessed whenever a few minutes are available.

4.3) Moderation/safety

A key benefit of online supports for Family Carers is their extent and their availability without constraints of time and location, in comparison with similar supports available offline. However, with the increase in online usage has come an increase in instances of cyber-bullying, aggression and harassment. It has become commonplace for those

accessing any kind of online service to experience some form of negative attitude from other users. As a group, Family Carers often experience higher levels of poor mental health than does the general population (Social Policy Research Unit, York, Carers UK & Carers Scotland, 2004; Stokes, 2010). Anxiety and low self-esteem are part of this. It is vitally important therefore that interventions which are initially set up to support Family Carers do not become part of the problem.



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Moderation is the act of moderating the comments and discussion which takes place on online fora. Often sites which encourage user interaction will have basic levels of acceptable behaviour, to specifically protect against negative experiences. The rules seek to ensure that those taking part feel encouraged to share their experiences and feel safe doing so. Online moderators read through message boards and posts, filtering out negative and/or abusive posts. If individuals continually break the rules, they may find themselves barred from accessing the site.

The act of moderation is resource heavy, primarily due to the time it takes to read the material. This can be worked around by employing a system of “self-moderation”, allowing users to report posts they feel are inappropriate. Regardless, a certain amount of time must be set aside on a regular basis to minimise the negative impacts of inappropriate posts, etc.

Particular challenges which arise for moderators on Family Carer-based websites include awareness of the high stress which posters may be feeling, which can often exacerbate their responses to seemingly innocuous posts. Many Family Carers feel angry at and unappreciated by government and indeed support services. They may lash out with comments that at best are insensitive and at worst potentially libellous, by, for example, “venting” of negative feelings, which, whilst understandable, can create a negative atmosphere. Respecting those opinions (and the fact that they may have merit) is important to ensure that Family Carers do not feel even more silenced by those purporting to support them, but at the same time it is crucial to respond in a responsible manner. Decisions on how to respond to particular comments can take time and can involve multiple members of the team charged with moderation.



Another key challenge in the moderation of Family Carer online supports arises due to the duality and in some ways co-dependent nature of caring. Family Carers, ostensibly, are not Family Carers unless there is someone to care for – a recipient of care. At all times, it is important to remember that in sharing their experiences, carers are also sharing some quite intimate details about their care recipient. Support organisations and moderators have a responsibility to ensure that private details are not shared by a “third party” (in this case, the Family Carer), even if the reasons for doing so are not malicious in any way.

5. Benefits

Having discussed the challenges for services who wish to provide web-based supports to Family Carers, we now detail some of the potential benefits. As this paper is designed to stimulate discussion, this is not an exhaustive list.

5.1) Efficient for organisations

While it is not true for all scenarios web-based supports are often more efficient than other types of supports if rolled out correctly, targeting the correct cohort. It is likely that an organisation will reach more young Family Carers using social media channels such as Facebook, Snapchat, Tumblr or Twitter than using more traditional methods, which younger carers may feel do not suit their requirements. The organisers of National Carers Week, for example, have received feedback that the events on offer during the week (each June) do not reflect the interests of younger Family Carers (in this case, those in their 30s and younger)¹¹.

For small organisations, the ease with which a website, blog or Facebook page can be set up has been a major boon across all sectors, with free options often available. A professional website with a distinct web address and message board functionality can be obtained for less than €100 per year, which means that in monetary terms a great deal can be achieved with relatively little outlay. Teaming up with organisations and volunteers who have an interest in web development can drive this cost down even further, and create opportunities to network and link in with others who may have little knowledge of Family Carer issues, but who may bring new ideas to the sector.

5.2) Convenient for Family Carers

Family Carers consistently report having little or no time to access the supports which may be available to them (Carers Association Ireland, 2008; O’Sullivan, 2008). In addition, many Family Carers struggle to make ends meet and cannot afford fees for

¹¹ Feedback from a large survey of Family Carers in March 2015. Please contact Care Alliance Ireland for further details.

participation in events and those costs incurred in general social situations¹². It can be very difficult for Family Carers to schedule time away from their caring role, as at all times their primary responsibility is to the person they care for. If they are unable to leave the home confident that their loved one is safe, they simply do not do so. Respite time is often spent undertaking daily living tasks, such as paying bills, doing grocery shopping, etc. For many, the only time they have to themselves is when the person they are caring for is asleep. Having access to a non-time-dependent social and support outlet, or an online course which can be undertaken in short bursts when convenient, means that the Family Carer can structure their day as best fits the person they care for, and still connect in to supports as needed.

5.3) Raises societal awareness of Family Carer issues

Many Family Carers report that society in general does not understand what it is they actually do each day. Myths about Carer's Allowance and other welfare supports, and the tasks carers undertake, have developed over the years, with Family Carers in some ways living in a "secret world" which outsiders do not understand.

When asked what is the hardest thing about being a Family Carer, some carers responded as follows (among other issues):

"Friends or some of the family will never understand how difficult it is sometimes, they are thinking that you are at home and doing nothing"

"Isolation - as soon as you mention depression or anxiety people assume it is just laziness"

"Others don't understand a tenth of how hard it is"

With an increase in Family Carers reaching out and sharing their experiences online (via blogs or other public fora), issues which the population in general does not understand or has not heard about can be raised and shared.

5.4) Increase in skills and knowledge

Family Carers who have online access to training courses, health information and first-hand accounts from those who have gone through the experience of caring are well placed to develop their skills in multiple areas, which in turn can increase the level of care they can provide. Best practice examples can be shared with Family Carers across countries and continents, again increasing the level of care and support

¹²For example, paying for coffee and cake if out with friends, transport costs, etc.



available to recipients. For example, online video-sharing website YouTube has scores of short “how to” instructional videos on safe patient handling and other very practical aspects of caring. These materials, whilst not a replacement for one-to-one hands-on training, may be invaluable for a person who suddenly finds themselves in an intensive caring role without prior experience.

5.5) Decrease in isolation and loneliness

As discussed above, Family Carers experience significant levels of isolation, loneliness and social exclusion (Carers Association Ireland, 2008; O’Sullivan, 2008). Whilst online social activities cannot replace one-to-one and “real world” group interaction, online support groups and social fora offer a viable alternative for those who are unable to leave home and are thus very isolated by their caring role, such activities being accessible at a time and place convenient for them.

6. Conclusion

The internet has emerged as a multifaceted tool for learning, communication and awareness building. Whilst not a short cut or replacement for the intensive supports which services provide to Family Carers, there are multiple advantages for service providers in providing some elements of support online. Being able to engage with a support community of their peers is highly valuable for Family Carers in combatting some of the social challenges they experience. Of course, it must be noted that the internet is not a catchall solution, and indeed there is a significant cohort of Family Carers for whom web-based supports will not be appropriate. The challenge for services and organisations is to understand the issues and to develop correct and appropriate interventions and supports, using all tools available to them.



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Guiding support for family carers

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