Online Resources:
What Family Carers Think

SURVEY

What Family Carers Think

☐ 132 Hours

☑ 168 Hours

☐ 60 Hours

☐ 96 Hours

Hours spent caring per week?

SUBMIT

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Overview

In 2018, a survey found that **82%** 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, 2018). **Ninety-seven percent** of those aged **between 16 and 29**, and nearly **half** of those aged **between 60 and 74**, had done so. It is clear, then, that increasingly the internet is becoming a tool that must be understood and utilised as a viable way to supplement supports for family carers.

In order to discover how family carers in Ireland are using – and *could* be using – online services and supports, Care Alliance Ireland (in consultation with the National Carers Week partner organisations) undertook a survey of Irish family carers in April 2019.

300 family carers responded online, and a summary of their responses are included here. The purpose of this report is to highlight how family carers are using the internet to **connect with others**, to **get supports and information** from not-for-profit and statutory agencies, and to **manage their lives as family carers**. It should be noted that this is not a representative sample of Irish family carers – the survey was administered online and disseminated via the National Carers Week Facebook page and other online channels.

Internet supports are not, of course, a substitute for significant one-to-one supports. There will always be a need for the timely and adequate provision of **in-home respite**, **therapies** and all the other supports which are necessary to create a positive environment for a family carer to provide the best possible care to a family member or friend. However, if used in conjunction with existing supports they can be a source of peer support and a way to tackle the social isolation and loneliness that many family carers experience – in particular in rural and geographically isolated locations.

82%
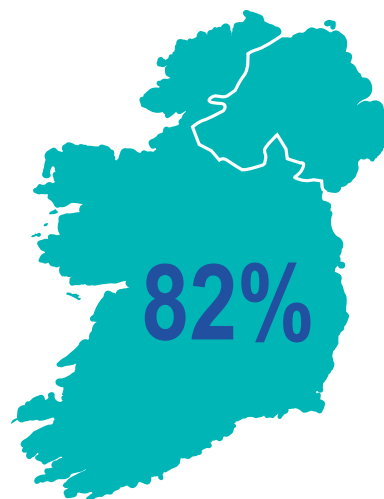
> " Living in a small rural village and being a carer is very isolating and having online supports and opportunities would make an enormous difference to me especially my mental wellbeing as I also have a chronic health condition. "

Rural
22.8%

City
24%

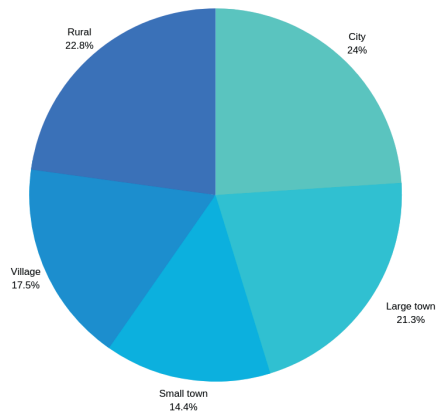Large town
21.3%

Village
17.5%

Small town
14.4%

Urban vs Rural

Always
2.6%

Often
9.7%

Never
23.3%

Sometimes
27.8%

Rarely
36.6%

"I am able to attend the social and support events I would
like to attend"

Rarely
4.4%

Always
19.8%

Sometimes
36.6%

Often
39.2%

"I feel lonely and/or isolated in my role as a family carer"

Care recipients

Who answered our survey?

Most people who answered our survey were between 30 and 69 **(84%)**. The average age was **50**, and the majority were women **(88%)**.

Each county in Ireland was represented in the responses, and while most respondents lived in some type of urban location ('city', 'large town' or 'small town'), **40%** of respondents lived in either a village or rural location.
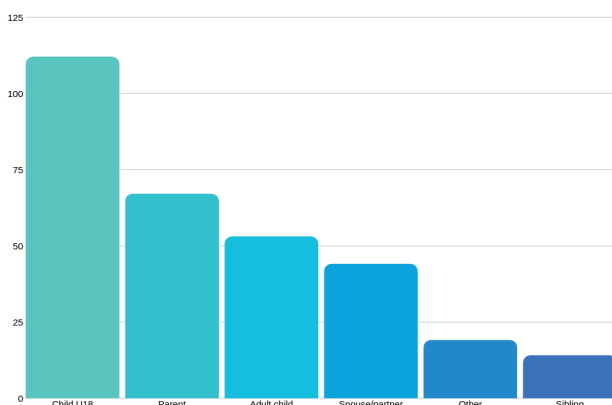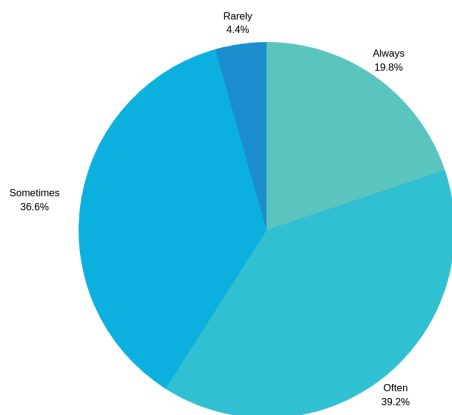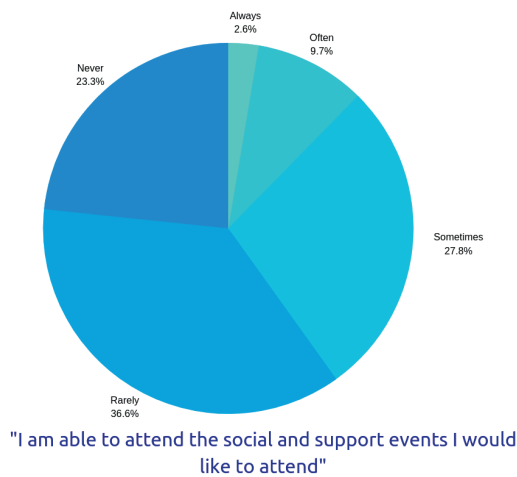
Most respondents are caring for a child under the age of 18 **(42%)**, an adult child **(20%)** or a parent **(25%)**. Some people are caring for more than one person.

The average number of hours that respondents were caring for their loved ones was **132 hours** per week – which highlights how many family carers are 'on call' and acting in a caring role **24 hours** a day, **7 days** a week. Most of the carers who responded are providing full-time care in the home and receive a modest social welfare payment such as Carers Allowance, Carers Benefit or Domiciliary Care Allowance **(69%)**.
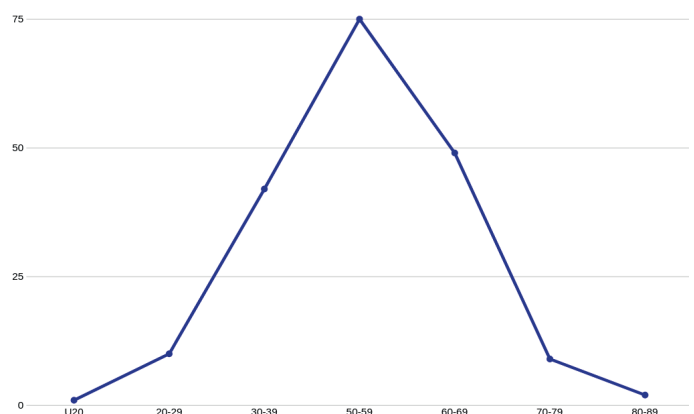
Over half **(59%)** of respondents said they felt lonely or isolated either 'often' or 'always', with a further 37% saying they 'sometimes' felt that way. Only **3%** of respondents said they could 'always' make it to social and support events that they would like to get to – with almost a quarter **(23%)** saying they can 'never' get to those kinds of events.

Age Profile of Respondents

How do family carers use the internet in their role as carers?

When it comes to using the internet, almost all of the family carers who took part in the survey use the internet at least **daily (95%)**, with 59% using the internet several times a day.

Over 90% of carers use a mobile phone to access the internet, with tablets and laptops also used. This is important, because it is clear that online information for family carers needs to be optimised for mobile devices like phones and tablets.

Family carers access many different types of information online relating to their role as a family carer. The top three types of information that family carers told us they have accessed online were:

> 1) **General information regarding the condition of the person they are caring for (76%)**
>
> 2) **Governmental/official information regarding being a carer (64%)**
>
> 3) **Social media groups for family carers (59%).**

It is plain that family carers want clear information and access to social supports online. The type of activities least accessed online were "undertaking an online course for family carers" (just **under 4%** of respondents had done so) and "attending an online event for family carers such as a livestream of an event, or a webinar".

When we asked family carers why they may not have accessed a particular type of information or support online, the most common response was that family carers want to be able to physically leave their house and meet people **face to face**. The other most likely responses were that they **did not know how to access carer-specific information online**, they were **nervous of their overall online skills**, or their **internet speeds were too slow** – which was particularly a problem in rural areas.

Regarding the usefulness of online information for carers, the majority of family carers have been able to find relevant information about the (health) condition the person that they care for has, with only 7% saying they could not. However, when it came to finding information about their role as a carer, 10% said they could not find any relevant information, and 15% had not tried to.

> 66 It never occurred to me to look up caring and its effects on me, I've looked up my child's conditions many times but never anything about being a carer. 99

What do family carers think the best uses of the internet are for them?

In our survey, we asked respondents to 'rank' a number of different types of services that could be offered online to family carers – in order of how important they would find them. This list that we provided was not exhaustive, but it does give an indication of the types of information and supports that family carers themselves would like to see online. The highest ranked item was **"specific information about rights & entitlements for family carers"**, followed by **"general information about being a family carer"**. The least chosen item was **"opportunities to take part in research about family caring"**.

Full list:

1) **Specific information about rights & entitlements for family carers**

2) **General information about being a family carer**

3) **General information about various conditions**

4) **Specific advice from family carers to family carers (e.g. blog posts etc.)**

5) **Online social opportunities (e.g. message boards, chatrooms)**

6) **Online training for family carers**

7) **Online events (e.g. video livestreams with staff, live events)**

8) **Opportunities to give feedback about services**

9) **Opportunities to take part in research about family caring.**

It is interesting to see that family carers would like to see more information *for* carers *from* other carers – peer support came up as a positive in the comments from a number of respondents.

However, others pointed out that sometimes family carers themselves can be dismissive of what might be perceived as a 'silly question'.

> Sometimes online support can be quite judgemental. There should be a no silly question approach like we take with our kids. I've seen parents get very abrupt answers to simple questions; it appears to be a growing trend.

What does this mean for services?
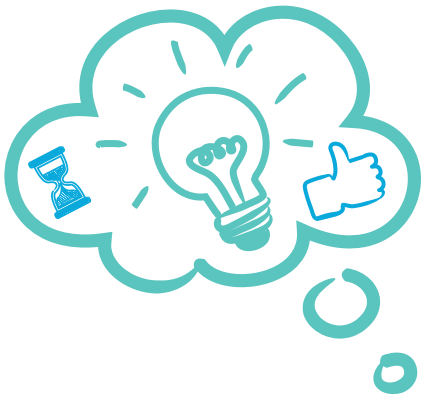
Family carers do not want online services to take the place of face-to-face supports or the other vital services that carers and those they care for rely on, such as respite or home care. However, there is certainly an appetite for some types of support to be available online as a **supplement** to existing 'on the ground' programmes. Family carers have taken to setting up their own **social groups online** on platforms like Facebook, and these have proven positive for the most part.

It is important that service providers understand that while setting up online services and supports can be time consuming and difficult to manage, as they require upskilling and extra resource allocation, for some family carers they are a valuable support. The information needs to be kept updated and relevant. The HSE and not-for-profit groups need to understand that family carers will be looking for very specific answers to very specific questions, usually using a mobile device. Websites and resources like online booklets etc. need to be readable on small-screen devices.

Other family carers who are struggling to cope with the challenges they face find it difficult to understand how online support can be of use.

Therefore, online supports should primarily be seen as complementary to adequate front-line services, and as an option for those family carers who would like to avail of them.

> " It takes ages of surfing which I do not have time for to find relevant groups "

> " I cannot see how online services can help me when the practical services i.e. community health nurse, home help are denied my wife and I. "

*This research was undertaken by Care Alliance Ireland in collaboration with the 2019 National Carers Week partners. Please see **www.carersweek.ie** for further information.*

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Guiding support for family carers