

# Online Support Project for Family Carers in Ireland: From COVID to Now

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WORLD  CARERS  
**Conversation**

A VIRTUAL GLOBAL SUMMIT HIGHLIGHTING INNOVATIONS  
IN CAREGIVING RESEARCH, PRACTICE AND POLICY

#WCC22 #worldcarers



- In March 2020 everything stopped
- Services all ceased – many overnight
- Time of confusion and misinformation
- Other organisations slow to respond
- In response, Care Alliance Ireland pivoted the work of the organisation and founded The Online Family Carer Support Project





THE IRISH TIMES



Visitors



Gatherings



Domestic travel



Public transport

	Level 1	Level 2	Level 3	Level 4	Level 5
Visitors	10 From 3 households	6 From 2 or 3 households	1 Other household	No Visitors permitted	No Visitors permitted
Gatherings	50 Outside your home or garden	6 Indoor 15 Outdoor	No Social or family gatherings	No Indoor gatherings	No Except funerals or weddings
Domestic travel	No Restrictions	No Restrictions	Stay In your county/ religion apart from work/education essential purposes	Stay In your county/ religion apart from work/education essential purposes	Stay At home except to exercise within 5km from home
Public transport	Travel Off-peak hours or walk/cycle, if possible	Peak Hours Essential workers/ purposes only; 50% capacity	All hours Essential workers/ purposes only; 50% capacity	Avoid Public transport; essential workers/ purposes only; 25% capacity	Avoid Public transport; essential workers/ purposes only; 25% capacity

Graphic: Paul Scott/IRISH TIMES GRAPHICS

## Covid Restrictions in Ireland

- Over the past two years, Ireland has had some of the toughest and longest restrictions and lockdowns in Europe
- Many services such as respite, day care and face to face support groups are still not back in service, and those that have restarted are often still operating on a reduced capacity basis

*“COVID was a very **lonely** time for a lot of carers.”*

*“Here is my mother-in-law was living next door...So **to keep my daughter safe** that’s who I care for and she has an intellectual disability and complex medical history And so to keep her safe, my **husband moved in next door with his mum** so we could keep the two houses separate and that end up then being for what? **Five months you know?** So it was just **myself and S literally in the house** would go for walks out in the woods, away from everywhere and **W and his mum and next door.**”*

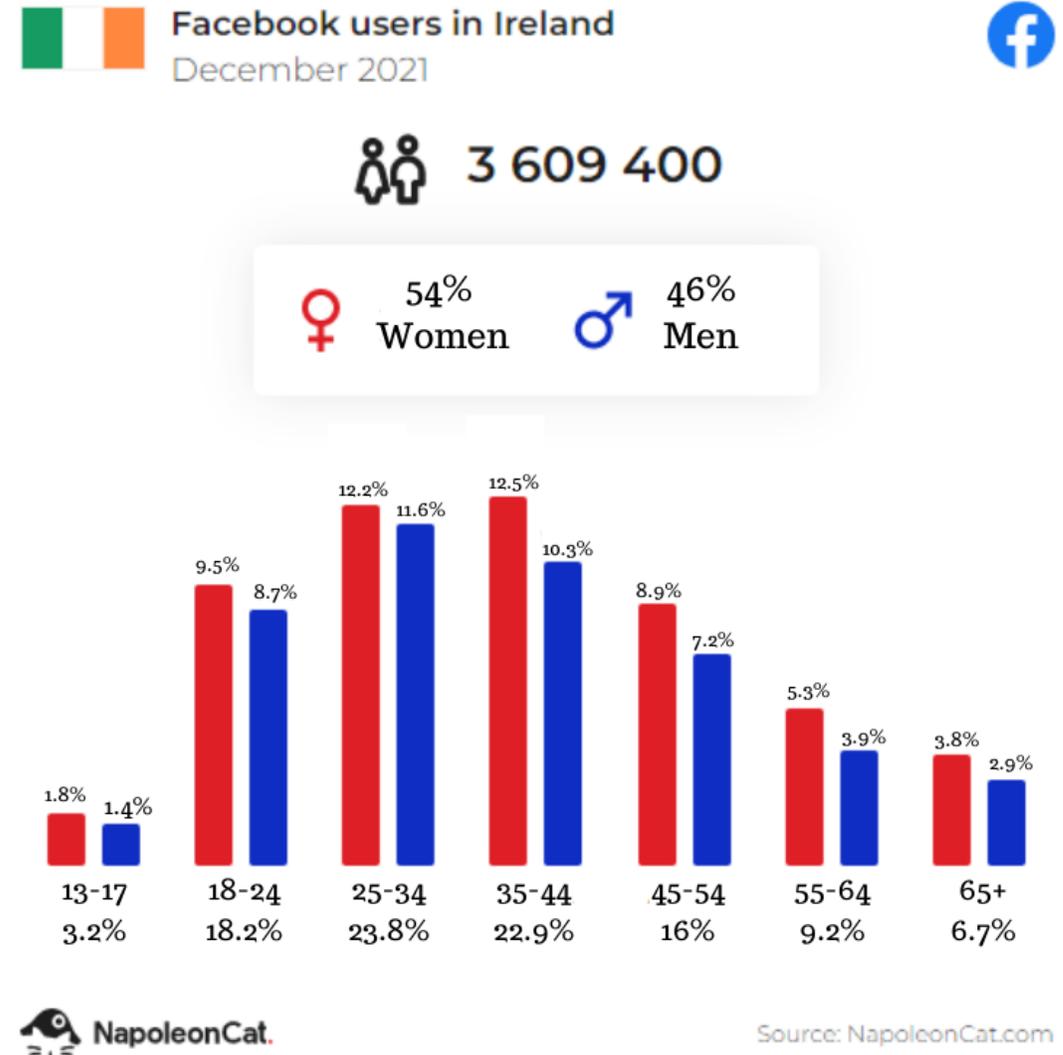
*“So here all of a sudden we're in lockdown. I'm trying to entertain these children and wondering what the hell is going on and you're trying to watch out for my parents as well and make sure that they are safe and the fear of covert back then. **The fear was very very real...**”*



- Main Objective:
  - Increase the well-being of family carers in Ireland
  - Reduce the negative impacts of caregiving, such as loneliness and isolation

# Why Facebook?

- The Online Family Carer Support Project is run as a private group, via the Facebook platform
- We chose to “go where the carers already are”
  - The largest cohort of family carers in Ireland are women in the 35-54 age group, an age cohort heavily represented in Ireland’s Facebook users
- Not just a “Facebook group” – a professionally moderated, fully funded support group that happens to use the Facebook platform



# Operations



- **Members**
- **Volunteers (former & current family carers)**



- **Social Workers**
- **Policy & Research**
- **Psychologists**
- **Wellness**



- **Book Club**
- **Gardening Club**
- **Quiz Nights**
- **Educational Talks**
- **Competitions**

- Some negative perceptions about Facebook
  - “they own us...that’s the price you pay for something being free”*
- Easy and accessible
  - “I have it set for notifications, so I get notification anytime anybody posts in us”*
- Came up in timeline – wouldn’t have found otherwise
  - “If it wasn't put on Facebook, I wouldn't know about it”*
- Available when carer available
  - “It would be an example of how Facebook is useful when it works.”*

- Mix of current/former family carers and professionals, such as social workers, dementia advisers and those working in the mental health field
- All posts pre-moderated
- 7 day a week rota
- Separate private ‘mods group’, where challenging issues and appropriate responses can be discussed
- Assist with the various activities we offer

- Put up content

*“There are a few things there for the moderators who put up posts, and those are usually **very enlightening, very entertaining** there, always something.”*

- Monitor content and comments

*“But **every single post** that someone submits **is approved**...The amount of work that goes into it, and it shows in the group”*

- Manage Group Dynamics and create Group safety

*“They have to be very special people because they have to be able to make sure while **allowing the group users and the group members to put up there, be open and honest**. I suppose they have to be careful again that **nobody is going to be offended or there’s nothing going off**, so I think they they take a lot of the **responsibility and credit for doing that**”*

# Activities

All of the various activities we offer have one aim in common:

To encourage caregiver participation and reduce loneliness and isolation. All of our activities are online, making them accessible for family carers.

## Book Club



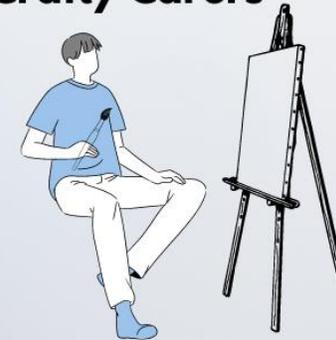
## Coffee Morning



## Quiz Nights



## Crafty Carers



## Chair Yoga



## Competitions & Giveaways



## Gardening Club



## Information & Educational Talks



- More than just a carer – **a person first**

*“The little things that the guys do you know in terms of organizing the quizzes or having like random little competition things? Or you know, **sending out little parcels**? You know it might only be bar chocolate in a book or something, but if somebody says I **recognize that you do something more** than you know the average parent or whatever”*

*“if you had gotten a gift that you didn't want at Christmas time you could send them on up. I thought that was just so lovely. And then **there were readers distributing them to other carers**. I thought like...so that's that's lovely*

*There is a lot of care going on in the Care Alliance world and I think if hit the nail on the head, there it is actually **care** that's coming forward*

## “Tribe”

## “Community”

*“I mean there are there is other groups as well that I've tried and they weren't as **welcoming**...as carers we're very...We've got very little voice like very small voices that you feel like **you're part of something**...it's a comfortable place that you can go to and **it's more welcoming than any other group that I've been on**”*

- Sense of understanding without having to explain

*“And it's a **non-judgmental forum** that you don't get at home, or you don't get from as close to a relative or a partner or a relative or a parent. They just don't get it. So it's nice to have that facility there*

- Safe Space

*“that it's a **safe environment**...there's no backlash”*

## Informational Support

*“It's a comfort to kind of just know that there is a place you could go and **ask a question and there is likely to be an answer based on people's experiences...**”*

*“There's **so much advice given** on it...but because there's so many different levels of caring on it, like just people caring for small children, people caring for kids and adults with physical disabilities, intellectual disabilities, emotional disabilities, everything like that, and you can always find **some little nuggets** in it to help you on your way.”*

*“I've **seen my own life reflected on it** either now or in 10 years time...you can see **it prepares you** for what's ahead, whether it's good or bad or hurts. I also find out that **the more information you have, the better you're going to have your situation**, regardless of what situation is going to be, whether it's going to be a very taxing future or whether it's going to be hard going. **If you're prepared for it, you're just you're going to manage better if you know what's ahead...**But it's nice to know that there are days that are going to be hard, but you will get through them. And **I've seen online people do manage it.**”*

## Emotional Support

*“so I found in the beginning that you just read some of the comments each day.*

*But occasionally I'll stick in a little comment and say I'm feeling really shitty today...somebody will immediately come back and go. No, you're doing alright or you're entitled... “*

*“I don't reply to all the comments, but sometimes someone will put something in and I go. Oh you poor old thing and I sent a comment on to them, you know and say well hopefully that made them feel better.”*

*that's a conversation piece and just somebody asked me how [my] day went.*

## Social Network Support

*“I've made some **fantastic friends**, I've got two best friends out with it, and which I've never met. And that's weird to say a best friend, but I speak more to them everyday about my problems.”*

*“I really felt, Oh my God, I'm actually making friends and then it got to the stage where I go. **Is it Friday yet?** [to attend coffee morning]”*

- Currently over 3,200 members
- Membership continues to increase at the same rate, despite the slow reopening of face to face support services
- Retention rate of 96% versus traditional face to face, where drop out rate can be as high as 50%
- Extremely high engagement levels – 89% of members have been ‘active’ within the last 28 days

# From the research – Engagement – what do we mean?

*“I would say 90% of the group probably don't interact on it on a regular basis, but **it's knowing that that there are people out there that are...voicing your concerns, voicing your opinions, you know...it it kinda helps you know...It's nice to know that that somebody knows we're here.**”*

“Lurker” to “reader”

*“**some comments that come up that I would get something out of them, you know or I would feel a bit better or you know like they do you know even though I'm a reader it does help you know do it.**”*

- Level of anonymity

*“ I don't want to meet local people. I suppose that's you know, UM...It's just the way I am. **It's too close to home. you know, people gossip about other people...**”*

*“ 'cause it's even though your name is there and people can see your page. **It's anonymous really...even though they can see your picture...It's just easier**”*

- Level of autonomy about how get involved

*“**The group isn't forcing anything of anybody** that they just. Yeah, the group is very active with a lot of you know groups that go with this, like the book and at this like that's another thing. There's something for everybody like OK, you might be above post or you might just like to read and maybe just put up a like are not even do that just to look.*

- Group rules and privacy understanding

*“ You have to follow them or you are discontinued of the group.”*

- Social Comparison

*“And I felt that I really shouldn't be here...because honest to God like I **have nothing to complain about compared to that lady** whose son is 24 hour care and she can't even get the basic things that he needs”*

*“a lot of them will be **short term carers**. You know, they might be doing it for five years or 10 years. Maybe 15 years, whereas the other groups I have you're talking about doing this for 50 years”*

- Group reinforcing own feels of isolation/guilt/loneliness
- Hard to engage in group activities
- Expectations not being met/different understanding of what group would be

- Technology itself

*“It's because everybody uses Facebook, but not **everybody is comfortable with the zooms....** when you have a zoom, **you're only talking about a handful of people that can actually be on zoom at the one time** and then once the zoom call is over you've had it, but if it's something on Facebook, it's there and you can kind of...Come back at it tomorrow or the next day”*

- Overwhelming

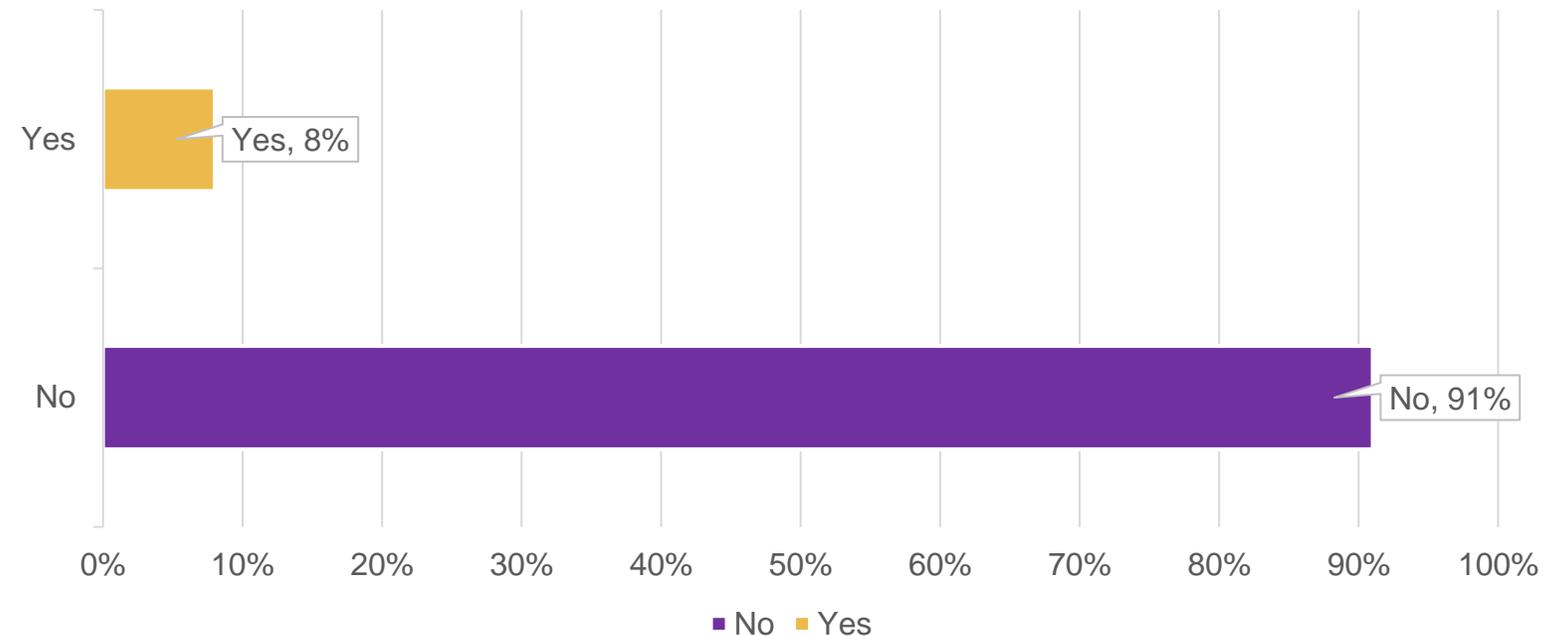
*“I would find a meeting like this hard because it's virtual, but **I'm not going to put myself into things like the book club or the quizzes that they used to do because it's ...the technology that puts me off.**”*

- Prefer physical group

*“It's just not for me”*

- 91% of members had no prior engagement in face to face support groups
- Indicates a cohort of family carers that were underserved by traditional support models

We asked: "Prior to Covid-19 were you involved in any face to face support groups?"



- Geographical distance

*“Sometimes if it's face to face, you tend not to open up as much...you know that **you don't actually have to face them people**. And so I could say what I need to do again and go about my business. I'm not meeting them downtown...it's from the people that were in town. And I wouldn't. **There's no way would open up because we know everybody**”*

- Flexibility

*“online, you know. **You just jump in**. If you're late, it's not going to matter so much **if you can't attend to tell you, just drop them a message and say look, you know, sorry.**”*

# Challenges/Risks

- Relying on an external platform, i.e. Facebook
  - Voluntary backup member list
- Need for ongoing funding
  - HSE service level agreement
- Group size
  - Organic growth
- Use of volunteers
  - Training/support

*“I hope it **doesn't lose...the magic** has of it now you know sometimes you know when you get so big or you know that that kind of lose...”*

*“I suppose you know just to be conscious at the group is going **so big** and you know **not to kind of lose people out there...**”*

*Uhm, just to be fair to everybody, there are **some fairly dominant people in the group...**”*

- How to manage group getting bigger?
- How to manage expectations?
- How to build relationships with people who join?

# From the research – Impact if group were to close

*“that would be awful...I'd say probably a lot of people would feel that that would be awful...there would be nothing positive out of that. I think it would **break a lifeline** for a lot of people come.”*

*“And I'd be sad to see it go because It's such an emotional and practical support. I would lose out on the **social connection** It's great...many carers unfortunately experienced **isolation**. And it's a great platform where you need help, that lived experience you can identify with the others.”*

*“I wouldn't be able to cope as well as had been coping. That's what gets me through the day and that's what gets me by.”*

- Succession planning – very strong relationship between moderators and group – how to manage people leaving

- Use of volunteer moderators – changes relationship within group

*“but I suppose the advice I gave now I would be maybe a little bit more careful about how I phrase it. And I'd be thinking more. **The role, maybe over the representative of Care Alliance rather than just myself.** So that would have changed that are more like a representative and as opposed to just saying it off my own bat now”*

- Funding

# Funding

- Initial funding in 2020 by the Community Foundation of Ireland and The National Lottery
- The HSE (Government Health Service Executive) recently agreed to fund the project on an annual recurring basis
  - Recognition of the value the project provides
  - Project is sustainable for the future

# From the research – Impact on group members

- Feel good factor

*“It's just something that **brightens up your day** when you're just having a hard time.”*

- Provide social, educational and self-care activities

*“there is opportunities that you've been, you know to join and offer you something for you which is good. when you're a carer **it's all about the person you're caring for and you are invisible** if you know I mean...so it encourages you to find something”*

- Encyclopedia – information there when you need it

*“And that's a great thing about it is **everybody's experience because somebody else's resource.**”*

- Inspiring personal growth and change.

*“Without the support of this group, I would not be able to be as good as a carer and a mum as I am now.... You know some days are bad, some days are brilliant...other days you really, really need someone to talk to. And **it's learning to open up and to talk** and people say God, **you found your voice now haven't you**”*

“definitely **a lifeline** and I'd say for myself, **life changing** as well.”

# Call out for survey

- Online survey looking at engagement or non-engagement in Online Support Groups  
Link to survey: [Survey about Online Support Groups for Family Caregivers](#)  
Like and reshare on twitter: @DaynesKearney, @ULPsych, @SASHLab  
Email: [rosemary.daynes.kearney@ul.ie](mailto:rosemary.daynes.kearney@ul.ie)
- If you would like to find more information about Care Alliance Ireland and the various family carers support programs that we run, please visit: [www.carealliance.ie](http://www.carealliance.ie)
- Find us on Twitter: [@CareAllianceIrl](https://twitter.com/CareAllianceIrl)
- If you have any questions about the Online Family Carer Support Project, please feel free to contact me via email: [tara@carealliance.ie](mailto:tara@carealliance.ie)

Thank you for your time and attention!