

Family Carer Training

A Resource for those working with Family Carers



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Purpose of this Booklet

This booklet is intended for anyone considering providing Family Carer training, or already doing so. It seeks to inspire, support and guide. It should prove useful in the planning, implementation and evaluation stages of an organisation's Family Carer training. It may also be of interest to those who have a general interest in the area of Family Carers and/or training.

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Who are Family Carers?

Ireland's most recent Census (Central Statistics Office, 2016) defines a 'carer' as someone who:

“provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems which are due to old age). Personal help includes help with basic tasks such as feeding and dressing.”

Broadly speaking, Family Carers are people who provide care, on a regular basis, to a family member in that person's own home. Those needing this support include ageing people, people with dementia and memory loss, people with intellectual, physical, sensory and neurological conditions, and people with life-limiting conditions and/or terminal illnesses. These individuals may be children or adults – as may be those caring for them. Around 10% of the population living in Ireland aged 15 and over reports providing unpaid care. Of these, 86% provide care to one or more members of their family; the remainder provides care to friends, neighbours or other people in the local community.

What is Family Carer Training?

Training, in this context, is any intervention that supports someone to be better equipped and more knowledgeable in their caring role, with a particular focus on how to look after themselves while providing care. There is no one-size-fits-all approach.

Sometimes training targets Family Carers who are supporting someone with a particular condition (for example, dementia or an acquired brain injury). At other times, training is highly applied and seeks to build specific skills (for example, in manual handling or first aid). But a lot of training is more generic in nature.

Training can be provided on a one-to-one basis or in groups. It can be offered face-to-face or online, for instance using video tutorials. It can be highly structured, with a set curriculum delivered over a predefined number of sessions, or it can be a once-off event or a looser arrangement.

Related interventions include signposting, phone line support and online support groups. Groups of Family Carers who initially come together for training purposes often end up evolving into peer support groups, either formally or informally.

Engaging Family Carers in training can be a challenge, and requires careful consideration of the specific audience and objectives. For instance, many people find the term 'training' off-putting and different words may have to be found to describe the activity. Training can often be successfully packaged in other, more indirect ways, such as 'information sessions', 'coffee mornings', or using generic event titles such as 'helping you care better'. Also, resources may have to be found to ensure the needs of the cared-for person are being met while the Family Carer is participating in the training.

Background to this Project

There is a growing body of evidence showing that Family Carer training and related interventions contribute to better Family Carer wellbeing. This, in turn, leads to better care.

There are various organisations delivering Family Carer training in Ireland. Thanks to financial support from the Dormant Accounts Funds in 2016, the availability of such training has increased. Due to significant expressed need, which is increasing in line with our growing and ageing population, it is very much hoped that this enhanced availability will be sustained into the future. It is vital that any Family Carer training that is delivered is of high quality.

During 2016, Care Alliance Ireland ran three seminars that brought together people involved in delivering Family Carer training.

Leading practitioners in the field were invited to share their expertise. They covered the following topics:

Family Carer training 2009-2016

Planning for good training outcomes

Implementing a personal outcomes approach with and for carers

Co-creation of open educational resources

Online support for carers

How to evaluate the success of your Family Carer training

Project reporting and evaluation

Their presentations can be found on the www.familycarertraining.ie website.

Over 90 participants representing 35 organisations from five countries attended the seminars. They came from generic carer, condition-specific, palliative care, intellectual disability, mental health and home care organisations. Some participants had previous experience in delivering Family Carer training; others had none. Many had recently secured funding to deliver Family Carer training. All came to learn and share their own knowledge and experiences with their peers, through groupwork and structured feedback opportunities.

Some Participant Feedback from the 2016 Seminars

Top tips from practitioners:

- Don't underestimate the time it takes to engage Family Carers
- Make sure there is a 'hook' to get Family Carers to come along (for example, a massage, a knitting club, a cookery demonstration, etc.), which you can then follow with an educational element
- Devise good quality advertising, and use outlets such as local noticeboards and church circulars to reach as many Family Carers as possible
- People like to know beforehand how big or small the group will be
- Providing an outline of the course will help to reduce anxiety for attendees
- Build in sufficient time for introductions: this can take far longer than you might expect as for some people it may be the first time they will be telling the story of their life as a carer
- Give Family Carers a proper chance to talk
- It's often a 'fishing exercise' to see what attendees want: they may not know themselves what they want/need from training
- Have the 'building blocks' of a course ready, but be prepared to be flexible and adapt these based on the group's feedback as the training is rolled out
- Appropriate language use is crucial: for instance, will you refer to those being cared for as 'patients' or 'service users' or something else?
- Be aware of previous 'conditioning': assumptions that have been made and fed for a number of years (particularly around mental health and disability issues)

What can be achieved as a result of high quality Family Carer training:

- People with care needs being able to remain living in their own homes
- Fewer hospital admissions
- Carers better informed about the illness/condition their loved one has
- Changed perceptions about the illness/condition
- Increased awareness of other services available for the cared-for person
- Increased awareness of other services available for the carer
- Easing of the 'carer burden', physically, emotionally and financially

- Knowledge gained that others also struggle in their caring role
- Reduced isolation
- Formal and informal support networks built
- Improved self-confidence in their role as a carer
- Better understanding of the full implications of their role as a carer
- Informed decisions about whether to continue or cease the carer role
- Increased focus on the whole identity of the person, not just as a carer
- Empowerment via upskilling and accessing new resources
- Increased resilience amongst carers
- Greater understanding of the need for self-care
- Improved physical health of carers
- Improved mental health of carers, including lowered stress levels
- Improved relationships at home
- Improvement in the wellbeing of the entire family unit
- Positive knock-on effects on the whole community
- Standardised good practice spread nationwide
- Carers increasingly seen as equal partners and having a stronger voice
- Greater recognition of the role played by Family Carers, young and old

The benefits of internet supports for Family Carers:

- Fun
- Progressive
- Reaches far and wide, including rural areas (provided there is broadband)
- Accessible (for example, those who cannot make it to face-to-face support groups or are otherwise hard-to-reach)
- Works well with younger carers
- Flexible

- Can cascade information quickly
- Opportunity to readily challenge/correct misinformation
- Can easily produce useful data
- Service providers can learn from carers' forum
- Increases interaction between carers
- Prevents isolation, by giving carers someone to talk to
- Carers can feel empowered by the use of IT and by networking
- Can become self-sustaining if members of an online forum are taught how to moderate

The challenges of internet supports for Family Carers:

- Can be hard to know where to begin
- Many organisations are very conservative and it may be difficult to get buy-in
- Uncertainty about the purpose of the internet support: is it for information, or for chatting, or for both?
- Lack of internet access
- Lack of IT skills (both carers and organisations)
- Resource implications, both in terms of time and money: ring-fencing is essential
- The need for ongoing, positive moderation that champions Family Carers
- Risk of information overload for carers
- Risk of misinformation
- Potentially too much reliance on the individual views of carers
- Overpowering group members may discourage other group members
- Potential for anti-social behaviour, even bullying
- Child protection issues
- Anonymity and confidentiality concerns
- Not appropriate for all carers, so there should not be an overreliance on internet support

Encouraging parents and other family members to identify as Family Carers:

- Provide information about the context and definition of the term 'carer'
- Value the role and its contribution
- Promote the benefits of being a carer
- Promote all types of carer support and services
- Change the way employers think
- Offer peer support
- Undertake one-to-one work about their role
- Use public information channels such as the radio, newspapers and posters
- Engage with primary health care professionals, including GPs
- Deliver a schools awareness programmes for young carers

Some More Food for Thought from the 2016 Seminars

- How can we support carers who are ageing?
- How can we support carers who are physically isolated?
- How can we manage a co-dependent carer/caree relationship?
- How do you define the success of your Family Carer training programme?
- Are there any potentially negative changes that may come about from your training?
- Have you considered all the pros and cons of your proposed training methods?
- In doing this, what has surprised you most about yourself and/or your colleagues?

Detailed feedback from seminar participants relating to the questions above can be found on the website www.familycarertraining.ie

Questions and Answers

Where do I start?

Don't reinvent the wheel! Read the information that is already available, including this booklet. Talk with others to get their insights. Then plan your training intervention. Think about the resources you will need, who your potential participants are, how you will persuade them to engage in the training, what the learning objectives are, how you will know if they have been achieved, where and when the training will be delivered, how and by whom, how the project will be wrapped up, etc. Simple to-do lists or spreadsheets with timelines for different tasks can be an effective way of managing a new training project.

Skills in group facilitation, active listening, reframing and paraphrasing will be valuable in any successful delivery of training with Family Carers. Traits such as empathy, honesty and compassion are also important. Remember to allow time to be available for Family Carers after each training session.

Do Family Carers get 'on the job' training from health and social care professionals?

Our experience is that this tends to be rather hit and miss. Some Family Carers report receiving excellent support from Public Health Nurses or Physiotherapists to master specific caring tasks, for example using a hoist, administering injections, giving massages, etc. Others may never have asked for training or may have received an underwhelming response when they did make an enquiry. However, increasing numbers of Primary Care Teams are seeing the need to work with families and treat them as 'partners in care', as per the 2012 National Carers' Strategy.

Does training for Family Carers need to be different to that for paid Care Workers?

Many of the skills required for unpaid Family Carers and paid Care Workers are the same. These include empathy, patience, strength (physical and emotional), an ability to negotiate and an ability to advocate. There are some topics which training for Family Carers will address more specifically, such as negotiating a change in relationship or how to come to terms with the bereavement of a loved one. Some Family Carers find it beneficial to undertake accredited courses alongside paid Care Workers (although most are not in fact looking for accredited training). After their caring ends, some Family Carers seek employment in the paid home care sector.

How can I persuade my manager to allow me to use my time to organise Family Carer training?

Be very clear on the unmet need you are aiming to address. Referencing national policy (for example, the National Carers' Strategy) as well as your own organisation's vision/mission etc., can be a powerful way of persuading others in your organisation to buy in to a new idea. In order to make a persuasive case, you may need to articulate the connection between supporting the primary client and the wider family unit. Family Carers can be the key determinant of a dependent person's wellbeing and their ability to continue to live at home. Be sure to highlight your work in this area to date and outline the offers of any support you have already garnered. Some people find writing a formal proposal a good way of making a coherent case.

Where can I secure funds to deliver Family Carer training?

Many individuals have managed to convince the managers in their organisations of the merit in delivering such training, thereby securing dedicated organisational resources. Such Family Carer 'champions' stress that neither the dependent person nor the Family Carer lives in isolation and it follows, therefore, that neither should the allocation of funds to support them. Sometimes it might make most financial sense to collaborate with local HSE staff or other Family Carer organisations in putting together training. Additionally or alternatively, small grants to cover the costs of materials, tutors and similar may be available from the HSE administered National Lottery Grants and from philanthropic organisations.

Care Alliance Ireland is available to support staff/volunteers in bringing an idea to fruition (by way of phone conversations, emails, review of proposals, etc).

How do I maximise attendance?

Despite your best efforts, securing good attendance at training can often be a challenge. You need to be both creative and determined. Think of where your potential audience is and how they hear about what is going on in the world. Is it via newsletters, the local newspaper, a community radio station, their church, on social media, or somewhere else? Optimise the existing relationships your colleagues have with families. Make sure it is absolutely clear from your publicity what the training is about and why attending might be an attractive option: address any fears people might have about participating. Even when people have signed up, remind them a day or two beforehand, in case it has slipped their mind.

How can I demonstrate real impact?

Be realistic about what your training is going to achieve. If it is a short session with light content, you cannot expect to make a big difference to someone's life (this is not to say that small interventions cannot be useful, especially if they are offered as part of a bigger suite of supports).

Think about the change you want to create before you start delivering your training. See if you can establish a 'baseline' that will show where people were before they did the training and where they are after they have completed the training. Alternatively or additionally, see if you can compare the experiences of those who participated in the training with a 'control group' of those who did not (or have yet to do it). Remember that outcomes are not always planned or positive; they can be unanticipated or negative too.

It is simplest to measure people's reaction to the training (did they like it?). It is also relatively easy to measure if they learnt anything (were there any changes in knowledge, skills or attitude?). It is more difficult to ascertain if there was any behavioural change as a result of the training (did they actually adjust their way of doing things?). Ultimate results or impacts are even harder to measure, because some of the changes might be long-term and might not even be for the trainee but experienced by other people, such as the person who is being cared for or other family members. Start with the easiest measures and build up to the more difficult ones. Use both numbers (for example, number of trainees and sessions) and stories (for example, case studies of trainees) when discussing results.

Should I be thinking of setting up a support group for the participants when the training sessions have come to an end?

This can be a logical next step when a course with a specific schedule has finished. When considering the need for and viability of such a group, think about logistics, the group mix, and your own availability in terms of facilitating the group, at least in the short-term. It may be more appropriate to work with other carer support organisations.

Useful Resources

There are many useful resources available to assist organisations providing Family Carer training. Here we provide a small sample of these.
For more, go to www.familycarertraining.ie/Information-For-Organisations.

CarerSupport is the platform for informal carers' training and collaboration, a new initiative led by a consortium of European partners
www.carersupport.eu

Equal Partners in Care is the Scottish framework for workforce learning and development related to unpaid carers and provides a range of excellent resources to ensure good outcomes for carers
www.knowledge.scot.nhs.uk/home/portals-and-topics/equal-partners-in-care/about-equal-partners-in-care.aspx

Family Caregiving Alliance in San Francisco published Mary A. Corcoran's 2003 guide Practical Skills Training for Family Caregivers which continues to be of interest
www.caregiver.org/sites/caregiver.org/files/pdfs/op_2003_skills_training.pdf

Joint Improvement Team in Scotland published Ailsa Cook and Emma Miller's practical 2012 guide to Talking Points: A Personal Outcomes Approach for carers
www.jitscotland.org.uk/wp-content/uploads/2014/01/Talking-Points-Practical-Guide-21-June-2012.pdf

National Carers Week is an annual celebration of Ireland's Family Carers and the website also contains useful handouts such as Ten Tips for Family Carers and Skills Family Carers May have to Offer an Employer
www.carersweek.ie

OpenLearn Works at The Open University makes available Caring Counts which is a self-reflection course for carers and a facilitator's guide is also available
www.open.edu/openlearnworks/course/view.php?id=1688
www.open.edu/openlearnworks/mod/oucontent/view.php?id=65075

The Wheel provides a range of supports to community and voluntary organisations, including advice on grants and outcomes-based working (the 2012 guide Knowing and Showing your Outcomes and Impacts)

www.wheel.ie/funding

www.wheel.ie/sites/default/files/KnowingandShowingYourImpactandOutcomes_Final_0.pdf

TRACK stands for TRAINing and recognition of informal Carer sKills and is a European initiative testing blended learning and mentoring for caregivers

www.eurocarers.org/track/index

There are also many resources for Family Carers themselves, including a database of all currently available training opportunities, links to numerous online courses and other useful booklets and sites.

Please visit www.familycarertraining.ie/Information-for-Family-Carers to find out more.



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Guiding support for family carers

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