



Family
Carers
Ireland
Fairness for Carers



Annual Report 2017

NOTES

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OUR Vision:

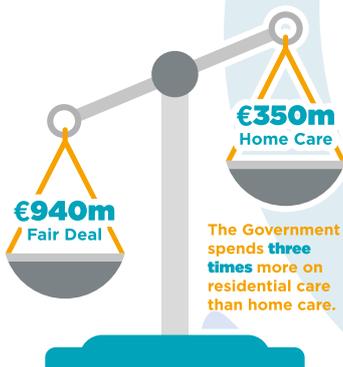
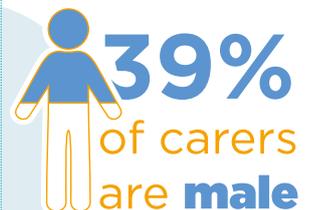
An Ireland in which family carers are properly recognised, supported and empowered.

OUR Mission:

To highlight the contribution of family carers to Irish society and to improve the lives of family carers throughout the country.



Save the State **€10 BILLION** each year



36% increase in older population & **63%** increase in people with a disability since 2006.



13,147 young carers under 25 years.

By 2030 1 in 5 people will be a carer

76,097 carers receive Carers Allowance
Only **one in five** carers

954 provide more than 43 hours of care each week

2.2 million the number of hours care provided per year by children under 15.

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INTRODUCTION

Company Information

Family Carers Ireland (FCI) is a national charity dedicated to supporting an estimated 355,000 family carers in Ireland. It came into existence on 1st January, 2016 following the merger of The Carers Association and Caring for Carers.

The key objectives of the organisation are to benefit the community by supporting and promoting the health, well-being and quality of life of family carers and those for whom they care; to facilitate the affiliation of groups and group members representing family carers throughout Ireland; and to liaise with, support and take counsel from such groups.

Family Carers Ireland's primary focus is on supporting the family carer as an individual in their own right as well as a key contributor to the sustainability of our health system. As such, we strive to promote carer resilience by enabling all family carers to:

- Be confident in their individual caring roles;
- Establish and maintain a regular caring routine;
- Feel listened to, valued, and not alone;
- Be able to access relevant training, advice and support;
- Be informed of their rights and entitlements;
- Meet and speak with their peers in a safe, relaxed environment;
- Take a break from a demanding and stressful caring role;
- Know where to seek additional support from the State and their community;
- Access emergency supports when needed.

FCI provides services to more than 2,000 family carers every day and has a database of over 30,000 active service users. Services provided include:

- Information and advocacy regarding rights and entitlements;
- Skills development training and nurse-led advice and support through our Careline;
- Networking groups and social events to share experiences and combat isolation;
- Advice on care planning including crisis support where needed;
- Support in accessing regular and appropriate respite breaks.

FCI is also an approved provider of home care under the HSE Home Care Packages Scheme. The delivery of home care gives FCI first-hand knowledge of the needs of people in their homes and enables us to deliver relevant services to the wider community of family carers.

FCI is a membership based organisation. Everyone involved in family caring is encouraged to join and become part of a wide community of those in a similar situation. Our constitution provides for a group based membership – this allows any of the 30,000 family carers who access our services each year to give their input into the governance of the organisation through a network of local groups if they wish to do so. It is the policy of FCI to support any family carer in need, whether they are a member or not.

FCI has an annual budget of c. €10m made up of a combination of grant support from the HSE and other public bodies; fees for services provided on a commercial basis (e.g. home care packages); membership subscriptions; and fundraising including sponsorship and individual donations. We acknowledge the vital support we receive from our various funding sources. **Thank you in particular to all of those who donated so generously to Family Carers Ireland during the course of 2017 and to all our volunteers and fundraisers who gave so willingly of their time – we could not do our work without you.**

INTRODUCTION

CEO's Welcome

2017 was the first year in which the new organisation began to move beyond the merger phase into a renewed focus on improving the lives of family carers.

We produced a completely new edition of our Carers Companion handbook, covering 14 major aspects of family caring. This is available through all our resource centres around the country and also accessible on our website.

We also launched a new online tool - the CareGuide - which enables family carers to identify what services and supports are of most relevance and benefit to their specific circumstances. We believe that this type of bespoke support is important since every caring situation is unique. In order to make it available to as many people as possible the tool can be accessed by a dedicated button on the home page of our website or via the Careline.

In addition to running a very successful national respite weekend for adult family carers in Killarney, FCI also hosted its first ever national gathering of young carers during 2017. This event blended a programme of outdoor

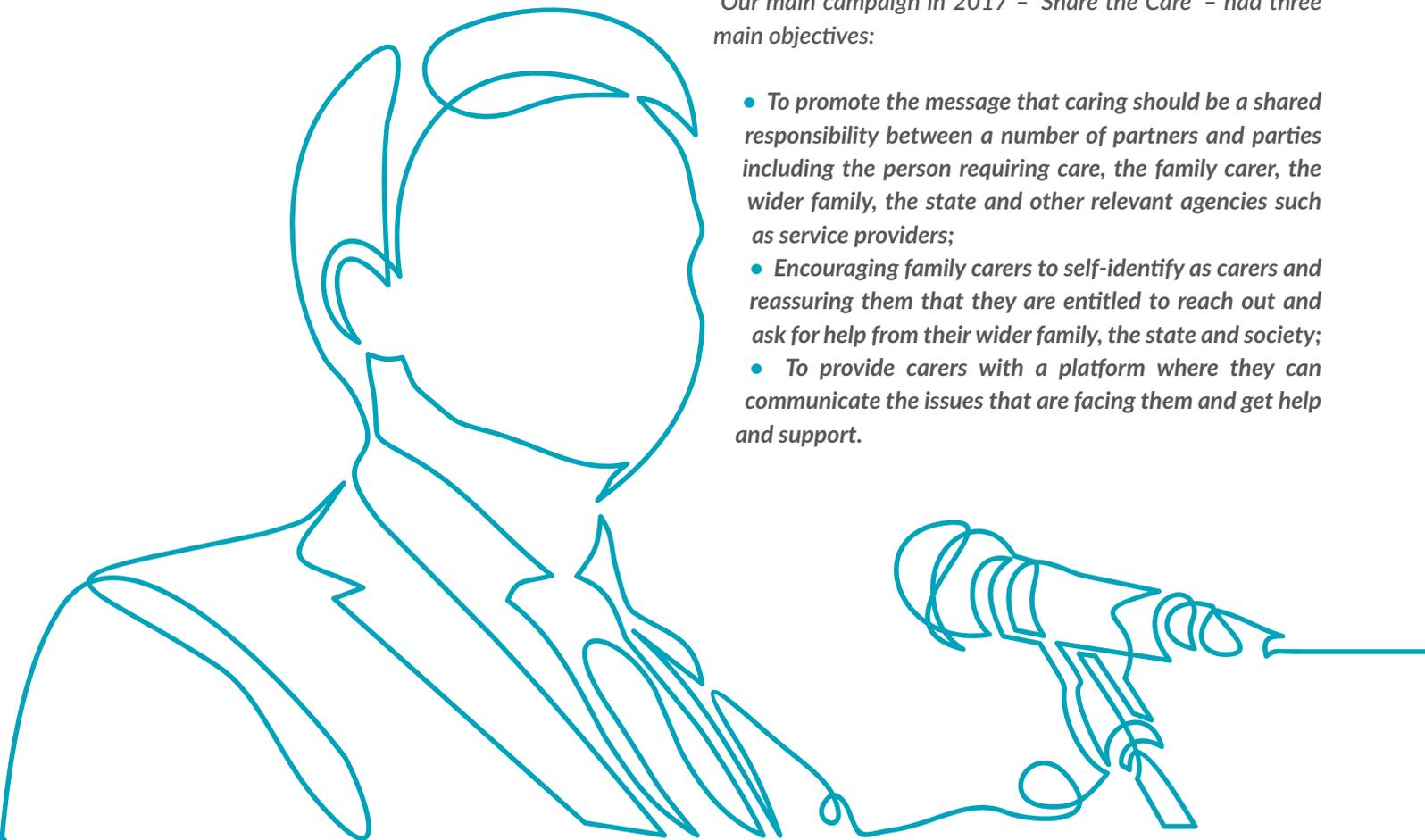
pursuits and other recreational activities with policy workshops featuring Marian Harkin MEP and Dr. Niall Muldoon, the Ombudsman for Children. This was a very successful event and will become a feature of our annual programme in future years.

We reorganised our training and skills development activities to shift the primary focus to family carers rather than home care workers. One highlight was the piloting of an advanced course for carers of people with progressive life-limiting conditions. This seeks to address the particularly difficult challenges facing families dealing with neurodegenerative diseases and organ failure. In keeping with the palliative care approach, feedback from participants on the first two pilot courses was amongst the most positive and appreciative we have ever received for a training initiative.

We remain committed to highlighting the contribution of family carers to Irish society and to fighting for a fair share of public resources in support of their role.

Our main campaign in 2017 - 'Share the Care' - had three main objectives:

- *To promote the message that caring should be a shared responsibility between a number of partners and parties including the person requiring care, the family carer, the wider family, the state and other relevant agencies such as service providers;*
- *Encouraging family carers to self-identify as carers and reassuring them that they are entitled to reach out and ask for help from their wider family, the state and society;*
- *To provide carers with a platform where they can communicate the issues that are facing them and get help and support.*



INTRODUCTION

CEO's Welcome

The project generated a significant increase in the number of family carers contacting the organisation for the first time. It also saw the creation of new regional forums to complement the National Convention and provide another way for family carers locally to connect with and help to shape the organisation's lobbying activities on their behalf. In the latter part of 2017 the government undertook an initial public consultation in respect of its plan to establish a statutory basis for home care. We strongly encouraged individual submissions to this consultation through our nationwide network of groups and projects. It is probably not a coincidence to say that the volume of submissions received was exceptionally high and distilling it continued well into 2018 - far longer than the Department had initially anticipated.

The 17th International Conference on Integrated Care was held in the National Convention Centre during 2017.

Family Carers Ireland was proud to be a local partner to this major international event, ensuring that family care received due recognition and attention as a fundamental enabler of integrated care. We were also happy to be associated with Ireland's first national Conference for Care Workers and Health Care Assistants.

In-home care provided by professional care workers is a critical support for families beyond a certain point in their caring journey. Existing provision in Ireland is ad hoc, inconsistent and inadequate and for that reason we believe it is important to be an active participant in that system so that we speak authoritatively when recommending service improvements on behalf of families as well as being an exemplar of best practice in the sector. The findings of our first ever national client survey satisfaction this year suggest that we are being quite effective in meeting these objectives.

I would like to thank the many individual family carers who assisted us throughout the year with feedback, ideas, suggestions, lobbying and media appearances. Our effectiveness in advocating for improvements in carers' health, well-being and financial security is entirely built on such courage and generosity of spirit.

I would also like to thank all those who served as on the board in the course of 2017 for their time and expertise. Just as with family carers, the directors of Irish charities are generally presumed upon and under-acknowledged for the onerous personal responsibilities they undertake in a voluntary capacity.

Finally, my sincerest thanks to all the staff of Family Carers Ireland who consistently perform above and beyond the call of duty. In practical terms, I was very happy to be able to recommend to the board that the organisation match public sector pay restoration in 2017 albeit on a once-off, ex gratia basis as we continue to fight to persuade the Government to restore funding to enable us to make such adjustments affordable on an ongoing basis.

John Dunne
Chief Executive



INTRODUCTION

Chairperson's Introduction

It gives me great pleasure to introduce the second Annual Report on the activities and performance of Family Carers Ireland.

I would like to begin by thanking the many individual family carers who have engaged with our activities and projects throughout the year and thereby helped to inform and support our work. If we are not relevant to individual carers then the work set out in this report would be neither possible nor meaningful.

2017 was the year in which the organisation began to look beyond the merger process and to look forward with confidence to its future as the national organisation for Ireland's family carers. This was expressed in practical terms by beginning work on developing a major five year strategic plan setting out how we will achieve the framework objectives adopted at our 2017 AGM – to improve the lives of family carers and to highlight their contribution to Irish society.

The AGM also took the opportunity to mark its history by presenting Family Carers Ireland's first ever Life Memberships to Judith Ironside and Frank Goodwin, in recognition and sincere appreciation of their sustained and outstanding contribution to the cause of family carers in Ireland over the past 25 years.

Everyone involved with FCI owes a very particular debt to our unpaid, volunteer directors who bear increasingly onerous responsibilities as a result of changes in company law and charity regulation. I would like to acknowledge particularly the enormous contribution that Pat Dolan, my predecessor, made to the development of the organisation as a key player throughout the merger negotiations, co-chairperson of the interim board during the merger transition and the first ever chairperson of Family Carers Ireland CLG.

I would also like to thank all our staff for their hard work and unflinching commitment to the organisation's mission.

Finally, I would like to acknowledge the critical support provided to Family Carers Ireland by a variety of state agencies including, in particular, the HSE. There is no question that without access to core funding we would be unable to deliver the range of services we currently offer. But it is also important to acknowledge the increasing levels of engagement across the public service with issues relating to family carers and the sustainability of long term care in Ireland over the coming decades.

Jim Waters
Chairperson

CAMPAIGNS AND EVENTS

CarePlus Pharmacy Carer of the Year Awards 2017

The 11th annual Carer of the Year Awards were held in the Westin Hotel in Dublin on November 22nd, 2017. The awards, sponsored by CarePlus Pharmacy, are a celebration and recognition of the wonderful work that family carers do and the invaluable contribution they make to society.

The CarePlus Carer of the Year 2017 was Paula Robinson from County Cavan. Mum of two Paula (48) provides round-the-clock, full-time care for both her parents. Her mother Mary (87) has Alzheimer's disease and father Jimmy (92) is living with bowel cancer. Paula sleeps in a room with her mother to ensure her safety, hand feeds her every meal and is up numerous times each night with both parents. She was presented with her award by broadcasters Marty Whelan and Mary Kennedy - both patrons of Family Carers Ireland.

Paula has four sisters who all live abroad between America and England and has been the primary carer for her parents for the past eight years while also raising her two children aged 20 and 14. Her husband works away from home a lot. She was nominated for the award by her sisters and extended family as a 'thank you' for all that she does. Her family describe

her as an amazing woman who always puts others first and someone who has a very positive outlook on life.

Four inspirational young people were also presented with special awards and announced as Ireland's CarePlus Young Carers of the Year 2017. Jack Cooney (10) from Tipperary helps care for his brother James (16) who is living with Cerebral Palsy, is a wheelchair user and requires round-the-clock care. Clondalkin teenager Adam Hyland (14) helps his mother care for his dad Pat who has multiple illnesses including dementia, diabetes and severe chronic pain and has suffered many heart attacks. Alannah Donnelly (15) from Offaly helps care for her brother Conor (12) who has intellectual disabilities and severe behavioural issues resulting in aggression and harmful behaviours towards others. Sligo's Alexandra Ajoji is the primary carer for her mother Susan (41) who is a wheelchair user with chronic pain and epilepsy.

All four young carers appeared for an interview on The Late Late Show on Friday, November 24th where they received a deservedly warm welcome from the audience and host Ryan Tubridy and a great reaction from viewers.



CAMPAIGNS AND EVENTS

National Carers Week

National Carers Week 2017 took place from June 12th to 18th with Family Carers Ireland centres around the country involved in organising events and activities for family carers. Highlights included a trip to the National Stud and Japanese Gardens in Kildare which was attended by 120 carers who travelled from Tipperary, Waterford, Wexford, Carlow, Kilkenny, Kildare, Wicklow and Dublin. Chanelle, Lady McCoy of Dragon's Den fame and Director of Medical Business at the Chanelle Group visited Family Carers Ireland, Galway on June 14th as part of National Carers Week. Lady McCoy spent a considerable amount of time in the office learning about the services provided by Family Carers Ireland and discussing how employers can support family carers in the workplace. To mark the week, Dun Laoghaire-Rathdown County Council lit up County Hall on Marine Road in blue.



CAMPAIGNS AND EVENTS



CAMPAIGNS AND EVENTS

'Share the Care' Campaign

On February 27th, Family Carers Ireland launched its 'Share the Care' campaign. One of the fundamental messages of the campaign was that nobody should care alone. Caring should be a shared responsibility between a number of partners and parties including the person requiring care, the family carer, the wider family, the state and other relevant agencies such as service providers. The present reality is that family carers prop up the health system through their dedication and are often expected to fill gaps in resources regardless of the personal cost – financially, socially or in terms of their physical and mental health and well-being.



Journalist Brendan O'Connor, who helped launch the campaign, said: "I'm delighted to be involved in Family Carers Ireland's 'Share the Care' campaign. The issues the organisation are highlighting are ones which I feel very strongly about and anything which can help to promote the difficulties facing carers and the lack of services available to them has my full backing."

National Respite Weekend

Family Carers Ireland held its second annual National Respite Weekend at the Gleneagle Hotel in Killarney in early March which was attended by over 270 family carers. It was a great event with people coming together from across Ireland to de-stress and unwind, meet and develop friendships with fellow family carers and enjoy the therapies and activities organised over the break. Senator Marie Louise O'Donnell was the guest speaker on the Saturday night.

SERVICES, SUPPORTS AND ACTIVITIES

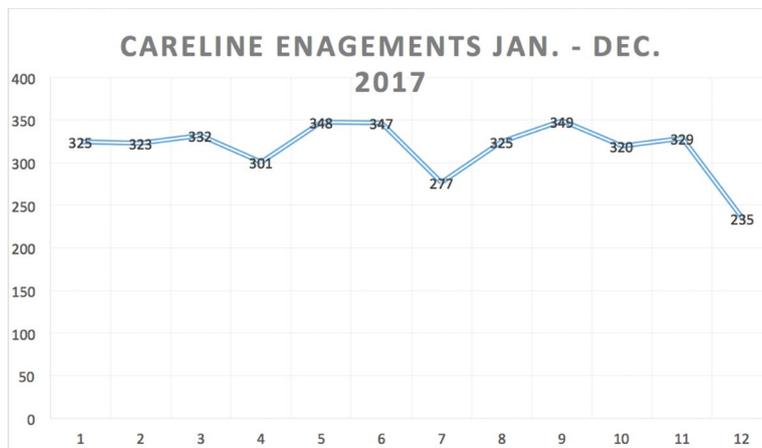
Services, Supports and Activities Careline Statistics

Family Carers Ireland offers a confidential, friendly and supportive Careline on Freephone 1800 24 07 24. Our experienced and trained staff listen to the concerns of callers and offer practical advice on a range of topics including supports and services available from the State, the HSE, local authorities and FCI in their area. Careline hours are 9am to 8pm from Monday to Friday and 10am to 12pm on Saturday. Since 2016, the Samaritans have taken calls from family carers who wish to speak to someone outside those hours. Those callers will be given the option to stay on the line and be diverted to a volunteer from the Samaritans.

Figures:

There were **3,811 calls** from **26 counties** in 2017.

- 16% of calls came from an unknown county (caller did not disclose this information)
- 13% of calls came from Dublin
- 3% of calls came from Cork
- 2% of calls came from Galway
- 2% of calls came from Limerick



The top five Careline queries for the period were:

1. Carers' payments
2. Family Carers Ireland's services (homecare, counselling, information)
3. Membership services
4. Personal alarms
5. Miscellaneous:
 - Changes to government schemes
 - DSP payments
 - Family Carers Ireland events (e.g. Carer of the Year)

Home Care and Respite Provision

In 2017, Family Carers Ireland provided in excess of 113,000 in-home respite hours to family carers in support of their critical caring role. In addition, almost 243,000 hours of clinical and social care services were provided to the cared for person in the home with the support of the Community Employment Scheme, the HSE and other funding.

Client Satisfaction Survey

Clients in receipt of home care services from Family Carers Ireland were asked to participate in an anonymous survey to enable the Quality and Safety Subcommittee of the FCI Board to evaluate the effectiveness of the home care services provided to them and/or their family member and identify areas of improvement and training needs.

The survey included questions about the client's service since it commenced, as this is the first anonymous client service survey conducted by FCI. Questions were asked about their interaction with staff in their homes as well as with office staff and managers; staff attendance and punctuality; access to client files in the home; their opinion of the quality of the overall service and whether they would like their home care worker to wear a uniform. The survey also invited respondents to provide any further feedback and their contact details if they wished to receive follow up contact from an FCI manager.

A total of 338 responses were received from 930 surveys mailed to customers. Surveys were stamped to identify each CHO area uniquely before being sent out. The results were very encouraging, with the response overwhelmingly positive.

SERVICES, SUPPORTS AND ACTIVITIES

Key findings include:

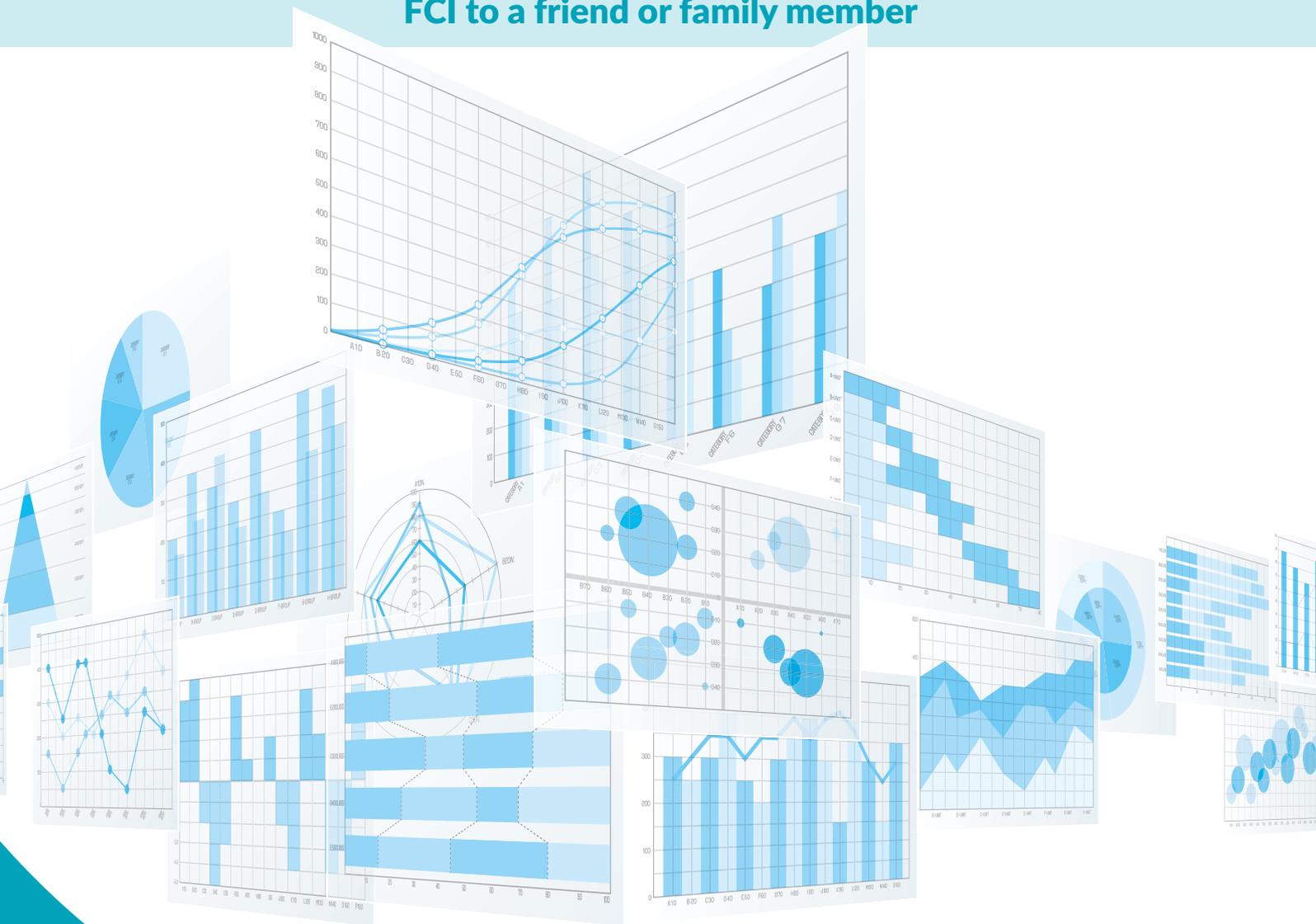
97.3% of respondents trust FCI to provide safe and effective care

84.1% of respondents were extremely satisfied with the quality of care provided by their care worker

85% of respondents were extremely satisfied that their care worker stays for the required amount of time

68.2% of respondents were extremely satisfied with the contact and support from FCI office staff

79.2% of respondents would be extremely likely to recommend FCI to a friend or family member



SERVICES, SUPPORTS AND ACTIVITIES

Carer Resource Centre Activities

In 2017, Family Carers Ireland's network of family carer resource centres:

- Handled over **30,000** visits or calls;
- Made representations on thousands of individual cases concerning a range of family carer support issues including **income support, respite, home care packages, transport, housing adaptation and nursing home subvention (Fair Deal)**;
- Helped to deliver **28 QQI Level 5 Modules in Care Skills or Care of the Elderly** and **74 topic specific workshops** to more than **1,100** family carers and staff nationwide;
- Supported over **60** active local family carer groups nationwide.

Centre Highlights

Galway

2017 All-Ireland Senior Hurling Champions Joseph Cooney (son of Joe Cooney, who officially opened FCI Galway), team captain David Burke and Johnny Coen visited our resource centre in Galway with the Liam McCarthy cup after their win. Gaillimh abú!



SERVICES, SUPPORTS AND ACTIVITIES

Dublin

Our Dublin bag packs in Dunnes Stores Cornelscourt and Tallaght were helped by a big push from the Heuston South Quarter office and the band of volunteers from the LA'IR Latvian Choir & Saulgriezīte Sunday School in Dublin.



SERVICES, SUPPORTS AND ACTIVITIES

Mayo

The Mayo office organised a wonderful day of inspiring guest speakers on June 14th for National Carers Week which featured an outside broadcast with Midwest Radio. Speakers included Helen Rochford Brennan, leading spokeswoman in Ireland and Europe for people with Dementia; Olive O'Connor, founder of MediStori and a candidate on RTE's Dragon's Den; Carmel Ryan, mother of Fiacre who appeared in the RTE 1 documentary Autism and Me; and Áine Gaffney, sister to the late Paddy Phillips, Mayo Carer of the Year. The event was opened by Councillor Michael Kilcoyne.



SERVICES, SUPPORTS AND ACTIVITIES

Carer Groups

While Family Carers Ireland engages directly with thousands of individual family carers each year, we also provide a platform for engagement with collectives through structures such as local support groups, regional forums and the National Convention.

We facilitate over 60 carer groups around the country whose primary aim is to provide peer support and advice to family carers while allowing them to communicate with the organisation on their needs and ongoing requirements. These groups vary in size, meeting frequency and mix of caring situations represented but all provide a vital helping hand to family carers in a rewarding yet difficult time in their life journey.

Carer groups offer an important social outlet and can be particularly beneficial for people in small towns or rural areas. Family carers often use the meetings to share coping strategies and offer emotional support while guest speakers such as public health nurses, HSE representatives and social welfare experts are invited to provide information on issues of interest. Groups provide a valuable opportunity for family carers to meet others with similar caring experiences and often mark the beginning of enduring friendships.

These groups are also integral to the operation of FCI. We operate on the basis of group membership because we believe that local networks best promote inclusion and support at local, regional and national levels. They play a vital role in promoting recognition of the identity, contribution and needs of family carers; in articulating existing and emerging need; and in representing family carers' issues both to policymakers and to the general community.

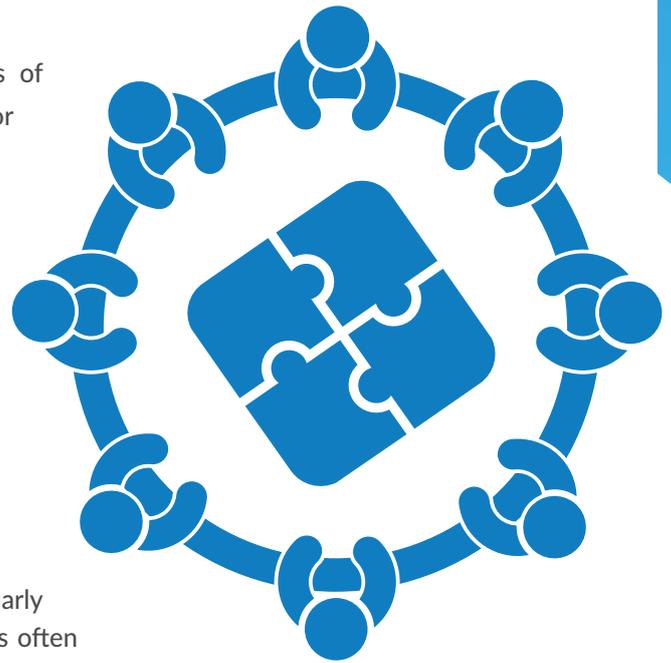
FCI maintains a number of specialist subcommittee groups which take an active role in helping to shape our advocacy in particular areas. These subcommittees include:

PAID (Parents of Adults with an Intellectual Disability) takes an active role in informing policy asks and advocacy regarding family carers for adults with intellectual disabilities. In January 2017, this group organised a video conference with Ms Licia Boccaletti of Anziani e non solo in Bologna to learn about the recently passed 'Dopo di Noi' law in Italy which seeks to secure the futures of people with disabilities after their carers have died or can no longer care for them. The group's chairperson Damien Douglas appeared on Prime Time on April 13th, along with Minister Finian McGrath, to discuss the difficulties in accessing respite provision for family carers of adults with an intellectual disability and the poor transition planning in place for this group in terms of moving from child to adult services or from home to residential care where required.

A **Subcommittee of Carers of Those with Mental Health Issues** advises on difficulties faced by a cohort of family carers which is often neglected because their caring role may be episodic rather than ongoing. In 2017, this group identified the Meriden training programme as potentially being of significant benefit. Funding for this training programme was confirmed in late 2017 under our Dormant Accounts Fund grant and is to be undertaken by select staff and carers in 2018.

A **Palliative Care Subcommittee**, which arose from the Palliative Care Project, continues to meet and informs our work relating to the care of those with life-limiting illnesses or who are receiving palliative treatments.

A **Young Carers Advisory Group**, convened by our Young Carers Development Officer, advises on issues that arise for young carers in social, educational or personal situations and helps us to devise ways to ensure they are recognised and supported.



SERVICES, SUPPORTS AND ACTIVITIES

Membership

Family Carers Ireland is 'owned' by its members and growing the membership base allows us to provide a stronger voice for family carers across all communities. It also means that more people are connected to our many services and in touch with our centres across the country, ensuring that the organisation remains best positioned to advance or address the greatest variety of family carers' interests and concerns.

At the end of 2017, total membership stood at 4,252 with 1,260 new members joining FCI in the year.

Our membership, which includes a unique benefits package, entitles FCI card holders to numerous deals and discounts and includes partnerships with Three Ireland, Omniplex Cinemas, Sky TV and Broadband, Doyle Mahon Insurance, Dalata Hotel Group, Dublin Zoo, HMCA Ireland, Murray's Medical Equipment and many more. The list of offers is updated regularly on the FCI website.

Young Carers



YOUNG CARERS



Family Carers Ireland's young carer support programmes continued to grow in 2017 as the organisation worked with various government agencies, schools and community bodies to raise awareness of, identify and support young carers. This included running support programmes in three schools, delivering presentations and talks to staff and members of several youth work organisations and meeting with professionals from government agencies including the HSE, Tusla and ETBs.

Through this work, a total of **239 young carers** were identified and supported. A new resource booklet was also developed to help young people deal with the challenges of caring. This booklet forms part of a wider suite of tools to help families and professionals better support young people with caring responsibilities.

SERVICES, SUPPORTS AND ACTIVITIES

In November, Family Carers Ireland organised the first ever national gathering of young carers which focused on the theme of children's rights. MEP Marian Harkin and Ombudsman for Children Dr Niall Muldoon both attended the event in Mullingar, Co. Westmeath and listened to the young carers speak about the issues affecting them.

This event also doubled as a respite break for young carers from around the country who participated in numerous organised outdoor and indoor activities. FCI was awarded almost €11,000 through HSE National Lottery funds in 2017 to provide respite for young carers.



**YOUNG
CARERS**

SERVICES, SUPPORTS AND ACTIVITIES

In a significant development in 2017, young carers were identified as a target group under the Department of Children and Youth Affairs' Targeted Youth Funding Scheme.

In May, FCI was represented at the 2nd International Young Carers Conference in Malmo, Sweden by our Young Carers Development Officer.

The Healthy Ireland magazine supplement in The Sunday Business Post on September 24th carried an article about young carers in Ireland. The piece featured two young carers who came to the attention of Family Carers Ireland in very different ways and detailed how FCI helped them in their role.



PROJECTS AND RESEARCH

Dormant Accounts Fund

Family Carers Ireland was successful in 2017 in securing a Dormant Accounts Fund grant of €338,464 under Measure 2 which is specifically aimed at supporting former carers. The 'Plan C' Programme, which began in December 2017 and runs until December 2018, is designed to prepare family carers for crucial transition periods related to the end of caring roles and for life after care, supporting them to participate in the labour force or engage with the community.

Key actions include:

- Nationwide Plan C Programme sessions with family carers;
- Seminars on 'Life after Care' and 'Returning to Work after Caring';
- Themed 'Life After Care' Carers' Forums;
- Mentoring project.



Help Yourself



Plan C

In 2015, The Carers Association secured a Dormant Accounts Fund grant of €300,000 for a project designed to meet the information, support and training needs of four family carer types (young, older, male and isolated) across the four stages of the caregiving journey (pre-caregiving, self-identification, adjusting & managing and life after care) offering timely support interventions when they are most needed.

Examples of training courses delivered between April 2016 and March 2017 include:

- Care skills – QQI Level 5;
- Patient moving and handling certificate;
- Palliative care support – QQI Level 5;
- Topic specific workshops;
- Infection prevention and control;
- Stress management;
- Understanding dementia;
- Elder abuse workshop;
- Legal workshop.

With the assistance of the Dormant Accounts Fund, FCI produced a new Carers Companion advice handbook which is available online on our website and through our resource centres.

Carers supported on the change journey through:

- ✓ **Counselling**
- ✓ **Life Coaching**
- ✓ **Mentoring**
- ✓ **Befriending Volunteers**
- ✓ **Returning to Work Supports**
- ✓ **Signposting to relevant support services**



PROJECTS AND RESEARCH

We also created a new **CareGuide** feature on our website. Simple to use, the **CareGuide** tool asks some simple questions of family carers before producing an individualised guide with information on rights and entitlements, health and well-being, finances and tailored supports specific to their caring situation.

Digital Skills for Citizens Programme

Family Carers Ireland was among 15 organisations awarded funding from the Department of Communications, Climate Action and Environment under the Digital Skills for Citizens Programme. The department describes the purpose of the scheme:

"The Internet is a wonderful resource and it's for everybody. However, almost one in six Irish adults has never used the Internet. The Department's 'Getting Citizens Online Programme' is, in line with the National Digital Strategy, focused on encouraging and empowering citizens to participate fully in Ireland's digital economy and society. The Programme includes a grant scheme to fund digital skills training for citizens who have never used the Internet with a view to removing a key barrier to digital adoption."

The programme targeted what it calls 'non-liners' - those who are not currently or have never been online - offering skills to give them confidence in using the Internet. Courses were offered throughout the country by FCI and over 800 people were trained in the basics of computer and Internet navigation by qualified tutors.

Palliative Care Project

In 2017, Family Carers Ireland, with support and funding from the Department of Health, developed a pioneering course for family carers looking after someone with a life-limiting illness. Discussion with members who had cared for recipients of palliative care or for loved ones with life-limiting illnesses indicated that this would be of huge benefit to them and to others.

Two pilot courses in Dublin and Limerick aimed to provide family carers with the skills, confidence and competence that they need to provide high levels of care including palliative and end-of-life care in the home in a safe manner. The project also aimed to reduce the level of isolation and frustration experienced by family carers on this difficult and challenging journey.

The project was aimed at family carers of those with neurological illnesses where the care needs tend to be longer and progressively more intensive. According to the Neurological Alliance of Ireland, there are over 700,000 people in Ireland living with neurological disorders - the most common being MS, Motor Neurone Disease, Parkinson's, Alzheimer's and other forms of dementia. Based on UK statistics adjusted proportionately, it is estimated that in excess of 30,000 family carers provide care to a loved one with such life-limiting illness in Ireland. The majority of these family carers have not received adequate training in areas such as palliative care or patient moving and handling or condition-specific training in areas such as respiratory problems, PEG-feeding, tracheotomy care, medication, etc. The practical aspects of the course included a range of topics while participants also named issues which were important to them.

These included:

- Patient moving and handling;
- Dealing with cognitive difficulties;
- Dealing with communication problems;
- Dealing with behavioural difficulties;
- Recognising the diversity of family structures and their supportive role;
- Reflecting on their own coping mechanisms - "But First You";
- Medication management, pain management, seizure control and side effects of medication;
- Bladder and bowel control – continence issues;
- Nutrition for family carer and loved one, PEG-feeding;
- Problems with swallowing and risks of choking;
- Life-limiting illnesses with a palliative care approach;
- Thinking ahead – life planning/end of life care.

It became apparent during the first pilot in Dublin that participants needed peer support in a structured format. The facilitator adjusted the sessions so that half of the time was used to allow participants to share their own experiences of caring. This helped to create a safe space for them to offload in terms of their intensive caring role and to enable them to support each other with emotional and practical advice.

PROJECTS AND RESEARCH

The courses were a great success, evidenced by the very positive feedback from participants. Both groups continued to meet beyond the duration of the course every six weeks as informal peer-support groups. This eventually developed a more formal role as the Palliative Care Subcommittee which advises Family Carers Ireland on its advocacy relating to life-limiting illness supports. The project also drove positive collaboration with other condition specific support and advocacy organisations in the voluntary sector. It is hoped that these successful pilots can be replicated in other parts of the country in future.

Research Highlights

During 2017, Family Carers Ireland collaborated with a number of academic institutions to secure significant funding for research into topics of direct relevance to family carers. A common theme of our involvement in these projects is that they have pragmatic outcomes for family carers who themselves play an active role in informing the research process.



Highlights include:

- A major four year Health Research Board-funded Emerging Investigator Grant will focus on supporting carers in the workplace (principle investigator: Attracta Lafferty, UCD). The grant, valued at almost €800,000, will focus on the development of a workplace-based programme to promote health and self-care behaviours among working family carers.
- A research project examining assisted decision-making in acute care and the involvement of family carers alongside patients and healthcare professionals. Ultimately, it will produce an educational tool to improve implementation of assisted decision-making legislation in the acute care sector (PADMACS, lead researchers: Thilo Kroll and Deirdre O'Donnell, UCD).
- A research project on how to best involve seldom heard groups like family carers in the public patient involvement activities carried out by UCD (PPI IGNITE, lead researchers: Thilo Kroll and Éidín Ní Shé, UCD).
- A research project looking at the post-caring experiences of carers. The 'Life after Care' report was launched in November 2017 (lead researcher: Carol Kelleher, UCC).
- An Irish/Canadian project on understanding and promoting resilience among family carers of people with dementia funded by the Canadian Institute for Health Research (lead researchers: Brad Meisner, Dalhousie University, Nova Scotia; Maria Pertl, Royal College of Surgeons in Ireland).

PROJECTS AND RESEARCH

Throughout 2017, FCI contributed to ongoing research projects about and of interest to family carers:

- We actively contributed to the SAFE (Systematic Approach to Improving Acute Care for Frail Older Patients) project which aims to co-design a frail older person pathway and develop an implementation model for incorporating this pathway within the Irish setting. Family carers carer-proof the project and FCI staff contributed to a research #tweetchat as part of the realist review process.

- We continued to contribute to the ENCARE (Enhancing Carers' Resilience) project. Core to the programme is a small group of family carers who work with the research team to develop a programme for family carers of people with dementia to enhance their resilience. FCI staff have also presented to the carers' steering group

FCI contributed its research expertise to thought leadership on family carers' issues in:

- Securing the role of local partner for the 17th International Conference on Integrated Care which was held in Dublin. We presented a paper on the National Carers' Strategy and co-authored another on supporting family carers of people with intellectual disabilities.

- Presenting at the inaugural Health Care Assistants and Carers Conference, Green Isle Hotel, Dublin.

- Presenting on carers' leave legislation to Hospice UK's Working Carers Conference.

- Co-authoring three papers for the 7th International Carers Conference in Adelaide - one on post-caregiving and two on family carers of people with intellectual disabilities.

- Facilitating engagement between an Italian advocate and the Parents of Adults with Intellectual Disabilities subgroup. This knowledge exchange focused on Italy's 'Dopo di Noi' legislation which aims to secure the future of those with disabilities when their parents have passed on or can no longer care for them.

- Publishing two briefing papers related to working carers on the FCI website.

POLICY AND PUBLIC AFFAIRS

National Carers' Strategy Fourth Progress Report

Published in 2012, the National Carers' Strategy (NCS) sets out Government's commitment to recognise and respond to the needs of family carers so that they have rights, choices, opportunities and the capability to participate in economic, social and community life.

Family Carers Ireland established a monitoring group in 2014 to drive delivery of the national goals, objectives and actions contained within the NCS and to do so through meaningful and positive engagement with Government departments and statutory bodies.

The group, which is made up of representatives from FCI, family carers and representatives from 98 organisations who work directly or indirectly with family carers, has developed a framework and scorecard to monitor implementation of the strategy.

On September 12th, 2017 Family Carers Ireland released its fourth NCS Scorecard which shows that, from a family carer's perspective, only 18 of 42 actions have achieved acceptable progress. Of the 42 objectives in the strategy, one action has been implemented in full and is making a real difference to family carers' lives, 17 actions have received a 'good progress' score; 11 have received an 'initial progress' mark; eight have received a 'no progress' grade and five have received a 'regressive' score - meaning the situation has worsened for family carers since the strategy was launched. These include:

- A serious lack of respite care to give family carers a much-needed break to continue their caring work.
- Family carers should be considered as partners in care planning by health and social service providers. This relates to discharge planning from hospital to home care and is simply not happening.
- Problems with the Housing Adaptation Grant scheme persist.



POLICY AND PUBLIC AFFAIRS

On a more positive note, Government has expressed a willingness and ambition to tackle the issue of financing home and community care by announcing a public consultation to establish a new statutory home care scheme. Equally positive has been the improving level of engagement from Government departments with family carers over the lifetime of the strategy.

The monitoring group is engaged with the Department of Health in planning for the next phase of the National Carers' Strategy.

Social Partnership

Since 2002, Family Carers Ireland has been a member of the Community and Voluntary Pillar of Social Partnership, giving family carers a voice in the national partnership process and informing the development of Ireland's social and economic policies. We are the only organisation on the pillar representing family carers. FCI is an active member of the CV Pillar, attending pillar meetings and departmental bilaterals, meeting Government ministers, formulating joint policy, making submissions to Government and working with other pillar members to ensure that commitments made by Government are developed and implemented. FCI is also represented on the Health Linkage and Social Protection Subcommittees.

Initiatives during 2017 include:

- Attendance and input at each quarterly pillar meeting (chairing when required);
- Input into collective policy submissions, press events and briefing papers;
- Input into the pre-budget submission of the CV Pillar;
- Attendance and input at each of the three bi-lateral meetings held with the Department of Social Protection's senior management team.

Policy Submissions and Briefing Statements

FCI regularly contributes to policy reviews or strategies being undertaken by Government and other relevant bodies in relation to a variety of issues. Our policy submissions aim to reflect the voice of family carers.

Policy submissions made during 2017 include:

- Pre-budget submission on Budget 2018;
- Proposal to the Department of Health on refreshed National Carers' Strategy;

- Submission to the Oireachtas Committee on the Future of Healthcare;
- Submission to the Citizens' Assembly on how to respond to an ageing population;
- Submission to the DoH on the creation of a statutory home care scheme;
- Submission to the Central Statistics Office on questionnaire content for Census 2021;
- Proposal to the Acute Hospital Division and Hospital Groups on patient and family empowerment;
- Submission to the Department of Communications, Climate Action & Environment on pay-by-weight bin charges;
- Collaborated with Carers NI on a submission to the NI Assembly on the impact of Brexit on family carers.

Representation on External Bodies

The Family Carers Ireland Policy Manager represents family carers on a number of national committees:

- Member of the CV Pillar of Social Partnership and member of Health Linkage Subcommittee and Social Protection Subcommittee;
- Member of the HSE's Oversight Group on the National Patient Satisfaction Survey;
- Co-Chair of the HSE's Healthcare Communications Working Group;
- Member of the HSE's Working Group on Advanced Healthcare Directives;
- Represents the caring sector on the HSE's Service Users and Clinical Advisory Group and on the Carers Needs Assessment Development Working Group for the development of a Single Assessment Tool for Older People (InterRAI SAT);
- Member of the HSE National Patient Forum.

International

Family Carers Ireland is an active Tier 1 member of Eurocarers. In 2017, CEO John Dunne continued in his role as President of Eurocarers. FCI is also represented on the Eurocarers Policy Working Group and Research Working Group. Information Website and Social Media The Family Carers Ireland website has grown in importance and reach in 2017 with very impressive numbers and impressions for the site as a whole and a constant stream of traffic from other sites such as Facebook and Citizens Information.

POLICY AND PUBLIC AFFAIRS

Website and Social Media

The Family Carers Ireland website has grown in importance and reach in 2017 with very impressive numbers and impressions for the site as a whole and a constant stream of traffic from other sites such as Facebook and Citizens Information.

Monthly Impressions

January	February	March	April	May	June
16,750	13,623	15,705	17,014	29,810	16,089
July	August	September	October	November	December
17,661	17,334	16,061	13,875	16,008	11,154

Daily Average

Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Avg
555	524	507	567	962	536	570	559	535	448	534	360	555

The most popular pages are the membership information and membership benefits list, followed by vacancies, The 'Find Us' page, which maps our centres nationwide, is the next most visited page, followed by supports category pages, training and rights and entitlements. Our most site visits and views in a single day came on Monday, May 29th with 6,317 impressions.

The national FCI Facebook page is one of our most effective channels for engagement with family carers. It is a platform for driving new membership, promoting causes and campaigns, publishing news relevant to carers, advertising fundraising activities and much more. The popularity of the page grew significantly in 2017 with more likes and follows, improved post reach and greater engagement from family carers and the general public. Across 2017, the number of 'likes' for the page increased from 9,605 to 11,390, while followers grew from 9,128 to 10,985.

There are also regional pages for Family Carers Ireland in Carlow/Kilkenny, Clare, Clonmel, Cork, Donegal, Galway, Limerick/North Tipperary, Mayo, Roscommon, Sligo, Waterford and Wexford.

Facebook has been a very useful driver of traffic to the website, particularly to promote campaigns, for the purposes of recruitment and for attracting nominations for and raising awareness of the CarePlus Carer of the Year Awards. In July 2017, we launched the Family Carers Ireland Jobs page on Facebook in order to give home care recruitment its own dedicated space, separate from the main national page. This allows us to reserve the national page for promotion of the organisation's other services, news and campaigns.

At the end of 2017, the Family Carers Ireland Twitter account, which took over the Carers Association's CarersIreland handle, had over 4,000 followers.

Data Protection Audit

On the March 28th, 2017 the Data Protection Commissioner carried out an audit to check Family Carers Ireland's organisational level of compliance with the Data Protection Act in a number of key areas.

Family Carers Ireland received minor recommendations, with the inspector outlining that they received excellent co-operation throughout the course of the inspection. The inspection team considered that there was a very high level of organisational awareness of the data protection principles in evidence generally.

The commissioner thanked the Family Carers Ireland Data Protection Officer, management and staff for the full co-operation provided to the inspection team during the course of the audit.

FINANCES

Statutory Accounts

The following is an extract from the Statutory Accounts:

FAMILY CARERS IRELAND LIMITED (A Company Limited by Guarantee)

INCOME FROM	Unrestricted Funds 2017 €	Restricted Funds 2017 €	Total Funds 2017 €
Donations and Legacies	64,760	--	64,760
Other trading activities:			
Charitable activities	5,826,060	4,015,940	9,842,000
Trading activities	526,416	--	526,416
Investments	4,432	--	4,432
Total Income	6,421,668	4,015,940	10,437,608
EXPENDITURE ON			
Raising funds	242,525	--	242,525
Charitable activities	5,728,886	4,103,725	9,832,611
Total Expenditure	5,971,411	4,103,725	10,075,136
NET INCOME / (EXPENDITURE) BEFORE TRANSFERS	450,257	(87,785)	362,472
Transfers between funds	(87,573)	87,573	--
Net Income/ (Expenditure)	362,684	(212)	362,472
Net Movement in funds	362,684	(212)	362,472
Reconciliation of Funds			
TOTAL FUNDS AS AT 1 JANUARY 2017	1,603,196	212	1,603,408
TOTAL FUNDS AS AT 31 DECEMBER 2017	1,965,880	0	1,965,880

Statement of Financial Activities includes all gains and losses recognised in the year.

FINANCES

FAMILY CARERS IRELAND LIMITED
 (A Company Limited by Guarantee)
 REGISTERED NUMBER: 572819

BALANCE SHEET AS AT 31 DECEMBER 2017

	€	2017 €
FIXED ASSETS		
Tangible assets		21,092
Financial Assets		3
		<u>21,095</u>
CURRENT ASSETS		
Debtors	1,555,196	
Cash at bank and in hand	2,054,666	
	<u>3,609,862</u>	
CREDITORS: amounts falling due within one year	<u>(1,665,077)</u>	
NET CURRENT ASSETS		1,994,785
NET ASSETS		<u>1,965,880</u>
CHARITY FUNDS		
Restricted funds		-
Unrestricted funds		1,965,880
TOTAL FUNDS		<u>1,965,880</u>

For further detail on Statutory Accounts please go to

www.familycarers.ie

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1800 24 07 24

Website: www.familycarers.ie

Charity Number: CHY 10962

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Dublin 8**

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Facebook: [Family Carers Ireland](https://www.facebook.com/FamilyCarersIreland)