

Annual Report 2018



Family
Carers
Ireland
Fairness for Carers



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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.

“2018 was another very successful year for the organisation — although our grant has not increased for several years, once again we were able to increase service levels across the country.”

Jim Waters
Chairperson

CHAIRPERSON'S INTRODUCTION

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

2018 was another very successful year for the organisation – although our grant has not increased for several years, once again we were able to increase service levels across the country. I hope you will take the time to go through the report and read about the many exciting activities and innovations that happened throughout the country and the year.

For the second year in a row, we made considerable strides in rebuilding our reserves following the costs associated with our recent merger. In line with government policy, we will move to chart a path for sustainable pay restoration for our staff in the course of 2019. June saw the launch of our new organisation's first five year Strategic Plan 2018-2023 at the AGM.

This is the result of a year of extensive consultation and reflection by the board and senior management on insights and suggestions received from family carers, staff and other stakeholders through a series of consultation meetings. I believe that it is a document we can be proud of that charts an exciting and important path for the development of the organisation over the next five years.

As I did last year, I would like to thank the many individual family carers who have engaged with us 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.

Everyone involved with FCI owes a very particular debt to our unpaid, volunteer directors who contribute many hours of their time travelling to and participating in meetings of the board and its various sub-committees. Each year their legal and regulatory responsibilities as directors become ever more onerous and without their willingness to rise to this challenge, organisations such as ours simply could not continue in existence.

I would also like to thank all our staff for their hard work and unfailing 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.



Chairperson

INTRODUCTION

“In response to strong and consistent feedback at regional forums across the country, Family Carers Ireland formulated the idea of a Carers Guarantee whereby every family carer, irrespective of where they reside, would be assured access to basic supports...”

John Dunne
Chief Executive



CEO'S WELCOME

This was a busy and exciting year.

In response to strong and consistent feedback at regional forums across the country, Family Carers Ireland formulated the idea of a Carers Guarantee whereby every family carer, irrespective of where they reside, would be assured access to basic supports including information and advocacy; training and technical advice; networking events to combat isolation; advice on care planning; regular respite and crisis support. Replacing the current postcode lottery with a coherent and consistent set of services and supports is now a key element of Family Carers Ireland's lobbying agenda.

At the same time as this proposal was taking shape, the government's public consultation on its plan to put home care on a statutory footing appears to have run into the sand. Ongoing declarations that the legislation will be in place by 2021 seem increasingly implausible but we remain willing and able to engage speedily and whole-heartedly with subsequent stages of the preparatory work. Whilst very supportive of the main provisions of the Assisted Decision-Making (Capacity) Act 2015, we remain concerned about certain operational issues in regard to how it might be commenced and implemented.

We were very pleased that the Oireachtas Justice Committee endorsed the position we argued before its members in September that Article 41.2 of Bunreacht na hÉireann should be replaced with a new provision that "recognises the contributions made by family life and carers to our society" rather than being deleted.

2018 saw another national tender for Home Support Services. FCI did not bid to continue providing services in the Greater Dublin area as we believe the current situation there is unsustainable and unduly focussed on quantity rather than quality.

We remain an active participant in that system in the rest of the country and therefore speak authoritatively when recommending service improvements on behalf of family carers. We also strive to be an exemplar of best practice in the sector – the findings of our national client satisfaction surveys suggest that we continue to meet these objectives.

As an organisation we remain committed to the very highest standards of governance. The commencement of GDPR in the year under review represented a new and challenging hurdle in this regard. We retain the 'triple lock' accreditation in regard to governance, fundraising and financial reporting.

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, wellbeing and financial security is entirely built on such courage and generosity of spirit. I would also like to thank all those who served on the board in the course of 2018 for their time and expertise and to acknowledge in particular the effort Jim Waters, our current chairperson, brings to the role.

Finally, my sincerest thanks to all the staff of Family Carers Ireland who consistently perform above and beyond the call of duty.



Chief Executive

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, wellbeing 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.

Our 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.

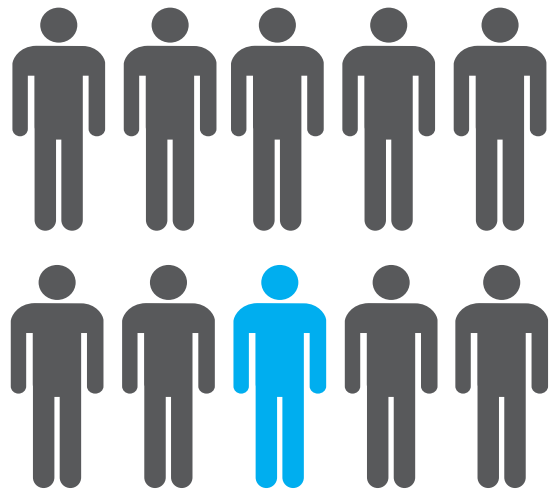
FCI has an average of 25,000 direct engagements with individual carers each year and delivers the following key services, primarily through its network of 22 resources centres around the country:

- 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.

Our carer focus means that the breadth of support provided spans from assistance with relevant application and appeal processes to researching and developing innovative projects to meet identified needs of family carers and those for whom they care.

355,000
family carers
in Ireland

1 in every 10 adults



Saving the state

 **€10**
BILLION
each year



We advocate on behalf of family carers at local, regional and national level along with lobbying and policy development in support of a comprehensive National Carers' Strategy.

We offer specific programmes of support for groups of carers including young carers, isolated carers, carers for children with special needs, carers of adults with intellectual disability and carers of persons with mental health difficulties.

FCI is a membership-based organisation. Everyone involved in family caring is encouraged to join and become part of a wider community of those in a similar situation. Our constitution provides for a group-based membership – this allows any of the 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.

We are also an approved provider of home care under the HSE Home Support Service 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's annual budget is 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 very generous support we receive from our various funding sources – we could not do our work without it.



STRATEGIC PLAN 2018-2023



Family Carers Ireland's Strategic Plan 2018–2023 was launched at the AGM in June. The plan was developed in consultation with family carers, staff and key stakeholders of the organisation and details seven anticipated change drivers over the next five years:

Demographics

Health & Social Care Practice

Ongoing Reorganisation of Health Services

New Public Management Workforce

Legislative Framework

Regulatory Context

An annual detailed Master Action Plan (MAP) is being developed towards the achievement of these key results.



IMPROVE CARERS' LIVES

KRA 1: Family Carer supports

KRA 2: Home Care services

KRA 3: Public policy towards Family Carers

HIGHLIGHT CARERS' CONTRIBUTION

KRA 4: Engaging with family carers

**KRA 5: Shining a light on the realities
of caring in Ireland**

**KRA 6: Making people aware of FCI
and what we offer**

GROW SUSTAINABLY

KRA 7: Optimise resources

KRA 8: Partnerships & Alliances



CARER OF THE YEAR AWARDS

The 12th annual Carer of the Year awards, held in the Westin Dublin on Friday, November 23rd, were a massive success and received a huge amount of coverage from both local and national media. The event seeks to celebrate, recognise and highlight the wonderful work that family carers do and the invaluable contribution they make to Irish society.

Twenty-seven family carers from across Ireland were recognised for their dedication and the many sacrifices made in their caring roles. Brenda O'Connell-Barry from Charleville, Co. Cork was announced as the overall Carer of the Year and was presented with her award by hosts and FCI patrons Marty Whelan and Mary Kennedy. Brenda and her husband Trevor care for their young son Fionn (4) who has NACCI, a rare genetic mutational condition.

Brenda, who has a highly debilitating illness herself called systemic lupus and has undergone chemotherapy treatment to alleviate the pain, also cares for her mother who has recently had a cancer diagnosis.



Our Young Carer Ambassadors Danny O'Carroll and Paddy Houlihan from Mrs Brown's Boys presented awards to our five Young Carers of the Year 2018. They were:

Munster: Harry (13) and Molly (11) Flynn from Ferrybank on the Waterford/Kilkenny border are siblings to Isabelle Flynn who has cerebral palsy and apnoea which causes her to stop breathing
Leinster: Sean Ryan (10) from Portlaoise, Co. Laois helps to care for his twin brother Liam who has severe quadriplegic cerebral palsy, is a full-time wheelchair user and has many other complex medical needs.

Connacht/Ulster: Alanna Connolly (17) is from Athenry, Co. Galway and helps to care for her twin sister Leah who was born with an undiagnosed rare syndrome. At birth, doctors told the family they did not know what the future held for Leah, whether she would ever walk, talk or what her life expectancy would be.

Dublin: Shauna Tighe (14) is from Tallaght and helps to care for her brother Daniel (11) who has a rare genetic condition called Sotos Syndrome causes severe intellectual disability, epilepsy and a sensory processing disorder. Daniel is non-verbal, incontinent and visually impaired with challenging behaviour and feeding difficulties.



Following the awards ceremony, Brenda, Shauna and Shauna's mother Sinead Tighe spoke to Ryan Tubridy on *The Late Late Show*, powerfully highlighting their own stories and the challenges facing many family carers. The feature made a massive impact on a Limerick businessman who contacted FCI during the show and made a very generous €5,000 donation.



NATIONAL RESPITE WEEKEND

The National Respite Weekend provides family carers with an essential break from often stressful and demanding caring roles and allows them to come together to talk, to laugh and to feel supported by their peers who understand only too well what you are going through.

Family Carers Ireland's third National Respite Weekend took place in Clayton Whites Hotel in Wexford from March 9th to 11th with 250 family carers in attendance.



All guests received a goodie bag while a range of activities and events were organised across the weekend including massage, mindfulness, nail painting, an exhibition area, an excursion to Johnstown Castle and a historical walk of Wexford Town. The highlight of the weekend was the gala banquet on Saturday night which was followed by live music and dancing into the early hours of the morning.

Thanks to all our exhibitors and sponsors for the event including the wonderful Wexford Male Voice choir and Clayton Whites Hotel who ensured that all guests felt welcome and relaxed.



SHINE A LIGHT

Family Carers Ireland held the first ever 'Shine a Light' day on June 21st.

Appropriately held on the longest day of the year (the summer solstice), the national awareness day aims to shine a light on the contribution of Ireland's 355,000 family carers (many hidden or unidentified) and raise vital funds to help FCI support them.

The campaign, which was launched by journalist and presenter Brendan O'Connor, featured well in national media and on Twitter with the hashtag #shinealight. It was also boosted by video messages of support from comedian Brendan O'Carroll and former Ireland footballer Ronnie Whelan.

The public were asked to get behind the campaign by purchasing a heart-shaped 'Shine a Light' pin for just €2 from towns/public places around the country, their local FCI resource centre, at one of 50 CarePlus pharmacies nationwide, in selected Dunnes Stores or online.

'Shine a Light' has been one of our most successful national fundraising and awareness campaigns and we hope to build on this success in the coming years.



CARERS IN CRISIS

One of Family Carers Ireland's key campaigns for 2018 focussed on Carers in Crisis. The campaign kick-started late in 2017 with a Prime Time extended show which outlined the issues which five carers face on a daily basis.

The campaign continued throughout 2018 with a national media campaign and lobbying at national and local level to highlight the effects of the postcode lottery with regard to services, the ongoing lack of appropriate respite breaks and increasing housing issues.

A Carers in Crisis public meeting took place in Wexford in September which was attended by 50 local family carers and focused on:

1. **The drop off in services for young people as they transition into adult services**
2. **The need for improved respite care (regular respite breaks and emergency respite)**

3. Transitioning into residential care.

Attendees filled out forms on the night to share their stories as part of the campaign while local councillors in attendance invited FCI to seek a deputation with the local authority and to submit questions to the HSE.

The Carers in Crisis campaign also included our proposed 'Flagship Proposal' or 'Carers Guarantee' which calls on the government to eliminate the current postcode lottery by providing equal funding in each CHO which would allow carers to access the same level of supports around the country irrespective of where they live.

This proposal includes funding for information and advocacy, training courses, mentoring, carer groups and individual one-to-one support along with a respite and emergency respite budget.



Family Carers Ireland's **Carers Guarantee** is a campaign to secure core support services for Family Carers in all parts of the country. By spending an extra **€3.2m** a year, the State can end the postcode lottery and guarantee access to:

 1 Emergency Respite	 2 Individual Support	 3 Training	 4 Networking	 5 Information & Advocacy
Major Family events, Medical Treatment for Carer 	One to one Support for families in distress or crisis 	Basic Care skills, more specialised training - end of life, life limiting conditions, challenging behavior 	Peer support meetings & clinics, shared experiences 	Advice, information on rights & entitlements, support with appeals

FCI launched its Carers in Crisis pre-budget submission in August with the priorities set out in our submission reflecting the voice of carers from across the country. Budget 2019 was largely a disappointing one for carers with only modest increases in weekly social welfare rates, reductions in prescription charges for the over 70s, changes to USC, an increase in funding for the recruitment of SNAs, the DCA to be paid for an additional three months where the child being cared for passes away and €300,000 to be provided to commission research in 2019 on the additional cost of living with a disability.

NATIONAL CARERS WEEK

National Carers Week is an important forum used to highlight the unseen work of family carers, support and bring those in a caring role together and publicly celebrate their many achievements. The 12th National Carers Week took place from June 11th to 17th with FCI centres hosting over 100 events and activities across Ireland for family carers.

Some of the highlights included a pamper day and picnic in the park in Cork, a trip to the Rivercourt Hotel in Kilkenny and tours of the grounds of Kilkenny Castle and the Smithwick's Brewery by Waterford, Wexford, Cork and South Tipperary family carers and treatment days, tours and meals in various venues in Clare.

The week was very successful and we would like to express our thanks to all Family Carers Ireland centre staff for their work, to local businesses who got involved in the week and to the family carers who created such a good spirit at all events.





CARER GROUPS

Family Carers Ireland facilitates close to 100 carer groups around the country whose primary aim is to provide peer support and advice to family carers while enabling two-way communication with carers back to the organisation on their needs and ongoing requirements.

These 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.

The discussions at these carer groups feed into shaping the national agenda through the National Convention with each carer group having the capacity to appoint two delegates to attend the convention meetings which take place during the year.

NATIONAL CONVENTIONS

The National Convention brings the 'voice' of carers around the country together through their delegates and the agenda focuses on carer issues, pre-budget submissions, progress of the National Carers' Strategy and other matters which may arise.

The organisation held two National Conventions for 2018 with over 150 participants attending.

The convention also supports the establishment of specialist subgroups where required and currently has two such groups - one supporting Parents of Adults with Intellectual Disabilities and another addressing the challenges of caring for someone with mental health difficulties.



REGIONAL FORUMS

Family Carers Ireland increased the number of Regional Forums held in 2018 by hosting a programme of seven in the spring and six in the autumn. The spring forums had two key components - a 'Listening to Carers' exercise and 'Life after Care - transition period' (Plan C project overview).

The **'Listening to Carers'** exercise facilitated carers to identify their key challenges/issues before the upcoming budget which helped to formulate Family Carers Ireland's pre-budget submission.

The **'Life after Care'** session was aimed at carers that may have experienced a change in their caring role or may be coming to the end of their time caring. For current carers, it also facilitated the preparation and planning for both of these eventualities.

FCI outlined the supports available to this group of carers with the support of the Dormant Accounts Fund which included: **One-to-one Counselling; Life Coaching; Mentoring Training; Befriending Training; Return to Work supports**

The Regional Forums in the autumn covered post budget announcements and FCI's lobbying campaign for 2019 with a particular emphasis on our flagship proposal "Carers Guarantee" which, if secured, would remove the current postcode lottery in the allocation of services and supports to family carers across the country.



HOME CARE AND RESPITE PROVISION

Family Carers Ireland provides a mixture of supports and services to family carers and during 2018, in excess of 113,000 in-home respite hours were provided to family carers in support of their critical caring role. In addition, just over 256,000 hours of clinical and social care services were provided to the cared for person in the home with the support of the HSE and other funding.

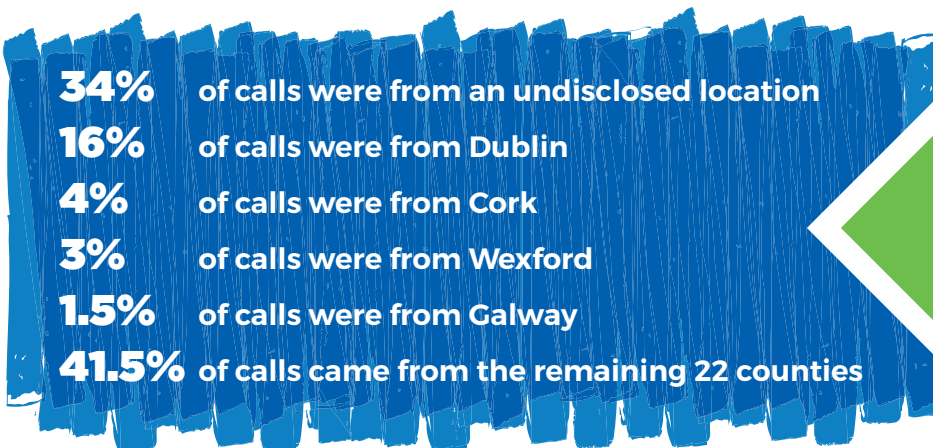
FCI was successful in the 2018 bid for the Home Care Package (HCP) tender competition as a Tier 1 provider in CHO 1 and 3 and a Tier 2 provider in CHO 2, 5 and 8. The provision of in-home support has become an important part of the organisation's activities, generating a modest surplus to subsidise our 'charitable' activities and also allowing us a much fuller understanding of and engagement with HSE social care services.

CARELINE STATISTICS

Family Carers Ireland offers a confidential, friendly and supportive Careline on Freephone 1800 24 07 24. This service could not operate without the essential support of a dedicated team of specially trained volunteers. 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 of these hours.

The Careline took **4,454** calls from **26** counties in 2018:



The top five queries for the period were:

1. Carers' Payments
2. Membership
3. FCI Services
4. Personal Alarms
5. Miscellaneous (which could include)
 - Advocacy/Counselling*
 - Mediation*
 - Location of our Centres*

Around 400 advocacy cases were dealt with on an individual basis. They involved issues in relation to caring such as:

- Payments and allowances
- Family issues
- Lack of supports
- Lack of information on rights and entitlements
- Counselling requests
- Carers under stress

CARERS' TRAINING AND SUPPORT TOOLS

Family Carers Ireland provided its practical caring skills course during 2018 to a number of carers. Through the Dormant Accounts Fund, the organisation trained 21 facilitators to deliver the Caring with Carers modular programme which is based on the same model as Family Behavioural Therapy. The key areas in this programme were: problem solving; dealing with crisis; recovery and hope; and looking after yourself.

The funding also facilitated a programme for carers who have just finished or who are coming to an end of their caring role. This programme focused on counselling, life coaching, mentoring

training, befriending training and return to work supports (see Plan C project overview). Workshops continue to be held around the country on carers' rights and entitlements to ensure they are able to access supports and services available to them. Staff in each of our 22 resource centres are also trained to provide such support to carers.

The organisation ran a number of digital skills courses around the country for carers and former carers helping them to get online and to be comfortable in the cyber world.

Carer Resource Centre Activities

In 2018, 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);
- Delivered 81 topic specific workshops to more than 1,200 family carers and staff nationwide;
- Facilitated and supported close to 100 active local family carer groups nationwide.



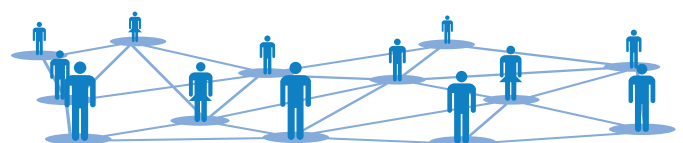
MEMBERSHIP

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 2018, total membership stood at 4,278 with 1,994 new members joining FCI in the year.

Our membership, which includes a unique benefits package, entitles FCI card holders to 100s of deals and discounts from the likes of Irish Country Hotels, AES, National Ploughing Association, Bloom by Bord Bia, Top Oil, Circle K, Sky and Three.

The list of offers is updated regularly on the FCI website.



YOUNG CARERS

Family Carers Ireland continued to provide support to children and young adults with caring responsibilities through our Young Carers Project.

The project aims to build young carers' resilience and confidence in order to help them manage their caring responsibilities more effectively; to minimise the impact of caring on their life; and to improve their health and wellbeing - both physical and emotional.

We do this by providing a range of targeted interventions including one-to-one support, information and guidance, group activities, respite breaks and educational supports as well as working to bring about policy improvements in the identification, public awareness and supports available to young carers and their families.

To achieve this the Young Carer Project works closely with government agencies including HSE, TUSLA and ETBs as well as schools, colleges, community groups and youth organisations across the country.

Our Young Carers Project continued to grow during 2018 with activities including running awareness and support programmes in 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 among others. Through this work, a total of 239 young people were supported.



In addition to the day-to-day work of our Young Carers Project, other highlights from 2018 include:



- Our annual Young Carers Respite Break at the Cavan Centre, Ballyjamesduff on June 20th – 22nd where 40 young carers from across the country came together for a weekend of activities, fun and relaxation.
- A meeting of the European Parliament Carers Interest Group exploring “Young carers – challenges and solutions” which took place on March 6th and was attended by four Irish young carers and our Young Carer Development Manager.
- The co-option of three young carers from Ireland onto Eurocarers’ Young Carers Working Group.
- The awarding of a total of €10,366 in National Lottery funding for counties Laois, Offaly, Westmeath, Longford, Meath, Louth, Galway, Roscommon and Mayo. This was used to provide hotel respite breaks for 27 young carers and their families.
- The agreement to create separate ‘Memorandum of Understanding’ arrangements with Youth Work Ireland and their Member Youth Services in order to provide targeted community-based young carer supports.
- The establishment of a European partnership involving FCI, Youth Work Ireland, Carers Federation (UK), Youth Scotland, Samana (Belgium), Kids in Action (Greece), Anziani e Non Solo (Italy) and Careum (Switzerland) to develop a tool for youth services to better identify, engage and support young carers across Europe.
- The Department of Children and Youth Affairs announcement of the Targeted Youth Funding Scheme and the publication of the Report on Consultations with Young People on Youth Work which both identify young carers as a target group and recognise the importance of targeted work with young carers.
- The involvement of three Irish young carers in the European Youth Parliament in Brussels on November 19th.
- A presentation on the impact of caregiving on the mental health of young carers delivered by an Irish young carer and the Young Carer Development Manager at the annual conference of the European Network of Ombudspersons for Children (ENOC) and the subsequent reference to young carers within the ENOC Position Statement on “Child Mental Health in Europe” (page 4, point f).

DORMANT ACCOUNTS FUND

Family Carers Ireland continued its support for former carers in 2018 through the delivery of the 'Plan C' programme which received €340,000 from the Dormant Accounts Fund. The programme, which began in January 2018 and continued into 2019, was 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 in their communities. The project engaged with over 1,200 family carers through a series of key actions, including:

- Nationwide **Plan C Programme** sessions with 40 local family carer groups - helping carers to assess and present their skills as marketable to employers.
- A **'Life after Care' seminar** with a keynote address delivered by Prof. Mary Larkin which focused on the different ways the role of a carer can change or end.
- **Nine 'Life After Care' forums** to promote the 'Plan C' programme to members of FCI who were not active in the local groups.
- A **befriending/mentoring project** whereby 29 former carers who had come to the end of their caring role or were approaching that point volunteered to mentor and befriend current carers in their county.
- A **'Caring for Carers' train-the-trainer** course which addressed the needs of carers supporting those with a mental health difficulty. Twenty-one facilitators were trained in total and went on to deliver a pilot programme. Feedback from those involved in the pilot programme was very positive (see below, left).
- **Counselling** was provided to 50 carers approaching an end to or change in their caring role.



'It took this course to make me really realise that I need to look after myself better. If I'm not well, I can't help anyone' (family carer, participant)

In 2018, Family Carers Ireland successfully applied for a further Dormant Accounts Fund grant of €645,000 for the "Empowering Family Carers" project to be delivered between January 2019 and June 2020. It includes a wide range of measures designed to enable family carers to be confident in their caring role, maintain their own health and wellbeing and participate as fully as possible in economic and social life.



RESEARCH HIGHLIGHTS

Family Carers Ireland undertakes research in order to provide robust evidence on carer issues, to develop our understanding of the nature, extent and impact of caring and to identify models of good practice. Research undertaken or supported during 2018 includes:

Research partners with UCD on the CAREWELL Project which aims to develop a workplace-based programme to promote health and self-care behaviours among working family carers.

Collaborator in a project led by UCD and the Royal College of Physicians 'Promoting Assisted Decision-Making in Acute Settings' (PADMACS). Its aim is to develop an educational tool to promote understanding of assisted decision-making among healthcare professionals working in acute settings.

Briefing papers - 'Balancing Work and Care: International Challenges and Irish Perspectives' and 'Carers and Employment: Data from the 2011 and 2016 Irish Censuses'.

Partner in UCD's PPI Ignite Project to Ensure Reciprocal Involvement of Seldom Heard Groups in Health and Social Care Research.

Book review - FCI reviewed David Grayson's book 'Take Care: How to be a Great Employer for Working Carers' (Emerald 2017) which was published in the International Journal of Care and Caring, Vol. 2, No. 1.

FAMILY CARERS HEALTH AND WELLBEING SURVEY

Data collection for a health and wellbeing survey of family carers began in the autumn and winter of 2018. The survey, a collaboration between Family Carers Ireland, the College of Psychiatrists of Ireland and UCD School of Nursing, Midwifery and Health Systems, was a repeat wave of a similar study undertaken in 2009.

This study aimed to explore the experiences of family carers who provide regular unpaid personal help for a friend or a family member with a long-term illness, health problem or disability and to identify their needs, allow further tailoring of our supports and services and shape our policy ask going forward.

Data collection was split into two phases. Phase one ran from October to November and involved the survey being disseminated to all FCI members either by hard copy or by email while phase two involved promotion on social media from late November and was open to anyone in a caring role.

The response to the survey was extremely strong with over 1,100 family carers completing the study ahead of the analysis and write-up stage in 2019.



SHAPING POLICY

Family Carers Ireland's vision is to create an Ireland in which carers are properly recognised, supported and empowered. Our work to inform and advance national and international policy is critical to the achievement of this vision. During these challenging times, this work has never been more important as we seek to protect carer entitlements and secure critical developments in carer policy.

FCI's policy and campaigning work is grounded in the reality of carers' experiences and supported with vital evidence through our programme of research.

Highlights of the achievements in policy and public affairs for carers during 2018 include:

- **Announcement by the Department of Health of an additional €10m to enhance respite services for people with a disability.**
- **Awarding of a GP Visit Card to fulltime carers in receipt of Carer's Allowance and Carer's Benefit.**
- **Contributory State Pension calculation changes for persons who reached 66 after 2012 including the introduction of carer credits for long-term family carers.**
- **Recipients of Carer's Allowance and Domiciliary Care Allowance were made eligible for SEAI's Better Energy Warmer Homes Scheme.**
- **Overhaul of Carer's Allowance application form to improve access for persons caring for a loved one with an intellectual disability or mental health difficulty.**
- **Continued to work collaboratively with the Department of Health and members of the HomeCare Coalition to work towards a fair and equitable statutory homecare scheme.**
- **Announcement of research to be commissioned by the Department of Employment Affairs and Social Protection to examine the cost of living with a disability.**
- **FCI continued to represent carers on the HSE's National Patient Experience Survey Oversight Group and are actively involved in a number of important working groups and projects including a Healthcare Communications Working Group.**
- **Announcement of €280,000 in funding to the HSE to pilot test the InterRAI Carer Needs Assessment in CHO 2.**



FCI hosted two separate events during 2018 in relation to the Assisted Decision-Making (Capacity) Act 2015. Firstly, a carer briefing was hosted by the organisation and the HSE for 30 family carers on April 23rd. This was an excellent opportunity to raise issues and seek clarification from the newly appointed Director of the Decision Support Service Áine Flynn and Patricia Rickard Clarke, a legal expert on the Act.

Secondly, the Law Society Human Rights Committee in partnership with FCI held a conference in October 2018 titled "Capacity in Ireland: challenges in balancing rights and practical realities" which critically explored the legal framework around capacity and the impact that the act has on all of those it affects, including the rights and responsibilities of carers.

The organisation made a submission to the Department of Employment Affairs and Social Protection on the Pension Reform Programme on behalf of family carers. The consultation will inform the design of a new Total Contributions Approach (TCA) to the State Pension (Contributory) which will come into effect in 2020. A TCA option is also being made available in 2019 as an interim measure for people who reached State Pension age after September 1st 2012.



FCI appeared before the Oireachtas Justice Committee on September 26th to call on members to support rewording Article 41.2 of the Constitution (referring to a woman's place in the home) to ensure the work of family carers (male and female) in the home is recognised and valued.

A report issued by the committee on December 6th stated that the majority of members believe that Article 41.2 should be replaced with a new provision that "recognises the contributions made by family life and carers to our society".

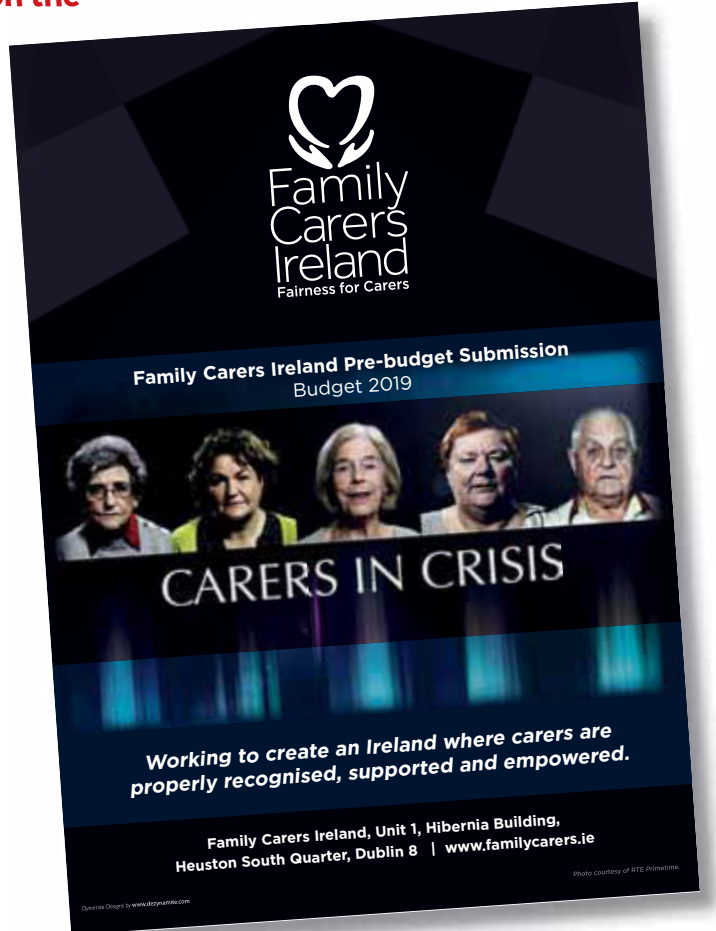
As part of the HSE's National Patient Experience Survey Oversight Group, the organisation is involved in a number of important working groups and projects which have emerged from the survey, including a Healthcare Communications Working Group (which Family Carers Ireland co-chairs) and the Digital Discharge Communications Working Group. Family carers also represent the organisation on the HSE's Early Warning Scores Working Group which is established to revise and update early warning system for adult patients in the acute hospital setting.

The Annual Carers Forum hosted by DEASP took place on November 20th. The event, which was attended by officials from DEASP, DoH, DCYA, Solas and Tusla, allowed carers and staff to discuss policy issues relating to carer income supports, life after care, transport, housing, young carers and carer health and wellbeing.

KEY CONTRIBUTIONS:

Family Carers Ireland regularly contributed to policy reviews and strategies being considered by Government in 2018. A summary of submissions made during the year include:

- **Pre-budget Submission on Budget 2019 - outlined in detail under our campaigns section.**
- **Proposal to Department of Health on a refreshed National Carers' Strategy.**
- **Submission to the Department of Health on Deprivation of Liberty Safeguards.**
- **Submission to the Oireachtas Committee on the Future of Mental Health Care.**
- **Submission to the HSE on National Guidelines for the assessment, promotion and management of continence.**
- **Submission to the Department of Health on the Provision of Respite Services.**
- **Presentation to the Oireachtas Committee on Health on Homecare Services.**
- **Submission to the Citizens' Assembly on how to respond to an ageing population.**
- **Ongoing collaboration with the Department of Health on the creation of a statutory home support scheme.**
- **Proposal to the Acute Hospital Division on Patient and Family Empowerment.**
- **Submission to the Department of Communications, Climate Action & Environment on Pay-by-weight Bin Charges.**



NATIONAL CARERS' STRATEGY FIFTH PROGRESS REPORT

In December 2018, the National Carers' Strategy Monitoring Group published its fifth and final scorecard for the National Carers' Strategy (NCS). Originally published in 2012, the NCS signalled the State's commitment to respect carers as key partners in care and respond to their needs across a number of policy areas.

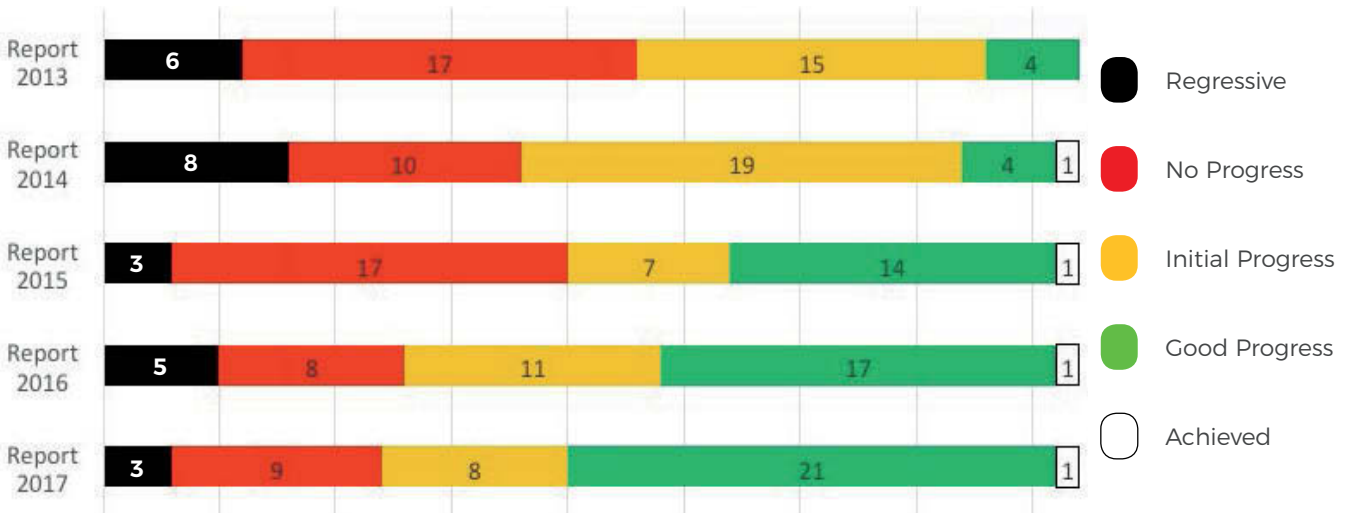
The scorecard showed an overall improvement in the progress reported for 2017. Of the 42 actions, one received an 'Objective Achieved' score; twenty-one actions received a 'Good Progress' score; eleven actions received an 'Initial Progress' score; eight received a 'No Progress' score and one action received a 'Regressive' score.

Throughout 2018, FCI continued to work with the Department of Health, the coordinating department for the strategy, to develop a 'refreshed' National Carers' Strategy for the five year period 2019-2024 and to secure ring-fenced funding for its implementation.

This work has included ongoing meetings with the Department of Health and the identification of priority actions for each designated Government department.



NCS Scorecard 2013-2017



WEBSITE

The Family Carers Ireland website www.familycarers.ie recorded steady growth in 2018 with a total of 211,971 page impressions across the year – a **5.4 per cent increase on 2017**.

Monthly Impressions

January	February	March	April	May	June
20,483	14,590	17,569	19,820	18,833	19,848
July	August	September	October	November	December
20,057	16,432	16,245	19,152	16,818	12,124

Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Avg
661	521	567	661	608	662	647	530	542	618	561	391	581



The top drivers of referral traffic to the site were search engines (particularly Google) followed by Facebook, Citizens Information, Irish Nursing Homes and Twitter.

Pages relating to membership (Become a Member and Membership Benefits) were the most popular on the website followed by Vacancies, Rights and Entitlements, Find Us, About Us, Carer of the Year Nominations and Help and Advice.

FCI launched 'CareGuide' in May 2018 using funding from the Dormant Accounts Fund. This is an online informational tool to help carers identify and access information relevant to them at this point in their particular caring journey. The information provided is based on details entered by the carer and includes advice on rights and entitlements, health and wellbeing and finances which are tailored to their specific caring situation.

SOCIAL MEDIA

Social media continues to be a hugely effective mechanism for engaging with thousands of family carers right across the country. Alongside the website, it allows us to keep family carers informed about the organisation's activities, campaigns and causes; supports and services offered by FCI, the State and other agencies; coverage of family carer related topics in news and politics and membership benefits.

The national FCI Facebook page had 13,153 followers at the end of 2018 – a **15.4% increase** across the twelve months – while the number of followers of **@CarersIreland** on **Twitter rose by 11% to 4,785**.

GDPR COMPLIANCE

General Data Protection Regulation (GDPR) came into force across the EU on May 25th 2018. Family Carers Ireland produced a new data protection policy which was launched nationally on May 18th and appointed a Data Protection Officer (DPO) in line with the new GDPR directive. All staff were provided with training and digitally signed the policy, indicating their acceptance.

The organisation took all necessary steps to ensure compliance with GDPR, with contact being made across our network and clear unsubscribe options being provided. This proactive approach ensured that we had up-to-date permissions for our data in line with GDPR.

Family Carers Ireland's privacy policy and processes and procedures around data breaches and data access requests were also updated in line with the regulation.



FINANCES

Statutory Accounts

The following is an extract from the Statutory Accounts:

FAMILY CARERS IRELAND CLG (A Company Limited by Guarantee)

Statement of Financial Activities Incorporating Income and Expenditure for the Year Ended 31 December 2018

INCOME FROM	Unrestricted Funds 2018 €	Restricted Funds 2018 €	Total Funds 2018 €
Donations and Legacies	49,446	3,495	52,941
Other trading activities:			
Charitable activities	6,612,789	4,142,468	10,755,257
Trading activities	489,338	--	489,338
Investments	3,919	--	3,919
Total Income	7,155,492	4,145,963	11,301,455
EXPENDITURE ON			
Raising funds	176,000	--	176,000
Charitable activities	6,415,819	4,275,049	10,690,868
Total Expenditure	6,591,819	4,275,049	10,866,868
NET INCOME / (EXPENDITURE) BEFORE TRANSFERS	563,673	(129,086)	434,587
Transfers between funds	(129,086)	(129,086)	--
Net Income/ (Expenditure)	434,587	--	434,587
Net Movement in funds	434,587		434,587
Reconciliation of Funds			
TOTAL FUNDS AS AT 1 JANUARY 2018	1,965,880	--	1,965,880
TOTAL FUNDS AS AT 31 DECEMBER 2018	2,400,467	--	2,400,467

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

FINANCES

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

BALANCE SHEET AS AT 31 DECEMBER 2018

	€	2018 €
FIXED ASSETS		
Tangible assets		20,861
Financial Assets		
		<u>20,861</u>
CURRENT ASSETS		
Debtors	1,186,377	
Cash at bank and in hand	2,247,581	
	<u>4,063,958</u>	
CREDITORS: amounts falling due within one year	<u>(1,684,352)</u>	
NET CURRENT ASSETS		2,379,606
NET ASSETS		<u>2,400,467</u>
CHARITY FUNDS		
Restricted funds		
Unrestricted funds		2,400,467
TOTAL FUNDS		<u>2,400,467</u>

For further details on Statutory Accounts please go to

www.familycarers.ie

FAMILY CARERS IRELAND CLG
(A Company Limited by Guarantee)

**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 31 DECEMBER 2018**

Directors	<p>Jim Waters, Chair Triona Fortune Antionette Green Susan Hogan Tess Hogan Barbara Kovach Shane McCarthy Eilish Smith Luke Mooney (re-appointed 23 June 2018) Johanne Powell (re-appointed 23 June 2018) Padraig Neenan (appointed 23 June 2018) Peter O' Connell (appointed 27 September 2018) Pat Dolan (resigned 23 June 2018) Reene O' Rourke Kelly (resigned 23 June 2018)</p>
Company registered number	572819
Charity registered number	CHY 10962
Registered office	<p>Unit 1 Hibernia Building Heuston South Quarter Dublin 8</p>
Company Secretary	Mary Conway
Chief Executive Officer	John Dunne
Senior Management Team	<p>Padraic Marrinan, Head of Operations Catherine Cox, Head of Communications and Carer Engagement Mary Conway, Head of Corporate Services</p>
Independent Auditors	<p>RBK Business Advisors Chartered Accountants & Statutory Audit Firm Boole House Beech Hill Office Campus Beech Hill Road Clonskeagh Dublin 4</p>
Principal Bankers	<p>Bank of Ireland 2 College Green Dublin 2</p>

FAMILY CARERS IRELAND CLG
(A Company Limited by Guarantee)

REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 31 DECEMBER 2018

Advisers (continued)

Solicitors	William Fry 2 Grand Canal Square, Dublin 2
	A & L Goodbody International Financial Services Centre North Wall Quay Dublin 2
Chairperson	Jim Waters
Finance & Organisation Committee	Luke Mooney (Chair) Jim Waters Jimmy Duggan
Audit & Risk Committee	Grace Dempsey (Chair) John Lonergan Shane McCarthy
Quality & Safety Committee	Triona Fortune (Chair) Tess Hogan Antoinette Green Joe Gannon Deirdre Laing
Member & Carer Engagement Committee	Barbara Kovach (Chair) Susan Hogan Johanne Powell Cora Long Eilish Smith Mary Murphy



Family Carers Ireland

National Freephone Careline:

1800 24 07 24

Website: www.familycarers.ie

Charity Number:
CHY 10962

Family Carers Ireland
Unit 1, Heuston South Quarter
St. John's Road West
Dublin 8

EMAIL: careline@familycarers.ie

 **@CarersIreland**

 **Family Carers Ireland**