



Family
Carers
Ireland
Fairness for Carers

ANNUAL REPORT 2016

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REFERENCE AND ADMINISTRATIVE INFORMATION

Charity Name: Family Carers Ireland
Company Registered Number: 572819
Charity Registered Number: CHY 10962
Secretary & Registered Office: Mary Conway,
Smithfield Business Centre, the Distillers Building,
New Church Street, Smithfield, Dublin 7

CEO & Executive Management Team:
John Dunne, Sean Dillon, Catherine Cox, Mary Conway

Directors at 31 December 2016:

Pat Dolan (Chair)
Eilish Smith
Antoinette Green
Ger Kavanagh
Barbara Kovach
Tess Hogan
Johanne Powell
Jim Waters
Reene O' Rourke Kelly
Susan Hogan
Luke Mooney

Directors resigned during 2016:

Tom Curran (3.06)
Ann Quinn (27.07)
Patricia Doherty (11.11)
John Lonergan (25.11)
Mary Murphy (25.11)
Lorraine Ryan (25.11)
Judith Ironside (25.11)
Cora Long (25.11)
Mary Savage (25.11)
Jimmy Duggan (25.11)
Noel Power (25.11)

Independant Auditor:

Russell Brennan Keane Business Advisers
Chartered Accountants & Registered Auditor
96 Lower Baggot Street
Dublin 2

Principal Bankers

Bank of Ireland
2 College Green
Dublin 2

Allied Irish Bank

9 Terenure Road
Rathgar
Dublin 6

Board Committees at 31 December 2016:

Audit & Risk

Grace Dempsey (Chair)
John Lonergan

Finance & Organisation:

Luke Mooney (Chair)
Jim Waters
Jimmy Duggan

Clinical & Social Care

Tess Hogan
Ger Kavanagh
Antoinette Green
Deirdre Lang
Ciara Hopper

Member & Carer Engagement

Barbara Kovach (Chair)
Cora Long
Susan Hogan
Johanne Powell
Reene O' Rourke Kelly

CHAIRPERSON'S INTRODUCTION

It gives me great pleasure to introduce the first Annual Report on the activities and performance of Family Carers Ireland (FCI).

Family Carers Ireland took over the combined activities of The Carers Association and Caring for Carers on 1st January, 2016 so this report covers a historic and busy year. Careful preparation seems to have paid off as the feedback from our most recent regional meetings is that carers believe that the merger improved our capacity to lobby for and provide supports to family carers.

At national level the board adopted a comprehensive set of policies and procedures for the new organisation and secured the highest level of Irish charity accreditation in terms of corporate governance, financial reporting and fundraising. A notable innovation in this regard was that all Group funds held in local bank accounts were transferred to the (virtual) Bank of Carers, thereby allowing groups to retain effective control of their funds whilst still complying with new regulatory requirements. This was only one of the changes incorporated in a new FCI group constitution – and I was delighted that over 55 groups were fully signed up to this document by the beginning of 2017.

I would like to pay a particular tribute to my colleagues on the board for their hard work in 'bedding in' the new organisation. Family Carers Ireland held its first AGM in November. The 'interim' board of 20 directors (comprising the outgoing boards of The Carers Association and Caring for Carers Ireland) retired at this meeting and a new board of 10 directors was elected under the organisation's new

constitution. 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 thank 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.

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 to support and affirm informal carers throughout Ireland. 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 coming decades.

Finally, I would also like to thank all our staff for their hard work and unflinching commitment to the organisation's mission of improving the lives of family carers.

*Pat Dolan,
Chairperson.*

CEO'S INTRODUCTION

In planning the merger of The Carers Association and Caring for Carers one of the objectives we set ourselves was that the only changes service users would notice as a result of the merger would represent improvements. To that end we worked hard throughout 2016 to ensure the successful integration of services at local level. This involved mapping those services on to the HSE's new CHO structures and re-negotiating several local funding agreements. Whilst there were many teething issues along the way, I'd like to acknowledge the energetic and constructive way that staff and carers all over the country engaged with and ultimately resolved them.

The organisation ran three major lobbying campaigns in the course of 2016 – the first linked to promoting carer issues in the general election at the beginning of the year, the second related to the importance of the 'Carer' question in Census 2016 and the third was our 'regular' pre-budget campaign in the latter part of the year. The National Convention worked well in informing these activities, not least in promoting a focus on previously underrepresented carer groups dealing with areas such as children with special needs, adults with intellectual disabilities, and people with mental illness. This process will hopefully be further strengthened by the establishment of Regional Forums as a new element of our engagement with carers at grassroots level.

The findings of the first Irish Health Survey were published towards the end of 2016. They were notable from our perspective for the finding that 10% of the population is providing care to someone with a chronic condition or an infirmity due to old age. This is considerably higher than any previous official estimate of family caring in Ireland. The average number of hours spent providing care is 44.7 hours per week.

FCI secured ISO9001 accreditation for its home care services in 2016, and was particularly successful in the HSE's 2016 tender competition, being selected as an approved provider in every part of the country. Family Carers Ireland delivers a significant volume of Home Care on behalf of the HSE. In addition to compensating for significant cuts in our core funding since 2009 this activity also underpins our core mission in other important ways as it allows us to:

1. engage with thousands of family carers who do not self-identify and therefore often remain unaware of supports available to them;
2. promote improved standards of home care by acting as a high-quality benchmark and drawing on in-depth
3. practical knowledge in recommending service improvements.

We anticipate significant changes to how home care is delivered in the latter part of 2018. This is likely to be underpinned by new legislation which will effectively define a legal context for family caring in Ireland for the very first time. As such it will represent another very significant milestone in the history of the carer movement in this country. We will use our nationwide network of groups and projects to engage with every element of the associated consultation process in a creative and constructive way.

In this regard I would like to thank the many individual Family Carers who assisted us throughout the year with feedback, ideas, suggestions, lobbying and media efforts. Our effectiveness in advocating for improvements in Carers' health, wellbeing and financial security are 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 2016 their generosity of time and expertise in a very demanding year. I hope I will be excused for highlighting the particular contribution that Pat Dolan and Eilish Smith made as co-chairs of the interim board. Just as with family carers, the directors of Irish charities are generally presumed upon and under-acknowledged by wider society 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 offer you all an undertaking that we will fight to ensure that, having made significant sacrifices over the past six years, you will receive a commensurate share of the ongoing restoration of public sector pay and conditions.

*John Dunne,
Chief Executive.*



LAUNCH OF FAMILY CARERS IRELAND

On Wednesday 13th January 2016 the merger between The Carers Association and Caring for Carers Ireland was made official with the launch of Family Carers Ireland. The launch was attended by Minister for Social Protection Joan Burton. The new organisation's goal is to support and advocate for the almost 200,000 family carers in Ireland.

The merger means the pooling of best practice, resources and experience from both organisations to create one stronger, national voice and an increased range of supports and services for family carers. The organisation will now be able to offer more resource centres and services to those in rural and isolated areas as well as stronger supports where existing centres are already located.



SUPPORTING CARERS: CARER GROUPS

Family Carers Ireland listens to the needs and requirements of family carers with an average of 25,000 direct engagements with individual carers each year as well as through structures such as local support groups, regional forums and the national convention.

The organisation facilitates over 60 carer groups around the country whose primary aim is to provide peer support and advice to family carers while enabling communication by carers back to the organisation on their needs and ongoing requirements. These groups vary in size, meeting frequency and mix of caring situations represented, but all are a very powerful platform giving an outlet and helping hand to family carers in a rewarding yet very difficult time in their life journey.

Carer groups offer an important social outlet, and can be particularly beneficial for carers in small towns or rural areas, as well as a way for Family Carers Ireland to reach carers in these areas and hear their concerns. The carers that attend groups set the agenda. Carers often use the time to share coping strategies and local information, in addition to offering emotional support. Guest speakers such as Public Health Nurses, HSE representatives and Social Welfare experts are invited to meetings to address carers on issues of interest to them. Groups provide a valuable opportunity to meet others with similar caring experiences. Indeed this is how many enduring friendships began.

Carer groups are also integral to the operation of Family Carers Ireland. 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. Groups 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.

CARERS IN FOCUS: MARY MCDONNELL

Mary McDonnell (80) has provided full-time care for her daughter Sinéad for over 50 years. Sinéad is a person with serious physical disabilities – she has profound cerebral palsy (diagnosed at just 10 months), has scoliosis and is a wheelchair user. Sinéad's care is now the definition of 'round-the-clock'. Increased medication has meant a special diet and constant feeding supervision, and constant management of pain. Mary, as an older carer, finds her caring role challenging, and navigating the bureaucracy for accessing vital supports and services very tough, in particular when it comes to accessing respite care.

Mary remains active in her community, and receives support from her local Family Carers Ireland centre in Tuckey Street, Cork, regularly attending meetings of the carer support group. She says the group is a lifeline which allows her a space to share a joke and news with old friends and to make new ones.



Sadly, at the time of going to print Sinéad passed away peacefully in her own home surrounded by her close family and friends. May she rest in peace.

NATIONAL FREEPHONE CARELINE

In 2016, our National Freephone Careline service was expanded with the help of the Samaritans. The Samaritans provide 24/7 service countrywide, entirely staffed by volunteers, and they have kindly offered to take calls from carers who wish to speak to someone during the hours we are not presently covering. Someone calling our Careline between 8.00pm and 9.00am will be given the option to stay on the line and be diverted to a Volunteer from the Samaritans.

CARELINE HOURS ARE
MONDAY TO FRIDAY,
9AM-8PM AND SATURDAY,
10AM-12 NOON.



THERE WERE **3,950**
CALLS FROM A
TOTAL OF
26 COUNTIES IN
2016.

30%

CALLS WERE FROM DUBLIN

16.5%

CALLS FROM UNKNOWN COUNTY (CALLER DID NOT DISCLOSE THIS INFORMATION)

5%

CALLS WERE FROM CORK

4%

CALLS WERE FROM LIMERICK

2.5%

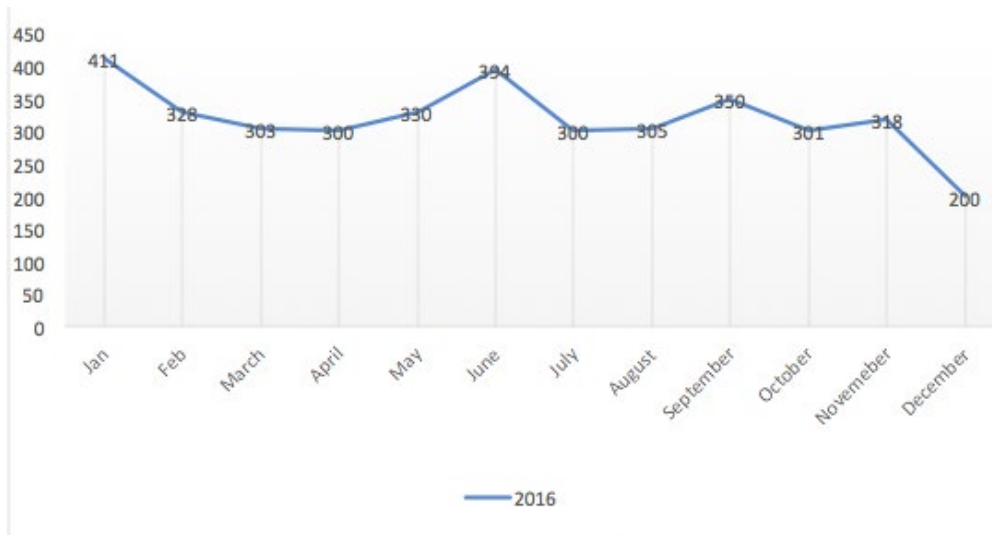
CALLS WERE FROM KILKENNY

42%

CAME FROM THE REMAINING 21 COUNTIES (2% FROM EACH COUNTY)

We would like to thank all our Careline volunteers for being so generous with their time, and also extend our thanks to the Samaritans for facilitating us in providing this very valuable 24hour service to carers.

NATIONAL CARELINE FIGURES 2016:



The number of calls to the Freephone Careline by month in 2016

THE TOP FIVE CARELINE QUERIES FOR THE PERIOD WERE:

CARERS' PAYMENTS

MEMBERSHIP

OUR SERVICES

CALLS REQUESTING INFO
ON OTHER CENTRES

MISCELLANEOUS EG. ADVOCACY/COUNCELLING,
MEDIATION, DSP PAYMENTS

CARERS' TRAINING

Specific training programmes were provided with the support of funding received from Dormant Accounts with over 1,000 carers attending these sessions during the course of the year in a mix of QQI Level 5 modules and carer specific workshops. In addition, some targeted workshops were provided to specific carer groups including three men's workshops which welcomed over 80 male carers participating.

Family Carers Ireland piloted two courses in Dublin and Limerick for carers of people with progressive, life-limiting conditions with the support of National Lottery Funding.

RIGHTS AND ENTITLEMENTS BOOKLETS

Over 5,000 Rights and Entitlements booklets were printed and distributed to our resource centres to ensure that carers are aware of the breadth of supports available to them and have information on how they might access these relevant supports.

1,011 people received Rights and Entitlements training during 2016. The training was delivered in a number of locations around the country to large and small groups. Carers in attendance found the training very beneficial.

VOLUNTEERING: CARER MENTORING AND BEFRIENDING PROGRAMME

We have many offers from former carers who wish to provide their support, advice and expertise to current carers, and by facilitating this carer mentoring, we both support current carers and allow those whose caring role has ended to give something back.

Our befriending project was piloted in Newbridge, Co. Kildare. The Befriending Service provides a visit to someone's home with the aim of providing companionship at a time of change in their life, or helps socially isolated individuals to build their resilience and self-confidence and reduce their sense of emotional and geographical isolation. The service may also provide the opportunity to give a carer a break from their caring role. Visits often simply involve a cup of tea and chat, or sharing a hobby like playing cards or doing a crossword.

Referrals typically come from Public Health Nurses or other HSE professionals – social workers, hospital discharge teams, general practitioners; there are also some from family carers or their families and other voluntary bodies, and a few self-referrals. Working in partnership with other voluntary and statutory agencies within the community is crucial to the success of the programme.

We continue to roll out our volunteer-based befriending and mentoring programmes, with new projects in Waterford, Wexford and Wicklow beginning in 2016.

IN 2016:

A total of **20** volunteers were recruited, selected, Garda vetted and trained.

30 families availed of the service.

12 families are currently on a waiting list to avail of the service (while volunteers are matched with families).

Jan-Sept 2016: **287** hours delivered.

ADVOCACY

Over **250** Advocacy cases were dealt with on an individual basis, they all 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

CARER OF THE YEAR AWARDS

On Wednesday 16th November, Family Carers Ireland hosted its 10th annual Carer of the Year Awards. Sponsored by Tunstall Emergency Response, the awards celebrate the dedication and commitment of family carers across Ireland.

Twenty-five regional family carers were presented with special awards and Dorothy Meaney from Dooradoyle, Limerick was announced as Ireland's Carer of the Year 2016.

For the first time, four regional Young Carers of the Year were chosen: Craig McSweeney (16 years old) was awarded Munster Young Carer of the Year, Sean Collins (13 years old) awarded Ulster/Connaught Young Carer of the Year, Seunfunmi Solanke (16 years old) awarded Leinster Young Carer of the Year and Úna Mc Nicholas (17 years old) awarded Dublin Young Carer of the Year. They were each presented with their awards by broadcasters and patrons of Family Carers Ireland, Mary Kennedy and Marty Whelan.





Carer of the Year Dorothy Meaney with daughter Zondra and FCI's Fianait Mitchell



The Young Carers of the Year 2016

CARERS IN FOCUS: DOROTHY MEANEY

Dorothy Meaney from Dooradoyle, Limerick was announced as Ireland's Carer of the Year 2016. Dorothy provides full-time care to her daughter Zondra, who has Ehlers Danlos Syndrome, which affects all the systems of the body. Zondra's illness has progressed in the past three years, and Dorothy gave up work to look after her daughter and Zondra's 9-year-old son Carrick. One of the most difficult things about Zondra's disorder is the fact that there are no specialists in Ireland who can treat her, and so Dorothy and Zondra travel to the UK every 12 weeks for treatment. Dorothy was also

caring for her own mother, whose passing unfortunately meant the family could not attend the ceremony.

As with many family carers, Dorothy did not think of herself as such: as she told The Irish Independent in the wake of the award, she felt herself only to be doing 'what any mother would'. The Awards brought some focus onto the family's ongoing fundraising efforts for Zondra's treatment, and following Dorothy's award there was a reception held in November by the Mayor of Limerick's office honouring her as carer of the year.



NATIONAL CARERS WEEK

National Carers Week 2016 ran from Monday, June 13th through Sunday, June 19th. This was the tenth year National Carers Week was celebrated. Each year it features events and activities for carers across the country, and is an important platform for building awareness of caring in Ireland. Family Carers Ireland hosted just over 80 events held throughout the country including pop-up café/hubs, targeted information days, pampering mornings, afternoon tea and much more.

NATIONAL RESPITE WEEKEND 2016

Family Carers Ireland held a national respite weekend in Westport in early March, which was attended by over 280 family carers. The weekend allows many of these carers to take an essential break from their caring role, to unwind and meet carers in a similar situation to theirs and to develop friendships through participation in the many recreational activities provided.

Respite overnight breaks are also provided in some local areas, and are usually sponsored by local groups, charities and business entities.

**Celebrating 10 Years
of National Carers
Week in Ireland**

**Give a Family Carer you know
a well deserved break this
National Carers Week**

June 13th - 19th

LISTENING TO CARERS: NATIONAL CARERS CONVENTIONS AND REGIONAL FORUMS

The National Carers Conventions are a way of listening to carers individually and in groups, and help to inform our policy priorities and improve our supports. Each carer support group appoints two delegates a year to attend the bi-annual convention meetings. The National Convention has an overall agenda focusing on carer issues, pre-budget submissions, progress of National Carers' Strategy and carers' representation on the Board along with clarifications on any national issues. The organisation held two National Conventions in 2016 with over 150 participants. The convention also supports a specialist subgroup for Parents of Adults with Intellectual Disabilities and in the course of 2016 it set up another specialist subgroup to address the challenges of caring for someone with mental health difficulties.

Family Carers Ireland has also established nine regional forums mapped to the Community Health Organisation (CHO) areas to facilitate engagement with family carers on specific areas of interest in the locality. Feedback from carers at these forums will allow regular review of supports in particular areas to see what is working best, and exchange of information and best practice between FCI centres and frontline staff; this feedback will also inform communication with the HSE representatives in each CHO area.

The inaugural series of regional forums were:

CHO Area 1: Cavan / Monaghan Saturday 1st October

CHO Area 5: Kilkenny / South Tipp / Carlow / Wexford / Waterford Wednesday 5th October

CHO Area 6: Dublin South East / Dun Laoghaire / East Wicklow; **CHO Area 7:** Dublin South City Dub SW / Dublin West / Kildare/ West Wicklow

CHO Area 9: Dub North / Dub North Central / Dub North West Thursday 6th October

CHO Area 1: Sligo / Donegal / Leitrim Tuesday 11th October

CHO Area 8: Laois / Offaly / Longford /Westmeath / Louth / Meath Thursday 13th October

CHO Area 4: Cork / Kerry Friday 14th October

CHO Area 3: Limerick / Clare /North Tipperary Thursday 20th October

CHO Area 2: Mayo / Roscommon / Galway Friday 21st October

POLICY, CAMPAIGNS & RESEARCH MATTERS: THE NATIONAL CARERS' STRATEGY

Family Carers Ireland remains committed to its proactive monitoring and support for the implementation of the National Carers' Strategy along with recognising the progress made to date on this principles-led strategy. Family Carers Ireland is now focused on the development of a second phase of this strategy with ring-fenced funding to enable better and more easily accessible support to family carers.

The Department of Health published the third annual National Carers' Strategy Progress Report on 10th February, 2016 and the NCS Monitoring Group launched its assessment, in the form of the third Carers' Strategy scorecard, on 14th July.



Carers Damien Douglas and Moira Skelly with Moira's daughter Ciara and FCI's Catherine Cox and Diarmaid O'Sullivan at the launch of the third NCS Scorecard

POLICY, CAMPAIGNS AND RESEARCH MATTERS: SHAPING POLICY

The Annual Carers Forum, hosted by the Department of Social Protection took place on Tuesday 23rd February and Family Carers Ireland was represented by a total of 13 carers and staff members. The forum included input from key Government departments as well as workshops on transitioning to life after caring; support for Young Carers; DSP Information and Income Supports; Housing and Transport; and Health and Wellbeing. Key management staff met with Minister Varadkar on 20th June, had a detailed working meeting with the Carers Section of the Department in DSP Longford on 6th July and participated in the DSP annual pre-budget forum on 22nd July.

Representatives of the organisation met Minister Helen McEntee in the Department of Health on 7th July about carer issues and participated in roundtable discussions convened on 8th September to review implementation of the Positive Ageing Strategy. In the course of the year FCI met senior officials from all departments engaged with the Carers Strategy.

Family Carers Ireland was invited to present before the Oireachtas Committee on the Future of Healthcare on 9th November. The committee was particularly interested in the question of a statutory basis for care in the home/ community. The organisation met with Willie O'Dea TD on 5th July about a private members bill he is introducing to allow access to 'Fair Deal' funding for Home Care Packages in certain circumstance and also met Senator Colm Burke on 14th July to discuss other legal issues relating to carers and the health system.

A group continues to work on pioneering the Carer Needs Assessment element of the InterRai needs assessment tool which is to be adopted by HSE workers. Work on this is ongoing, with Family Carers Ireland liaising with an international team involved in developing the suite of InterRai assessments.

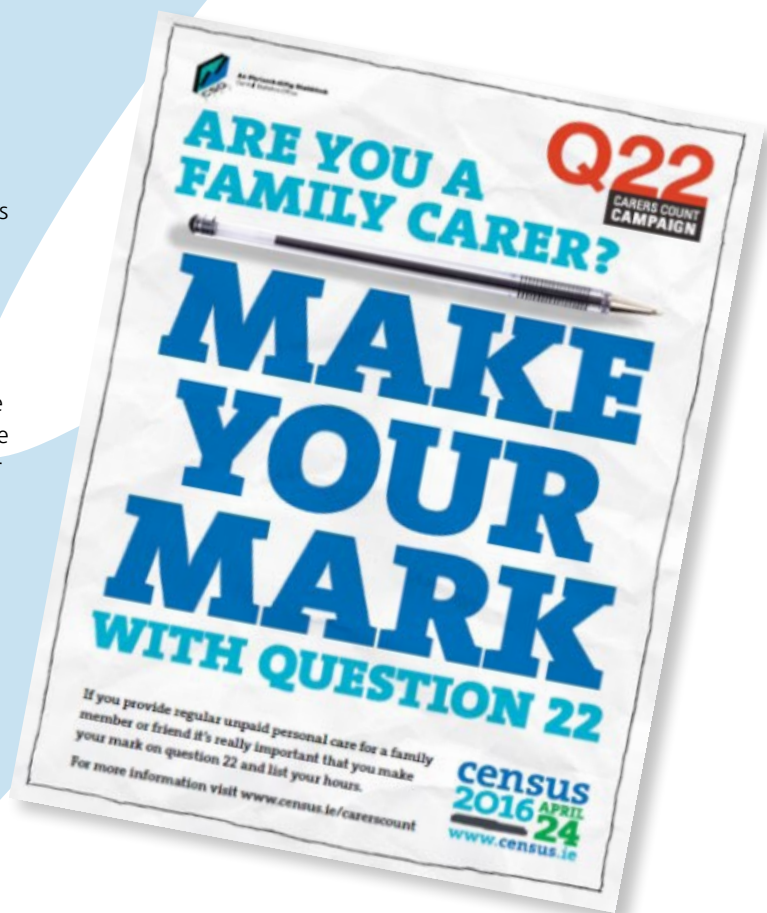


Family Carers Ireland undertook a number of national and local campaigns during the year to improve conditions for family carers in Ireland.

The pre-election campaign launched on 3rd February, 2016, comprising election hustings in several constituencies, direct correspondence with candidates throughout the country and detailed engagement with Party HQs with regard to manifestos. The campaign's focus was on asking candidates to stand with the organisation in making specific commitments to family carers.

Our pre-budget submission was launched on 5th July, 2016. The budget was largely positive for family carers, with the announcement of a €5 weekly increase in welfare payments, including carer's allowance and benefit, and the extension of carer's allowance payment for 12 weeks after a care recipient enters residential care, and a number of significant improvements in health and social areas that affect carers and their loved ones.

The Census 2016 campaign held throughout March and April, with the message 'Make Carers Count', encouraged family carers to self-identify and complete Question 22 in Census 2016 correctly. The campaign reached out to family carers through seminars and group meetings around the country, and dissemination of promotional and informational leaflets and posters by our centres in their counties.



INVEST IN HOME CARE EVENT

On September 27th, a grouping of Ireland's leading not-for-profit organisations and campaigners came together to call for increased investment in home care. Carers Shirley Thornton and Moira Skelly outlined to an audience in Buswells Hotel how the cutting of home care and home respite hours had negatively impacted their lives; and Sinead McArdle from Ardee, who suffers from multiple sclerosis and whose husband now works part-time in order to spend more time caring for her, spoke of how a few hours of home help would make a world of difference, as she can experience extreme fatigue. The meeting highlighted a recent study published by the School of Social Policy, Social Work and Social Justice in UCD, Age Action, The Alzheimer Society of Ireland and the Irish Association of Social Workers which found that

more than half of older people could remain in their own homes instead of going into long-term care if more home support services were available.

On November 10th, speaking before the Oireachtas Health Committee, Minister for Health Simon Harris for the first time raised the possibility of a statutory entitlement to home care, noting that this could only be accomplished with contributions from recipients, in the manner of the Fair Deal Scheme for residential care. Shirley Thornton, who returned from the UK a number of years ago to care for her parents (see profile below), was subsequently interviewed by TheJournal.ie about how reductions in home care hours had affected her home life.



CARERS IN FOCUS: SHIRLEY THORNTON

Shirley Thornton, from Stillorgan, Dublin, moved home from England to care for both of her parents; since her father passed away, she has been a full-time carer for her mother Eva. Eva suffers from heart problems, compounded by severe blood flow difficulties in her legs and periods of depression.

Shirley falls into the category of so-called 'sandwich generation' carers, i.e. those caring for children as well as for ageing parents, caring as she does also for her son Lewis. This is a trend becoming much more common throughout Europe, with increased life expectancy and ageing populations resulting in a higher demand for care, a burden which still falls mainly on family.

Shirley has frequently discussed her own caring role and the broader issues facing family carers in Ireland in various media. She has spoken at the launch of National Carers Week 2015; addressed the Invest in Home Care event in Buswells Hotel in 2016; given video and print interviews to the Irish Independent, Irish Examiner and thejournal.ie; and appeared on RTE radio's Drive Time and on television on Prime Time. Shirley gives her time to support the advocacy work of Family Carers Ireland as she considers it essential in securing fairness for family carers, ensuring they are recognised for their work, better supported and equipped to participate fully in Irish society.



POLICY, CAMPAIGNS AND RESEARCH MATTERS: RESEARCH HIGHLIGHTS

Family Carers Ireland were partners in a number of research initiatives with academic institutions and other members of the community and voluntary sector in 2016. These included:

NDA Resilience in Carers Project

A National Disability Authority Funded project on resilience in family carers of persons with an intellectual disability and also carers who care for multiple people. Led by UCD academics with collaboration from the DSP, the report, *Carers' Experiences of Caring for a Person with an Intellectual Disability*, was published in December 2016.

Long-Term Care Forum

This forum was held on 15th June, bringing together private enterprise, HSE and government workers and NGOs. FCI's presentation focused on 'Carers and Irish Health and Long-Term Care Policy'

Human Rights of Older Persons Working Group

We are researching as part of this group how best to deliver and fund a statutory entitlement to homecare and ensure that a range of considerations are taken into the model with particular reference to family carers.

All-Ireland Institute for Hospice and Palliative Care (AIHPC)

Collaboration over a number of years saw the launch of the palliative care online hub in January - <http://aiihpc.org/palliative-hub/adult-public>, with the full website due to come on stream in early 2017.

Post-Caregiving

Family Carers Ireland supported and collaborated on research by Dr Carol Kelleher of the Department of Marketing at University College Cork, which resulted in the publication of the report *Family Carers Experiences of Role and Identity Transition on Cessation of the Caring Role - Implications for Policy and Practice*.

HRB Emerging Investigator Awards

FCI is an invited co-applicant or collaborator on three applications for these major awards for early career researchers.

INTERNATIONAL

FCI CEO John Dunne continued to serve as President of Eurocarers, the European Association working for Carers, throughout 2016. Family Carers Ireland is an active member of the Eurocarers Research Working Group, and will also join the Policy Working Group to be established in 2017.



COMMUNICATIONS AND CARER ENGAGEMENT

SOME MEDIA HIGHLIGHTS AT A NATIONAL LEVEL IN 2016 INCLUDED:

Family Carers Ireland and carer Damien Douglas appeared on *TV3's Ireland AM* for the launch of Family Carers Ireland.

The Late Late Show featured the Young Carers of the Year on November 18th, and the following Friday 25th, an interview with Wexford carer Johanne Powell, which generated a very positive reaction online

Johanne had featured in an *Irish Times* profile the week before *The Late Late Show*, and the paper subsequently ran a 'Carers in Crisis' series, profiling different carers and highlighting the difficulties they faced. In its Saturday, November 26th edition, the Times carried an opinion piece by Family Carers Ireland, "Family Carers are Being Exploited by State".

Family Carers Ireland appeared on RTE for Budget Day, and on October 11th Dublin carer Shirley Thornton appeared on *RTE's Prime Time Budget Special*

SOCIAL MEDIA

A teal silhouette of a house with a chimney, used as a background for the text.

OUR **WEBSITE**,
WWW.FAMILYCARERS.IE,
AVERAGES ALMOST
4,500 VISITORS
MONTHLY, AND ABOUT
14,000 VIEWS.

AT THE END OF **2016**, THE
FAMILY CARERS IRELAND
FACEBOOK PAGE HAD OVER
9,500 'LIKES' AND **9,000**
FOLLOWERS, WHILE OUR
TWITTER ACCOUNT HAD
OVER **3,500 FOLLOWERS.**

YOUNG CARERS

Our Young Carers support programmes continue to grow and during 2016 Family Carers Ireland ran a number of initiatives to raise awareness of, identify, and support young carers in school and in the community. This included an in-school support programme which was run in four schools and through this programme a total of 1,087 secondary school students attended awareness talks, while 103 young carers were identified and supported. Separately, a total of 114 young carers were referred to the organisation for information and support, largely as a result of our collaboration with several national youth work organisations. Our Young Carers website launched in March and is a critical part of reaching out to young carers seeking support and advice. A support guide for young carers was also developed, which will be circulated in 2017.



The four regional Young Carers of the Year 2016 with representatives of Totterdells 3 Mobile and FCI Young Carer Development Officer Padraig McGrath and Head of Communications Catherine Cox.

CARERS IN FOCUS: SEÁN COLLINS



Seán Collins from Smithboro, Co. Monaghan was the Ulster/Connaught Young Carer of the Year in 2016. He helps his parents Annette and Donal care for his sister Kathryn. Kathryn has profound intellectual disabilities; she is a member of Special Olympics Ireland and Seán attends the club each week to assist her with the activities. Seán is a wonderful support to both his parents, even finding time to fundraise during the summer raising over €2000 for Kathryn's school. Seán is one of the increasing number of young carers in Ireland, which estimates from a study by NUIG researchers suggest is much higher than currently acknowledged. Family Carers Ireland's Young Carers Development Officer plays an important role in supporting and connecting with young carers, and promoting awareness of their situation; directly as a result of advocacy by Family Carers Ireland, young carers have been identified as an at-risk group in Ireland's National Youth Strategy. FCI also operates the website www.youngcarers.ie.

MEMBERSHIP

At the end of 2016, membership stood at 3,383. While many members were carried over from The Carers Association and Caring for Carers, new membership of the merged organisation Family Carers Ireland through 2016 stood at 888.

Our membership with unique benefits package entitles FCI card-holders to numerous deals, and includes partnerships with Totterdells/3; Omniplex Cinemas; Doyle Mahon Insurance; Dublin Zoo; HMCA Ireland; Murrays Medical Products; and Healthwave Pharmacy.

Family Carers Ireland is 'owned' by its members, and growing our membership base is an important element in developing an ever-stronger voice for family carers throughout the country. We aim to represent and to support carers in all counties, who themselves support care-recipients with a broad spectrum of conditions. An expanding membership means more people are connected to Family Carers Ireland's many services, and in touch with our centres across the country, ensuring that we as an organisation remain best positioned to advance or address the greatest variety of carers' interests and concerns.



OPERATIONS: HOME CARE AND RESPITE PROVISION

In 2016, Family Carers Ireland provided in excess of **121,000 in-home respite hours** to family carers in support of their critical caring role. In addition, almost **228,000 hours** were provided of clinical and social care services to the cared for person in the home with the support of the Community Employment Scheme and of the HSE and other funding.

Family Carers Ireland was successful in the 2016 bid for the Home Care Package (HCP) tender competition in all nine CHO areas, both organisations having previously only operated in five CHO areas. HCPs have become an important part of the organisation's activities, generating a very important surplus to subsidise our activities and supports for carers, and also allowing us a much fuller understanding of and engagement with HSE social care services.



OPERATIONS: CARER RESOURCE CENTRE ACTIVITIES

Handled **OVER 20,000** visits or calls from Family Carers to local centres.

Made representations on **THOUSANDS** of individual cases in regard to a range of family carer support issues including income support, respite and home care packages, transport, housing adaptation and nursing home subvention (Fair Deal).

Helped to deliver **12 QQ15** Care Skills Modules, **24** Patient Moving and Handling courses and **53** topic specific workshops to **MORE THAN 1000** family carers and staff nationwide.

SUPPORTED OVER 60 active local Family Carer groups nationwide throughout the year.

Continued to roll-out volunteer-based befriending and mentoring volunteer programmes with **NEW PROJECTS** in Waterford, Wexford and Wicklow.

SECURED ISO 9001:2008 certification for FCI's Home Care services.

OPERATIONS: SOME CENTRE HIGHLIGHTS

Family Carers Ireland's network of Carer Resource Centres and Outreach Centres is what gives us a presence in communities and allows us to maintain contact with carers and understand what issues they feel most affect them, whether locally, regionally or nationally. We work in every county in Ireland, and have centres in most; this nationwide reach is essential if we are to represent carers in Ireland. Our mandate comes from the positive feedback and participation of carers throughout the country, and initiatives on a national level depend for their effectiveness on the support and hard work of our centre-based staff. The work our centres do in and for their communities is the patient, often behind-the-scenes work that any organisation depends upon for its success.

CAVAN

In 2016, a new initiative was launched in Cavan aimed at providing support for male carers. Male carers often find it difficult to identify themselves and are more reluctant to ask for help or make themselves known to health service providers. The new initiative was warmly received, and two events were held in the Errigal Hotel, Cootehill, Co Cavan, attended by over 40 male carers from Cavan and Monaghan who enjoyed hot towel shaves and other activities laid on especially for them.

CLONMEL

A very successful training day was held for Clonmel Carer Support groups in May 2016. Carers present said the day was of immense practical help in the daily work involved in caring for their loved ones.



CLONMEL TRAINING

OFFALY

A particular highlight of 2016 was the success of the first Black Tie Ball, which was attended by over 200 guests.

LONGFORD/WESTMEATH

Longford and Westmeath ran a particularly successful series of events for Carers Week 2016, which were attended by over 200 family carers.

In Westmeath, the Midlands Regional Hospital now displays a stand in the hospital foyer offering 'Information and Advice for Family Carers', referring carers who come with their loved ones to our services. Longford meanwhile provided a good example of the importance of our expanding network of carer groups, where a new Carer Support Group established in 2016 attracted over 15 family carers who continue to meet on a weekly basis.

GALWAY

Family Carers Ireland in Galway enjoyed a fantastic first year in operation, with its operations and reach going from strength to strength, as its numbers show. Expanding provision of respite and home care, and large and very active carer support groups ensured prominence in communities throughout the county.



MIDLANDS/NORTHWEST

15,000 in-home respite hours were delivered to family carers in the midlands region through the Community Employment Scheme, while, in advance of Election 2016, pre-election hustings to represent the interests of family carers were held in Mullingar, Tullamore and Sligo. TDs from all parties were in attendance.



Family Carers Ireland Limited (A Company Limited by Guarantee)

Statement of Financial Activities Incorporating Income and Expenditure Account for the Period Ended 31 December 2016

The following is an extract from the Statutory Accounts.

INCOME FROM	Unrestricted Funds 2016	Restricted Funds 2016	Total Funds 2016
Donations & Legacies	62,165	-	62,165
Other Trading Activities:		-	
Charitable activities	4,887,726	4,467,828	9,355,554
Trading activities	538,173	-	538,173
Investments	9,636	-	9,636
Total Income	5,497,700	4,467,828	9,965,528
EXPENDITURE ON			
Raising Funds	247,375	-	247,375
Charitable Activities	5,503,178	4,467,616	9,970,794
Total Expenditure	5,750,553	4,467,616	10,218,169
NET INCOME/EXPENDITURE BEFORE TRANSFERS	(252,853)	212	(252,641)
NET MOVEMENT OF FUNDS	(252,853)	212	(252,641)
RECONCILIATION OF FUNDS			
Total funds arising from merger	1,856,050	-	1,856,050
TOTAL FUNDS AT 31 DEC 2016	1,603,197	212	1,603,409

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

Family Carers Ireland Limited (A Company Limited by Guarantee)

Registered Number: 572819

Balance sheet as at 31 December 2016

FIXED ASSETS

Tangible assets	9,622
Financial assets	3
	9,625

CURRENT ASSETS

Debtors	1,448,613
Cash at bank in hand	1,460,356
	2,908,969

CREDITORS:

Amounts falling due within 1 year	(1,315,185)
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Net current assets	1,593,784
Net assets	1,603,409

CHARITY FUNDS

Restricted funds	212
Unrestricted funds	1,603,197
Total funds	1,603,409

For further detail on Statutory Accounts please go to www.familycarers.ie

FINANCE

