



Family
Carers
Ireland
Fairness for Carers



Strategic Plan 2018–2023



Introducing Family Carers Ireland

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.

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

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

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

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

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

FCI is a membership based organisation. Everyone involved in family caring is encouraged to join and become part of a wide community of those in a similar situation. Our constitution provides for a group based membership – this allows any of the 25,000+ family carers who access our services each year to input into the governance of the organisation through a network of local groups if they wish to do so. It is the policy of FCI to support any Family Carer in need whether they are a member or not.

FCI has an annual budget of c. €10m made up of a combination of grant support from the HSE and other public bodies; fees for services provided on a commercial basis (e.g. Home Care Packages); membership subscriptions; and fundraising including sponsorship and individual donations. FCI acknowledges the very generous support it receives from its various funding sources – we could not do our work without it.

Demographics

- Socioeconomic divergence in terms of income, health and birth rate.
- Growing ethnic diversity within the overall population.
- In addition to aging other forms of dependency increasing e.g. Census 2016 showed an increase of 40,000 in the number of children with disability since 2011.
- Family structure changing, extended families increasingly dispersed.
- Delayed parenthood increases 'sandwich generation' pressures.
- Individuals increasingly time poor with higher aspirations/expectations

Health & Social Care practice

- Asset-based approach to social care places a premium on local roots and partnerships.
- Growing two-tier healthcare 'market' – quality becoming primary driver in privately funded sector, cost in publicly funded one.
- Increasing but distinct pressures on cost in each tier – new technology should enable blended services and supports as a partial response to this.

Ongoing reorganisation of health services

- Realignment of Hospital Groups and CHOs will require further reorganisation of FCI.
- Sláintecare report reaffirms strategy of shifting chronic care to the primary care system and the community which moves the family carer closer to the 'nexus' of the health system.

New Public Management

- Recovery in public finances leading to public sector pay crowding out other priorities – section 39 organisations being doubly disadvantaged in this regard.
- HSE using voluntary organisations to lower the average cost of service and fill gaps that their own staff are not willing to address.

Workforce

- Economic growth leading to staff and skill shortages
- Organisation of Working Time Act a barrier to continuity of care (quality indicator)
- Technology enables more efficient centralised support services (e.g. call centre) but also potentially undermines personal support for family carers

Legislative framework

- Proposed statutory entitlement to Home Care, commencement of Assisted Decision-making legislation and follow through on LRC recommendation on changes to Succession Act all have major implications for the situation of family carers.

Regulatory context

- Charity Regulator developing new codes and standards.
- General Data Protection Regulation coming into force.
- Funding requirements in terms of reporting and auditing becoming increasingly onerous.

EIGHT KEY RESULT AREAS

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

Why this is important

Support for family carers is at the heart of why we exist. This plan envisages a fundamental review of what we do and how we do it and a sustained effort to ensuring that services are equally accessible in every part of the country.

Background analysis

The assurance of a consistent level of supports for family carers in every part of Ireland would have an immediate practical impact on the welfare and resilience of all carers. It would also directly assist the continuing reorientation to primary care services, by allowing these carer supports to be factored into the design of care plans being devised by Primary Care Teams. Finally it would assist the HSE to achieve better outcomes at lowest cost since family carers assist with many KPIs such as fewer cancelled hospital appointments; better medication compliance; delayed admission to hospitals and nursing homes; reduced length of hospital stay; and reduction in hospital readmission rates.

6

Key measures

1. Information and advocacy regarding rights and entitlements;

- a. Comprehensive rights and entitlements guide
- b. Consistent professional response to all individual queries where and as they present.

2. Skills development and technical support

- a. Comprehensive training calendar to equip carers with required skills
- b. Nurse-led support and advice on care queries through our National Careline.

3. Networking groups and social events to share experiences and combat isolation;

- a. Continue to develop local carer groups (including new forms of peer support and networking).
- b. Use key National Events to build solidarity with and between carers.
- c. 'Friendly call' programme and local befriending service linking new carers with experienced former carers

4. Advice on care planning including crisis support where needed;

- a. New tools to enable FCI to systematically assess and respond to carers' well-being needs.
- b. New emergency supports developed over the lifetime of the plan to include an emergency contact service in the event of incapacity of a carer away from home and on-call emergency home care cover.

5. Support in accessing regular and appropriate respite breaks.

- a. Authoritative assessment of full range of respite needs/offers in every community, in-home, day care, overnight, week-end and longer.

How we will measure success

- Skills and capacity of Family Care Support teams throughout the country
- Adequate Section 39 Funding to sustain core family support activities in each CHO
- New emergency services in place on a sustainable basis
- Significant increase in all types of respite care

KRA 2: Home Care services

Why this is important

At a certain point in the life of most family carers they begin to rely on the assistance of third parties to enable them to continue to manage their caring duties. Family Carers Ireland is one of 32 approved providers of homecare on behalf of the HSE. In 2017 we delivered almost 350,000 hours of care in the home throughout the country – 100,000 hours of in home respite and 250,000 hours of Home Care Packages/Home Help.

Background analysis

There are many positive reasons for FCI to engage in the provision of Home Care Services:

- (i) we get to engage with thousands of family carers who do not self-identify as carers and to point them to supports for themselves which are not part of the HSE's HCP service;
- (ii) we focus on value-added service delivery by being more efficient, effective and skilled as well as having a better understanding of the needs of the family and other carers;
- (iii) we gain an in-depth operational understanding of home care provision which greatly enhances our capacity to advocate on behalf of family carers on this very important support to their daily caring role;
- (iv) we get to benchmark ourselves against other providers and can act as an exemplar as well as advocate of best practice when necessary;
- (v) any 'surplus' we generate goes toward funding additional charitable activities i.e. Carer Support services.

Key measures

1. Ongoing investment in staff skills and support systems
2. Undertake a fundamental business process review of Home Care services to deliver a clear positioning within the FCI operational framework
3. Update/streamline existing Home Care Manual in line with 2018 Tender specifications throughout the organisation and undertake

How we will measure success

- Superior Measured Client Satisfaction ratings
- Home Care and Family Support services have been separated operationally
- FCI has a comprehensive appropriate response to commissioning and regulatory changes
- Operating target for HCP/HH agreed by board once terms of 2018 Tender are known
- New accreditation secured to replace ISO2001



KRA 3: Public policy towards Family Carers

Why this is important

Family carers need state supports that are effective and relevant to the reality of their circumstances.

Background analysis

The first National Carers Strategy published in 2012 was an important personal initiative of the Taoiseach at the time. It was an extremely positive milestone in public policy towards family carers but it needs to be refreshed at this point.

The Department of Employment Affairs and Social Protection spends over €1 billion per year providing income supports to family carers in a very responsive and constructive manner.

Even allowing for its budgetary constraints the position of the Health system is disappointing. The health service depends on family carers. This is a good thing which reflects Ireland's strong social capital, in terms of family and inter-generational bonds, in a tangible and positive way. However, without the 6.2 million hours of unpaid care they provide each week, the service would collapse. Logic would suggest that services to support care in the home should therefore increase in line with demand, but this has not been the case. The HSE spent just €19m more on home care in 2016 (€350m) than in 2008 (€331m) despite a 36 percent increase in the older population during the period. At best, home care services are being maintained at the previous year's level, and at worst they are being rationed to the extent that even those assessed as needing home support cannot access help until another person dies and hours can be 'recycled'.

Key measures

1. Effective input into mix of carer related services across the government system including Local Government, Education, Transport etc.
2. Annual assessment of progress implementing the National Carer Strategy informing regular meetings with relevant politicians and public servants.
3. Persistent lobbying for a refreshed National Carer Strategy with designated funding.
4. Active engagement with all relevant consultation processes and calls for proposals.
5. Devise a mechanism to provide legal advice and support to family carers and resource judicial review initiatives.
6. Engage in international links between carer organisations as a way of learning from others, raising Ireland's profile internationally and securing overseas funding for research and operational activities

How we will measure success

- 'Refreshed' National Carer Strategy encompassing all aspect of the lives of family carers
- Statutory Entitlement to Home Care offering fair and equitable access to all who need it
- Cross party interest Group informing legislators' perception of carer issues
- Effective legal support service for family carers

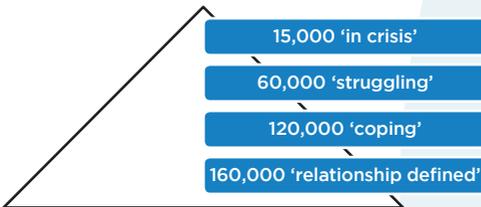
KRA 4: Engaging with family carers

Why this is important

We need to be firmly rooted in the experiences of all family carers in order to inform our work on their behalf.

Background analysis

There are 355,000 family carers in Ireland according to the Irish Health Survey 2016 yet only 195,000 self-identified as such in Census 2016. The gap between the two is explained by those carers who see themselves in terms of their relationship with the person they care for rather than their caring role.



At the other end of the scale, however, we estimate that at least 75,000 carers throughout Ireland are struggling to cope with an increasing care burden and that 15,000 of these carers are in crisis. Regrettably too many carers only approach us for help when they have reached that stage.

Key measures

1. Conduct a Membership survey and use the feedback to continue to promote membership of and engagement with Family Carers Ireland.
2. Launch new working carers programme (the largest cohort of 'unconscious' and 'coping' carers) through a network of supportive employers.

3. Grow Young Carer engagement programme in partnership with schools and youth organisations.
4. Targeted outreach to significant neglected groups of carers e.g. carers of people with rare conditions; carers of adults with substance dependency.
5. Launch programmes for former carers which support transition into employment and provide volunteering opportunities to use their experience in support of current carers.

How we will measure success

- Increased number of contacts and paid membership
- Significant engagement with new categories of carer, particularly young carers, working carers and other priority groups
- New programmes for former carers



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

Why this is important

Our capacity to influence evidence-based policy-making depends on being acknowledged as expert on the realities of caring in Ireland; our ability to win public sympathy for our cause increase the chances of success.

Background analysis

Carers themselves typically neglect or suppress their personal welfare in their concern for looking after the person they love. Without support, the effects of stress and physical exhaustion lead to increasing isolation, loneliness and depression for the carer and ultimately make the caring situation unsustainable. If current family carers are to sustain their caring roles and, indeed, the carer participation rate increased to compensate for our emerging demographic challenge Ireland needs a new focus on supporting the resilience of individual carers as well as 'treating' those they care for.

10

Key measures

1. Review the effectiveness of current dialogue structures (National Convention; Regional Forums; Local carer groups; On-line tools).
2. Compile basic dataset on family caring in Ireland with annual trend analysis and more detailed analysis of major topics of interest on a rotating basis.
3. Collaborate with significant research institutions to ensure emerging research agendas are informed by family caring issues and perspectives.
4. Liaise with CSO for improvements to Q22 of the Census and a repeat of Irish Health Survey.
5. Create voluntary register of family carers and lobby for it to be placed on a statutory basis under the proposed Home Care Act.

How we will measure success

- Regular treatment of family caring issues across a range of media
- Annual 'State of Caring in Ireland' publication
- One significant piece of research on a topic affecting family carers completed each year.
- Carers register established
- FCI the main repository of key data on family carers in Ireland



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

Why this is important

We need to increase awareness of and empathy for the organisation's brand if we are to reach our potential in terms of engaging with family carers throughout the country. This will require a prolonged multidimensional campaign and careful sequencing to maximise cumulative impact.

Background analysis

The carer movement in Ireland has traditionally focussed more on raising awareness of carer issues than of carer organisations themselves. As we extend the range and volume of supports we are able to offer we need families to be aware of our existence so that they will approach us to avail of these services – otherwise we will never find them. As that awareness builds it should enable us to develop a significant national cause-related fundraising campaign.

Key measures

1. Recruit relevant marketing expertise at board and executive level

2. Carry out a strategic assessment of the organisation's capabilities and devise detailed plans to achieve the following key objectives:

- Self-identification as a carer and self-referral to FCI;
- Awareness of and engagement with family carers by GPs, PHNs and other health professionals;
- Greater sharing of carer burden by family members, neighbours and, most importantly, the state;
- National cause-related fundraising campaign.

How we will measure success

- Increase in brand awareness of Family Carers Ireland
- Increase in self-identification by family carers
- Stronger association with carer issues in families and wider society
- Significant national fundraising event running annually



KRA 7: Optimise resources – Grow sustainability

Why this is important

We need to maximise our efficiency and effectiveness because we owe that to our funders and to our clients; we need to grow to enable us to meet increasing numbers of family carers and we need to do it all sustainably to ensure that we will continue to be there to meet those needs into the future.

Background analysis

FCI has invested heavily to meet the highest standards in corporate governance and management systems and must continue to strive to go beyond compliance to act as a model of best practice in the sector.

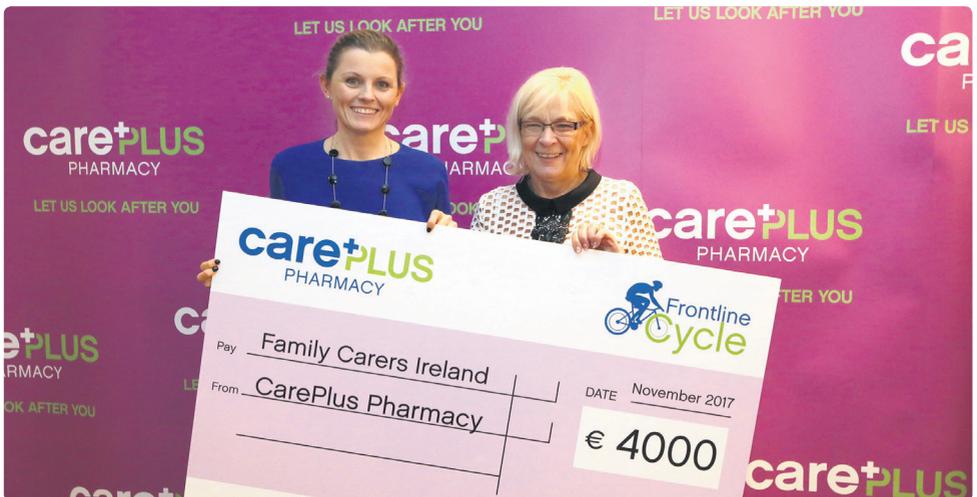
Key measures

1. Diversify existing revenue streams; grow unrestricted income
2. Continue to develop HR systems appropriate to the needs of the organisation, particularly in regard to employee development, performance management, sustainable pay and staff participation

3. Build on existing pilots to roll out major national volunteer programmes to support staff in the field (e.g. advocacy) and to meet gaps in existing funded services (e.g. befriending, home help).
4. Continue to develop electronic communications systems including new content appropriate to the needs of the organisation
5. Continue to invest in IT infrastructure
6. Develop and implement a National Blueprint for offices/points of presence network

How we will measure success

- Financial resources will match plan objectives
- Staff resources and skills will match plan objectives
- IT capacity matches plan objectives
- There is a nationwide network of presence (i.e. offices, clinics, meetings) of FCI. These are high quality facilities that reflect a high quality, national organisation.



KRA 8: Partnerships & Alliances

Why this is important

The scale of the challenge in setting out to support 355,000 family carers as and when they need it is immense and FCI will not be able to achieve it without effective partnerships across the health and social care sectors.

Background analysis

Greater specialisation and partnership amongst voluntary organisations that support health and social care in the community has the potential to improve standards and volumes of existing supports. It is also essential that every part of the formal Health System be more aware of and engaged with supporting Family Carers – at present the issue remains primarily located in the Older Persons sector of Social Care within the HSE.

Key measures

1. Ensure that FCI is seen as a valuable partner by virtue of its expertise on carer entitlements and the generic competences of care in the home
2. Initiate discussions with key condition specific organisations with a view to agreeing formal cooperation agreements whereby FCI provides support to their members in these generic areas in return for condition specific support from them for our members.
3. Engage in local resource mapping to maximise synergies and minimise duplication between different support organisations at local level
4. Pilot hospital projects in regard to (i) Patient and Family Liaison and (ii) Hospital discharge planning

5. Pilot primary care projects in regard to (i) Primary Care Clinics for Family Carers and (ii) links with GP practices

How we will measure success

- FCI has partnerships with a number of condition specific organisations leveraging recognised expertise in family carer rights and entitlements and generic care topics such as patient moving and handling; nutrition and continence care
- all Carers are signposted to local partner organisations to provide them with extra supports/services they may require
- Positive engagement with each CHO and the main HSE directorates across all areas of relevance to family carers.







National Freephone Careline:

1800 24 07 24

Website: www.familycarers.ie

Charity Number: CHY 10962