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Family Carers Survey – June 2013

Background

As part of the 7th annual National Carers Week, which takes place from the 10th to the 16th of June, Family Carers were given the chance to share their experience of caring for a loved one. 250 respondents completed this survey. The findings provide a snapshot of people's lived experiences of caring for a family member in Ireland today.

While caring can be a major source of burden and stress, particularly where unrealistic expectations are placed on individuals or when support is absent, the responses to this survey demonstrate that providing care *can* be both an enriching and rewarding experience.

The findings support previous research in confirming the satisfaction that many Family Carers feel at being able to support people they care about. The findings also reiterate the importance of providing adequate supports, as this week's 19% cut to the Respite Care Grant looms large for full-time Family Carers across Ireland.

Summary

Best Things about Being a Family Carer	Personal Satisfaction – Closeness – Offering Protection
Advice from Family Carers	Take Breaks – Have Patience – Look After Yourself
What have Family Carers Learnt?	Range of Skills – Patience – Caring can be Rewarding
Most Difficult Things about Caring	Constantly On Call – Isolation – Financial Worries
Main Sources of Support	Family – Carer/Condition Orgs – Health Care Professionals





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Main Findings

Best Things about Being a Family Carer

Top Three: Personal Satisfaction – Closeness – Offering Protection

- Respondents were first asked what the best things about being a Family Carer were. Many spoke about the positive aspects associated with providing care. Indeed, these may be important indicators as to what motivated them both to undertake and continue in their role. A sense of personal satisfaction was the most cited response.

‘Knowing his needs are met to the best of my ability’

‘Great satisfaction when you see the other person happy’

- This was followed by the feeling that, through caring, they maintained an important sense of togetherness with the care recipient in the time they spent with them.

‘Allowing my Mum to still be the centre of the family. The grandchildren can wander in and out and have her as part of their life every day.’

‘Being with your Loved one each day and able to help them’

- In spite of adversity, they felt that they became closer to their loved one. Indeed, many carers also stated that caring was a way in which they could display their love for the care recipient.
- Protection was an important feature in the responses of those carers who stated that, through the provision of care, they could ensure that the care recipient was safe, and this gave them a sense of reassurance.





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'providing comfort of mind as well as of body for them'

'knowing that the family member is getting the best possible care'

'You know they are being cared for properly'

- Ensuring that the individual with care needs was able to remain at home was an important aspect for other carers.

'Knowing that they can remain in their own home because of my caring for them'

- Some other 'Best Things about Being a Family Carer'

'Remember that caring and sharing your life with the one you love is the greatest, care you can give.'

'knowing what's important'

'Teaches you values you would never learn in any other job'

'Looking at yourself in the mirror and know you're doing the right thing by them'

'Being able to give back some of the care my mother gave me.'

'He is surrounded by people and things he is familiar with'

'Life slows down and away from the urban professional treadmill gives one a new perspective on life'





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Advice from Family Carers

Top Three: Take Breaks – Have Patience – Look After Yourself

- In terms of giving advice to other people in a similar role, the advice most frequently given was the importance of getting support in the role of carer and of taking time away from caring.

'It is a hard task and takes all of your time so when you get a chance to some time for yourself take it. It doesn't happen very often and it might only be for 5 mins. or 30 mins. but take it. We all need time out.'

- While many carers recognised the challenges in caring, they advised other carers to learn to enjoy the caring experience and thus the satisfaction and rewards associated with providing care.

'patience love consideration , but also remember to look after you too'

- Many carers spoke about the importance of coping mechanisms. Maintaining a positive attitude is important, as is remaining both determined and confident.

'It's important to take the time to rest and keep yourself well. A tired, poorly fed carer is a cranky carer and your people - and you - deserve better than that.'





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What have Family Carers Learnt?

Top Three: Range of Skills – Patience – Caring can be Rewarding

- Evidence of how caring can be a positive experience can be found in the answers to the question: 'What have you learnt about yourself from your caring role?' For instance, the most common response was the realisation of existing personal skills and strengths, followed by a recognition that caring can be rewarding.

'I have learned how strong I can actually be and how much I can learn when I need to'

'I am stronger and more patient than I thought.'

'That I am very resourceful, that I can (because I have to) make money stretch further. I have also learned to take care myself and am not afraid to ask for help.'

'that I'm a fighter for my children, I'm an advocate, speech therapist, social worker, educator, OT and physio and most of all a mum'

'I'm good at it. I may not be educated on paper but I could give most nurses a run for their money :-)'

'It takes a strong person to care full time for someone else. It's the best thing anyone could do for another person. For me hard as it is It's rewarding'.





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Most Difficult Things about Caring

Top Three: Constantly On Call – Isolation – Financial Worries

- The most difficult thing about being a carer for the majority of respondents was the feeling of being overwhelmed, and the constant responsibility associated with providing care, such as needing to be there 24/7.

'Have to be at home all the time getting ready for the next day'

'mental emotional demands 24/7'

'All the appointments! And the feeling of wanting a "normal" life without having to check the diary to see what appointments need to be planned around!'

- Many carers also spoke about the isolation and loneliness they experienced in their role.

'It can be a very lonely life'

'Your whole lifestyle changes, life outside your home doesn't mean the same anymore'

'friends not calling.'

'sometimes you get so lonely and things get on top of you when you don't get a break'

'Having to forgo many social occasions'

- Financial issues were another source of concern for carers in this survey.

'Money, or the lack thereof... This caring lark aint' cheap!.....'

'constant cuts and threat of cuts'

'that I have been refused carer's allowance and am therefore not given the recognition for what I contribute to this country'





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'Loss of income opportunities as one faces an unpredictable and irregular schedule doing a job for which one is not qualified and learning 'on the fly' gives rise to fear about future

economic security e.g. I cannot secure a mortgage as I have no full-time job and my professional skills are diluted by time away from the labour force (I have a PhD).'

'Not have access to services and support and the financial burden of giving up work'

'not getting any payment or recognition for this valuable task that is saving the HSE thousands every year'

- Many carers were highly critical of the lack of support from the health and social care systems.

'having to constantly fight for services for things that are in the persons best interest'

'Ignorance met in dealing with most officials whose job it is to provide essential help, financial, physical, mental.'

'Having no help from the local health service i.e. public health nurse etc.'

'Dealing with government who treat us like we are a burden and not their most precious resource.'

'HSE assume I am there so my mum needs no other supports'

- The attitude of others, such as a lack of understanding about the role of carer, was also important.

'not been recognised in society as a valuable worker'

'looked down on'

'People's insensitivity.'





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'Lack of understanding. People assume that if you are a carer you must have given up a dead end job. The Social worker suggested that I maybe think about getting a qualification. I've got a 1st class honours degree from Oxford! I'm a carer because the system let down my Mum & wrote her off.'

'Most people in your life will disappear'

Main Sources of Support

Top Three: Family – Carer/Condition Organisations – Health Care Professionals

- Family members were by far the main source of support cited by carers in this survey.

'My spouse. He assists in the caring duties with positivity and humour. This is invaluable.'

'My siblings are for the most part very supportive and we communicate well about issues and decisions related to our elderly parents.'

'my self and my brother do it together'

'We as mother and father have each other's support.'

'my own family not my in laws'

'Granny/grandad'

'My mother who is also a carer. It's harder on her as she is there 24/7'

'My partner...although I feel he doesn't quite understand and isn't always there for me when I'm feeling down.'

'My beautiful sister God bless her.'

- This was followed by the support received from a range of healthcare professionals.

'My family doctor is a great source and has never let us down.'





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'Local services especially the public health nurse, the community mental health nurse, the local day care centre and the local carers association all provide key supports, especially in terms of information and in terms of moral support.'

'Palliative nurses - WONDERFUL people!'

- Family Carer organisations and condition-specific organisations also provide an important source of support for many carers. Financial support provided by the Government is also crucial for many..

'The Carers Association always on hand to help and answer queries'

'Respite when I can get it.'

'other parents I've met through organisations i.e. special Olympics'

'Knowing the Alzheimers Society is a phone call away'

'HSE - carers and medical supplies'

'carer's allowance as without it couldn't look after them'

'Carers allowance and respite care grant.'

- 10% of respondents reported that they did not receive any source of support in their role.

'I have no other family so there is nobody else to help me. My Dad died in 1989. I have no siblings and my mother's family all live abroad.'

'I have no support as I can't find anyone'

'I don't have any support networks I rely on myself'

'emotionally - no support'

'Nobody'





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Other Comments

- Respondents were given the opportunity to add any further comments. Many carers noted feeling frustrated and overburdened, particularly as a consequence of the gaps that exist within the support systems.

'There is huge difficulty in getting any support from the state. You are on constant battle mode to get the smallest things from the state such as DCA, carers allowance etc. the support network is nearly non-existent'

'Carers need more support from agencies like HSE for respite. We are very much on our own trying to cope as best we can, it is not easy especially now with all the government cuts.'

'More training at times that suit carers'

'Not enough home help - hours and equipment'

'Caring for a loved one is one of the hardest things to do, You don't get financial or other support such as training'

'Being a carer you are left to it. We save the government millions, yet no adequate financial support,'

'I spent a disproportionate amount of my time filling out paperwork and trying to access to services/benefits for my children. I have had to go as far the High Court to get my son's DCA reinstated. Since becoming a carer my own health has suffered and I am on multiple medications. Still the government continue to treat us like beggars.'

- Some carers were highly critical of the lack of recognition of their role

'Should be more help & recognition of Carers in this country'

'I feel that being a carer is the hardest profession anyone could do, we are underpaid firstly, secondly a lot of the medicines/creams my child needs are not covered by medical care and are v expensive, every spare penny goes towards medicines etc. for his health'





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'It is like a job, should be seen that way, some days its 14 hour day going, its hard work. We are not invisible. U have to be nurse, cleaner, cook, everything,'

'I care for three elderly relatives and I know my work is valuable, necessary and makes a difference. My government, however, see me as a drain on their money. This takes my work and makes it into nothing.'

- However, many carers took the opportunity to speak about the rewards associated with their caring experience.

'I have spent 5+ years caring and I would not have missed out on this time with my mum for the world, when she is gone at least I know I spent as much time as possible with her and I done all I could to make her happy and live as best she can'

'Wouldn't change any if it. He is worth everything'

'It's not how I expected my relationship with my second daughter to be but I can't imagine it any other way now she has taught us as a family more than we can ever teach her.'

'Although at times, the worth of what I do daily is sometimes over-looked in my own brain, I know I'm contributing to the quality of my mams life and that she feels safe and secure and I remind myself of this when I'm struggling. Family caring is probably one of the most worthwhile jobs going.'

'If I had the chance to do it all again for a wonderful, most loving mother, I would willingly do it all over again, despite many a sleepless night, and many a bad fall. God Bless you mother, I love you now and always will, even when you are gone. Xx'

'Life as a carer is very rewarding, it is hard on your soul sometimes but at the end of the day it is the best job that I have ever done. I gave up fulltime paid employment to look after my mother and brother. We have had some wonderful times that are going to be treasured memories for all of my life. It's the time spent with them that make is so easy to do.'



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Discussion

The selection of quotes in this report demonstrates the strength and courage shown by Ireland's Family Carers. Compassion, patience and determination are some of the key attributes necessary to care.

The vast majority willingly care for their loved ones, often in spite of inadequate support in their caring role.

It is perhaps not surprising that other family members are the most important source of support.

For many Family Carers, in giving they receive, and their lives have been enriched through their caring.

It is striking that a greater number of positive aspects of caring were reported than negative. Nonetheless, a significant proportion of Family Carers do not feel adequately recognised, supported and empowered. These are three key things that the National Carers Strategy aims to deliver on. It must succeed.





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Appendix I

Survey Questions

The survey asked the following questions:

- What are the best things about being a Family Carer? (Please list up to 3)
- What helpful advice would you give to others in a similar role as yourself?
- What have you learnt about yourself from your caring role?
- What are the most difficult things about being a Family Carer?(Please list up to 3)
- What or who is your main source of support?
- Any other comments?

Methodology

Six open-ended questions were created, and 250 responses were captured through an extensively used online survey tool, SurveyMonkey. The survey was advertised and promoted on the National Carers Week website (www.carersweek.ie), Facebook page (www.facebook.com/nationalcarersweek), by NGO partners in Carers Week (www.carersweek.ie/partners), and by way of a press release on April 16th. The survey was opened to respondents on April 15th and closed on May 4th. After some minor cleansing of the data, a thematic analysis approach was used and from this, themes emerged. The full data-set is available on request.

About National Carers Week 2013

The 7th annual National Carers Week takes place from June 10th to 16th this year. Over 150 events are taking place nationwide to celebrate and recognise the role of Ireland's Family Carers. Nine national organisations are partners in Carers Week, and will organise events around the country to acknowledge the valuable contribution that Family Carers make, not only to their individual families, but to Irish society as a whole. The 2013 partners are: The Carers Association of Ireland, Caring for Carers Ireland, The Alzheimer Society of Ireland, The Disability Federation of Ireland, Parkinson's Association of Ireland, Brí, MS Ireland, The Irish Hospice Foundation and Care Alliance Ireland.

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