A new vision for care Nurse-led carers clinic evaluation

2012

A New Vision for Care

Nurse-Led Carers Clinic Evaluation

Caring for Carers IRELAND
Cúram don lucht Cúraim

Report By

Sarah Delaney
Philomena Stapleton
Isabelle Jeffares
Work Research Centre

Brigid Barron
Mary McMahon
Helena Dixon
Caring for Carers Ireland

A new Vision for Care

Nurse Led Carers Clinic Evaluation

Report by

Sarah Delaney, Senior Research Consultant

Philomena Stapleton, Senior Research Consultant

Isabelle Jeffares, Senior Research Consultant

Work Research Centre Dublin

Brigid Barron, Innovation & Programme Manager

Mary McMahon, CEO

Helena Dixon, Administrator

Caring for Carers Ireland

October 2012.

Acknowledgements

Firstly and most importantly we would like to express our sincere gratitude to the Family Carers throughout County Clare who participated in this research. They have generously shared their caring experiences and views on the role and value of the Carers Clinic. Their contribution has helped make this report rich and informative.

We would also like to acknowledge the considerable work undertaken by the staff of the Work Research Centre, Caring for Carers Clare/Limerick/ Galway and Caring for Carers Ireland in particular Clinic Nurses Mary McDermott, Kathleen Lee and Susan Hogan, Training and Development Officer.

Thanks are also due to our Founder President Judith Ironside who has always believed in the concept of the clinic; to the Board of Caring for Carers Ireland for their support and to the HSE for funding the initiative of the Carers Clinic since its inception.

Special thanks Kathleen Lynch TD Minister of State, Department of Health and Department of Justice, Equality & Defence with responsibility for Disability, Older People, Equality & Mental Health who is launching this report.

Foreword by Judith Ironside

Carers Clinic has provided a first class support system to Family Carers. As this evaluation shows, "Group Time" is not always adequate in stressful situations. Having a professional at hand giving one-to-one help has proved time and again to be of the utmost importance.

One of my biggest learning curves was the "John and Mary" story. Mary gave up her job to care for her husband John. The Nurse Led Carers Clinic became a lifeline for Mary, where she got all the support she needed both during and long after her caring role had ended. The clinic is there for Mary. In a gentle unhurried way Mary's wellbeing/problems will be discussed and solutions sought. This is an ongoing process.

The Clinic nurses keep regular touch with the Carers and give above all much needed emotional support, both during the caring period and beyond if bereavement occurs.

I know that all the Carers to whom I have recommended the clinic have found the service they receive to be second-to-none.

Congratulations to Brigid Barron, Director of Development and Innovation for having the foresight to set up the first Clinic in 2001. May we have the means to increase beyond the current three clinics in the future.

Congratulations to all the nurses in the Clinic who have given of themselves and touched the lives of so many Family Carers.

Table of Contents

List of figures

Introduction

Mary's story

Mary* (62 years) worked full time and cared for her husband (65 years) who had Picks Disease, a form of dementia. Mary spent a lot of time looking after her husband, attending to his personal care needs, working full time and managing the household which left little time for herself. She was stressed and fatigued when she was first referred to the Nurse Led Clinic by the Public Health Nurse.

The Nurse listened to Mary in confidence and provided her with the encouragement and support she needed. The clinic organised a care worker for a few hours a week which gave Mary time to herself. As Mary's husband condition worsened and his care demanded more of her time she had to give up her job. Mary found this transition extremely difficult and would speak to the Nurses on an ongoing basis where she received a confidential listening ear. Mary received reassurance that what she was feeling was normal.

Even through the bereavement of Mary's husband she received support from the clinic.

Family Carers

A Carer is a person of any age who takes on the responsibility of looking after someone else - a close family member, a relative or friend, who cannot manage at home without help because of frailty, illness or a mental or physical disability. They are people who provide care and are also people in need of services and supports when the demands of caring exceed their ability and personal resources. The Family Cares may be the voice for the person receiving care.

It is imperative that the needs of Family Carers are recognised and that an infrastructure of care is provided to enable them to continue to care without detriment to their own quality of life. This role may involve a 24-hour day and a 7 - day week commitment without respite or very often - financial help or support.

Every day in this country, 160,971 (CSO, Census of Population, 2006) family members, friends, partners, parents, children, or neighbours, provide care for someone who, through a variety of circumstances, needs it. These are Ireland's Family Carers and what they do not only makes a profound difference to the health, well-being and quality of life of those for whom they care, but makes an important, often unacknowledged contribution to the economy (National Carers Strategy 2012).

Caring for Carers Ireland

Caring for Carers Ireland is an independent voluntary support organisation working in partnership with Family Carers and those for whom they care. Currently there are 109 Caring for Carer groups and over 160,000 Family Carers forming a nationwide network in this country.

Rooted in the Carers' Charter launched by Soroptimist International Republic of Ireland in the 1980's, Caring for Carers Ireland focuses on the recognition of the role of the Family Carer, the provision of respite care, information and training while advocating for the rights and needs of Carers at local, national and European levels. It is supported by the HSE, the Department of Environment, Community and Local Government, Local Development Companies and other statutory and voluntary organisations.

The mission of Caring for Carers, in collaboration with Family Carers, is to "promote the health, wellbeing and quality of life of Family Carers and those for whom they care, by promoting recognition of their role, providing respite care, information, training and advocacy to promote social inclusion within the context of the Carers Charter".

Some of the important activities carried out by Caring for Carers Ireland include

- Advocacy
- Assistive technology including Telecare
- Befriending service
- Family Carers groups
- Home Library Service
- Information and advice
- Research (LEADER funded research on social connectedness and use of technology in older people and Family Carers in County Clare),
- Respite care
- Social inclusion for Family Carers through group development and Care in the Home training
- Training (such as mobile phone training, Care in the Home training, Care of the Elderly training at FETAC Level 5, Training the Trainer at FETAC Level 6, and life-long learning).

Background to the Nurse-Led Carers Clinic

Since 1988 services to meet the collective needs of Family Carers were established, such as Caring in Home Training and Carers Groups. It emerged that

Family Carers needed time for themselves and required access to services and support. In 2001, Caring for Carers in partnership with the Mid Western Health Board agreed to establish a Nurse Led Carers Clinic in Co. Clare (on a pilot basis) to meet the needs of Family Carers of older people and older people who were themselves Carers. Around the same time the Midland Health Board followed by other Health Boards appointed Carer Coordinators almost all of whom had a background in Public Health Nursing

There was an expressed need to provide a focus for Carers to seek help or services for themselves. The concept for the Nurse-Led Carers Clinic arose out of knowing that many Carers felt excluded and isolated and there was no place where they could express themselves in terms of their own needs. The Nurse Led Carers Clinic was a unique initiative being the first of its kind in Ireland. This service was initiated by Caring for Carers Ireland and funded by the Mid-Western Health Board. The funding was designated to support the care of older people and older Carers.

Following the success of the first clinic, a second clinic was opened in Limerick in 2003 and a third in Tuam in 2009. Caring for Carers have implemented a detailed Carers Needs Assessment Programme identifying the health and social care needs of both the Family Carer in the context of the person receiving care. The development includes the establishment of eight outreach clinics in County Clare.

The Nurse-Led Carers Clinic Service

The Nurse-Led Carers Clinic is a health care facility focusing on the care of Family Carers and those for whom they care. The objectives of the Nurse-Led Carers Clinic were to develop good practice in identifying and meeting the needs of Family Carers as identified by Carers themselves, to promote the health, wellbeing and quality of life of Family Carers and those for whom they care.

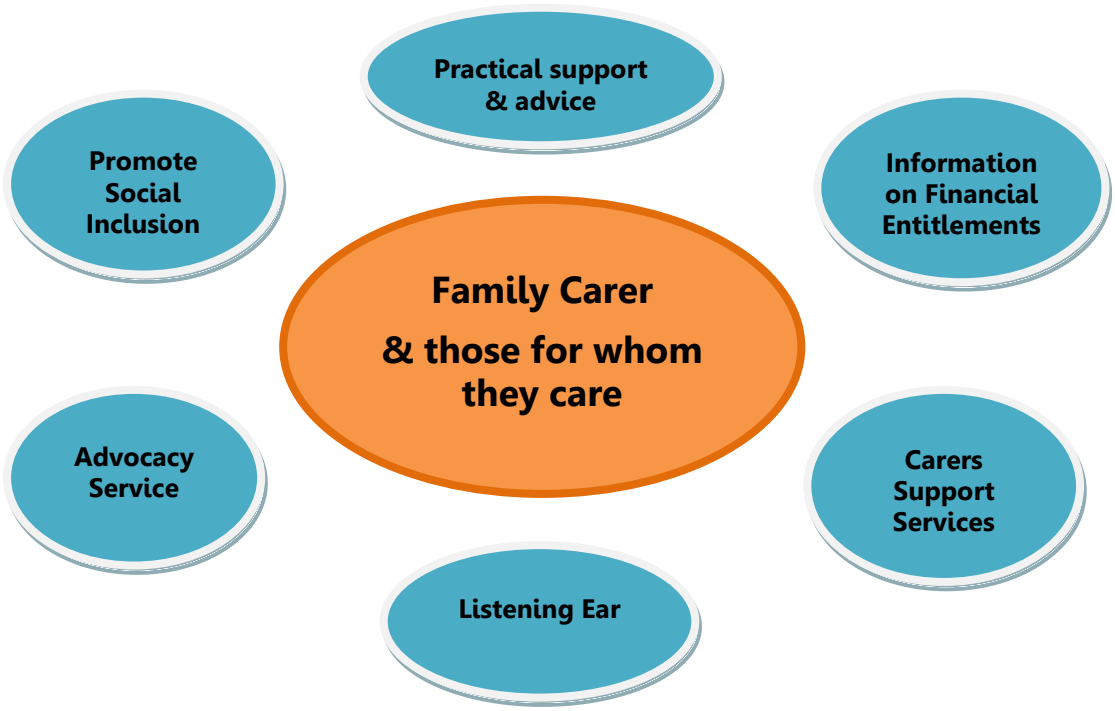
This includes identifying the reality of caring for the Carers, taking a holistic approach to meeting identified needs and providing on-going follow up care and support.

The Nurse-Led Carers Clinic is Carers-led and provides a welcoming and informal setting where Carers can access confidential support, where they are listened to in confidence, receive free information, and get advice and advocacy to promote the quality of life of Family Carers and those for whom they care.

The clinic provides a personalised caring service. Following the first meeting of Family Carers, a full assessment and comprehensive records are maintained. This forms the basis of the on-going support and care management provided over time to the Family Carers.

The clinic seeks to see the problems of care provision through the eyes of the Family Carer. This forms part of the needs assessment process. We ask the Family Carers how they think they can best work with the clinic staff to meet those needs together.

Figure 1: Organisational map of the Nurse-Led Carers Clinic



The specific objectives of the clinic are:

- To develop good practice in identifying and meeting the needs of Family Carers as identified by Carers themselves
- To carry out a comprehensive needs assessment including care provision, access to health and social services, income, entitlements, transport and social support
- To provide a focus for Carers, where they are listened to in confidence and where they can feel that their concerns are being acted on in their own best interests
- To provide information, advice and support to the family in cooperation with other Health and Social Care Agencies
- To promote an integrated approach to care provision
- To provide on-going follow-up care and support, including bereavement support
- To promote the health and well-being of Family Carers
- To facilitate social inclusion for Family Carers.

The following services are available to Family Carers from within the Carers Centre (this list is not exhaustive):

- Time to talk in confidence and at the Carers pace
- Information and help on the services needed
- Advice on the care of the Family member at home
- Family Support Service
- Explore with Family Carers their entitlements to financial support, benefits and entitlements
- Information on independent living and Senior Alert Scheme (pendant alarms).
- Practical assistance through the Home Care Package scheme in partnership with your local Public Health Nurse
- Carers Support Packages and Respite care services
- Advice on Health Promotion activities and Family Carers Training Programmes, i.e. Caring in the Home Courses
- An advocacy service to support Carers in getting the services they need for the Carer and the person for whom they care.
- Promotion of social inclusion through involvement of Carers in Caring for Carers Ireland Carers Group Network.

Terms of reference for the evaluation

1. In October 2001 the Carers Clinic compiled an evaluation form that was distributed to sixty out of the seventy referrals to the clinic. 57 Carers responded. Ninety-five per cent of Carers said they had benefited in some way from the service, 91 per cent were satisfied with the service they had received from the clinic, and 93 per cent said that they would recommend the clinic to a fellow carer.
2. An audit of clients' needs was conducted and the findings presented at the WHO/IJIC International Conference on New Research and Developments in Integrated Care, in Barcelona in 2003. A total of 94 Carers were included in this audit.
3. The audit found that the services most commonly availed of were advice and advocacy, information on benefits and service entitlements, and inclusion in Carer Groups and training programmes.
4. Caring for Carers Ireland wished to follow on from these initial evaluations, to conduct an updated and more detailed evaluation of the Carers Clinic service. The aim of the evaluation was to assess the aspects of the project that are working well, in terms of client satisfaction and service delivery, and those aspects that need to be improved.

Methods

A mixed methods approach was used in this evaluation, consisting of three main components:

1. Interviews and focus groups with staff and key stakeholders
2. Survey-based assessment of client satisfaction
3. Synthesis and reporting.

Interviews and focus groups with Staff and Stakeholders

One-to-one and focus group interviews were conducted with frontline staff and key stakeholders in the Carers Clinic in Ennis, County Clare. Interview schedules were designed by Work Research Centre (WRC). All interviews were conducted by WRC. The recordings were transcribed in full and content analysis was performed to identify key emerging themes. Interviews were conducted with four staff and stakeholders

Client survey

A survey of clients of the Carers Clinic in County Clare was conducted. The questionnaire was developed by WRC in collaboration with Caring for Carers Ireland, and was based in part on findings from the staff and stakeholder interviews. Questionnaires were sent in the post to clients for self-completion and return by stamped addressed envelopes. Questionnaires were sent to 250 clients of the Carers Clinic.

Results from the questionnaires were inputted into Microsoft Excel and converted to SPSS. Basic frequencies and descriptive statistics were then derived from the data.

Ethics

Informed consent was sought from all qualitative interview participants. Participants had the right to terminate the interview at any time, and to withdraw from the research if they wished. Qualitative interviews were transcribed and anonymised. Audio recordings of the interviews were erased once the final report had been agreed with Caring for Carers Ireland. The names of the participants have been changed in the report to protect their privacy and confidentiality.

Questionnaires were posted to clients of the Carers Clinic by Caring for Carers Ireland, however they were returned anonymously to WRC for data entry and analysis.

Results from staff interviews and focus group

John's story

John (60 years) was referred to the Nurses Led Carers Clinic by the Public Health Nurse. John works full time and cares and lives with Catherine* his 91 year old mother. Catherine has poor circulation, mild to moderate dementia and has a pacemaker.

John felt very isolated and exhausted and was in desperate need for respite as he was the sole carer for his mother. He had tried to avail of services from other agencies and required practical help and advice regarding his entitlements.

The Nurse-Led Carers Clinic provided John with on-going support, encouragement and advice, including how best he could manage care for his mother, and advice on his health and wellbeing. John received the respite he needed and he was able to continue to work full time with the confidence that his mother was been well cared for. The Nurses in the clinic have kept in regular contact with John and are available to him to provide advice and support when needed.

This chapter presents the findings of focus group and individual interviews conducted with staff of the Carers Clinic service. The findings represent the perspectives, opinions and experiences of staff in relation to the support needs of Family Carers with whom they come into contact, and how these are met by the service. This qualitative material allows us to contextualise and explore in greater detail the survey results presented in the next chapter.

Conduct of staff focus group and interviews

Four staff members took part in a focus group, three of whom also participated in individual interviews. A focus group approach was used in order to allow the staff of the Carers Clinic to discuss issues relating to the service from a shared perspective. The purpose of the focus group and the individual interviews was to gain an in-depth understanding of the aims and objectives of the Carers Clinic service, the ways in which these are achieved, and to identify any gaps in service provision. Such an understanding is important to evaluating how the service is currently meeting the needs of its clients. Interview topics included how the needs of Family Carers are addressed by the Carers Clinic, how services are delivered and the outcome of these services for Carers, and where improvements might be made. A number of cross-cutting themes emerged from the focus group and individual interviews and these are outlined below.

All participants have been allocated pseudonyms for the purpose of maintaining anonymity. Where information contained in a quote might identify the staff member the pseudonym is omitted from the text.

Overview of Carers Clinic Services

Staff were asked to outline the services provided by the Carers Clinic. Those described related to addressing the information, social, health, and home environment needs of Carers. They described in detail the range of services provided.

The primary role of the Nurse-Led Carers Clinic was seen by as staff as being the provision of one-to-one advice, support and information to Carers on their rights and entitlements to benefits and services, and practical support on issues about caring on an on-going basis.

Emphasis was placed on the importance of the Listening Ear service, where Carers can talk to the Nurses about their anxieties and concerns in confidence. Another key service provided by the Carers Clinic is the Carer Support Service which provides two hours of care support a week to Carers who have no other services going into the home. This service is limited and is not available to all Family Carers accessing the clinic. The clinic staff refers Carers to HSE services and personnel such as the Public Health Nurse, Physiotherapist, and Occupational Therapist. Carers are also referred to other services such as Day Centres, the local Carer Group and the FETAC accredited carer training courses.

The Clinic nurses may deliver training on various aspects of caring .They also undertake assessment of participants for certification of the Caring in the Home Training Programme.

Information on rights and entitlements

Often Carers present to the clinic staff not knowing what **services or benefits** they may be entitled to, or where to go for information or support. Providing Carers with information on their rights and entitlements to services is a key element of the service provided by the Carers Clinic.

The staff commented on the lack of support that Carers receive elsewhere and expressed the opinion that Carers' needs are not being met. Formal community services prioritise the needs of the care recipient and seldom take account of those of the carer.

> *'…When service providers go into the home they are talking about the patient. But they don't …notice the carer. They don't even see the carer'. [Helen]*

Main aims of the Carers Clinic service.

Participants were asked to describe, from their own perspectives, the main aims of the Carers Clinic service. Responses showed that the staff contextualised the aims of the service within the need for a specific, individualised and carer-centred support service for Family Carers and those for whom they care. Carer-specific support from Carers Clinic

One staff member emphasised the role the Clinic plays in attempting to support Family Carers and alleviate their key concerns. .

> *'[When] Carers come in here we do try to show them how to solve or alleviate whatever is upsetting them, and we try to support them as best we can.'[Deirdre]*

The staff explained how they support Carers who use the Carers Clinic. While they aim to help with the particular issue that a carer presents with, they are mindful that Carers are likely to have other needs and they try to help them to identify and articulate these.

> *'People come in with different problems and sometimes the initial problem isn't the problem at all. They come in about the Carers allowance…and…something else will emerge.' [Deirdre]*

This is not always an easy task as Carers focus on the person that they care for and are often not aware of, or do not acknowledge, their own needs. The staff see their role as caring for Carers.

> *'They come in about their mother.....or their fathers. But really we are caring for them, for the Carers.' [Ann]*

Carer-centered ethos

The staff saw the ethos of the Carers Clinic service as one of carer-centeredness and of adopting an 'holistic' approach to supporting Carers. This ethos facilitates an individualised and personal service.

> *'The one thing about the service is that....Carers are given all the time in the world that they need to speak. They know they are speaking in confidence.' [Deirdre]*

> *'I think the time that you can give people...to focus in on the person [carer] and their needs and their story really [is important], …because nobody wants to know. And I'd say that's the most valuable aspect of it...' [Julia]*

The staff believed that giving Carers time and space enables them to talk about issues that they may not be able to talk about with anyone else.

'They will talk to you in confidence you know. And they haven't that freedom within the family either because they are afraid of upsetting one another or they are afraid of voicing their resentments.' [Julia]

As well as listening to Carers, being carer-centred also means that Carers are acknowledged. Carers' needs are individually assessed when they make initial contact with the service and the staff make sure that they follow-up on an ongoing basis to meet those needs.

The staff consider it important that the support and services of the Carers Clinic are available to Carers on an on-going basis, and that they proactively continue to support their wellbeing.

'Service providers in most professions discharge people. We never do really, while they have issues or problems.' [Helen]

The need for an individualised support service for Carers

The participants felt that the primary aim of setting up the Carers Clinic in 2001 was to provide a place where Carers could come and talk about their needs to professional staff on a one-to-one basis. This way of meeting individual needs is considered by staff to be a central part of the overall service.

'Up until we established the Carers Clinic we met people collectively. And one could have a minute or two-minute conversation with them and try to help them,...but it wasn't in a relaxed environment.' [Helen]

The Clinic staff have an understanding of how caring impacts on the lives of Carers and their need for on-going support.

'Carers welcome having someone that they can turn to, because we all know that if we go into a new job we don't know who to turn to. This is a new job that they haven't chosen.' [Ann]

One staff member felt that the small size and flexibility of Caring for Carers allows the Carers Clinic to fulfil a role that cannot be undertaken by the more rigid statutory services.

'We do tend to pick up [situations], .you know where the HSE or statutory agencies have no mechanism to deal with certain issues.' [Helen]

Having formerly worked as a Public Health Nurse, Ann described how much she had learnt about the demands of the caring role since working for the Carers Clinic.

It's only since I came in here [to work at the Clinic] that I realise...the amount of time that Carers need...I hadn't the time to give that. A carer needs time to be listened to'. [Ann].

Expected outcomes of the service

The staff were asked about the outcomes they expected for clients from the Carers Clinic service and to what extent those outcomes have been achieved.

Family Carers receiving services and supports

The lack of resources in community services was identified by other staff members as a major issue and one that can result in Carers presenting to the service in distress. The staff said that they would expect Family Carers to get the services and supports they need to improve their own quality of life.

> *'Very often people come here who are not getting services any place else. They are at home, they are caring ….They often only come to us when they are in a crisis.' [Helen]*

> *'Well, ultimately you would like to see the carer get the supports and services to enable them to have a quality of life on [a] par with most people...it's about them being … happy and satisfied, and giving them choice.' [Helen]*

Acknowledging the value of the work of Family Carers

Another outcome identified was to help Carers to recognise and acknowledge the value of the work that they do, and to also recognise that they need to focus on their own lives outside of caring.

> *'But it is also about Carers acknowledging the work that the carer does... [It] is very important that they also live their own lives.' [Helen]*

Another desired outcome is that the experience and expertise of Carers will be recognised and valued by service providers.

> *'[It] is about recognition; Carers being treated equally and able to work in partnership and collaboratively with service providers. And that service providers respect Carers for what they do.' [Helen]*

Training for Family Carers

The training provided to Carers by Caring for Carers Ireland, to which Carers are referred by the Carers Clinic, aims to help Carers to be assertive when they are dealing with formal services.

> *'We have put in assertiveness [training] in the course...I think it's very important. It's not so much for the carer but for the people you are meeting; the doctors and people you are dealing with.' [Deirdre]*

Benefits of the Carers Clinic Service for Carers

The staff were asked to describe how the service benefited Carers.

Obtaining information on services and entitlements

One participant noted that Carers can be fearful of losing services that they may already have and that getting relevant and timely information on what they are entitled to is a source of reassurance to them. This makes it easier for the carer to seek and avail of the services that they need.

> *'[Carers] are frightened [that] "if I apply for this will I lose that?" There is a myth out there and we really can reassure them. And we tell them what is definite and what they can have and what they can't have, or at least refer.' [Julia]*

The confidential listening ear service

Some staff members pointed out that Carers benefit greatly from the opportunity to have a listening ear and from being able to share their worries and concerns with the staff there.

> *'They see that you are giving them time...you listen to them. You don't listen with your ears, you listen with your eyes, do you know...they feel that you can put your hand on their shoulder.' [Ann].*

> *'[Carers] come in [to the Clinic] and they are very upset, and everybody goes out feeling better. I can honestly say that everybody goes out feeling better.' [Deirdre].*

Social contact

The on-going contact that the staff maintains with Carers through the Carers Clinic and through the recently introduced Friendly Call service helps to combat the social isolation that many Carers experience. This contact was described by staff as being a 'lifeline' for some Carers.

> *'Now some people mightn't think that talking and supporting is ringing and asking "how are you feeling today?" Another person might think "that's absolutely my lifeline".' [Julia]*

Similarly, the bi-monthly letter to Carers is regarded as a vital communication tool. Although it is an expensive exercise for the service, the staff feel that the benefit that Carers get from it outweighs the financial cost.

> *'We continue to do it simply because so many Carers have said that when that letter drops in on the mat on a morning, on the day that they are not feeling too good, even just by receiving that letter they know that there is somebody out there who knows and who cares about them.' [Helen]*

The Carers Group

The Carers Group is regarded by staff as integral to the Carers Clinic. Carers are referred by the staff to the support group meetings. These meetings have a social, recreational and an educational role and include activities for Carers such as health promotion activities, respite opportunities, social and moral support.

> *'I think the [Carers] group is integrally linked with the clinic…they come to the clinic, they ask to put their name on the database, they get the notice about the meetings, they come to the meetings, they make friends.' [Deirdre]*

Another participant explained that Carers who go to the group meetings tell other Carers about the support group.

Training Programme

Clinic staff have the ability to respond to the varying needs of the Family Carers at local level and provide services which the statistics agencies may not have the mechanism to deal with.

Carers Support Service

Staff identified practical help with caring as Carers' greatest need. Many Carers do not receive any help with caring and the Clinic provides them, with two hours paid care a week so that they can have a short break from caring. The Carers Support Service is greatly appreciated by Carers and it is regretted that it is limited by funding.

> *'We have found [that] the greatest success is, …the Carer Support [Service]…[where] we pay somebody to go into those people who get nothing… and they [Carers] seem to get more out of that.' [Ann]*

Contribution to the wider policy agenda

The staff discussed the way in which the Carers Clinic contributes to the wider policy agenda on caring and the needs of Carers. Clinic staff are in the unique position of interacting with Carers on an ongoing basis and they develop a good understanding of their needs and their perspectives. This knowledge and experience is fed back into Caring for Carers Ireland who aim to promote the perspective of Carers at policy level.

> *'We respond to what Carers say. We have responded to the Law Reform Consultation, the Garda Strategy on Older People, Active Ageing, Citizenship. Any national call for submissions, we respond to. We always try to get the Carers perspective in there.' [Helen].*

Helen also felt that Caring for Carers had been influential in certain policy decisions such as the implementation of the Home Care Packages and the Respite Care Grant, the inclusion of questions on family caring on the CSO census and the National Carers Strategy.

Factors that support the Carers Clinic service

Staff were asked to describe and discuss the factors that support the Carers Clinic service and support them as members of the staff team. Those supports identified related to factors both internal and external to the organisation. Internal factors include the support of colleagues, positive feedback from clients and the professional background of staff.

> *'A lot of the success of the clinic is down to the personnel. I have to say that the personnel are very committed to the clinic, and they are all people of huge experience.' [Deirdre]*

Good working relationships with colleagues were identified by one staff member as being important to her as a member of the staff team.

> *'I suppose support from your colleagues. A very good atmosphere, a friendly atmosphere. We share our experiences and assist in problem solving [for carer]). We also support each other.' [Ann].*

For Deirdre, it is the feedback that the service receives from Carers that helps her most.

> *'I'd say mainly it is the feedback from Carers. That's really it. The feedback, it makes it worthwhile taking that extra step.' [Deirdre]*

The majority of the staff members previously worked as Public Health Nurses. This experience was identified as being advantageous both in terms of the support that they can provide to Carers and their knowledge and understanding of caring in the home and the needs of the Family Carer across the services at local level.

> *'The fact that we were public health nurses, that we have that we understand the whole service, how it operates and how they are managed.' [Julia]*

External supporting factors that were identified by staff related to the relationships with other voluntary and statutory organisations. These relationships have been developed over the years and are considered to be crucial to the service, enabling it to work in partnership with others to best support Carers. External organisations identified included; the Alzheimer's Society, the Irish Wheelchair Association, the Irish Red Cross, Enable Ireland, the Citizens Information service, the Home Library service, and Clare Volunteer Centre. Other organisations include; The County Development Board.

The staff also noted the good working relationships that they have with the local HSE services.

> *'We've worked within the HSE and with that experience we now work with them to support Family Carers.' [Ann]*

Barriers to service provision

The staff identified a number of barriers to service provision. These were both internal and external to the organisation. Internal barriers included limited operating hours and communication difficulties. External barriers related to a shortage in funding, lack of awareness of the service in the community, and the non-inclusion of the service in the Primary Care Team structure.

Internal Barriers

Limited operating hours of the service

Funding levels allow the clinic to operate on a part-time basis only. All clinic staff work part-time and while the service is open all day on Mondays, from Tuesday to Friday it is open in the mornings. The staff noted that this has a number of disadvantages. Firstly, it was highlighted that case loads have increased to the extent that the part-time hours of operation are insufficient. In addition, Carers often need a lot of time when they call in to the Clinic and staff feel it is important that they are given that time. Indicating that she has approximately 400 clients on her case load Ann commented:

> *'I work twenty-four hours [a week] [in the Clinic]…and it's not enough…now so many are coming in to us that it is very hard to follow…up as much as I would like to…but I make sure I prioritise them.' [Ann]*

The limited operating hours of the clinic can lead to difficulties with balancing the important work of the clinic with the demands of administering other services such as home care packages.

> *'You see we coordinate the home care package and we have to get the workers and vet them and make sure they are trained. It's quite a lot of work.' [Julia]*

Communication

An additional disadvantage associated with the restricted hours of operation relates to the communication difficulties that it can give rise to within the service. Carers who call to the clinic when it is not open may not get the assistance that they need at that time.

> *'You see we are also at a disadvantage if we are only here…there is nobody here in the afternoon. So if they [Carers] come looking to talk to one of us we are not here, so they are redirected upstairs. So we mightn't even know they have come to talk to us.' [Julia].*

External Barriers

Funding issues

The lack of funding was a repeated theme throughout all interviews. The contraction in government funding allocated to long term care and to community care services was noted by some participants.

> *'Five years ago there was twenty-five thousand people in nursing homes and in residential care settings. You know it's just being cut away year on year. And where does all this caring end up? It ends up in the home.' [Helen]*

The lack of funding to community care services impacts on the coordination of Home Care Package by the clinic staff. One staff member noted the difficulty with funding to care workers' mileage when they have to travel longer distances in rural areas where care recipients live in remote areas. This increases the cost of care provision which may present significant difficulties.

> *'Yes, mileage….When I have a worker, and I have a great worker there but she has to travel a distance.' [Ann].*

More specifically to the Carers Clinic, funding levels affect the types and levels of services that they clinic can provide to Carers. The two hours a week carer support is of great benefit to Carers but funding levels limited this service.

> *'Well, the money is always a problem isn't it? And I would love if there was more money for carer support because its only two hours a week but its one of the [services] that is most valued...it gives them [some] respite.' [Julia]*

Lack of awareness of the service

Another barrier that was noted by staff is the lack of awareness within the community, and amongst Carers, of the Carers Clinic and the services that it provides. This is compounded by a lack of appreciation amongst those who are unaware of the service and of the value of the model of support that the Carers Clinic provides.

> *'Now I suppose the biggest drawback is [that] people aren't aware [of the Clinic]..I think too that people...don't appreciate the value of being able to talk,. But I think … to talk is one of the major things a carer will need.' [Julia]*

Paradoxically, the lack of awareness of the service is paralleled by it being viewed in some circles as unique in meeting the needs of Family Carers. While Helen noted that being small and flexible was a positive thing as it allowed the Carers Clinic to fill in gaps in services, Julia expressed the opinion that other agencies refer Carers to the Carers Clinic simply because they themselves have nothing to offer them.

> *'They will send to us cases where no one else has a solution.' [Julia]*

Patient Discharge Planning

Although the staff reported that they have a good working relationship with personnel in HSE services, and with Public Health Nurses in particular, some noted that the non-inclusion of personnel from the Carers Clinic is a barrier to service delivery. Helen noted that the staff had been trying for some time to be represented on the Primary Care Teams and that this would be beneficial for Family Carers.

> *'Well one thing where I think it would give it great acceptance would be if the Clinic Nurse were included as part of the multi-disciplinary team.' [Helen]*

Improvement of service provision

Staff were asked about how the services provided by the Carers Clinic could be improved. Suggestions offered related to addressing the barriers to service provision that they had described throughout the interviews.

A specific budget for the Nurse Led Carers Clinic

Helen expressed the view that along with funding for the Carers Clinic as a whole, the clinic should be allocated a specific budget to meet "immediate" or "humanitarian" needs. Helen explained that being able to give Carers who are in need a small amount of money for a specific purpose and can make a big difference to them. This sort of financial help is carefully allocated by staff and it is rarely abused by Carers.

> *'I do think a small budget to get people over a hump...It changes their lives. It makes a huge difference to be able to give people something... where you identify a real need, an immediate need and that a small amount of money can make the difference for those people.' [Helen]*

Embedding the Carers Clinic into the organisation and into the community

One participant said that more could be done in terms of embedding the Carers Clinic into the overall organisation. This participant also felt that greater integration into the community would be beneficial.

For a number of years Caring for Carers and clinic staff have participated in the Hospital Health Expo which is attended by the general public. Health information and health screening are provided.

The service is continuing in its efforts to be included on the Primary Care team which, if successful, would be regarded as a great advancement.

> *'We had a meeting with the manager here in Clare. We've spoken to Professor Drumm when he launched the Primary Care Team in Scarriff. He was in agreement of having a representative of the organisation on the Primary Care team. So we are working on that. And that certainly would be a major step forward.' [Helen]*

In addition, the clinic are phasing the promotion of services through different medias such as leaflet distribution (HSE service providers, libraries, clinic..), local and national radio, raising awareness through training programmes.

> *'We do have referrals from professional service providers. We circulated a leaflet to them with a referral slip on it...we've just had leaflets printed. We have distributed them to the GPs, to the Chemists, to the hospitals…we are hoping to meet with all the Primary Care Teams, tell them what we do and give them the leaflet.' [Helen]*

Results from Carers Clinic user survey

Michael's story

Michael (47 years) is married with a young family and cares for his 78 year old mother. Michael lives 30km away from his mother and travels every day to care for her in the evening after work. Although there are other family members, his mother didn't want any additional help and was very dependent on her son. He spends a lot of time with his mother and this is affecting his marriage and family life.

Michael felt overwhelmed because of his commitments to his family, work and also from other family member's expectations. Michael contacted the Nurse-Led Clinic in a distressed state.

The nurse assessed Michael's situation and through this assessment worked with the Public Health Nurse and GP to help to get the best possible outcome for Michael.

The nurse helped to organise a day care centre for his mother, organised a home help, telecare service and got meals delivered.

The nurse supported Michael and his family in having a Family meeting.

The Nurse-Led Clinic has helped Michael prioritise his family life and he doesn't have to travel to his mother's house every day as other members of his family are now on board to help with her care.

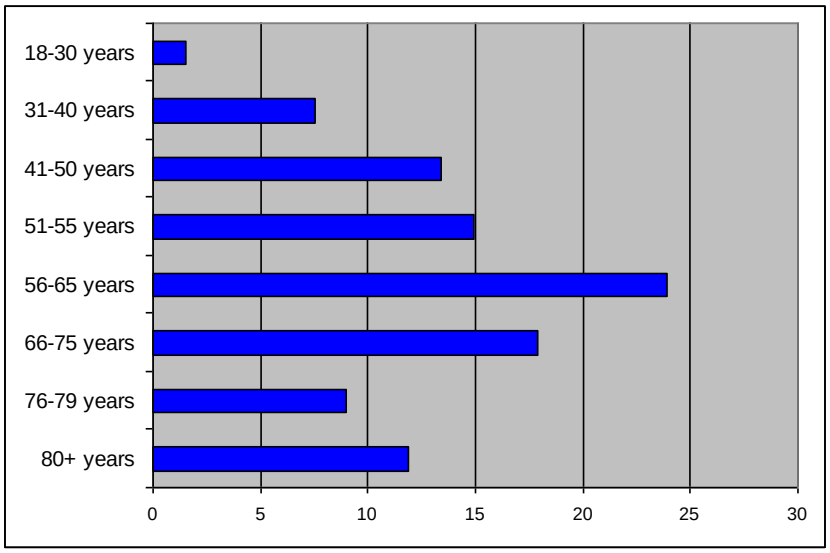
The questionnaire consisted of closed questions, where respondents would tick a box to indicate their answer, for example 'yes' or 'no'. There were also open-ended questions allowing the respondent to write in their own answer to the question based on their opinion. It is worthwhile noting that open-ended questions will yield percentage totals which together often do not add up to 100 per cent. There are a number of reasons for this; for example not all respondents will be eligible to answer, i.e. where the question requires that you answered *"Yes"* to the previous question; where the feedback provided by respondents varies widely across the group; and where respondents simply do not answer the question. For example, respondents were asked to answer "yes" or "no" to whether they would recommend the Carers Clinic service to another carer. Those who answered "yes" were asked to explain why they would recommend the service by writing in their answer.

Background information

A total of 69 service users completed the Carers Clinic evaluation questionnaire. The majority of respondents were female (n=52, 75%), and a total of 17 men (25%) took part in the survey.

A total of 67 respondents indicated their age. Over a third of the sample were aged 66 years or older (39%), with eight individuals indicating their age as 80 years or older (12%). Almost 60% of respondents were aged between 31 and 65 years. Only one respondent was aged between 18 and 30 years.

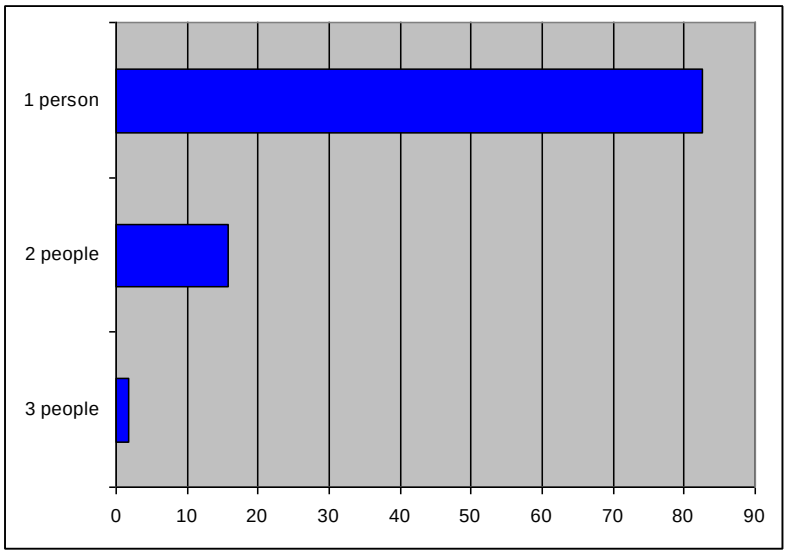
Figure 2. Respondent age group



Number of persons cared for

The survey respondents were asked how many people they were caring for. A total of 57 participants answered this question; twelve people did not indicate an answer, possibly because the person they cared for was deceased at the time of the survey. Of those that did respond, 47 people (83%) said they cared for one person. Nine people (16%) said they cared for two people, and one person reported caring for three people.

Figure 3. Number of persons cared for

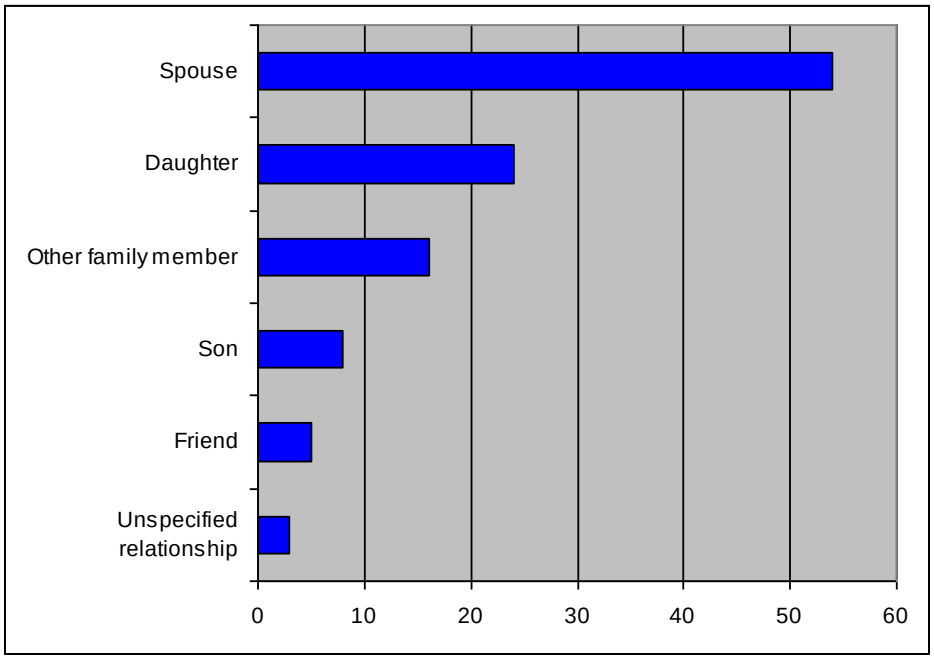


Relationship to person cared for

Respondents were also asked to specify their relationship to the person or persons they were caring for. To allow for those who were caring for more than one person, respondents could select one or more options.

Thirty-six people (54%) said that they were the spouse of the person receiving care. Sixteen people (24%) said that they were the daughter of the person receiving care. Eleven people (16%) said that they had another type of familial relationship to the person receiving care. Five people (8%) said that they were the son of the person receiving care. Three people (5%) said they were a friend of the person they were caring for, and two people said that they had another, unspecified, type of relationship.

Figure 4. Relationship to person cared for



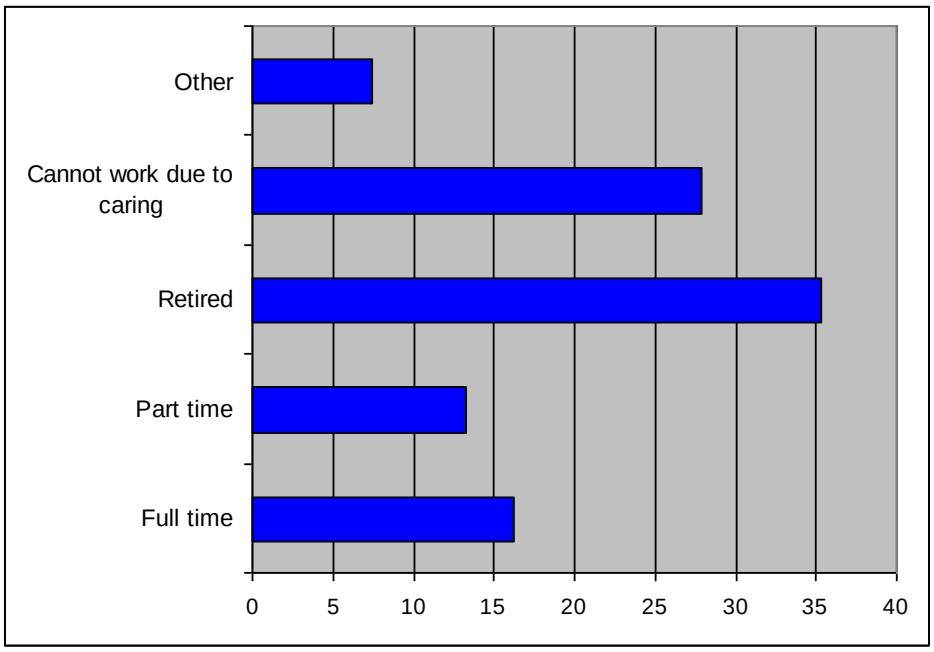
Working outside the home

The survey participants were asked whether they worked outside the home. A total of 68 respondents answered this question. Twenty-four people (35%) said that they were retired. A further nineteen people (28%) said that they could not work due to their caring role. Eleven people worked full-time (16%), and nine worked part-time (13%). Five people reported another employment status (7%). When asked to specify their status, responses included:

- Not working due to illness and/or old age (n=3)
- Working as a farmer (n=2)
- Unemployed (n=2)

One person did not answer the question.

Figure 5. Working outside the home



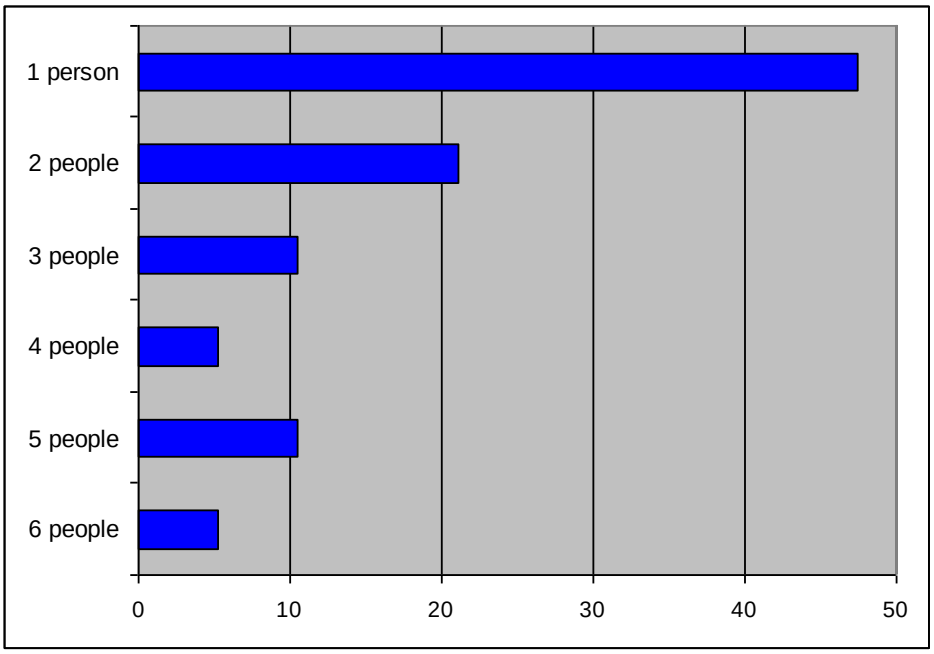
Living with the person cared for or not

The respondents were asked whether they lived with the person they cared for. Sixty-six people answered this question. Forty-nine people (74%) said they did live with the person they cared for, and 16 (24%) said they did not. One person answered 'not applicable' as the person they cared for was deceased. Three people did not answer the question.

Other people living in the household

When asked whether there were other people living in the household apart from the person being cared for. Sixty-five people in total answered this question and, of these, 20 people said that there were other people living in the household (31%). Of these twenty respondents, nine said that there was one other person living in the household (47%), while four said that there were two other people in the household (21%). One person said that there were six other people living in the home.

Figure 6. Number of other people living in the household



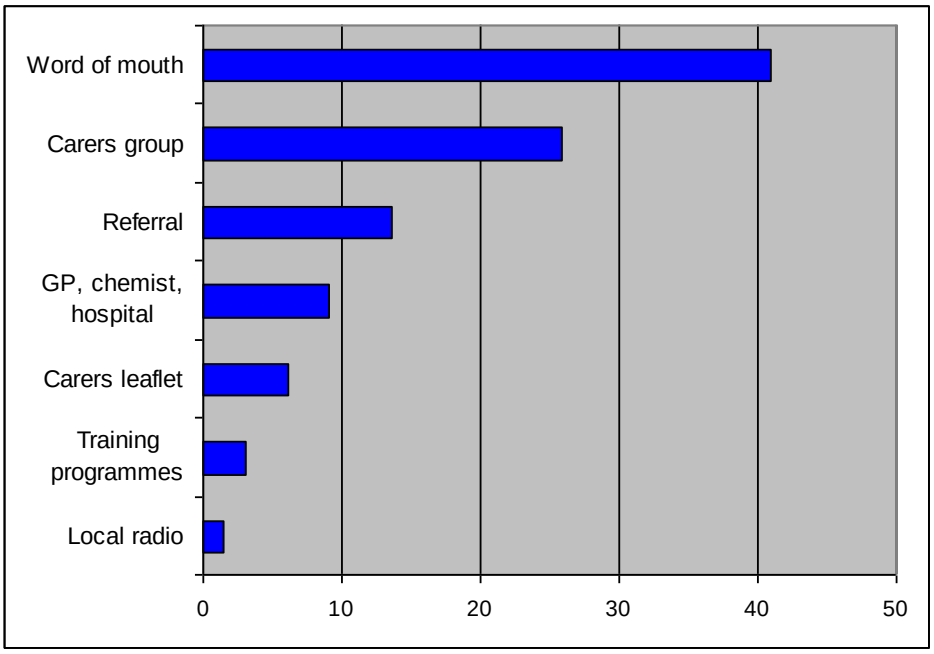
Use of Carers Clinic

This section deals with how the survey respondents heard about the Carers Clinic, and how they made use of the service.

How users heard about the Carers Clinic

Respondents were asked how they had heard about the Carers Clinic. Sixty-six people answered this question. Forty-one cent said they had heard about the clinic through word of mouth (n=27). Another 26 per cent said they had heard about it through their Carers' support group (n=17). Nine people (14%) said they had been referred by another agency. Six people (9%) said they had heard about it via their GP, a chemist or a hospital, while four others found out about the service through a Carers' leaflet (6%). The remaining three participants heard about the clinic through training programmes or local radio.

Figure 7. How did you hear about the Carers Clinic?

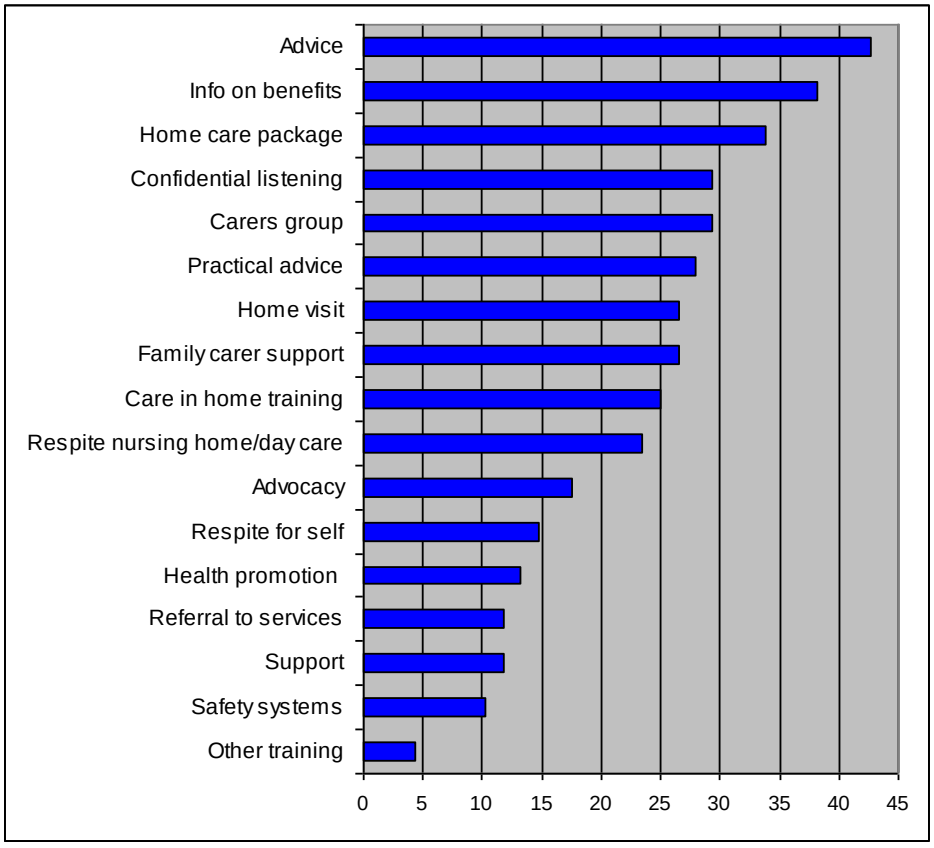


Services used via the Carers Clinic

The survey participants were asked which of the services offered by the Carers Clinic they had used. Respondents could select more than one option. Twenty-nine people (43%) had received advice. Twenty-six (38%) respondents had received information on benefits and service entitlements. Twenty-three people had used the HSE Home Care Package service (34%), while twenty people (29%) said they had availed of the confidential listening ear service. A further twenty people (29%) had used the Carers group as a social support. Nineteen people (28%) said they had received advice on practical aspects of caring, while eighteen people (27%) said they had received a home visit from the Carers Clinic staff. Another eighteen people (27%) reported using the Family Carer support service. Seventeen people (25%) said they had received care in the home training. Sixteen people (24%) said they had used the respite nursing home/day care

service, while 12 respondents (18%) said they had received advocacy support. Ten people (15%) reported that they had used respite for themselves. Less than 10 people respectively said they had received health promotion information (n= 9); Referral to other services (for example the GP/Public Health Nurse/housing/social welfare; n= 8); Support (for example following a bereavement; n= 8);, Telecare or a related safety and security system (n= 7).

Figure 8. Services used via the Carers Clinic



Services found to be of most use

Thirty-four respondents identified which services they found to be the most useful. This was an open-ended question, where respondents could enter their own answers. This means that some people entered more than one response, so the figures below add up to more than 35.

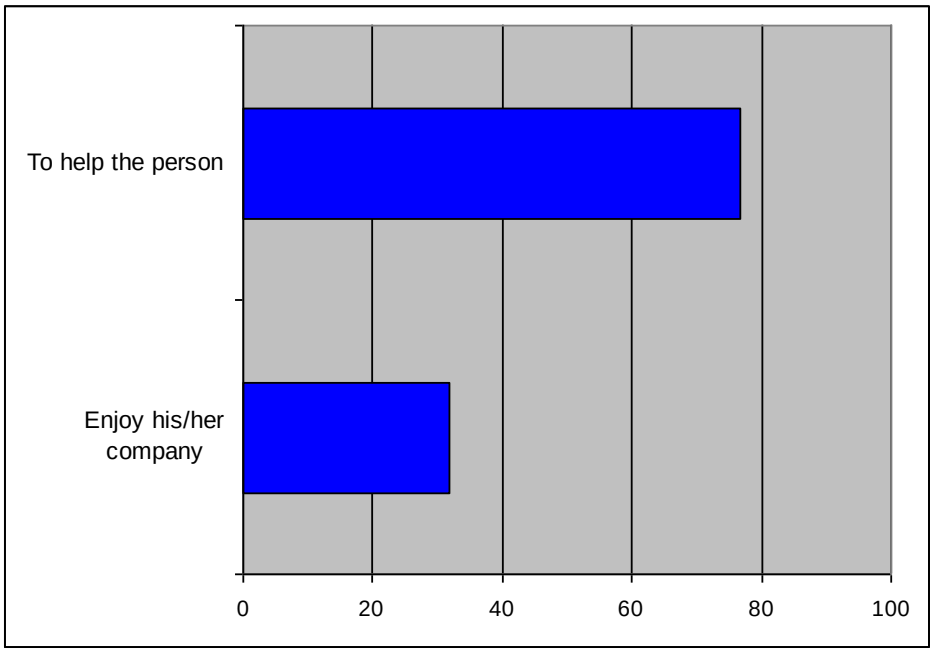
Ten people said that they found being listened to (the confidential listening ear service) was of most use to them. Seven people found training, especially Care in the Home training, to be of most use. Five people said that the advice they received was of most use to them. Three people said that all the services they received were useful. Other useful services identified were the Home Care Package (n=2), the Carers' Group (n=1), the newsletter (n=1), home visits (n=1), nursing (n=1), occupational therapy (n=1), and respite (n=1).

Perceptions of the caring role

Perceptions of the caring role – positive aspects

The survey respondents were asked which aspects of the caring role they found positive. Respondents were able to select more than one answer. Twenty-two people (32%) said they found enjoying the company of the person cared for a positive aspect. Fifty-three people (77%) said they found being able to help the person they cared for a positive aspect.

Figure 9. Positive aspects of the caring role

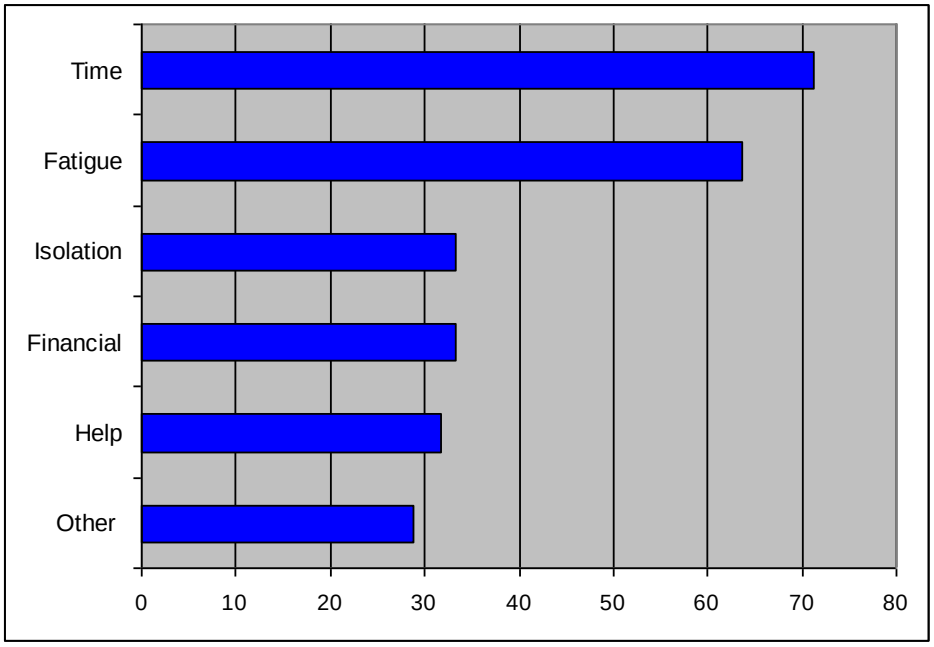


Seven people identified other aspects, however not all these comments were positive. One person said that there was no positive aspect to the caring role. Two people felt that caring was a duty that they should perform. Another person said that 'surviving caring' was a positive aspect. On a more optimistic note, one person identified love as a positive aspect of their caring role. Two others said that receiving support and information was positive.

Perceptions of the caring role – difficulties

The participants were also asked to identify the main difficulties they experienced in their caring role. Sixty-six people answered this question. Respondents were able to select more than one option. Forty-seven people (71%) said lack of time for themselves was a main difficulty. Forty-two people (64%) said that fatigue was a main difficulty. Twenty-two people (32%) said that social isolation was a main difficulty. Twenty-two people said that the financial cost of providing care was difficult. Twenty-one people (31.8%) said that lack of help with caring tasks was a main difficulty. Nineteen people (29%) identified other difficulties.

Figure 10. Main difficulties of the caring role



Three people identified lack of time due to the 24-7 nature of caring as difficult. Three people identified lack of support from family or services as difficulties. Two people said that it was difficult to deal with the psychological and emotional impacts of caring. Two people said that the physical aspects of caring were difficult. Other difficulties reported were the inability to take the person cared for out and engage in activities (n=1); poor relationship between the carer and the person cared for (n=1); caring for someone who had no speech (n=1); worrying about the future of the person cared for (n=1); setting boundaries and handling the change of lifestyle that comes with caring (n=1); affording the costs of transport (n=1); the geographical distance between the carer and the person cared for (n=1); the reluctance of the person cared for to use respite care (n=1); and the loss of income associated with caring (n=1).

Needs of Carers

The respondents were asked to identify the main needs they had before they engaged with the Carers Clinic. Respondents could select more than one option. Needs were categorised according to the following:

Information on entitlements

Thirty-four people (57%) identified information on entitlements as a main need. Nine people did not answer the question.

Assistance with caring tasks

Thirty-one people (52%) identified assistance with caring tasks as one of their main needs.

Social contact

Twenty-five people (42%) identified social contact as one of their main needs.

Respite care

Nineteen people (31%) identified respite care as a main need.

Financial assistance

Sixteen people (26%) identified financial assistance as a main need.

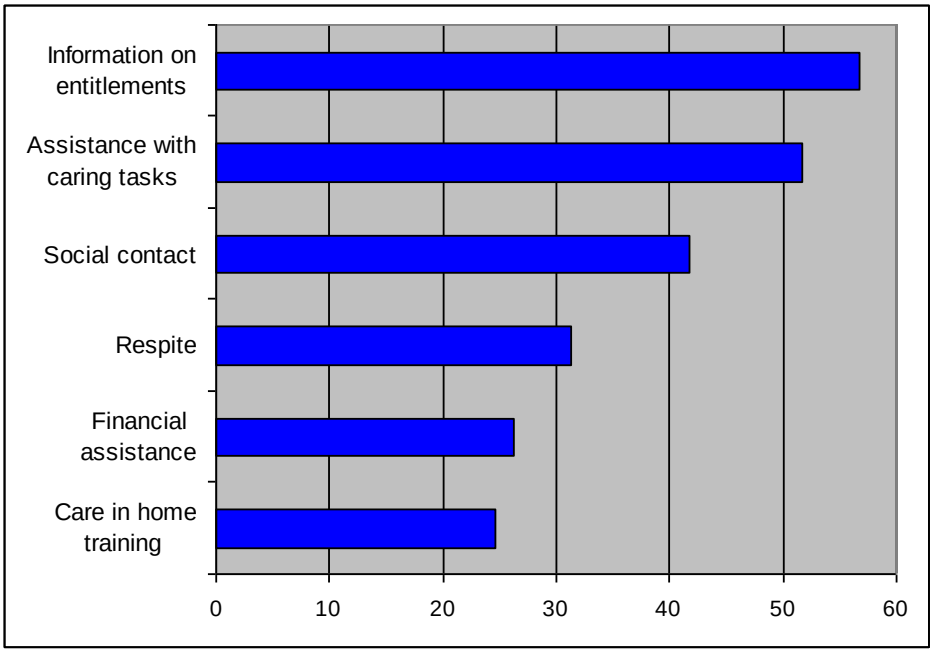
Care in the Home training

Fifteen people (25%) identified Care in the Home training as one of their main needs.

Other

One person identified another need. It should be noted that some of those who did not select the 'other' option still identified a need in the open ended question.

Figure 11. Main needs identified by Carers



However, when asked to specify 'other' needs in an open-ended question, eight people responded. Two people identified isolation as a main concern. One person identified 'a listening ear' as a main need. Two people identified advice and information as needs. One person expressed a concern about lack of entitlement to financial assistance, and another about lack of assistance in filling out forms (that they felt they had not received from the Carers Clinic). One person said they had received practical and financial help.

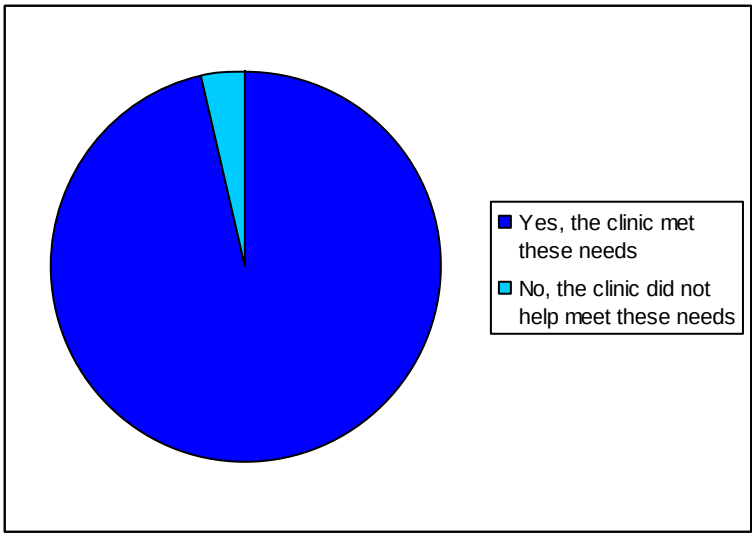
Satisfaction with Carers Clinic

Meeting the needs of Carers

The survey respondents were then asked whether they felt that the Carers Clinic had helped them meet the needs they had identified. Fifty-six people answered

this question. Of these, 54 (96%) said the Carers Clinic had helped them meet their needs.

Figure 12. Extent to which Carers Clinic met needs of Carers



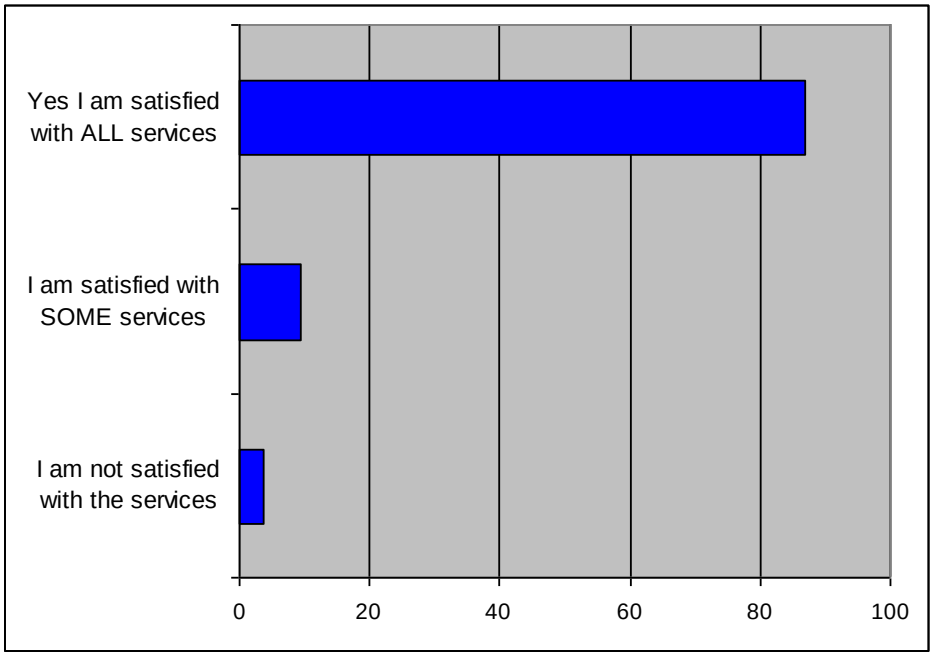
Other supports required

Carers were also asked to identify other supports they would like from the Carers Clinic. Nineteen people responded. Three people said they would like more hours of care assistance or home help, and one person requested assistance in obtaining a HSE Home Care Package. Two people said they would like access to respite care, and one of these also requested financial assistance. Two other people said they would like more flexibility in-service provision for special cases, or when needs change. Other required supports identified were: practical training in caring tasks (n=1); a transport service to facilitate social outings and get-togethers (n=1); more social outings (n=1); an advocacy service (n=1); support in times of stress (n=1); an opportunity to talk and be listened to (n=1); and to continue the good work being carried out by Carers Clinic (n=1). Three people said they did not require further supports, and one person said they did not know what further supports they would like.

Satisfaction with Carers Clinic

The survey participants were asked whether they were satisfied with the services provided by the Carers Clinic. Only 53 people answered the question. Of these, 46 (87%) said they were satisfied with all the services provided by the Carers Clinic. It is not clear why 16 people did not answer.

Figure 13. Satisfaction with Carers Clinic



Suggestions for improvement

The respondents were also asked whether there was anything about the Carers Clinic that could be improved. Forty-six people answered this question. Seventeen of these answered 'yes', however, 23 people went on to respond to the open-ended follow-up question that invited them to specify areas for improvement.

Four people said they would like more resources (either time, funding or staff resources) given to the Clinic. One person said that extra staff would improve the Carers Clinic service. Another said that longer opening hours would be a good idea. One person suggested holding Caring for Carers meetings during the day as well as in the evening. Finally, a participant suggested that if more funding were available, more help in the home could be provided to Carers.

Three people said that they would like more follow-up from the service. One person illustrated this by saying that 'if a carer falls through the loop there is no follow-up or no phone call to see if they are ok'. Two people said that they would like to see improvements in the home care service, either through more training and upskilling in administering medication (n=1), or making sure replacement cover is available when home Carers cannot attend (n=1).

One person would like occasional home visits, and another person wanted annual updates on Care in the Home Training. Finally, one person suggested that more support be provided to Carers caring for a younger person.

Two people wanted to express their thanks to the staff of the Carers Clinic for the support provided.

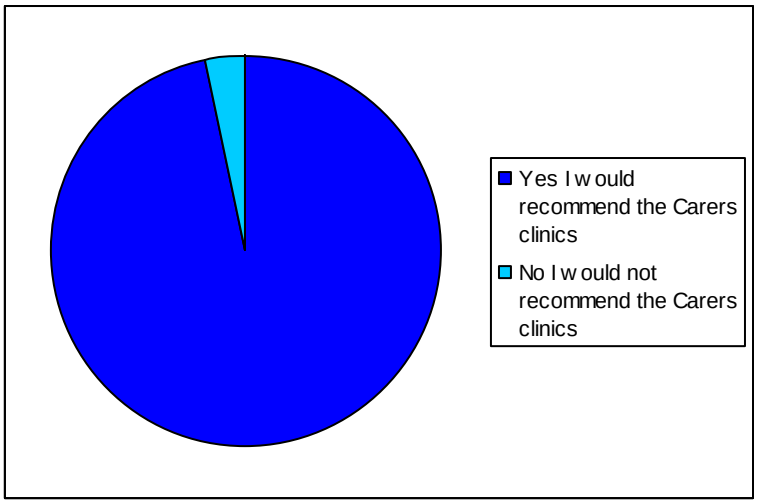
Five people said that they would like more external support and benefits. 'External support and benefits' refers to services provided by the HSE and/or social welfare such as Carers' Allowance, or some form of compensation in lieu of

Carers' Allowance (n=1), home improvements and payments for the carer (n=1), more home help and personal care (n=2), and relief cover for holidays (n=1).

Recommending the Carers Clinic to other Carers

The survey participants were also asked whether they would recommend the Carers Clinic to another carer. Sixty-two people answered this question. Sixty respondents (97%) said they would recommend the Carers Clinic, and two people (3%) said they would not.

Figure 14. Would recommend the Carers Clinic to another carer



When asked to give reasons for their answer, 34 respondents provided more detail. Sixteen people said that the Carers Clinic offer good information, advice and support. Seven people said they would recommend the Clinic because it was a place they could go to discuss any problems and feel listened to. Four people said that the service provided a sense of companionship and reduced isolation. Four other people said that the Carers Clinic were very friendly and caring. Three people said that any help available is of benefit to Carers.

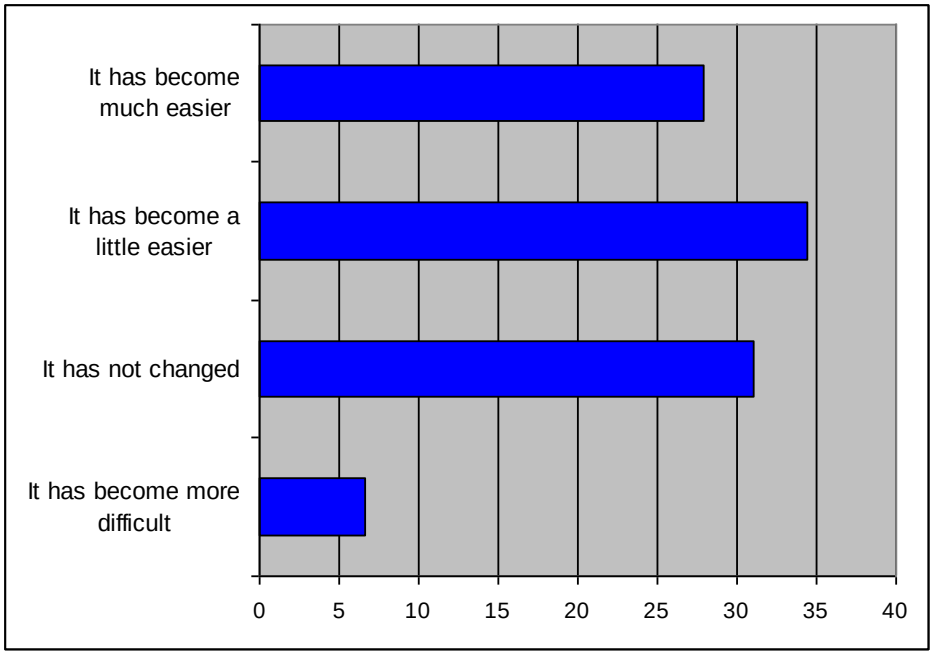
Impacts of Carers Clinic

The survey also investigated how users of the Carers Clinic felt their individual roles as Carers had been affected by engaging with the Clinic.

Change in caring role since engaging with Carers Clinic

Respondents were asked whether their caring role had changed since engaging with the Carers Clinic. Sixty-one people answered this question. Of these, 17 (28%) said that their caring role had become much easier since engaging with the Clinic. Twenty-one people (34%) said it had become a little easier. Nineteen people (31%) said their caring role had not changed, and four people (7%) said it had become more difficult.

Figure 15. Change in caring role since engaging with Carers Clinic.

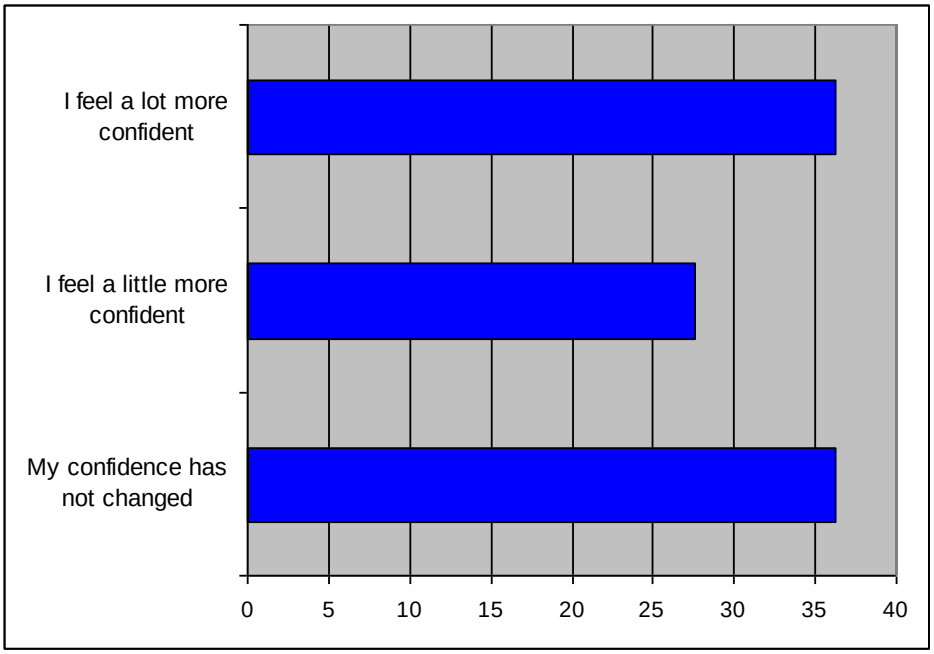


Thirty-one respondents gave more detail on their responses to this question. Seven people said that they had benefited from the support and listening service provided by the Carers Clinic. Six people said that they had been helped overall by the services they had obtained through Caring for Carers Clinic. Five people said that their role had either stayed the same or become more difficult because the person they care for has a progressive disease. Three people said the caring role was very difficult on a constant basis. Three people said they had received no service from the Carers Clinic. Two people said they would rather cope alone with caring. Other respondents said that they had benefited from Care in the Home training (n=1); that they now have more time for themselves (n=1); that they were reluctant to use Carers Clinic services because they didn't want to take up the time of Clinic staff (n=1); that the person they had cared for was deceased (n=1); and that the Carers Clinic seemed to focus more on Carers of older people than other Carers (n=1).

Change in confidence in ability to care

The survey participants were asked whether their confidence in their ability to care had changed as a direct result of using the Carers Clinic. Fifty-eight people answered this question. Twenty-one people (36%) said they felt a lot more confident, and 16 people said they felt a little more confident (28%). Twenty-one people (36%) said their levels of confidence had not changed.

Figure 16. Change in levels of confidence in ability to care.

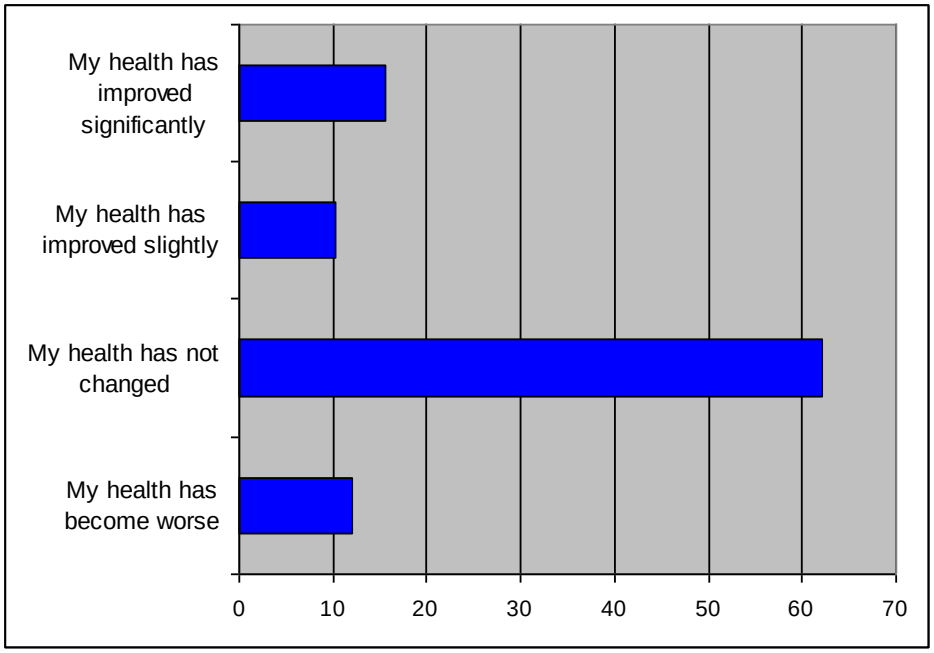


Twenty-four people gave further detail on their levels of confidence in their ability to care. Five people said that knowing they were not alone had increased their confidence. Three people said that the practical support they had received from the service had helped them. Two people said that being listened to had helped their confidence, and two others said that they were confident in their ability to care. Other responses provided by one person each were: the person cared for was deceased; the advocacy received from the service was helpful; no help received from the service; lack of support from HSE had affected confidence; found it difficult to return to work after caring; feeling under skilled as a carer; the burden of caring is difficult; rapid change in lifestyle has been difficult to cope with; no change in confidence levels; enhanced ability to cope with caring since engaging with Carers Clinic; confidence levels change from day-to-day; Care in the Home training was beneficial.

Change in health as a result of using Carers Clinic

Respondents were asked whether their health had changed as a direct result of engaging with the Carers Clinic. Fifty-eight people answered this question. Nine people (16%) said that their health had improved significantly, and six (10%) said that their health had improved slightly. Thirty-six people (62%) said that their health had not changed, and seven people (12%) said that their health had become worse.

Figure 17. Change in health as a result of using Carers Clinic.



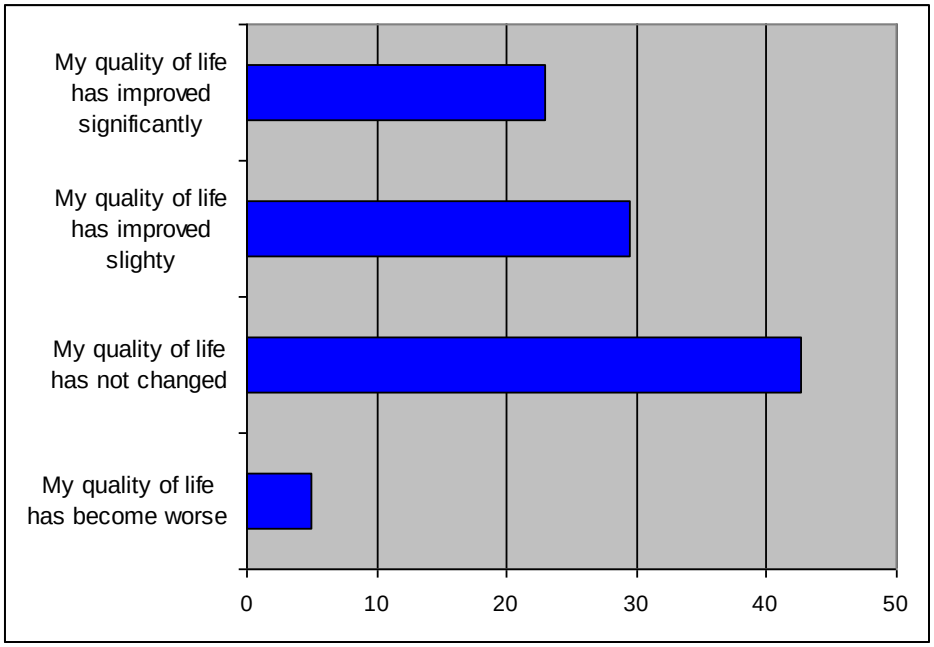
It should be noted that it is not clear whether all respondents were attributing their health status directly to the intervention of Carers Clinic, or whether some were attributing their health to external factors. From the comments made, it seems that external factors were important to at least some respondents.

Twenty people added more detail on their responses to this question. Six people said that they were still negatively impacted by the significant burden of their caring role. Four people said that they had pre-existing health problems that negatively impacted their health. Four people said that their stress levels were lower wince using the Carers Clinic. Four people said that their health was generally good, and two people said that their health was negatively impacted by ageing.

Change in quality of life as a result of using Carers Clinic

The survey participants were asked whether their quality of life had changed as a result of using the Carers Clinic. Sixty-one people answered this question. Fourteen people (23%) said that their quality of life had improved significantly. Eighteen people (29%) said that their quality of life had improved slightly. 26 people (43%) said that their quality of life had not changed, and 3 (5%) said that their quality of life had become worse.

Figure 18. Change in quality of life as a result of using Carers Clinic.

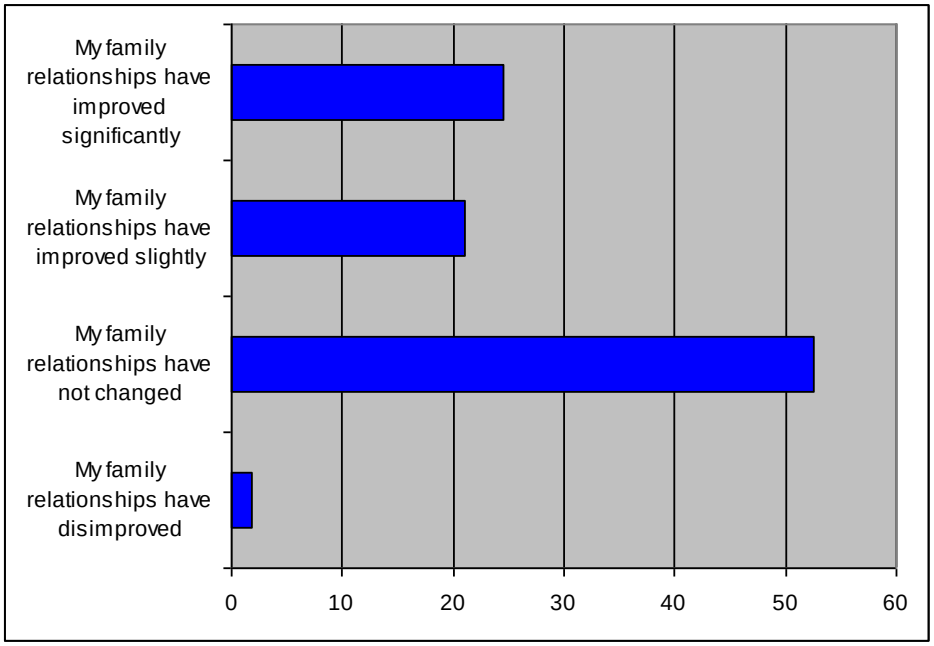


Twenty-one respondents provided more detail on their quality of life. Three people said that they had benefited from the advice they had received from staff at the Carers Clinic. Three other respondents said they did not feel as isolated as they had before engaging with the Clinic. Three respondents said that since using the Clinic they had more time for themselves. Two people said the Clinic had helped them plan for the future. Other comments provided by one person respectively were: information provided on available services was beneficial (n=1); no positive help received from Carers Clinic (n=1); staff at Clinic do their best but cannot be there all the time (n=1); the burden of care is difficult to cope with (n=1). Two people said that their quality of life had not changed since using the Clinic.

Change in family relationships as a direct result of using Carers Clinic

The respondents were asked whether their family relationships had changed as a direct result of using the Carers Clinic. Fifty-seven people answered this question. Of these, fourteen (25%) said their family relationships had improved significantly. 12 (21%) said that their family relationships had improved slightly. Thirty (53%) said that their family relationships had not changed, and one person (1%) said that their family relationships had become worse.

Figure 19. Change in family relationships as a result of using Carers Clinic.

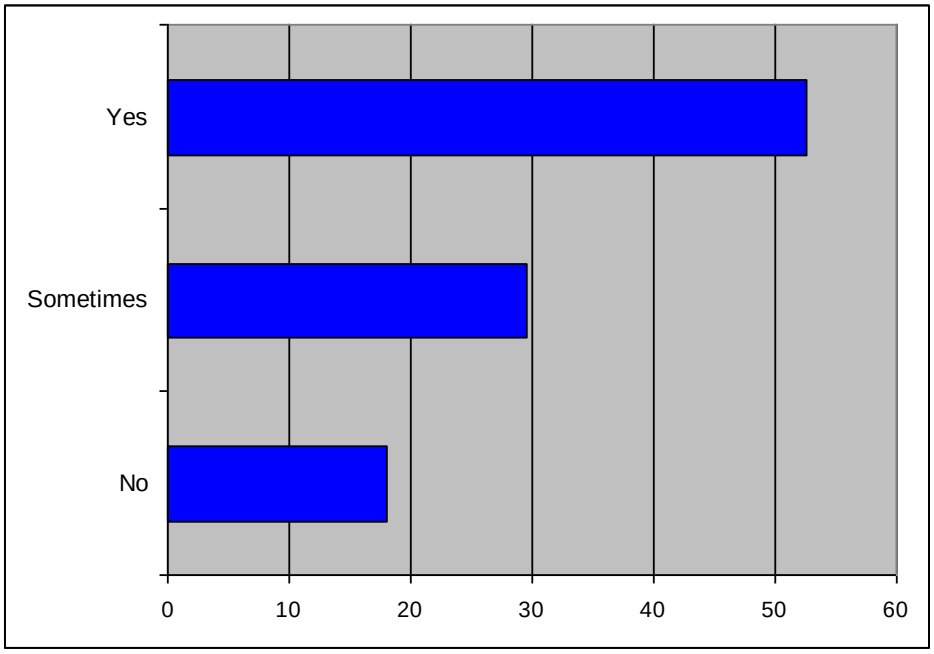


Sixteen people provided more information on the impact of the Carers Clinic on their family relationships. Three people said that their family relationships had always been good. Two people said that the services they had received via Carers Clinic had helped family relationships. Two people said their family relationships had not changed, and that their families lived far away. Other comments given by one person each were: being listened to improved the ability to cope; having to be with the person cared for all the time; Care in the Home training was helpful.

Impact of supports received from Carers Clinic on carer stress

Carers were also asked whether the supports they had received from the Carers Clinic had helped to reduce the stress they had experienced as Carers. Sixty-one people answered this question. Of these, 32 (52%) said that the supports received had reduced their stress. Eighteen people (almost 30%) said that the supports received had sometimes reduced their stress. Eleven people (18%) said that the supports received had not reduced their stress.

Figure 20. Impact on level of stress as a result of using Carers Clinic.



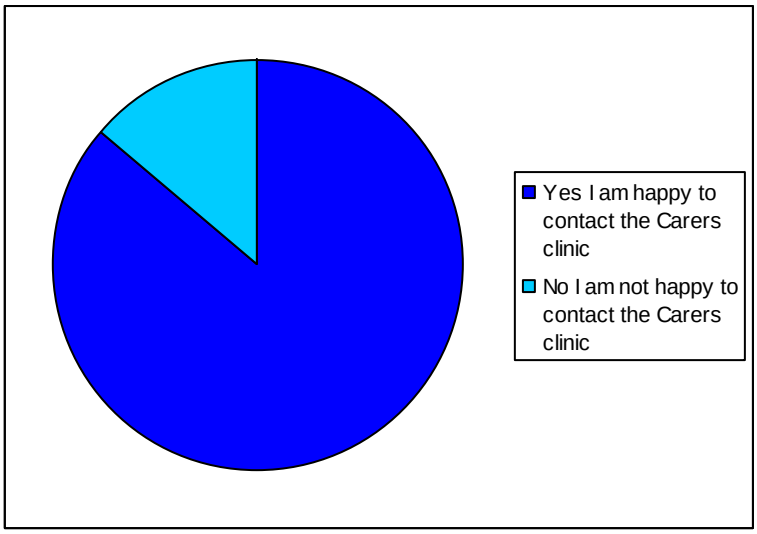
Twenty-four people added more detail to their answer. Three people said that knowing they had someone to talk to and who would listen to them had reduced their stress. Four people said that their stress had not reduced because the burden of care is stressful no matter what supports are available. Three people said that the services they had received from the Carers Clinic had been helpful. Three people said that financial support/grants had been helpful. Three people said that engaging with the Carers Clinic had reduced the amount of pressure they experienced in providing care. Three people felt that the advice they had received from Carers Clinic had reduced their stress. Three people said that they had little or no help from services: of these, one person said that while they now had little or no engagement, the Clinic had been very helpful at the outset; another person said that they do not use the Carers Clinic service; and the third person said that there did not appear to be any help available for stroke victims. One person said that their stress had reduced because they had more time to themselves and they were less tired than before. Finally, one person said that while the Clinic was very important, the support they were able to give was limited (although this was not the fault of the Clinic).

Engaging with Carers Clinic

Contacting the Carers Clinic

Carers were asked whether they were happy to contact the Carers Clinic to speak to a staff member about their needs. Sixty-five people answered this question. Fifty-six of these (86%) said they were happy to contact the Carers Clinic. Nine people (14%) said they were not happy to do so.

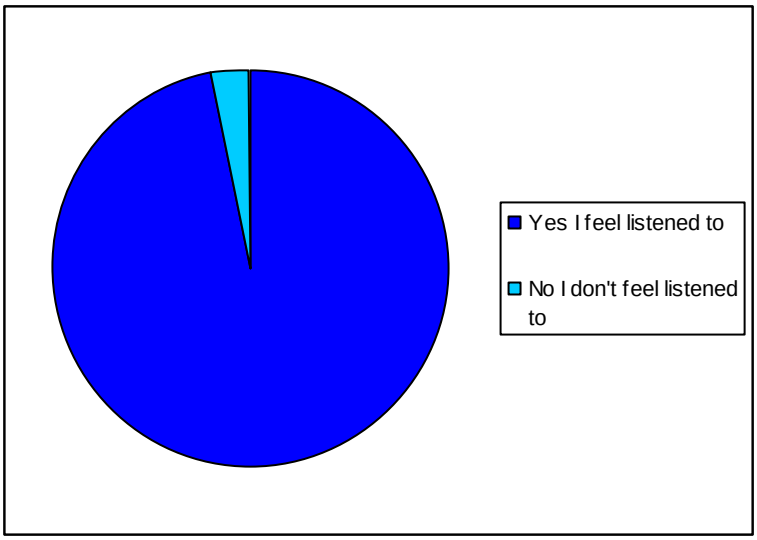
Figure 21. Happy to contact Carers Clinic to speak to a member of staff.



Feeling listened to when contacting the Carers Clinic

Carers were also asked whether they felt listened to when they contacted the Clinic. Fifty-seven people answered this question. Of these, fifty-five (97%) said they did feel listened to, and two people (3%) said they did not.

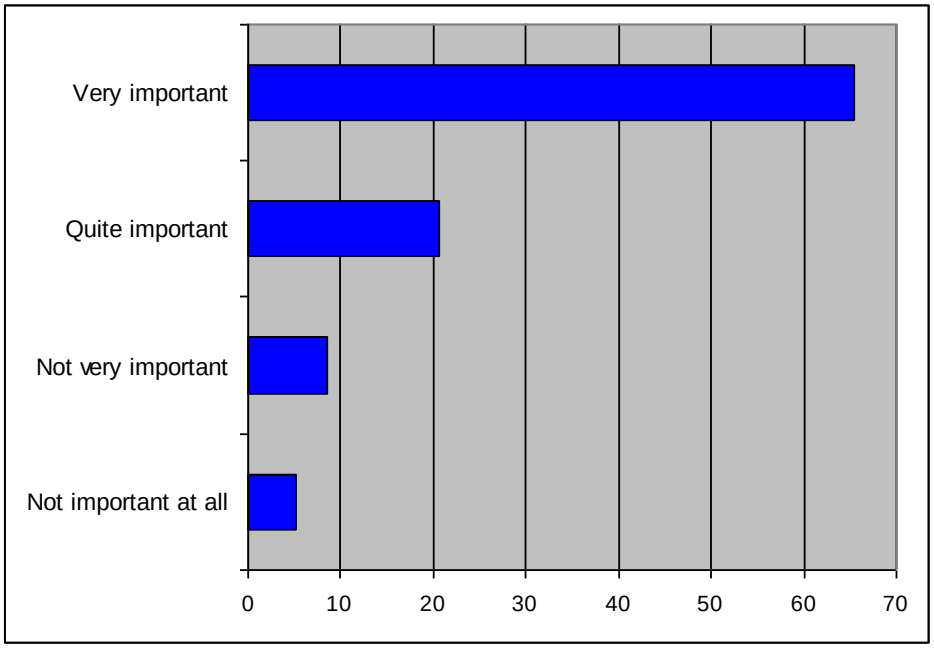
Figure 22. Feel listened to when contacting Carers Clinic.



Importance of Carers Clinic as a private space

The Carers were asked how important they felt it was that the Carers Clinic provide a space for them to talk, separate to the location where they provide care. Fifty-eight people answered this question. Thirty-eight of these (65%) said it was very important, and 12 (21%) said it was quite important. Finally, 5 people (8.6%) said it was not very important, while 3 people (5.2%) reported that this was not important at all.

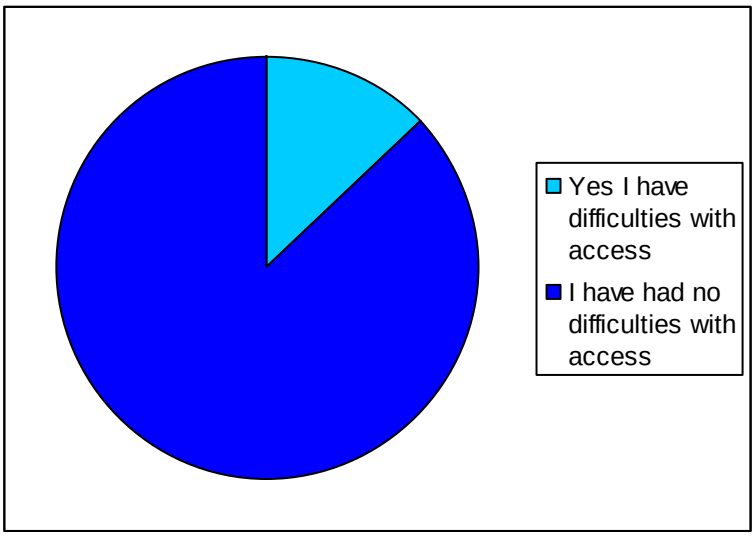
Figure 23. Importance of Carers Clinic as a private space



Accessing the Carers Clinic

Respondents were asked whether they had any difficulty in accessing the Carers Clinic. Fifty-six people answered this question. Seven people (13%) said that they had had difficulty accessing the Clinic. Forty-nine people (87%) said they had not had difficulty doing so.

Figure 24. Difficulty accessing Carers Clinic.



Eight people provided more detail on their answer. These comments were very varied and covered a number of aspects, not all of which were directly relevant to the issue of access.

One person stated that they valued the support received from staff of the Carers Clinic. Another respondent said that they had had to move from a rural area to a

house on a local authority estate so that the person they cared for would be closer to services. A third person said that they do not drive much due to pain. This comment may be linked to a difficulty in accessing services due to geographical distances. Two other people said that the Clinic was too far from their homes. Another respondent said that they felt reluctant to contact the Clinic because of a concern that Clinic staff members were too busy with other clients. One person said that parking was a difficulty, that it was difficult to contact the staff member who had been recommended to them, and that it was hard to find the time to call into the Clinic. This was echoed by another respondent, who also said that they had no contact number for the Clinic.

Environment of the Carers Clinic

Carers were asked whether they found the atmosphere and environment of the Carers Clinic pleasant. Fifty-five people answered this question, and all said they found the atmosphere and environment pleasant.

Eighteen people provided more detail on their answers. Six people said they found the staff at the Clinic friendly and pleasant. Four people said they found the staff easy to talk to and able to listen well. Other comments made by one person each were: that the Clinic is confidential and a pleasant quiet place; that requests for advice or information are met with speed and efficiency; that the office is very pleasant and bright and even when they are busy they always find time to talk and make you welcome; and that the front staff are wonderful. Four people said that they had never attended the Clinic in person.

Additional comments about the benefits of the Carers Clinic

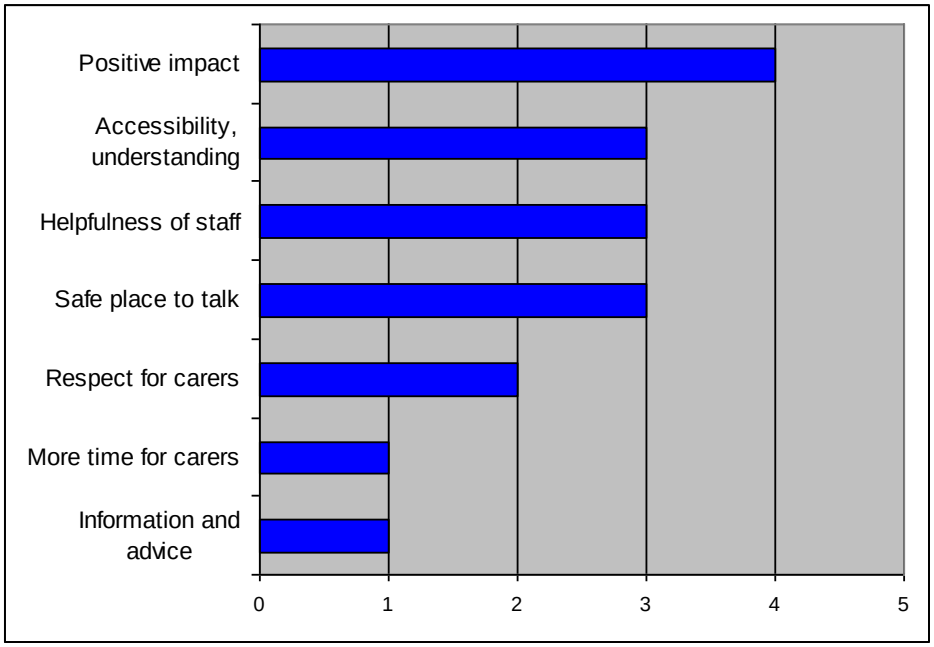
In the last question of the survey, Carers were asked whether there was anything else they would like to add about the benefits of the Carers Clinic. Twenty-four people provided comments.

Two people made general comments about the need for Carers to be treated with more respect by the HSE, and national government, and to be provided with comprehensive financial assistance.

Fifteen people said that the Carers Clinic had had a positive impact on them in a variety of ways:

- General positive impact (n=4)
- Information and advice (n=1)
- Accessible, understanding and professional (n=3)
- Helpful (n=3)
- A safe place to talk and be listened to (n=3)
- Allows more time for Carers (n=1)

Figure 25 Positive feedback regarding the Carers Clinic (n=count)



Four people had had less positive experiences. One person had a negative experience both in terms of talking to a staff member, and lack of follow-up. Another person also wanted to see better follow-up of clients. Two people said they had received no help from the Clinic when they had contacted them.

Discussion

Tanya's story

Tanya is a 35 year old Family Carer, she cares for her two children a 15 year old daughter and a 4 year old son and her 64 year old husband Piotor who has dementia. He requires full time care and supervision as he is prone to wandering. Tanya works part time with the support from her friend who cares for Piotor enabling her to go to work. Piotor was attending the Day Centre four days a week, however this ceased as he needed to be taken to the Centre by his wife who could not do this due to work and family commitments. As an alternative Tanya paid for a private taxi service to get him to the Day Centre, but this was not sustainable due to high cost. Piotor also presented with challenging behaviour at home.

Tanya arrived at the Carers Clinic in great distress and seeking assistance. As a result appropriate transport was sourced at a reasonable cost. Also, a short respite break was provided for Tanya and her son through the Crisis Intervention Fund whilst Piotor was in residential respite care.

The outcomes for the Family Carer resulted in her being able to continue in her part-time job. The high cost of transport was not now an issue for her. There was greater harmony in the home as Piotor was out and about and socialised more.

Overall, the quality of life for the family was greatly improved. Tanya greatly appreciated the help and ongoing support provided by the clinic and as a result she was less stressed and appreciated the help received in the care of her husband.

The evidence is presented in this study indicates that the objectives of the Nurse-Led Carers Clinic have been met. This professionally- led service has proven to be a unique and useful service to Family Carers. The study provides us with an objective and independent view of the value to Family Carers of the Nurse- Led Carers Clinic and the extended services provided by Caring for Carers such as the Caring in the Home Training courses, Carers groups, practical support, one-to-one confidential listening and advice.

Caring is a fact of life, we may all be called on to provide care to family member and we will all need care. Now more than ever we need to acknowledge the unique contribution made by Family Carers in Irish society. Family Carers are largely seen as a resource by service providers and as a consequence services to support caring in the home have been inadequately developed. To date the main aim of this support has been to ensure that they continue in their role with little attention given to the needs of Family Carers, their own health and the changing demands they face. Responding to the needs of Family Carers should be a primary objective of health and social care policy; with the aim of enabling Carers to continue to care for as long as they and the person they are caring for, wishes, without detriment to the Carers health, well-being or inclusion in society.

The challenges and changes presented in Irish society today impact on the delivery of health care. These include resource constraints and pressure for early discharge from hospitals. This calls for a new thinking in the way that professionals perceive Family Carers. Services still focus on the patient/client needs. There is now a greater need to work collaboratively with Family Carers, whilst also recognising the needs of the Carer and other family members. Supporting Carers in their caring role and in their relationship with the person cared for is crucial. It is important to recognise that Carers have their own needs and aspirations. Whilst these may be closely interlinked with those of the individual with often long-term care needs, they must nevertheless be seen as separate and distinct. The need to provide practical assistance in the form of home care and flexible respite care services are critical to enabling people to continue to be cared for at home.

The number of people in Ireland living and requiring care in the long term is increasing. One of the main reasons for this is the changing demographics of the population. People are now living longer and over the next 20 years the numbers of people over 85 years of age will more than double. As people get older they are more likely to develop a long-term condition which impacts on their ability to maintain their independence. As a result their need for health and social care interventions increases significantly.

People with long-term conditions will usually require ongoing management and treatment over a period of years or decades. They are wide-ranging in their nature and may be physical, neurological or mental health conditions.

People being cared for at home with long-term conditions will have very different experiences of how their condition affects them. This will often influence their needs and priorities. For many their condition will be relatively stable over a period of time with only irregular flare-ups. For others with more complex needs or with more than one long term condition, their situation may be less stable; requiring more intense and on-going periods of care and support.

Long-term caring can have an adverse impact on the mental, emotional and physical health of Carers. This can be particularly so where Carers themselves are older or have a long-term condition. This may also affect young Carers. This can also be the case where the health of the person cared for is deteriorating.

There is a requirement to assess and respond to Carers needs. We know from research that

- Caring is a major source of strain and psychological distress,
- 23% of Family Carers find the work of caring completely overwhelming at times.
- 70% find caring a financial strain
- 73% score poorly on a General Health Questionnaire.
- Research has shown that up to 47% of Family Carers have no major source of help with their caring duties resulting in social isolation.

Fortunately most wish to care, but it is essential that they are adequately prepared and supported throughout the caring process. This means providing a more holistic model of carer support, thinking clearly about intended goals and actively promoting a more equitable relationship.

To meet this aim, policies which promote partnership and empowerment should be developed. If this is to be achieved, there is a need for considerable remedial action, requiring the development of practical approaches which responds to Carers changing needs over time. Moving to a position where partnership working is the norm requires acknowledging the Family Carer as an expert in the day to day management of care provision in the home. Healthcare professionals may also need to develop new skills in communicating and interacting with Carers as partners in care.

Now more than ever there is a greater need for a new vision of care to be developed to provide a framework in which Family Carers will be recognised and valued for the contribution they make to their families and to society. The Carers Clinic provides a model of how this may be achieved. Through the clinic Carers who are experiencing fatigue are referred to the many respite opportunities provided by Caring for Carers. Where they lack time due to the demands of caring, they may be offered practical assistance through the Carer Support Service.

Where they express feeling isolated they are invited to join one of the nine Carers groups local to them. The Family Meditation /family relationship services is also a vital services that is provided in the Nurses Led Clinic. The nurses' focus is on addressing concerns and issues in a respectful and inclusive way.

If safety and security in the home was a matter of concern appropriate telecare services would be provided. As advocates Clinic Staff have supported Family Carers to obtain their entitlements in relation to caring needs. Health promotion is a key aspect of the advice provided and may include personal health checks.

Family Carers can be linked to health promotion programmes run by the HSE and other agencies. Other training opportunities include IT training which has been offered to all Family Carers in the catchment area to promote social inclusion.

The support given by Caring for Carers to Family Carers and their dependents through the Carers Clinic Service has been recognised externally by other service providers. Caring for Carers receive referrals of clients presenting complex needs where others may not be in a position to provide a service. When presented with complex care needs, the clinic nurses have the experience and competence to recognise the additional training and resources required to facilitate care in the home. Home Care Workers are provided with additional training in areas such a s peg feeding, care of tracheotomy tube, nutrition and communication needs, lifting and movement. In certain cases home care has been sustained for up to four years.

Recommendations

Caring for Carers Ireland are calling for a new way of thinking on the part of health and social care professionals regarding who Family Carers are, what they do, their skills and expertise and their own needs for understanding, respect and support. Now more than ever there is a greater need for a new vision of care to be developed to provide a framework in which Family Carers will be recognised and valued for the contribution they make to their families and to society, and the high price they pay every day for carrying out their vital work.

1. Caring for Carers recommend **greater integration** of the Nurse-Led Carers Clinic into primary and community care via integrated working with members of the Primary Care Teams

2. **Enhanced awareness** among health and social care professionals of the reality of caring in the home and the impacts on the health and wellbeing of the Family Carer is vital if a whole systems approach is to be taken in the care of older people and people with chronic and/or life-limiting conditions.

3. Caring for Carers strongly advocate moving to a position where **partnership working** is the norm. This requires acknowledging the Family Carer as an expert in the day-to-day management of care in the home

4. **Carer-centeredness and a holistic approach** is fundamental to the Nurse Led Carers Clinic. Caring for Carers recommend adopting this ethos to any work undertaken by health and social care services, and voluntary organisations in supporting Family Carers. This ethos facilitates an individualised and personal service.

5. Primary and community care services should take into account the needs of Family Carers when planning care, and adopt a **flexible approach** as the needs of both the Family Carer and person cared for change.

6. Caring for Carers Ireland emphasise the urgent need to **properly resource primary and community care services**, to **integrate care** for service users and Family Carers, and to follow a **Care and Case Management** approach in situations of multiple and complex needs.

7. **Responding to the needs of Family Carers** should be a primary objective of health and social care policy; with the aim of enabling carers to continue to care for as long as they and the person they are caring for, wishes, without detriment to the carers health, well-being or inclusion in society.

8. Part of the funding for the Nurse-Led Carers Clinic should include a **specific budget to meet "immediate" or "humanitarian" needs**. Giving Family Carers in need a small amount of money for a specific purpose can make a big difference.

9. Staff of the Nurse-Led Carers Clinic should be represented at **patient discharge planning meetings** in order to represent the needs of the Family Carer, and how these needs impact on the care plan.

10. Staff of the Nurse-Led Carers Clinic should be presented at **crisis intervention meetings** in order to provide the perspective of the Family Carer and therefore inform the planning of patient care in the home.

11. An **administrator** should be appointed to the Nurse-Led Carers Clinic in order to provide administrative services to the Nurses working in the clinic. These services should include establishing and documenting administrative procedures, communication/follow-up, scheduling and supervising of Carers, and computerising nursing records.

12. The rapid development of **Information and Communication Technologies** (ICT) has created a new way to support Family Carers, older people and people with disabilities. These technologies can support independent living and provide reassurance, security and peace of mind. Caring for Carers Ireland recommend increased funding for roll-out of new technologies in the community (for example Telecare, Telehealth and social connection technologies).

Appendix 1 Survey questionnaires

Carers Clinic evaluation of services

This questionnaire aims to evaluate the services provided by Caring for Carers Carers Clinic. We are interested in finding out whether or not you are satisfied with the services provided by the Carers Clinic or if there are any changes or improvements which you think could make the service better.

Instructions for filling out the questionnaire:

1. The questionnaire will take about **15 minutes** to complete
2. Some questions ask for a "Yes" or "No" response where you simply tick the box which applies to you
3. Other questions ask you to write your answer in the space provided
4. If you do not want to answer a question, you can leave it blank
5. We do not require your name or personal details, so your identity will remain **confidential**

Section 1: Background information

It would be helpful if you could complete the following sections, as they will help us obtain a clearer picture of the range of people who have given us evidence and so we can be sure we are reaching all Family Carers.

Q1. Are you:

Male ☐

Female ☐

Q2. How many people do you care for?

_____

Q3. What is your relationship to the person(s) receiving care (please tick all boxes that apply)?

Spouse (married)	☐	Friend/Neighbour	☐
Partner	☐	Other (Please specify below)	☐
Son	☐		
Daughter	☐		
Other family members	☐		

Q4. Could you tell us which of the following age groups apply to you by ticking the appropriate box?

18 - 30	☐	56 - 65	☐
31- 40	☐	66 - 75	☐
41 - 50	☐	76 - 79	☐
51 - 55	☐	80 or older	☐

Q5.Do you work outside the home?

Yes, full-time	☐
Yes, part-time	☐
No, I'm retired	☐
No, I cannot work due to my caring role	☐
Other (Please specify below)	☐

Q6. Do you live with the person(s) you care for?

Yes ☐

No ☐

Q7. Apart from the person(s) you care for, are there other people living in the household?

Yes ☐

No ☐

Q7a. If you answered **YES** to **Q7** above, please indicate how many other people live in the household.

Section 2: Information about the kinds of services you use

Q8. How did you hear about the Carers Clinic?

Word of mouth, friend, other Family Carer ☐

Carers Group ☐

Carers' Clinic Leaflet ☐

GP, Chemist, Hospital ☐

Local Radio ☐

Internet (website/twitter etc) ☐

Training programmes ☐

Referred by other agency ☐

Q9. Which of the services offered by the Carers Clinic have you used? Please tick all services which apply.

Respite care (nursing home/ day care) ☐

Respite for yourself as a carer (e.g. Carers' Group activities) ☐

Family Carer support service (e.g. practical help in the home) ☐

Home Care Package (HSE) ☐

Carers Group (e.g. Social Support) ☐

Information on benefits and service entitlements ☐

Advice ☐

Advocacy (supporting you in getting the services you need) ☐

Care in the home training ☐

Other training ☐

Safety and security systems (e.g. Telecare) ☐

Support (e.g. following a bereavement) ☐

Referral to other services e.g. GP/PHN/Housing/Welfare ☐

Advice on practical aspects of caring ☐

Home visit ☐

Health promotion information ☐

Confidential Listening Ear Service ☐

Other (please specify): ☐

Q10. Which of these services did you find the most useful?

Section 3: Satisfaction with the Carers Clinic services

Q11. Are you satisfied with the services provided by the Carers Clinic?

Yes, I am satisfied with all services ☐

I am satisfied with some of the services ☐

I am not satisfied with the services ☐

Q12. Is there anything which you think could be improved?

Yes ☐

No ☐

If YES, please specify:

Q13. Would you recommend the Carers Clinic to a fellow carer?

Yes ☐

No ☐

If YES, please explain

Section 4: Impact of the Carers Clinic on your role as a carer

Q14. In your opinion, what are the positive aspects of your caring role?

Enjoying the company of the person I care for ☐

Being able to help the person I care for ☐

Other aspects (please specify):

Q15. What are the main difficulties you experience in your caring role (please tick all answers that apply)?

Lack of time for myself ☐

Lack of help with caring tasks ☐

Fatigue ☐

The financial cost of providing care ☐

Social isolation ☐

Other difficulties (please specify):

Q16. Has your caring role changed since engaging with the Carers Clinic?

It has become much easier ☐

It has become a little easier ☐

It has not changed ☐

It has become more difficult ☐

Please provide reasons for your answer in the box below

Q17. Has your confidence in your ability to care changed as a direct result of using the Carers Clinic?

I feel a lot more confident ☐

I feel a little more confident ☐

My confidence has not changed ☐

I feel less confident ☐

Please explain the reason(s) for your answer below:

Section 5: Contact and Support

Q18. Has your own health changed as a direct result of using the Carers Clinic?

My health has improved significantly ☐

My health has improved slightly ☐

My health has not changed ☐

My health has become worse ☐

Please explain the reason(s) for your answer below:

Q19 Has your own quality of life changed as a direct result of using the Carers Clinic?

My quality of life has improved significantly ☐

My quality of life has improved slightly ☐

My quality of life has not changed ☐

My quality of life has become worse ☐

Please explain the reason(s) for your answer below:

Q20. Have your family relationships changed as a direct result of using the Carers Clinic?

My family relationships have improved significantly ☐

My family relationships have improved slightly ☐

My family relationships have not changed ☐

My family relationships have disimproved ☐

Please explain the reason(s) for your answer below:

Q21. Have the supports you receive from the Carers Clinic helped reduce the stress you experience as a carer?

Yes ☐

Sometimes ☐

No ☐

Please explain the reason(s) for your answer below:

Section 5: Contact and Support

Q22. Are you happy to contact the Carers Clinic to speak to a staff member about your needs?

Yes ☐

No ☐

Q23. Do you feel that you are listened to when you contact the Carers Clinic?

Yes ☐

No ☐

Q24. Do you have any difficulty accessing the Carers Clinic?

Yes ☐

No ☐

If YES, please explain

Q25. Do you find the atmosphere and environment of the Carers Clinic pleasant?

Yes ☐

No ☐

Please provide more detail about the atmosphere and environment of the clinic in the box below:

Q26. What were the 3 main needs you had before you engaged with the Carers Clinic (please tick all boxes that apply)?

Respite	☐	Social contact	☐
Financial assistance	☐	Assistance with caring tasks	☐
Information on entitlements	☐	Care in the home training	☐
Others (please specify below)	☐		

Q27. Did the Carers Clinic help you in meeting these needs?

Yes ☐

No ☐

Q28. What other supports would you like from the Carers Clinic (if any)?

Q29. How important is it to you that the Carers Clinic provides a space for you to talk that is separate from the place where you provide care?

Very important ☐

Quite important ☐

Not very important ☐

Not important at all ☐

Q30. If you have anything else that you would like to add about the benefits of the Carers Clinic, please provide details in the box below:

We appreciate you taking the time to answer this questionnaire. We hope that the feedback received will enable us to improve the current service

Appendix 2 Interview schedules

Focus group questions:

Introductions – names, privacy, confidentiality, informed consent

We will be evaluating the service offered by Carers Clinic, focusing on service outcomes for Carers, and gaps in service provision. In this interview with the major stakeholders of the organisation, we would like to investigate a number of key areas associated with the service, including how the service addresses the needs of the Carers, gaps in provision, and where improvements might be made.. By exploring these issues with staff members and Carers, the Carers Clinic service will be better equipped to identify gaps in service provision and develop and improve the supports they provide to Carers. The interview will last approximately one hour and we appreciate your participation. The interview will be audio-recorded with your consent.

All information will remain private and confidential. You have the right to refuse to answer questions, you can withdraw from the interview at any time and you may terminate the focus group discussion if you wish.

Overview of the service

1. **Could you give us an overview of the overall Carers Clinic service?**

Probes:

- Specific services/supports provided

2. **What are the main aims of the Carers Clinic?**

Probes:

- How are these aims achieved?

The aims of the service

3. What factors do you think support and facilitate Carers Clinic?

4. Are there any barriers to service provision?

Probes:

- Possible solutions to barriers

Service Outcomes

5. Can you describe the main outcomes you expect from this service?

Probes:

- To what extent have these outcomes been achieved to date?

6. Do you think the Carers Clinic have improved the lives of Carers?

Probes:

- In what way (e.g. supports them to carry out their caring role, helps them to identify their own needs and in having those needs met)?
- Separate space to talk in confidence?

7. Have the Carers Clinic contributed to the wider policy agenda on supporting Carers?

Probe:

- In what way?

Key issues and gaps in service

8. Where are the main gaps in service provision?

Probes:

- Where can improvements be made?
- Which gaps cause significant difficulties?

9. In your opinion, what supports / services do Carers need most?

Monitoring and evaluation

10. How is the service monitored to ensure that it is achieving its aims?

11. How are the needs of individual Carers monitored or reviewed after the initial needs assessment is carried out?

Probes:

- How does this happen (e.g. is it documented, are the needs assessment forms updated)?

Anything interviewees want to add

12. Do you have any additional comments to make?

Thanks and end

Carers' Clinic evaluation: one-to one interviews

Introduction

We will be evaluating the service offered by Carers Clinic, focusing on service outcomes for Carers, and gaps in service provision. In this interview with staff in the organisation, we would like to investigate a number of key areas associated with the service, including how the service addresses the needs of the Carers, gaps in provision, and where improvements might be made. By exploring these issues with staff members the Carers Clinic service will be better equipped to identify gaps in service provision and develop and improve the supports they provide to Carers. The interview will last approximately one hour and we appreciate your participation. The interview will be audio-recorded with your consent.

All information will remain private and confidential. You have the right to refuse to answer questions, you can withdraw from the interview at any time and you may terminate the interview if you wish.

Uniqueness of the service

1. **What, in your opinion, makes the Carer's Clinic service unique as a way of supporting Carers?**

Probes:

- Partnership approach in identifying and assessing Carers own needs

2. **Do you think that the Carers Clinic model is the best way to support carer's needs?**

Probes:

- Variety of needs – service, information, financial, training, social, emotional

3. **Do you think that there are ways that the current model could be improved to support Carers better?**

Probes:

- What way?
- How could this be done?

The aims of the service

4. **What factors do you think support and facilitate Carers Clinic?**
5. **Are there any barriers to service provision?**

Probes:

- Possible solutions to barrier

Impact of Carers Clinic on Carers lives

6. **In your opinion, what supports / services do Carers need most?**
7. **From your professional experience, do you think the Carers Clinic have improved the lives of Carers?**

Probes:

- In what way (e.g. supports them to carry out their caring role, helps them to identify their own needs and in having those needs met)?
- Separate space to talk in confidence?

8. **Do Carers themselves ever tell you that engaging with the clinic has made their caring role easier?**
9. **Are there categories of Carers that benefit more from the clinic services than others?**

Key issues

10. **What, in your opinion, are the key issues currently facing the service?**

Probes:

- Internal?
- External?

11. **What do you think needs to be done to address these issues?**

Probes:

- Internal actions
- External

12. **Where are the main gaps in service provision?**

Probes:

- Where can improvements be made?
- Which gaps cause significant difficulties?

Organisational Support

13. What factors support you as member of the Carers Clinic staff team?

Anything interviewees want to add

14. Is there anything that came up in the focus group discussion that you would like to comment on in more detail?

15. Do you have any additional comments to make?

A New Vision for Care

Nurse Led Carers Clinic Evaluation 2012

Work Research Centre, 3 Sundrive Road, Dublin 12, Ireland
014927042 www.wrc-research.ie

Caring for Carers Ireland
2 Carmody Street Business Park
Ennis
Co Clare
0656866515

www.caringforcarers.ie

The Carers Clinic receives funding from the HSE