

# **West Cork Carers Support Group:**

**Consultation with Carers**

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**Submitted to:**

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## **About the Author**

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She co-founded research consultancy firm **kelleherassociates** in 1987 and has a long track record of working with the voluntary and statutory sectors. Her interests include: class, social exclusion and poverty; gender; violence against women; and community planning, policy formulation and strategic planning.

**MEMBERS OF THE BOARD OF MANAGEMENT OF THE WEST CORK CARERS SUPPORT GROUP**

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Patricia Kelleher (PhD)

## **Executive Summary**

### **The Role of Carers**

Having a person with a serious illness or disability in the home impacts on all family members. However it particularly affects the main carer as s/he strives to come to terms with and manage the illness. The invisibility and non-recognition of the caring role is a key issue raised by carers.

Caring tasks in the home involve:

- Carrying out personal care tasks such as lifting, feeding and bathing
- Housework such as washing, shopping, cleaning, house maintenance and cooking
- Dealing with the emotional disposition of the person cared for and dealing with one's own grief and sadness
- Negotiating and coordinating appointments with the medical profession and hospitals
- Managing medications.

Caring impacts on the physical health and the emotional well-being of the carer and many carers suffer ill-health. Social isolation in the home is also experienced as many carers are on-call 24:7. Additional financial demands, as a result of cut-backs in public services, additional prescription charges, extra heating requirements and added transport costs to travel to medical appointments contribute to further stress on the carer to manage an already difficult financial situation.

### **West Cork Carers Support Group**

The West Cork Carers Support Group (WCCSG) established in 1998 is a non-governmental organisation which is core funded by the Health Service Executive (HSE). The four main goals of the WCCSG are:

- To continue to build the organisational capacity of the WCCSG
- To develop carer support programmes
- To positively influence policy and practice
- To network and raise awareness of carer issues

With a dedicated and motivated staff that is greatly valued by carers, the WCCSG has established itself as a highly regarded and effective organisation in West Cork. Its high rating (95 per cent of carers give the WCCSG a very positive rating) is the result of the: caring response of staff; the fact that carers feel understood and listened to by staff; and, the professionalism of staff (Section Four). The fact that carers feel understood and listened to is highly significant as it allows for carers' experience to enrich the style and character of the WCCSG and to ensure that the organisation remains carer-led. This together with regular feed-back from carers and the large proportion of members of the management board who

are carers (eight of the ten members are carers/former carers) ensures that the WCCSG continues to be carer-directed.

Staff together with the management board have shown considerable leadership and vision and have spent much time over the last couple of years ensuring that the organisational structures and policies are fit for purpose. Information Technology (IT) has also been enhanced and the WCCSG website had been upgraded and Facebook developed. This will allow for greater connectivity with carers and networking with statutory and voluntary organisations. This continued priority given to IT is important for success in the modern “information” world. Importantly too, is the ground floor shop-front premises in the centre of Bantry town acquired by WCCSG. These premises are highly visible and accessible.

The WCCSG is an important innovation and resource as it is the only professional organisation which has a specific brief for carers in West Cork. It has a broad range of services which outreach to carers. Its innovative development of the Men’s Group is noteworthy.

The WCCSG has contact with 475 carers. This is 16 per cent (one in six) of the 2,890 carers living in West Cork. In 2012, 77 new carers took up membership of the WCCSG.

The WCCSG is operating within severe financial restraints with cut-backs to its funding and an increase in demand for its services. This continues to be a major challenge to the organisation.

### **Consultation with Carers**

The overall aims of this consultation are to:

- Document the work, experiences and needs of the carers who are members of the West Cork Carers Support Group (WCCSG)
- Identify issues for the board of management to consider in developing its Strategic Plan (2014-2018)
- Identify issues for the Carers Issues Forum to consider

This section is based on:

- An Internet Survey of 65 carers/former carers. Questionnaires were sent out to 120 carers/former carers and there was a response rate of 54 per cent (65) which is regarded as satisfactory
- Face to face interviews with 26 carers/former carers
- Written submissions from four carers/former carers

### **Issues for the Management Board to Consider**

Key issues emerging from the study for consideration by the management board are outlined below.

## **Public Awareness of Carer's Role**

Carers would like to see the WCCSG highlighting publicly the value of carers. Suggestions include that the WCCSG should:

- Shadow a carer in the home and document the broad range of caring work that is undertaken
- Make a documentary film on the role and work of carers. EU funding for this could be investigated

## **Public Awareness Campaign Aimed at "Hard to Reach" Carers**

Despite the fact that the WCCSG continues to increase its membership, many carers noted the need to identify carers who are not in touch with the WCCSG either because they do not know about the organisation or do not self-identify as carers. This means that some carers do not receive the supports that they are entitled to. A public awareness campaign could reach out to carers. The WCCSG Newsletter could play an important role in this campaign.

## **Young Carers**

There is a need to know more about young carers. In this context a scoping study which would identify the numbers and needs of young carers could be undertaken. It was suggested that an element of this study could be carried out through the schools.

## **Continue Support for the Men's Group**

The Men's Group is highly valued by members and it is important that funding and supports continue to be made available to it.

## **Listing of Carers Available to Assist and Scoping Study for Peer Support (Buddy System)**

The WCCSG should make a listing of carers who are in a position to transfer their knowledge/experience to other carers, for example, a carer whose loved one is in the early stages of Alzheimer's illness would like advice and informal contact (by telephone for instance) from people who have experience of caring for this illness.

A carer who has dealt with mental health difficulties would like to transfer her knowledge to people who are starting out caring for a person with mental health difficulties.

A scoping study could be undertaken on how this informal peer support could be developed. Issues such as insurance, transport costs and other out of pocket expenses would need to be considered.

## **Social Events**

Carers suggested that the range of social events organised by the WCCSG could be expanded to for instance a movie night and a show and overnight stay. It was also suggested that an outing to Myross Wood Retreat Houses could be organised.

## **Funding and Building Organisational Capacity**

There is now a strong request from carers that the core services of the WCCSG be expanded. There is a demand that services of the WCCSG be delivered more locally. In particular, many carers would like a more localised drop-in service. Carers are cognisant of the fact however that expanding and localising the service has resource implications.

The WCCSG is operating at full capacity. It is not only the overall amount of funding that is an issue but the fact that there is a delay in the allocation of annual budgets by the HSE. This delay and the insecurity of staff positions need to be addressed as a matter of urgency.

Carers also noted the need to:

- Complete the review of the Articles and Memorandum of Association
- Continue to implement safety procedures, and, staff policy and complaints procedures
- Assess regularly training needs of staff and board members
- Launch carers' log book and card
- Examine possibility of employing part-time staff for longer hours
- Examine possible role for volunteers in over-seeing the social events programme

## **Issues for the Carers Issues Forum to Consider**

The Carers Issues Forum which is a multi-agency partnership is an important innovation which aims to address broader policy issues of concern to carers. Several issues emerging from the consultation with carers need to be considered by the Carers Issues Forum.

### **Mainstreaming Needs of Carers**

The needs of carers and families of carers coping with complex illnesses need to be inserted into care plans of patients. They also need to be integrated into service planning and decision making processes of the HSE and carers' needs should become a routine part of training of primary care teams.

### **Training for Carers at the Early Stages of Illness**

When a person first starts caring for a person with complex needs there is need for intensive home-based training from the medical professionals on how to cope with the illness. Many carers need advice on specific problems, training in medications and training on how to cope with difficult behaviour. Ideally there should be a care plan for the patient and the needs of the carer should be inserted into this plan.

### **Shared Training with Other Voluntary Organisations**

There is need to identify whether or not there is scope for "shared training" between organisations that are working with carers and funded by the HSE.

### **Upgrading Home Help Service**

There is need to upgrade the status of the home help service to reflect the personal care work undertaken. Additional training on specific illnesses such as Alzheimer's illness should be made available.

### **Volunteering Sitting Service**

There is need to document the volunteering services, if any, which are available from organisations working with carers in West Cork. A feasibility study of establishing a volunteer-sitting service should be undertaken.

### **24-Hour Helpline**

The feasibility of establishing a 24-hour telephone helpline, similar to the Samaritans should be investigated.

### **Carers Allowance**

It was felt strongly by many carers that the carer's Allowance should not be means-tested.

### **Discretionary Nature of Items Available**

Items such as grab rails, sliding sheet, bed and hoist available from the state should be listed. Eligibility criteria also need to be made available and HSE personnel such as public health nurses should actively make carers aware of these items.

### **Review of the Operation of the Carers Issues Forum**

There is need to review the effectiveness of the Carers Issues Forum in terms of the number of meetings held, issues addressed and attendance level at meetings. The composition of its membership, the level of seniority of personnel and the reporting relationship back to the organisation represented on the Forum need to be reflected on.

This section is based on:

- An Internet Survey of 65 carers/former carers. Questionnaires were sent out to 120 carers and there was 54 per cent (65) which is regarded as satisfactory
- Face to face interviews with 26 carers/former carers
- Written submission from four carers/former carers

## 1. Profile of Carers

Sixty-five carers/former carers participated in the Internet Survey.

Fifty-eight per cent (38) of carers/former carers that participated in the Internet Survey are between 46 and 65 years of age. Twenty-three per cent (15) are 66 years or over and 3 per cent (2) are 35 years or less. (For more detail on the profile of carers/former carers, see Appendix A).

Twenty-eight per cent (18) of carers/former carers are male and 72 per cent (47) are female.

A large proportion (78 per cent) of carers are Irish nationals and one carer was an Irish national and a member of the Traveller community.

Nationality	Number	Percentage
Irish national	51	78.5
Irish national and member of the Traveller community	1	1.5
Non-Irish national	13	20.0
<b>Total</b>	<b>65</b>	<b>100</b>

Ten of the 13 non-Irish nationals are from Britain and two are from Germany. There is no information on one person.

Fifteen per cent (10) of carers are caring for more than one person.

Eighty-nine per cent (58) of carers/former were living in the same house as the person being cared for.

No carer/former carer is working full-time outside of the home. Fifteen per cent (10) are working in part-time work and 12 per cent (8) are self-employed.

## 2. The Caring Role

Personal care tasks involve a broad range of activities including bathing, attending to toilet needs and lifting and turning the person in the bed at regular intervals. It includes washing clothes, house cleaning and maintenance, ironing, shopping and cooking.

For many of the 26 carers/former carers interviewed, caring means being on-call 24 hours a day:

*You are very tired. It (caring role) is 24:7. It is hard work. I would like to see the group (WCCSG) coming into a carer's home and documenting the work that is involved*

*I do everything for her. I get her up at nine o'clock and shower her, dress her and feed her. I have most of the housework such as washing and ironing done before that. During the day I do all the shopping and cooking*

Personal care tasks can be challenging:

*Many people being cared for are incontinent. Dealing with incontinence and changing incontinence pads is difficult....The caring role needs better recognition by the state. I would like to see the group do a documentary film on the role and work of carers*

*The difficulty and time it takes to do the ordinary things that many people take for granted, like getting dressed, getting showered can be exhausting*

Many carers stated that they were catapulted into the caring role without any training:

*He was brought home to me on a Monday night by ambulance. I was left there with him by myself. I did not know what to do. I cried all night. The following day I got the doctor to come over and give me advice on how to manage him*

*You are left to your own devices. There is very little training*

*When he had his first bowel movement (in the bed unplanned) I thought "how am I going to change him. I had no training"*

*I keep telling myself "I am not trained for this, but I still have to keep on doing it"*

*Dealing with mental illness does not come naturally. I had no training for it. If I had someone who would have explained how to handle it (mental illness) or what the patterns were, it would have helped. I would like to get involved in helping others who are dealing with mental illness*

Carers feel that some illnesses such as Alzheimer's illness is little understood:

*One carer lived alone with her husband who had Alzheimer's disease for six years. She found that supports were inadequate. Although she had home help and respite services, she had only one hour a week from the Alzheimer's Association. Home helps were of limited assistance as she feels that home helps do not understand the illness and need specialised training. Her husband is currently receiving long-term care in hospital. As an ex carer, she would like to do voluntary work with Alzheimer's patients as she has in-depth experience of the illness*

A second woman whose husband is in the early stages of Alzheimer's would like to meet other carers who are caring for Alzheimer's patients:

*I would like to have support from other carers where we could phone each other and get informal support. We could also exchange DVD on the illness*

Family members are often in shock when the illness is diagnosed:

*I was told she had a tumour I said to myself "This cannot be happening". I was in shock and did not understand the complexity of it*

Grief and sadness can be acute as the illness progresses:

*I found it extremely difficult to watch my husband's health deteriorate. He was always very active. I knew he would end up in a wheelchair. It was heart-breaking*

*I found it very hard when it came to the stage that he did not know me*

*The hardest thing is watching her suffer and knowing that you cannot take her pain away*

Carers worry about what would happen to the person being cared for if the carer was not able to care as one man explained:

*Once you get to 80 years, you have to pull out and think "if anything happens to me what will she do"? She is now in residential care*

## **Managing Medication**

Managing medication is a concern to many:

*My daughter was let out of hospital with three prescriptions. We were not told what they were for. We got a big bag of medication from the chemist. I said to him "would you mind telling me what these are for"? He tried to explain. We spent days sorting the medications out. We were up in a heap*

## **Managing Illness**

Dealing with difficult behaviour can be upsetting:

*He would clench his fist as if to hit you. It was very difficult. This negative behaviour was related to his illness*

*You could not get him to bed at night-time. He would walk around the house all night. He would do things like take all of the clothes out of the wardrobe*

One carer wanted to know:

*How do you protect yourself against aggressive behaviour?*

Others have worry about the cared for person taking their own life:

*He would go around looking for a cord or belt. I was terrified. Once he nearly did it*

One carer whose son has a mental health problem found coping very difficult:

*He would go missing. You were expected to find him and calm him down*

People with mental health difficulties can experience great “highs”:

*He would go out on shopping sprees. He was on top of the world. I was left to cope*

## **Sleep Deprivation**

Being on-call 24 hours a day means sleep disturbance and sleep deprivation:

*You are on high alert all day. It is non-stop alarms. It is difficult to get sleep*

*I don't sleep. I am on edge in case she wakes up to go to the toilet*

*I start thinking about all that has to be done and who has to be contacted and then I cannot sleep because of the thinking*

Lack of sleep means total exhaustion:

*When respite time comes I am so exhausted that I just collapse into the chair*

## **Social Isolation**

Caring responsibilities can mean social isolation. While some people being cared for can be left alone for a few hours in the day, other people need a person present 24 hours a day. For many carers there is little time off:

*I missed events (WCCSG events) as I had no one to sit with him (her husband who had Alzheimer's)*

*I have missed out on events run by the group (WCCSG) as I find it hard to get people to cover for me. It would be a good idea if we had a network of volunteers who you could call on in emergencies or when the carer needs to attend events or appointments*

*I had an appointment with the GP and had to bring my husband (who had Alzheimer's) with me. You can ask neighbours to help out but you cannot expect them to be there all the time*

Getting out for even a small number of hours can involve intense planning and negotiation:

*To come to the social event here today I had to negotiate that the IWA (Irish Wheelchair Association) hours would follow on from the home help service hours. It took a great deal of energy to make sure everything was in order before I left*

## Financial Costs

Caring involves severe financial costs both in terms of lost employment and additional expenses incurred. Extra costs are involved in everyday expenses for clothing and diet and the costs of travel to hospitals. Heating costs were particularly noted:

*The additional heating costs are enormous. My daughter is in a wheelchair. She has to have heating from 9 am to midnight. I cannot put heavy bedclothes on her during the night or she goes into spasms so that you need a light heat during the night*

*My mother is 91 years. She needs a fire on all day*

Medical expenses not covered by the medical card are also an issue:

*A lot of stuff is not on the medical card. Some things you need are now not considered "essentials" such as the dressings my daughter needs*

Charges for respite care and the additional charges for prescription charges alongside other cut-backs in public services place financial pressure on families.

Currently the income of the household in which the carer is residing is taken into consideration in deciding on whether or not a carer qualifies for the Carers' Allowance. Several carers were of the opinion that not only should household income not be taken into consideration but that the Carer's Allowance should not be means-tested.

## Impact on Carer and Family Members

A key point raised in discussions is that the stress experienced by carers can in turn lead to the carer becoming ill:

*I was full of anxiety and eventually had a breakdown from doing everything on my own. My mother (person cared for) cannot do anything for herself*

In many cases however the carer does not have the time to look after her/his own health:

*I have felt sick all year with a pain in my face/head. I have not had the time to have it looked into it*

*I had my veins done (operated on) but had no time to rest. The veins are now bad again*

The impact on the family of having a person being cared for at home can mean that other family members can feel left out:

*The whole concentration goes on the ill person. The other kids get left out. They end up living in their bedroom as the whole house is taken over*

*You want to protect the ill person and don't want them seeing the other kids going out for the night enjoying themselves. You have to play-down their enjoyments*

*The others (siblings) get no attention. It is all about the person who is ill. I regret that I hardly raised my other daughter. She is now leaving to go to college*

### **Invisibility of Carers**

The invisibility of carers and the non-recognition of their role came in for much discussion:

*Carers become non persons with professionals. Professionals never ask "how are you coping"? No one bothers about you*

*You are invisible. You are like the faery*

The importance of carers getting a life of their own if at all possible was noted:

*Carers need to get a life of their own. They need to do everyday things and feel normal*

*You have to separate yourself out from the illness*

Many people feel that they would like to see the WCCSG highlight the role and value of caring.

### **3. Community-Based Services**

Families appreciate many of the community based services that are available and acknowledge the skills and commitment of workers in the Home Help, Public Nursing and the General Practitioner Services:

*The public health nurses are fantastic. I love to see the nurses coming to the house*

*The palliative care nurses are great. They explained the illness to me and this gave me great confidence*

### **Home Help Service**

The home help service is a key service received by people who need fulltime care and most carers are happy with the high quality of home help service:

*We are very happy with what we are getting for my mam. Before the service started my mam stayed in bed all day. She would not let me give her a bath or get her up. Having someone else coming into the house changes the atmosphere*

Some carers however feel that they do not get sufficient home help hours and many have had hours reduced since the cut-backs in public services. This is stressful on carers. Also the type of work which home helps can undertake has been restricted and home helps are now not authorised to undertake household work such as cooking and cleaning. They are also not permitted because of the insurance implications to, for instance, change bandages or administer medicine.

One carer feels that more regulation needs to be introduced into the home help system, particularly in relation to hygiene:

*They (home helps) are dealing with very vulnerable sick people. There is need for more attention to hygiene. They should wear gloves at all times and change them at appropriate times*

A second carer feels that home helps need specialised training in Alzheimer's illness

The main role of the home help service is personal care work. A key point made by one carer was that the role played by home helps needs better recognition:

*Basically, they do personal care work. They are more like personal care assistants. Their work is casual insecure work with no retainer. There is need to upgrade the status of home helps*

### **Eligibility Criteria for Services and Items**

A key issue raised related to the eligibility criteria for some services:

*I was shot down for the Carers' Allowance and the respite grant. They said that I did not need the allowance as I was not full time caring. They did not come to assess whether or not I needed respite. I appealed and they came to the house and did an assessment and I got it*

*I eventually got the home help service. After some time they made a decision to cut the hours. There was very little sympathy from the public health nurse who stated "They are our orders". I burst out crying. The supervisor came out to the house and did an assessment and increased the hours. Making a decision without an assessment is not right*

As the illness progresses patients need access to many different support items such as grab rails, special beds, sliding sheets, shower seat and different type of cushions. Carers expressed great frustration about the fact that items they were entitled to or the eligibility criteria are not publicised:

*It is difficult to know what you are entitled to. You just seem to find out things by accident*

In this context it was considered important by carers that the public health nurse and other health care officials play a more active role alerting carers to what is available and how items can be accessed.

## **4. West Cork Carers' Support Group**

Results of the Internet Survey indicate that people heard about the West Cork Carers Support Group (WCCSG) from a variety of sources.

<b>How people heard</b>	<b>Number</b>	<b>Percentage</b>
Friend	22	33.8
Leaflet/newsletter	11	16.9
Public health nurse	9	13.8
Newspaper	9	13.8
Community Information service	6	9.2
General Practitioner	5	7.7
Other health professional	5	7.7
Social worker	1	1.5
Other	6	9.2

N = 65

Just over one-third heard about the WCCSG from a “friend”. Other important sources were by a leaflet/newsletter, public health nurse and newspaper.

The “other” category included window of WCCSG office, church leaflet and a meeting of the Co-Action Group.

Carers appreciate the comprehensive nature of the supports they receive from the WCCSG. Staff are highly valued by carers as is indicated by the high satisfaction rating (95 per cent) by carers. Reasons for the high rating by staff include: caring response of staff, feeling understood and being offered a listening ear.

<b>Most helpful about staff</b>	<b>Number</b>	<b>Percentage</b>
Caring response of staff	57	87.8
I feel understood and supported	52	80.0
They offered me a listening ear	48	73.8
Responded with professionalism and confidentiality	48	73.8
I feel respected and valued	44	67.7
Find staff non-judgemental	42	64.6

N = 65

What carers found helpful about the service was the useful information which they received. This was followed by being referred to relevant services, being put in contact with other carers and being helped to plan and sort out difficulties.

<b>Most helpful about service</b>	<b>Number</b>	<b>Percentage</b>
Gave me useful information	55	84.6
Referred me to relevant service	28	43.1
Put me in contact with other carers	25	38.5
Helped me to plan and sort out difficulties	25	38.5
Increased my caring skills through training	24	36.9

N = 65

Contact with the West Cork Carers Support Group (WCCSG) has had significant positive impacts on carers as outlined in the table below. Sixty-six per cent felt that contact with

WCCSG helped them to cope/manage better, 54 per cent felt that their emotional well-being was increased and 52 per cent felt that their confidence was increased.

Positive impacts on carer	Number	Percentage
Helped me to cope/manage better	43	66.2
Increased my emotional well being	35	53.8
Increased my confidence and self esteem	34	52.3
Increased my network of supports by putting me in contact with other carers	33	50.8

N = 65

Comments on the Internet Survey included:

*They helped me to access other services such as the Carers Allowance and gave me confidence when I was at a very vulnerable stage*

*Knowing that someone was always there to speak to and have the difficult questions answered... and there was always a cup of tea to soothe one's nerves. You never felt alone*

*They are very caring and empathetic staff. It is a privilege to know them*

In the face to face interviews with the 26 carers/former carers, the high quality of the skills of staff came in for special mention and the warm and respectful attitude of staff was specifically noted:

*They are devoted to their work. They do it with great passion and love. If you have a problem they cannot do enough to help*

*You get great satisfaction talking to staff. It is a brilliant organisation*

*They are very special caring people. They are wonderful. There is great kindness*

The ability and skill of staff to listen was appreciated:

*I update staff on what is happening in my life. I began to realise that things were improving*

*They are great listeners. If anything crops up they are always there for you. Although we all have different situations, we have similar problems. It is great to talk about it*

The fact that the brief of the WCCSG relates specifically to the needs of carers was appreciated:

*While other services focus on the person who is being cared for, they (WCCSG) are there for you*

*When I heard about them (WCCSG) it was like having a weight lifted off my shoulders*

*You get looked after. This is great for a carer who is normally doing all the looking-after*

*The focus is on you as a carer. Most of the time, it is all about the sick person.*

*Nobody says "Can we take you out for the day"? Just to get out of the house is great*

The types of services availed of by carers are outlined below:

Types of services availed of	Number	Percentage
Drop-in service	39	60.0
Social outings	36	55.4
Training event	24	36.9
Support group meetings	22	33.8
Support –line	21	32.3
Information seminar	20	30.8

N = 65

### Drop-In

Sixty per cent of carers had availed of the drop-in service. This service is highly appreciated by many carers:

*When I am in town, I pop in for a chat. I update them on my situation and if I have difficulties we sort them out*

*It is a wonderful place. They have a great collection of books*

Many carers however would like to see a more localised drop-in service in the main towns throughout West Cork.

### Social Outings

Fifty-five per cent of carers have availed of social outings organised by the WCCSG. The social/recreational activities organised are highly valued:

*I love it. It is an amazing opportunity. It gives me a bit of "me-time". You go away feeling much better*

*It is great to make contact with people in the same predicament*

*The outings help you to relax*

Social outings also help to combat social isolation:

*It is great to be able to meet people who understand your situation. They help you to get out of yourself and are a great antidote to being isolated in the home*

Many women do not always feel comfortable going out alone to public events and in this context the social outings are highly valued by women:

*Women do not feel comfortable going out on their own. In this regard the social events are great. I would like to see more events maybe a show or an overnight stay somewhere*

*I love a day like today (event organised in the leisure centre in Westlodge Hotel, Bantry). I can go on my own. Most places a woman needs someone to go with. It cheers you up. I love it*

The point was made that women in particular can find it difficult to go out alone socially and in this context the social events organised by the WCCSG are invaluable:

One carer mentioned that he would like a *movie day* which would allow him to completely switch-off.

### **Support-line**

Just less than one-third of carers (21) avail of the support line. This service is highly appreciated:

*If I have any problem whatsoever, I just ring up and they are there for me. This means a lot*

*If you ring up you will always get an answer. They are great*

Some carers mentioned that they would like more online support for carers unable to attend group meetings and/or seminars due to caring responsibilities. Others mentioned that they would like a 24 hour telephone service, like the Samaritans so that they could talk to someone during the night-time.

### **Men's Group**

The Men's Group has been recently established by the WCCSG and between 12 and 15 men attend regularly. This group is highly valued:

*The men's group is a big breakthrough. There is a real bond between the men*

*It (men's group) is terrific. Women are natural carers*

The outings organised by staff for the men's group were seen as well chosen:

*The yachting in Schull was terrific*

*The sailing and the Christmas party were brilliant*

*The men's group is brilliant. It is the best thing that could have happened.*

There was a difference of opinion as to whether men discussed their caring role with other men:

*We discuss caring among ourselves. I find this great*

Other members however were reluctant to discuss their caring role:

*Men are less likely to talk about caring*

*Men are slow to get into the caring role and to talk about this*

All men interviewed (5) feel strongly that the Men's Group should be continued.

## Newsletter

The importance of the newsletter came in for specific mention by many carers:

*The newsletter keeps us informed of all that is being done and the activities in the areas for carers. ...the articles in the Newsletter on "Knowing Your Rights" is vital*

*I really look forward to the newsletter and to see what events are on*

*I find the newsletter and online communication fantastic. It is very clear and concise*

## Other Programmes Attended

Other programmes attended included a training event (37 per cent of carers); support group meetings (34 per cent) and information seminar (31 per cent).

## Expansion of the WCCSG Services

In the Internet Survey a high proportion of carers felt that carers would benefit from an increase in services of the WCCSG. The highest demand is for more social outings, followed by more information sessions and increased opening times of the drop-in service.

Increase in services would help carers	Number	Percentage
More social outings	44	67.7
Number of information sessions increased	39	60.0
Opening-times of drop-in service extended	39	60.0
Number of training sessions increased	37	56.9
More support group services made available	35	53.8

N = 65

## Aspects of Service that could be improved

Just less than one-quarter (16) of carers felt that there were aspects of support being received by the statutory and voluntary sectors that could be improved. Answers related mainly to the provision of additional services. Items included the need for:

- A drop-in service for carers to be made available in the main towns of West Cork
- A general informal drop-in once a fortnight where a "bring your craft" (knitting, embroidery, crochet) and a different topic discussed at each event
- More events tailored to the needs of carers caring for disabled children

- Carers caring for similar types of illnesses i. e. special needs, autism, mental health and Alzheimer's illness to come together to discuss specific difficulties
- More respite care
- More home based support
- Support at night-time and weekends
- A 24-hour helpline like the Samaritans
- More support for siblings and families as a whole
- An annual medical check-up for the carer
- An information pack on rights and supports for carers

## Appendix A Profile of Carers

Fifty-eight per cent (38) of carers that participated in the Internet Survey are between 46 and 65 years of age. Twenty-three per cent (15) of carers are 66 years or over and 3 per cent (2) are 35 years or less.

Age	Number	Percentage
18-25	0	0
26-35	2	3.1
36-45	10	15.4
46-55	19	29.2
56-65	19	29.2
66+	15	23.1
<b>Total</b>	<b>65</b>	<b>100</b>

Twenty-eight per cent (18) of carers are male and 72 per cent (47) are female.

A large proportion (78 per cent) of carers are Irish nationals and one carer was an Irish national and a members of the Traveller community.

Nationality	Number	Percentage
Irish national	51	78.5
Irish national and member of the Traveller community	1	1.5
Non-Irish national	13	20.0
<b>Total</b>	<b>65</b>	<b>100</b>

Ten of the 13 non-Irish nationals are from Britain and two are from Germany. There is no information on one person.

The number of people being cared for with an illness by any one carer is outlined below.

Number of persons being cared for	Number	Percentage
1	55	84.6
2	7	10.8
3	3	4.6
<b>Total</b>	<b>65</b>	<b>100</b>

Fifteen per cent (10) of carers are caring for more than one person.

Eighty-nine per cent (58) of carers were living in the same house as the person being cared for.

The broad range of illnesses and disabilities which carers and people cared for have to come to terms with include physical, intellectual, mental health and sensory difficulties.

Type of disability	Number	Percentage
Physical	43	66.2
Sensory	14	21.5
Intellectual	24	36.9
Mental Health	23	35.4

N = 65

Many people have multiple disabilities.

Illnesses cared for by carers in the current study include neurological degenerative disease, Alzheimer's/dementia, post stroke difficulties, post liver transplant illness, cardiovascular diseases and mental health illnesses.

No carer is working full-time outside of the home. Fifteen per cent (10) are working in part-time work and 12 per cent (8) are self-employed.

Work outside the home	Number	Percentage
Not working outside the home	47	72.3
Part-time work	10	15.4
Self employed	8	12.3
<b>Total</b>	<b>65</b>	<b>100</b>

Just less than 40 per cent (25) of carers are in a caring role for more than 10 years.

Number of years	Number	Percentage
Less than one year	2	3.1
1 o 2 years	6	9.2
3 to 5 years	13	20.0
6 to 8 years	9	13.8
8 to 10 years	10	15.4
10 plus years	25	38.5
	<b>65</b>	<b>100</b>