Think Carer®

Carers Support
Working with West Sussex Carers

Carer Needs Analysis

September 2015

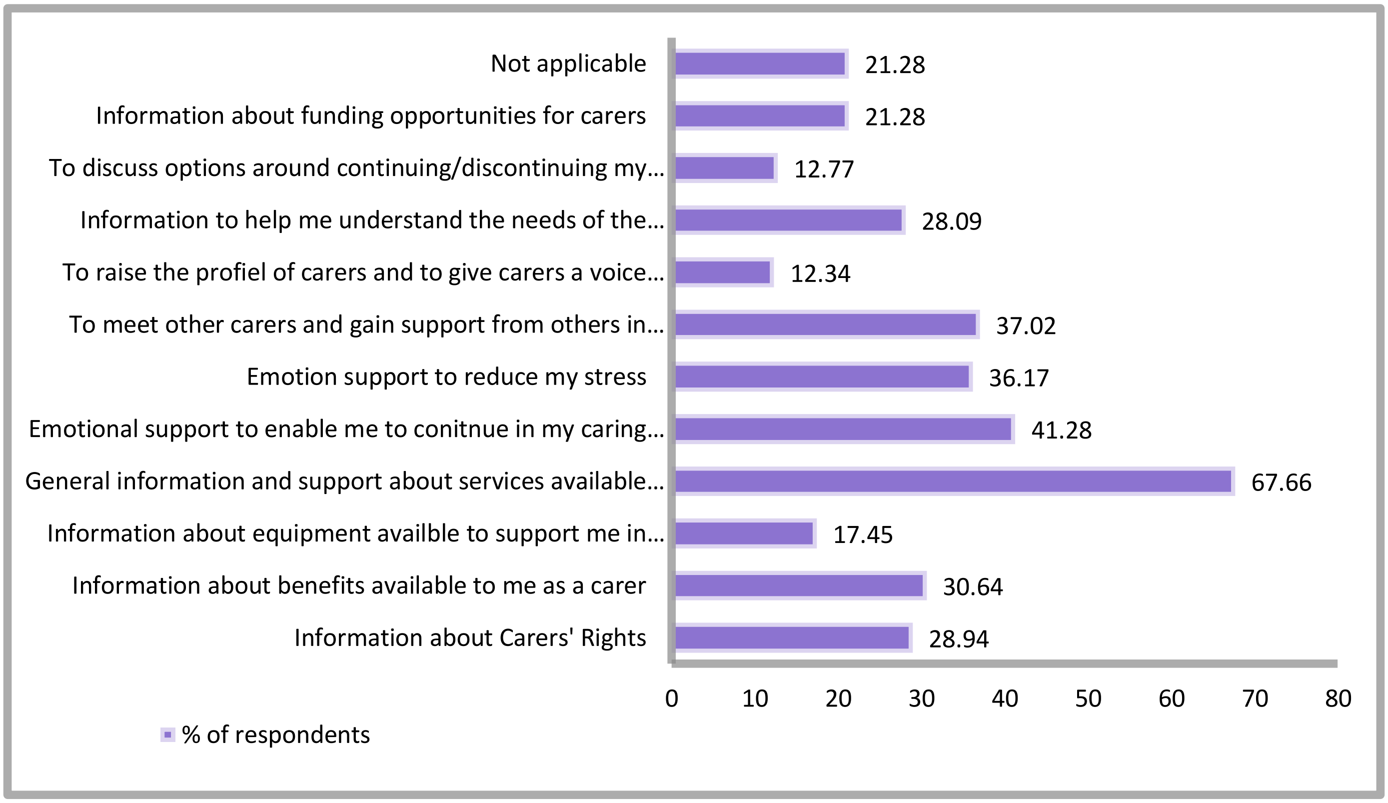
A Summary
Of Carer Feedback from a
Consultation Survey
August-September 2015

To Note:

- 235 completed surveys were received from Carers
- Some carers who responded thought they were replying to either their Care Provider or the County Council or other health and social care organisation. It is not possible to filter these responses out and their comments and feedback are used on the basis they are valid in determining carer needs across the County.

Which Services Do Carers Access Most?

Chart 1

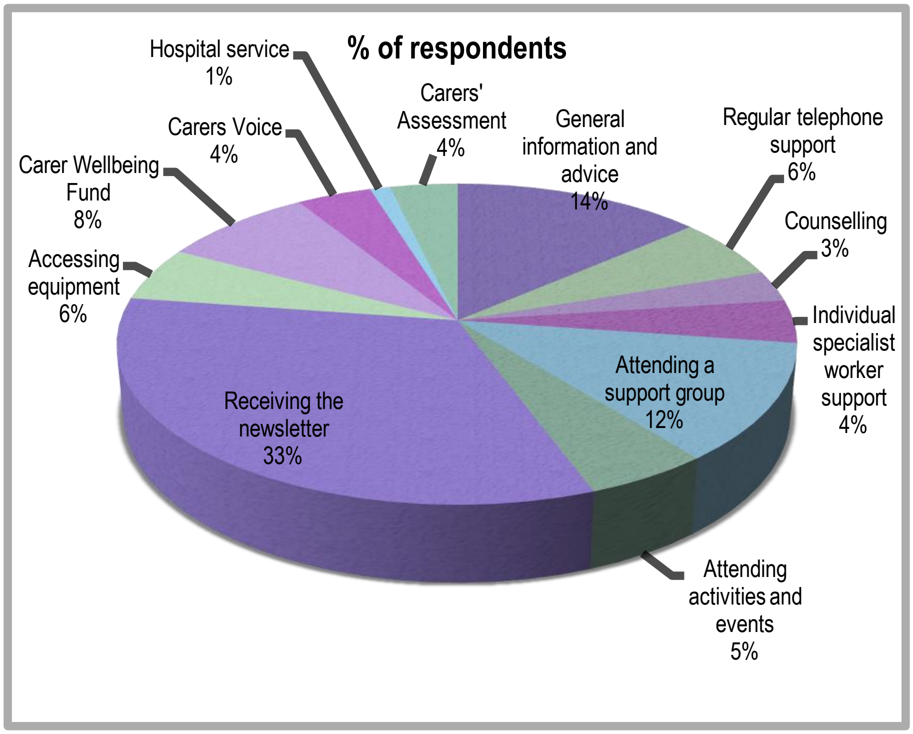


The above graph shows that the **majority of contact** with CSWS **is related to general information and advice** at 67.66%, **followed closely by emotional support** at 41.28%. Meeting other carers, benefit advice and information to understand the needs of the people they care for are also high on the list of needs when contacting CSWS.

However, carers were also asked whether they were currently using services, have used services in the last 2 years, 5 years or never. They were also asked if they knew about the services. The majority of respondents were currently receiving the Newsletter (60.19%).

Chart 2 indicates **current usage** by respondents.

Chart 2



When comparing current use with past use of services and bearing in mind changes arising from the current Universal Services contract and merged organisations there are some notable headlines :-

General Information and Advice is higher: 33% usage in the last 2 years compared to 26% in the last 5 years.

Regular telephone support usage is fairly steady across the 5-year period.

Counselling take-up was greater at 11% 5 years ago, 8% 2 years ago and now 6%.

Attending a Support Group has increased in line with the growth of the number of groups available which now stands at 52 across the county. This has grown from 10% 5 years ago, 18% 2 years ago to 22% in the current year, although 44% of carers have never attended a support group. Many comments reflect the fact that for many carers, attending a support group without the person who they care for is not an option open to them.

Access to the Carer Wellbeing fund has been fairly static over time but 38% of carers have never used this fund and 12% say that they don't know it exists.

The number of Carers' Voice respondents was relatively low. 51% of carers do not know the Carers' Voice exists.

43% have not had a Statutory Carer Assessment. Given this is a new CSWS service and because numbers were previously very low this is not surprising. 18% of carers do not know a Carer Assessment is available.

"I cannot access carers support groups as there is no provision for me to bring my parents and I have no respite care for my mother."

"The short break funding is invaluable because as I also work full time alongside my carer responsibility for my husband and parents I am unable to attend coffee mornings and other support events."

"To be a carer is not so easy at time to time. It is so nice to know there is someone out there who can help"

Clearer Communication

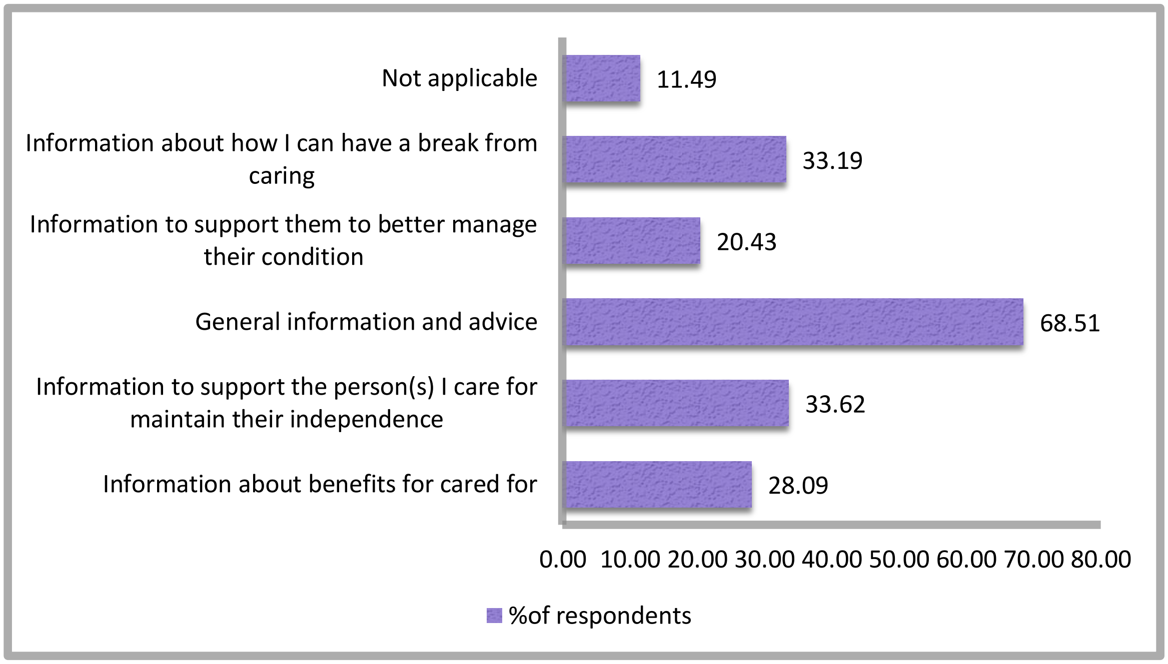
Given that some respondents clearly thought the survey was from the statutory sector it is difficult to assess their open- ended comments. Results suggest however, that there is a communication issue to resolve through even clearer publicity and promotion and information-giving. Not just about what organisations Carers Support West Sussex is but also about the role of CSWS and services it can offer to support carers in their role.

Consider Support Groups with Respite

CSWS may need to consider support groups at times of day and that have support for the person cared for to reach those carers who do not get any respite at all. Other ways of collaborating to increase the market place and menu of opportunities would also offer respite to some carers.

Support for the person or people who are being cared for

Chart 3



Some carers who responded are unable to take up other services available - the most commonly cited reasons are:

- Unable to leave the person(s) who they care for
- They work and most activities are during working hours, or when not at work they are caring
- Geographical constraints
- Little time, energy or will to battle with professionals to follow-up on advice and information provided
- Not able to access face-to-face support

Carers would like more flexible services, where they can bring the person who they care for, or in the case of Parent-Carers their other children who may not be in school.

> *"I found the carer experience was made more difficult by seeing multiple people from numerous agencies and became very confused as to who I had seen.*
>
> *What would be helpful would be to have one person who would be aware of who had been to see us and who would coordinate the necessary help. When one is stressed and there is an overload of difference agencies it adds to a stressful situation."*

> *"There seems to be much information available to carers and the issues are highlighted such as the need for respite, but the reality is there is not much meaningful respite available locally. For example My husband with Alzheimer's and is disabled, has previously been to Elizabeth House, but this time has to go to East Preston which is very inconvenient for myself and visitors (we live in Hunston).... it is pointless offering information and support unless it is backed up by the reality of the meaningful services which some of us have the misfortune to depend on."*

During August and September 2015 we undertook a survey of Carers and Collaboration partners. Below we summarise the key themes from this consultation which have informed our Strategy.

Carers Support aims to provide a gateway service to Universal Services provide and to other available support across West Sussex.

General Information and Advice

68% - the majority of enquiries (68%) received are for general information and advice about support available to the Carer themselves as well as for the person they care for. 42% felt that through the information and advice provided they were better recognised as expert partners in care.

Carers Rights and Expert Partners

Many carers appear not to be aware of their rights and what is available to them, are frustrated by the many professionals they have to deal with and having to continuously explain their situation.

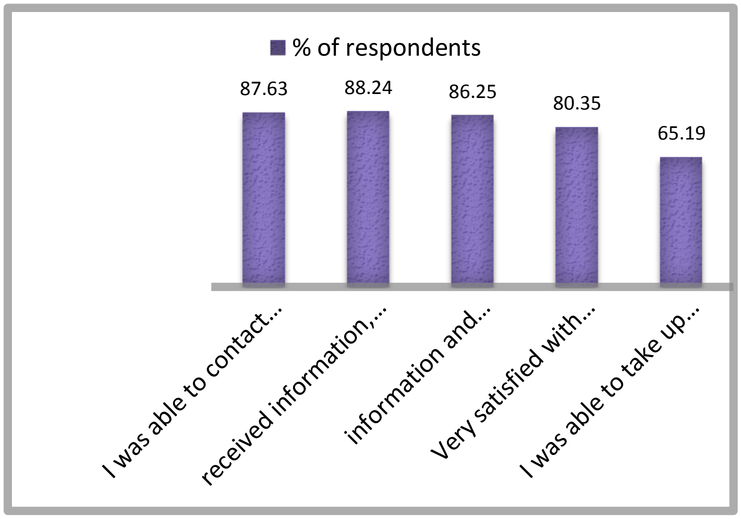
Although 34% felt more informed about their rights many carers quoted lack of time and frustration in trying to deal with professionals as a barrier to accessing services they need.

Through the Carers Voice Newsletter and Carer Assessments this situation should change significantly over time. Raising the profile of the needs and rights of carers in West Sussex is an area CSWS will continue to invest in.

Carers Voice and Carers Groups CSWS will also be a route to continuously keep Carers informed, through which to engage carers and gather evidence and feedback for carer-shaped service development.

Satisfaction with Service Provided

Chart 4

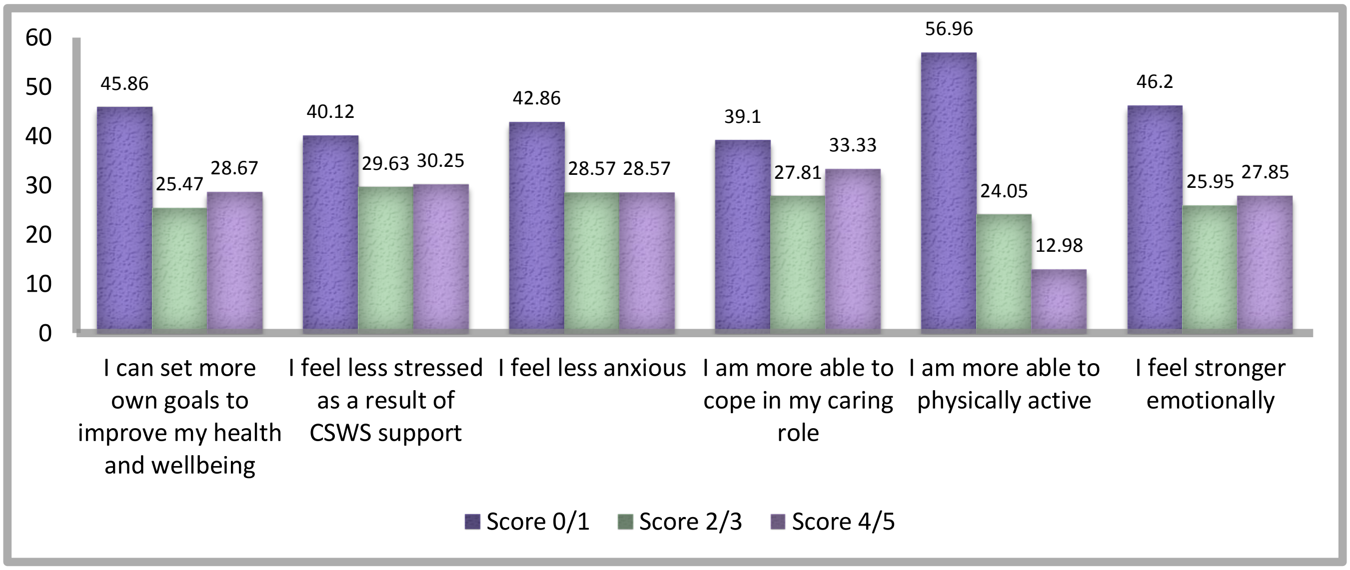


"To be a carer is not so easy from time to time, it is so nice to know there is someone out there that can help."

"I just don't feel that carers are listened to by the powers that be who make the big decisions. It's as if lip service is paid but, in truth, we are not heard. The awful truth is that if we carers were not prepared to take our role seriously the NHS would have a catastrophe on their hands. What we are paid, for what we do, is a pittance and a disgrace. Spend time in our shoes, hour by hour, day by day, week by week, month by month, year by year and THEN they would have some idea of what things are like. Professionals themselves are full of advice and may work with patients on shifts, but I have yet to meet ONE who has actually lived alongside a loved one who is struggling with a mental illness. A parent/carer cannot afford emotional detachment which makes the task even more heartbreaking."

Health and Wellbeing

Chart 5



Carers Health and Wellbeing

It is well evidenced that carers suffer high levels of stress, anxiety and have poor emotional, physical and psychological health. Carers can suffer physical injury as well as the stress of their caring role.

There is often a clear link between carers suffering poor health as a result of their caring role. Statistics from reports found 86% of carers reported suffering from stress, anxiety and depression and 54% felt isolated. 96% reported a negative impact on their health and wellbeing.

The above chart shows this is still the experience of many carers in West Sussex. However, we need to look at the context in which the responses were given to fully understand these results.

> *"I now meet people, go for a healthy walk once a week. I very much look forward to that I don't feel so invisible that way."*

> *"Feel less isolated and know where to turn for help or just for a chat, knowing my needs will be understood."*

The most common reasons cited for not being able to address issues of stress, anxiety, to reduce isolation, be socially or physically active is simply that carers do not get any breaks from their caring role making it impossible to address their own health and wellbeing needs.

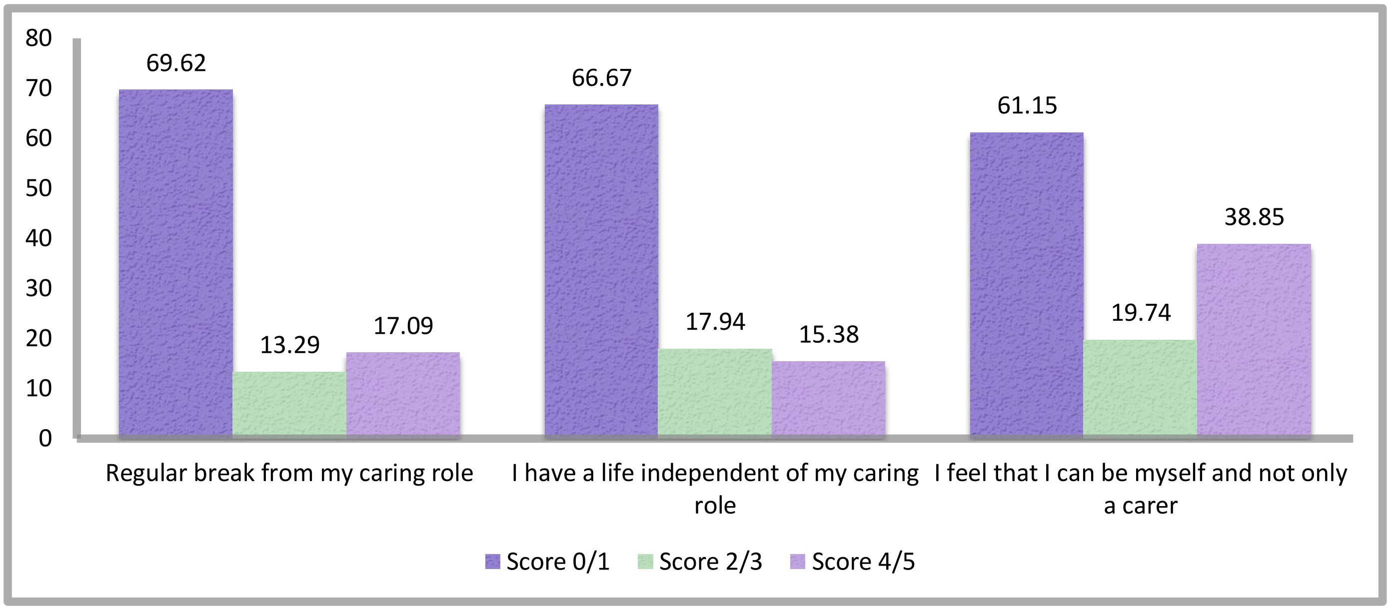
Continuing provision of our services such as counselling, groups and activities to reduce stress, anxiety and isolation is essential.

The Carer Wellbeing Fund is also cited as an essential lifeline for many carers.

> *"The emotional support from other carers and staff from Carers Support has been invaluable and both have been good sources of information."*

> *"I have been forced into a change of my previous life due to my role as a carer.*
>
> *I am less able to pursue my hobbies outside the home such as playing golf and membership of societies which need time away from home where I am needed."*

Chart 6



The above chart shows that many carers in West Sussex do not receive any respite or have a life of their own outside their caring role.

Many carers are self-funders on limited incomes or with reducing savings.

There are very limited opportunities for respite to support the needs of the person who is being cared for and provide space and time for the carer to be themselves, have time to relax or pursue their own interests.

This critical issue affects carers regardless of their age, whether a parent-carer, young adult carer or older carer.

Many carers also expressed their anxiety about what would happen to the person they care for if something happens to them.

Many carers expressed financial worries and are living on low incomes, especially carers in receipt of state pension who have no other source of income. The cost of caring can be high with hospital visits and higher utility costs such as for heating.

The most commonly requested support was:-

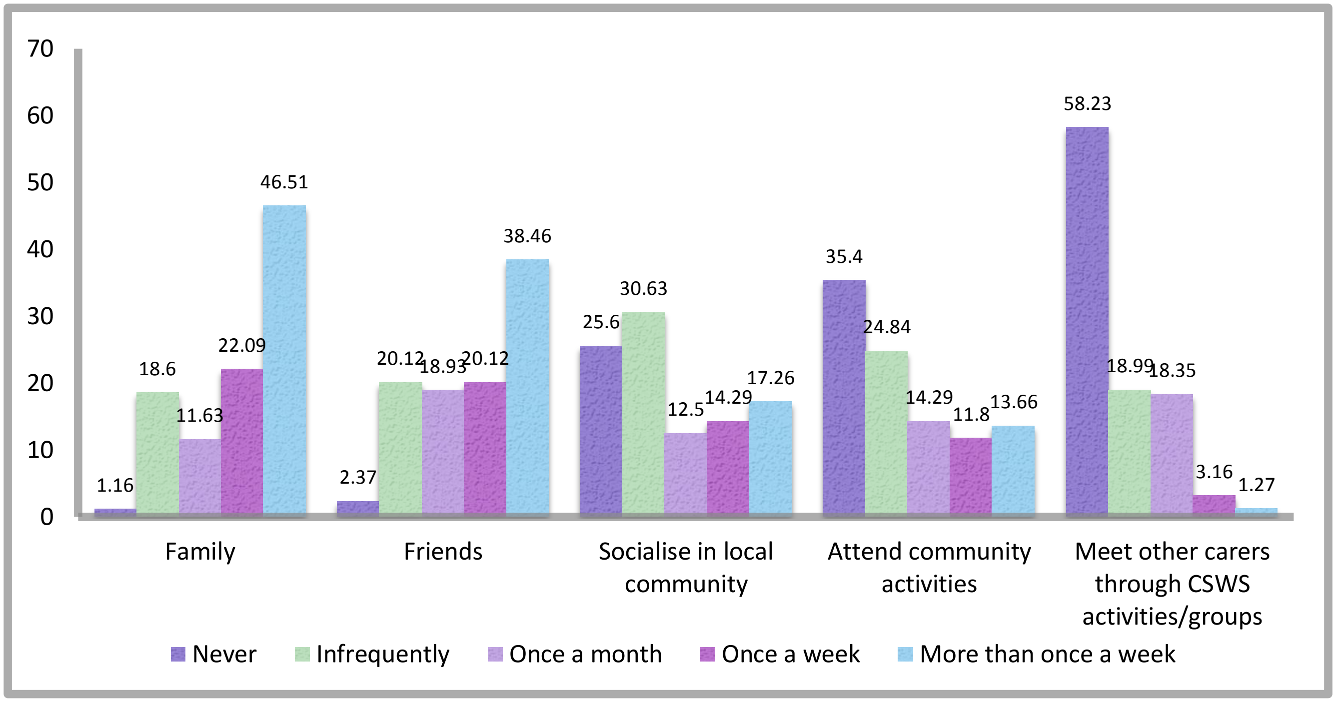
- affordable day respite
- emergency support
- more access to the Wellbeing Fund
- more counselling face-to-face
- male carer groups

"I care for my wife 24/7 except for the time my wife spends in the day care centre because of her condition I have to be close all the time / caring for my wife is reducing my savings rapidly and unable to entertain the idea of respite."

"No difference at all. My entire life is determined by what my son can and cannot manage on a day-to-day basis. He cannot be left so I have no option but to be with him all the time."

"Although I have accessed the short break funding a couple of times this is not a regular break, hence the 3 rating. however, it should be stressed that these breaks were invaluable to myself and my family at the time - I wish these were a regular treat to look forward to as I am unable to access any of the support groups given that I work full time (40 hours per week)."

Chart 7



Losing social contact with friends and family, losing social life and life outside caring is a significant gap identified by many carers.

The quotes recorded here show challenges carers face. For carers who are able to attend Support Groups and other community activities such as being able to attend their local church – these opportunities are invaluable in helping maintain carer health and wellbeing.

One carer reported….

"I think if I had gone on the way I was before I joined the Carers Support Group I would have had a physical and mental breakdown. I had a strong sense of the danger of this and this made me join the Carers Group.

I didn't, I admit, have much hope of it at the time but I am amazed at how huge a difference it has made and I am VERY VERY grateful."

Many respondents referred to difficulties with transport or lack of transport to enable them to socialise.

One carer commented….

"I miss going out it is very depressing".

"I have lost all my confidence, I am isolated now use to be sociable, no circle of friends."

"We are prisoners in our own home."

"So much depends upon the duties placed upon the carer. This is different in each individual case. For me it was necessary to give up all the external interests I had as my wife became more incapacitated. Also finding the time and making arrangements for care of my wife in my absence restricted the amount of time I could give to any outside

"It's hard for me to attend carers group meetings as I care for my mum I can't leave her on her own for a long time. I would like to go along to these meetings but at the moment it's not possible."

Work, Volunteering and Learning

33% of carers are working.

Of these only 20% work regularly and a further 15% work sometimes.

A notable number of carers also stated that they had given up work or felt pressured to give up their jobs.

There were similar comments such as….

“carers are not taken seriously by employers, and they think we won’t show up because of our caring duties.”

Some comments do highlight good experiences but overwhelmingly the responses indicate that balancing work and caring is precarious.

Many carers responding were retired where working was not an issue.

Only 11% of carers who responded volunteered regularly.

“Had to give up work to care.
Was fired from the job before as I had time off to care as my dad became sick.”

“My work were always very supportive in my role as a carer. However anytime I needed away from work to care meant that I did not get paid.”

“My employer is very flexible but I am unaware of the legislative rights.”

“The strain of working and caring. I need to work both for my own sanity (what's left of it) and for financial reasons, we have a family to support - but this makes it very difficult to access outside help and to have the time to do so.”

“Some Carers who are retired are unable to work to increase their income because of the restrictions of the benefit system.”

Services you would like CSWS to develop

81 responses were received to this question and a wide range of suggestions provided.

The most common suggestions:

1. Practical help such as day centres and home based respite that is affordable, local, and accessible and can meet a wide variety of needs.
2. Reduced costs to various activities for carers eg health club membership.
3. The newsletter needs to be news not information about what has happened.
4. Medical check-ups, reduced rate alternative therapies.
5. Male carers groups.
6. Out of hours helpline or access to a counsellor and more counselling.
7. Events and outings for carers.
8. Befriending services for cared for.
9. More support for parent carers and information and support for older adult children with disabilities and mental health issues.
10. Regular breaks and outings.

"The emotional support for carers is what I have taken up and benefitted from - both the aroma therapy massage and the counselling. I would like to be able to access more of these kinds of services. It helps me with my on-going mood and wellbeing."

"Extension of counselling beyond 12 weeks if needed."

"Provide easily accessible and affordable GOOD respite care."

"More flexible approach to your regular contact services."

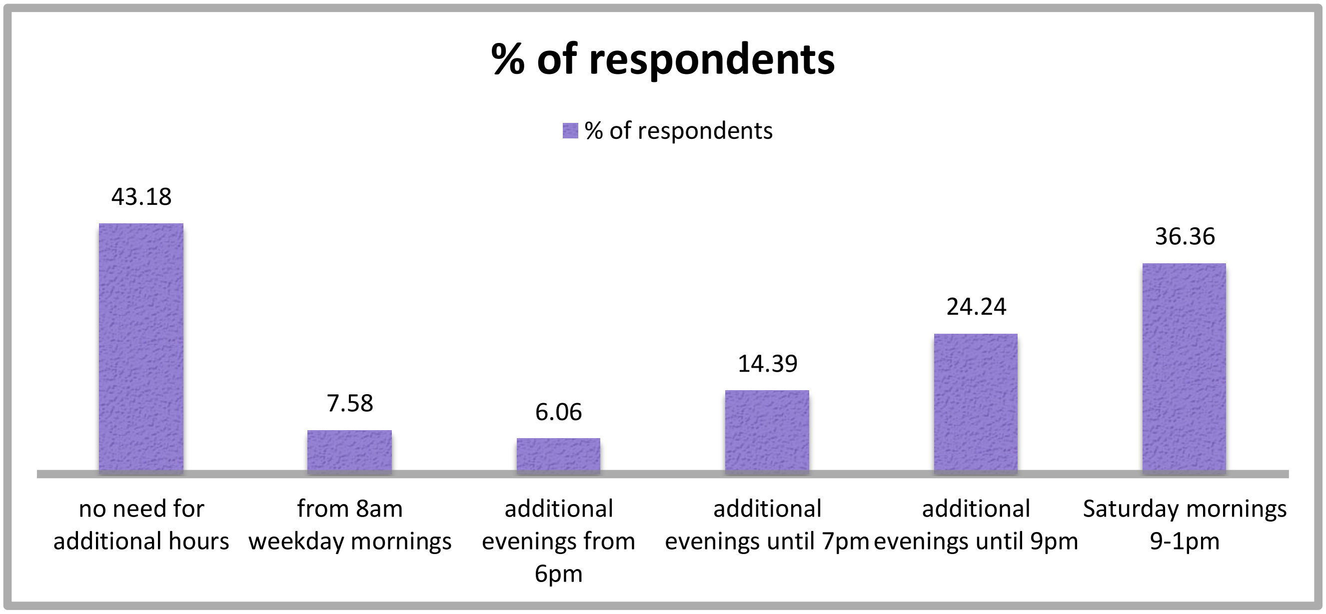
"Services that support working people – we have 2 full-time jobs not just one!"

"I would like to see more representation of LGBT (ie, Lesbian/Gay/Bisexual/Transgender) carers)"

"Events and outings for carers are always welcome as they take you away from your normal caring role. Perhaps arranging some support meeting by type of carer eg dementia spouse/family member, parent of autistic child as we have some different needs."

What are the main issues affecting you as a carer?

Chart 8



We asked carers if they wanted telephone support times extended - this is what carers told us.

Responses indicate that 43% of carers are currently happy with the hours available.

However a number of carers say that later in the evening up until 9pm and Saturday mornings would be welcomed.

Carers also indicated that it is often out of normal office hours when things go wrong or emergencies happen.

Access to telephone support was also raised by one respondent who has a hearing impairment. Given the number of elderly carers this might be an issue for a significant number of carers.

Many carers also commented that they never use the service or they have had problems accessing it.

> *"I can't use the phone as I am deaf. An email service would really help."*

> *"Set times each day, not differing as this can be confusing."*

> *"I can't do DIY so a register of trusted handymen would be useful. I'm struggling with the family finances which has not been in my control before, so help with that would be a great help."*

> *"Health implications and impact of long-term stress on the wider family."*

> *"Longer telephone hours access could be useful, as some emergencies, urgencies don't always happen 9-5. Is there an answerphone for out of hours?"*

Most of the issues are covered elsewhere in this summary although there were some additional issues raised such as:

- Financial pressures already mentioned but more particularly changes in welfare, benefit cuts, and no care cap.
- Lack of mental health services for young people.
- Parking availability and costs for frequent hospital visits.
- Carers save substantial amounts of money to health and social care services, carers should be paid a decent wage.
- Carers allowance shouldn't cease when a carer reaches retirement age.
- Emergency care for the person who is being cared for.
- Lack of financial support for self-employed carers.
- Easy ways to navigate the systems and not have to access so many different services.
- Housing issues.

> *"Things tend to go wrong after 5pm and at weekends. Some sort of on call emergency number for any time would be useful."*

> *"As a 78 year old Carer, I receive no financial support, as I receive a state pension. Should I become incapacitated and unable to care for my wife. I would still receive my state pension, but it would cost the state a lot more than the £63 Carers Allowance. So why don't they pay all Carers, irrespective of age. Is this not age discrimination?"*

> *"Information on transition from Children to Adults, and what rights someone you care for has."*

> *"Housing issues to be prioritised for parent carers and individual being cared for. CSWS to talk to them on individual behalf. Time and time again it is frustrating to hear the person is 18 or over the person you care for so not really their place to get involved but it is when the carer is poorly them self someone by your side when sorting issues out."*