

Carer Survey Report

An evaluation of VOCAL (Voice of Carers Across Lothian) services and consultation on future priorities for carers in Edinburgh and Midlothian



October 2011

"The help I received has definitely made a difference. Yes, I am more aware of things now, I am working towards having time for myself, to improve my health. I feel a difference within myself knowing that I can contact my local VOCAL if I have any worries - although they can't help at times, just talking it over with someone you can trust is a big, big help."

"I appreciate the support given by VOCAL when I need it. As a carer it's easy to feel frustrated or isolated, staff seem to generally understand how carers feel. Still I feel there should be a lot more awareness raised so that carers are fully supported financially, emotionally, and socially."

"Someone listened and advised where to access more help when necessary. I found out more about how the 'system' works, i.e. what services were available immediately, when we really needed help - not having to wait to be heard. My health improved so I could continue working."

"My parents and my GP were insistent that I speak to you. At the time I was not sure you could help me. Since phoning you I have been given information, reassurance and help when I didn't know what to do. I cannot think of any improvements you could make to your excellent service."

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Introduction

Every year, VOCAL invites carers to feed back their views on the quality of the support received and on priorities for future services.

In July 2011, VOCAL asked 4,248 carers who had received information and support over the previous year for their views and priorities. 611 carers replied – a response rate of 14% - representing an almost 200% increase compared to previous years.

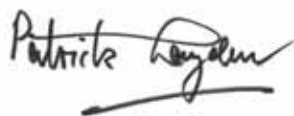
The survey was anonymous: carers were not asked to give their name or personal details. It included a total of eight questions, six offering space for individual comments to capture carers' personal experiences and impressions.

Four questions focused on carers' experiences of using VOCAL services and on the impact this support had on their lives. Four further questions asked carers about their priorities for future developments and improvements to VOCAL's services.

This report sets out carers' responses to specific questions and reproduces all substantive comments to reflect the full diversity of carers' experiences.

We share these findings with other partner agencies, because carers' views obtained through this survey are not only relevant to VOCAL. They reflect a wealth of caring experience and priorities which should be of interest to planning and commissioning officers and other service providers.

All too often, carers speak, but are not heard. We hope this report can strengthen the voice of carers.



Patrick Layden, QC
Convenor of the Board, VOCAL

Acknowledgements:

We are grateful to all carers who took the time to contribute to this survey. We produced this report to ensure their voices are recorded, heard and reflected in future developments.

We are grateful to all those who helped process the wealth of information and data, and helped in producing this report. In particular, we wish to thank Christine Winton, a long-standing volunteer at the Edinburgh Carers Centre; Susan Guenther, who worked for VOCAL as part of a six-month international student placement; and Rosie McLoughlin, VOCAL's Information and Communication Manager.

Executive Summary

The survey met with a high response, particularly from older carers and carers of older people.

- 53% of respondents were over 60 years of age (262 aged 61 – 79, 64 aged 80+)
- 37% under 60 years of age (225 carers),
- 10% did not declare their age range (60 carers)

With regard to the age of the person receiving care

- 50% cared for someone over 60 years old (306 carers)
- 32% cared for someone under 60 years old (195 carers)
- 18% did not specify the age of the person they cared for (114 carers).

A geographical analysis shows

- 74% of respondents live in Edinburgh (449 carers)
- 19% live in Midlothian (119 carers)
- 6% live outside Edinburgh or Midlothian (36 carers)
- 1% did not state where they live (8 carers).

The survey provides reassurance to VOCAL and its funders that in 2010-2011 the overwhelming majority of carers who used our support and services recorded very positive feedback about their experiences:

- 87% of carers rated the quality of the response received when contacting VOCAL either excellent or good (352 excellent, 147 good, 34 satisfactory, 9 unsatisfactory, 34 can't say).
- 81% of carers reported that the help they received made a positive difference to them (416 yes, 77 no)

VOCAL's range of services appears to meet the needs of the majority of carers, although some carers report difficulty accessing or attending services.

69% (425) of carers offered comments about which of VOCAL's services they found *most useful*. Of these

- 36% of carers found training courses, group meetings, peer support and meeting other carers most useful
- 25% rated information received, including Carers News and VOCAL's website and e-bulletin most useful
- 14% specifically mentioned financial advice and legal support, including help to fill in forms
- 7% quoted counselling; 7% advice and support; 3% advocacy; 3% the Edinburgh Leisure card; 3% valued VOCAL's links to other services and 3% simply felt knowing that VOCAL is there is most useful.

29% (179) carers offered comments on the *least useful* aspects of VOCAL's services. Their comments largely referred to difficulties attending events because of their caring situation, transport, work, having no time, lack of respite or the timing of meetings. We made sure all critical comments were grouped and fully reproduced in this report. The Board and staff team will take specific action to consider these comments in a review of our practice.

The survey produced a wealth of personal comments – over 1,700 individual comments were received and all substantive comments included in this report.

From carers' individual comments we note several important themes and trends:

- Carers reported feeling better informed and supported following contact with VOCAL. Many mentioned in particular the carer training courses, financial and legal surgeries

- Carers value reassurance – knowing VOCAL and the Carers Centre are there when needed, being reminded through receipt of Carers News and e-bulletins. This supports carers to self management and feel more confident in their caring role - *“You have a bit more confidence knowing that you have someone to turn to if the need arises”*
- Carers value VOCAL’s support in navigating health, social care and education systems and acting as a gateway to other services and agencies
- Carers also report feeling isolated, not having enough time for themselves and valuing peer support from other carers and a listening ear.

Asked about future priorities, we concentrated on two detailed questions on financial support and employment.

On financial support . . .

- 352 carers (74% of respondents to this question) said improving their income was an issue.
- For 301 carers (65% of respondents) planning financially for the future was an issue
- 155 carers (36% of respondents) said managing or reducing personal debt was an issue, and
- 283 (63% of respondents) stated paying for or planning for long term care was an issue to them

13% of carers added individual comments to these questions on the importance of financial support.

With regard to the **balance of caring and employment and training** . . .

- 139 carers (32% of respondents) stated that remaining in paid employment was an issue
- 95 carers (23% of respondents) said entering or re-entering paid employment was an issue
- 94 carers (23%) stated accessing training or volunteering to lead to paid employment was either a small or big issue for them

Finally, we asked carers about the future importance they attach to 9 different service areas which the following number of carers considered very important or fairly important:

- Booklets, newsletters, regular information 470 (95% of respondents)
- Emotional support and counselling 419 (91%)
- Carer support groups 411 (89%)
- Website and support to find information online 364 (85%)
- Carer advocacy 370 (87%)
- Stress management courses 364 (82%)
- Training and learning opportunities 330 (77%)
- Healthy living initiatives (diet, exercise, weight) 348 (79%)
- Social and leisure opportunities 334 (76%)

39% (237) carers offered comments on improvements to VOCAL’s services. Many felt they could not suggest any improvements however some of the areas where suggestions were made included scheduling of events, lobbying, wider promotion of VOCAL services, financial and legal support, increase provision of services and more social and leisure opportunities.

In this report, VOCAL grouped carer comments to the best of our abilities, to enable readers of the report to identify key areas of carer concern and satisfaction – not only for the improvement of VOCAL services, but also to influence future planning and commissioning of carer support across Edinburgh and Midlothian.

Getting your views about VOCAL's services now

1. How did you find the response(s) you received when you contacted VOCAL?

94% (576) of carers answered this question. 87% (499) of carers who answered this question rated the response as excellent or good.

Excellent	352 [61%]
Good	147 [25%]
Satisfactory	34 [6%]
Unsatisfactory	9 [2%]
Can't say	34 [6%]

Breakdown of how carers answered this question:

Area	Can't say	Excellent	Good	Satisfactory	Unsatisfactory	No answer
Edinburgh	19	266	109	23	8	24
Midlothian	11	67	25	8	1	6
Other area	4	16	9	3	0	4
Area not given	0	3	4	0	0	1

Carer age	Can't say	Excellent	Good	Satisfactory	Unsatisfactory	No answer
Under 60	15	133	52	15	3	7
61 - 79 yrs	11	155	62	13	6	15
Over 80 yrs	4	29	20	2	0	9
Age not given	4	35	13	4	0	4

Summary of comments

- 54% of carers provided comments to this question.
- Of the 34 carers who answered 'can't say', 62% stated that they have not been in personal contact with VOCAL to seek advice or support, but do receive regular correspondence.
- Key themes mentioned and valued by carers included staff and volunteers (21%), support including financial help and advice (7%), and the reassurance of knowing VOCAL is there.
- 8% of carers commented on the prompt response received.

1.1 Individual carer comments on the response received:

Staff and volunteers

- A warm caring and understanding voice at the other end of the phone and a meeting
- All responses were very friendly, informative and efficient. Also extremely caring and reassuring, especially meetings with carers at Currie last summer 2010.
- Always ready to listen and offer support
- Andrea helped me a lot - she is very good at what she does
- Anyone I spoke to was friendly and encouraging
- Easy to talk to. Can help you by talking through issues and therefore help the person caring make important decisions.
- Every team member I have met has been very positive and empathic. It has been great to meet all of you.
- Everyone was so helpful from the front desk onwards
- Ex - colleague Justine helped to fill in the form for attendance allowance. It was rejected first time but she applied again and it was granted.
- Fast, efficient and very supportive.
- Found contact helpful and supportive. Gave feeling of not being alone.
- Found the staff really friendly, easy to talk to, reassuring
- Good but could be slow due to worker being part-time and working in more than one location.
- Had great chat with Jane, she is a good listener.
- Had very good support until Lissa retired. We are trying hard to keep our group going.
- Helpful and friendly staff. Signpost to right groups to support.
- I attend VOCAL every 1st Tuesday of the month and think the staff are very professional and helpful
- I found the lady at the end of the phone very understanding
- I found VOCAL very friendly and efficient over the phone and in person
- I have always found my contacts with VOCAL very helpful and the staff extremely kind and understanding
- I have been very impressed with VOCAL. The staff have been very friendly, helpful and professional. Help filling-in the vast form for claiming Attendance Allowance was amazing.
- I have found my initial contact with VOCAL, both on the phone and in person, both welcoming, patient and warm
- I have not needed to use VOCAL often but when I have visited, the staff have been unfailingly helpful and welcoming. I now know that they will give me prompt help and directions to where else I need to go for help. Irreplaceable knowledge!
- I know I can lift the phone and speak to the staff mostly Claire. When I have problems at home.
- I phoned your Edinburgh branch regarding my carers allowance. The gentleman was very supportive, he gave me excellent advice and phone numbers. I found he was very caring and most helpful.
- I used Vocal more when Sheena was there as we got on particularly well. All the staff have been very helpful and friendly.
- Information, friendly and helpful
- It is a while since I phoned VOCAL. Always satisfied with answers, staff always nice on phone.
- I've found the staff to be extremely helpful, supportive
- Jan could not have been more helpful and supportive
- Jane was welcoming and reassuring. She hosted the 'Looking to the Future' course with an efficient and friendly manner.
- Justine was very helpful in filling in forms and very good listener. Also the people in the office in Edinburgh.
- Lovely staff always willing to help and advice
- Moira was very helpful to me in 2010. I don't think I could have done it myself, she was very good and helpful.
- Nicest person to come to the house
- Nothing is too much to ask. You always seem cheerful and all my queries have been answered.
- On my first visit I was met by nice people and felt quite at ease
- Rachael was very supportive when I first called her and contacted the relevant people in order to get help for my mum
- Reception volunteers always responsive and helpful. When you speak to any member of staff, both permanent and voluntary, you feel as though they are devoting their whole attention to your problems.
- Staff always friendly and helpful, and if they can't give you information then will get someone to phone you back with the details.
- Staff always polite, professional and caring when dealing with any enquiry or offering

support. It's good to have an organisation who are willing to support and advocate on behalf of the carer, as most services revolve around the cared for.

- Staff are always very helpful and friendly /pleasant / understanding /informative/welcoming /knowledgeable/professional /polite/ courteous and sensitive / supportive/interested/ approachable **[mentioned 49 times]**
- Staff at VOCAL are able to help with all manner of problems in a sympathetic way.
- Staff very supportive and always ready with information and advice to me as a carer!
- Staff very well informed if they don't know an answer they will find out
- Supportive and sensitive communication by telephone
- The girl I saw was friendly, approachable and knowledgeable. I was able to meet her at a time convenient to me and did not feel rushed in any way.
- The people you speak to are always very supportive and take time to listen
- The person was good and a lot of information helped us with benefits
- The service has always been good - the staff are all very polite and willing to help, especially on the phone.
- The staff are extremely helpful. I have been at courses, asked advice etc. I have always been pointed in the right direction.
- The staff are very knowledgeable and always have time to listen and advice
- They made sure I had all the information necessary and they came to the house as well as speaking over the phone
- The people I have been in contact with are very helpful and nothing is too much bother
- Understanding, keen to help
- Very experienced people, good range of training and services
- Very helpful and they listen to what you tell them and with this information they know exactly how and when they can help you
- Very helpful staff, professional help and support regarding legal advice, benefits and local services
- Very helpful, in enquiring about my needs, and well being
- Very kind - friendly - helpful. Let us get our affairs in order. The advocacy service was extremely helpful.

- Very supportive and helpful in arranging to meet. However some front of house staff seem not to be totally aware of all the services provided by VOCAL.
- Very supportive, caring, helpful service. Staff showed empathy, knowledge about the subject. If they did not have an answer, they would find out. **[mentioned twice]**
- Very welcoming staff. Good interviews - excellent listening. Given good information "follow-up".
- VOCAL staff are always helpful and friendly. Information provided on a range of topics is accurate and up to date. My wife and I have attended a number of seminars and workshops and I have found value in them all.
- We are just new to your services so have no experiences. Claire Easton phoned me to arrange a visit.
- When I became upset and felt that no one understood how I was feeling I phoned Lisa just to talk to someone and she seemed to understand how I felt and was able to offer me support.
- When I called and the contact was busy, she called back all the time
- You are always assured of a warm welcome, informed staff, and simple information, passed on promptly.

Advice and support received

- A great help when husband was so ill, also got very worthwhile information re: parents rights and care (they live in sheltered accommodation) and big changes mooted - your info helped me fight their cause.
- Actually they were very helpful in filling the form, assistance and quick response. Thanks so much.
- Advice about migration from IB to ESA
- Always received good advice and help whenever I needed it **[mentioned 6 times]**
- But at the time there was so much to cope with that the amount of information was overwhelming. Everything was new to us. The most valuable help was a booklet of lists of care agencies and nursing/care home at the time.
- Clear, independent advice and support. Helped me to understand the vagaries of mental health.
- 'Connections, choices and changes' course helped me in various ways. As my caring role has developed I needed help to reflect on it.

This course provided it. The weekly regime helped. We found ourselves a good group and were helped to bond by the end of the programme. I learned a good deal from the documentation.

- Extremely helpful, information was given in detail and in an informal manner. Various leaflets covering different aspects of care were useful.
- Good communications
- Good information pack
- Great help filling in forms for Attendance Allowance. Lots of info - ie. VOCAL courses. Good to know a solicitor will give his time free of charge for POA application. Very friendly, open staff.
- Had a complex care matter to resolve and advice service was excellent and very helpful and understanding
- Have done one course and the service was very good. To meet other people.
- Have learnt from all the courses that I have attended. Info received from other carers has also been a great help.
- Have made contact by phone and email - always had good practical advice.
- Helped me sort out charities and helped get things for new house
- Helped us to fill in all forms (carers allowance). Keeping us up to date with information for carers and patients.
- Helped with the info we needed
- I began as a carer in Musselburgh, but moved to a bungalow in Edinburgh so my aunt could live with me. The help I received at the beginning (information, help with Carers Allowance, someone to talk things through with) was crucial to the success of the whole endeavour. The lady helping me was so very helpful, understanding and she gave me all the time I needed.
- I came into contact late in my caring 'career' and was very reassured to find that I had found my own strategies very much in line with your advice and help.
- I did not think, let alone realise, that there was this service available in a (prelim) capacity. As I am not recognised by DWP as being a carer and at moment I'm give support to my mum whose 78, my father who's an alcoholic and coming up to 81 has onset dementia (undiagnosed) and it's all very difficult as my brother and sister are dead. Coming to VOCAL has given me some

direction and somewhere to vent and just time to get things off my chest.

- I do not go to VOCAL's meetings as I am a bit embarrassed to attend
- I do not need a lot of help at present and have read all the literature. I did go on a course. The people who ran the course were very nice and provided a lot of useful information. My husband only has memory problems at present.
- I found the course very satisfying. Learnt a lot about caring needs: also very happy about the way the course dealt with carers needs. Also enjoyed the way the course deals with carers needs. Liked the group set up to understand other carer's problems. Would welcome any further course that I could attend.
- I got excellent information and help when my husband was diagnosed with dementia. I was given help to fill in forms, and introduced to outreach workers at Alzheimer's who have also helped. VOCAL were then and are now of great support.
- I had replied to an offer of a free exercise class. I received a Leisure Card free but unfortunately the class was cancelled. This slowed down my drive for fitness (joke) but eventually I got myself to a class and am now truly appreciating the card.
- I have always received responses which have helped make our life easier. eg. assistance with respite and [unknown word]
- I needed help with becoming a guardian for my sister, I received very good advice. Thank you.
- I only contacted VOCAL with an enquiry once and have not contacted them since but the advice I received was excellent and I have passed their name on to other people since.
- I only ever attended one carer's conference held at Liberton Hospital where my mother was an inpatient. The information received that day was useful.
- I received a pack with useful information
- I received excellent advice about everything I wanted and was informed of all services available.
- I was given good advice and stepped in the right direction when I needed to. Unfortunately, due to a lot of problems lately, I haven't been able to go to any of Vocal's events/meetings etc. and missed the last Book group.
- I was treated very kindly and courteously and given all the help needed to fill in forms to

claim attendance allowance for my husband. I was given an information pack on other services I might need in the future.

- Information, help, superb.
- Initial response good - immediately got counselling intake appointment. They then referred me to a carer support officer who sent a background pack. The pack is a little overwhelming but I hope to drop in to it to find relevant support. Carer support officer was very helpful in chasing an appointment with the hospital social worker.
- Is a very good service, they are very helpful. I had an eye operation last year, I couldn't afford home help - they arranged it for me without any charges which I am grateful for to VOCAL.
- It helped my father fill in form to claim his attendance allowance
- It is a long time now since I contacted VOCAL for help, but the most appreciated and useful was the one time approach. It was such a help to unload oneself of all the trauma. Finding someone to listen is the most valuable thing on offer.
- It is now quite a number of years since I first contacted VOCAL. I do not require the same amount of help first hand as all care is set in place, but I do love still to read your newsletters, helps me keep up to date with all the help on offer - thank you VOCAL.
- It was great to be helped to fill in forms for attendance allowance and carers allowance as I could not cope with it
- It was my CP Nurse Carla Johnston who suggested that I attended the course at Vocal to help me with the care of my husband who had Alzheimer's. With the help of family I was able to attend Vocal and the information I received there was excellent. It was helpful to meet other carers in the same situation.
- Kept me up to date with the progress of getting a place at a day centre for dad
- Luck was on my side as VOCAL was about to have a DHDS consultant & information course. A lot to take in, the benefits kept me caring for ten years.
- My case was very complex - so perhaps that was the reason. My view when Mark Johnston took on my case, it was like a prayer answered as the support was excellent.
- My husband has been in Braeside N. Home for 2 years now. I am able to attend Reading Group at Gracemount now which I could not do while Matt was at home. This has been so

helpful while I recover (get over being a carer) difficult to describe. It has taken me 2 yrs to feel normal, better adjusted.

- My husband has since died but VOCAL helped me to get a new day care centre when Firrhill couldn't
- My wife suffered her stroke in 2001 and I contacted VOCAL for general info as a 'new boy' carer! Received general details and was recorded on your lists.
- On previous courses I met and learnt more which held me in good stead. It was easy to understand and a very relaxed atmosphere.
- Provision of a befriender for Steven makes such a difference to him - he looks forward to his weekly outings so much.
- Returning to Scotland after 50 years in Africa, VOCAL assisted us as we knew nothing of the systems etc. Their assistance in getting Attendance Allowance was great, I don't think I would or could have been able to fill in the form and answer the questions.
- Someone to listen to your worries and problems on how to deal with mental health
- The service was extremely helpful while caring for mum. Info easy to read and well laid out. Courses very helpful and give time for questions.
- Very good information and courses for carers
- Very good support and welfare benefits, power of attorney, support and leisure access card to promote good health among carers.
- VOCAL are extremely helpful to carers. They understood the position I am in and assist me with benefit forms. The courses/seminars run by VOCAL which I have attended are excellent, informative and essential to carers.
- VOCAL contacts are very helpful. My problem has been not always knowing what/who to ask and what is available.
- VOCAL has been very helpful, when I have needed them, especially the information to attend any appointment up to now, as the gentleman I was caring for is now my husband - he is very possessive.
- Was grateful that you sent on details of Care for Carers (Lochend House) as I had no idea that it existed (when I first contacted VOCAL).
- We attend the set of meetings in Prestonfield Avenue, and found the advice and understanding most helpful. My wife, who has Alzheimer's, is a rather shy person, and does not mingle readily.
- Were very helpful when it came to trying to change my tax credits, putting me in touch

with the action group. Also put me in touch with Fragile X Society which was and still is invaluable.

- When my wife first took ill, VOCAL were excellent in telling me all she was entitled to. Re finance and equipment for the home.
- Yes I've just joined VOCAL and I am very pleased with your information pack.

Prompt and good responses

- All the information and responses from VOCAL is exceptional, have recommended VOCAL to friends in similar situations.
- Always get a call back or info sent out when asked **[mentioned twice]**
- Always prompt and to the point
- As soon as I phoned someone arranged to come out and see me
- Asked about mobility and found reply a bit late. Joined a book group but decided it was not for me.
- Could not have received better or more considerate attention with my home visits and phone calls, just excellent
- Excellent responses and very informative. Meantime we can (just) cope on our own but I have kept the info you sent and will get in touch if need arises.
- Good telephone response with follow up printed information.
- Help was available immediately. I was given information and offered help.
- I am new to VOCAL. I got a wonderful response in regard to short break funds.
- I did call last week as seen on your website above gym buddies - still waiting on call back. Other than that always been good at getting back to me even though I haven't used VOCAL for a few years now.
- I found the response that I received from VOCAL right from the beginning has been excellent. I was given a lot of information of what was available to me, and phoned regularly about my situation in looking after both my parents.
- I had a face to face meeting only a few days after first getting in touch
- I have not actually sought particular advice but was promptly sent very useful info on joining Vocal and receive newsletters which are interesting and informative
- I requested an update card for Edinburgh Leisure and was greeted by a friendly helpful person, the card was updated shortly after.

- I was contacted very quickly once my circumstances were known. I had a home visit from a VOCAL employee making things so much easier for me, lifting a weight knowing I had help at hand.
- I was visited promptly by a very helpful member of VOCAL's staff
- If by "response" you mean contact, the answer is "excellent". If by "response" you mean content, the answer is "good"
- If the person who answered the phone didn't know the answer or could not help, passed me on to someone who could **[mentioned 3 times]**
- Information sent out quickly and frequently
- My response was quick, very helpful. I was able not only for help but to talk about things you can't talk to others about
- Prompt response, home visit, follow up e-mails, information requested was sent promptly
- Quick response and excellent information **[mentioned 4 times]**
- Someone will always get back to me
- Swift response on the telephone. Listened and gave advice. Sent out leaflets to inform me. Gave me an interview time within 10 days.
- The home visit was much appreciated
- The initial request for a meeting was very promptly responded to. A follow-up invitation from the meeting (by VOCAL person) was very delayed.
- When I called and the contact was busy she called back all the time
- When I first contacted VOCAL I was sent a very useful introduction pack, and have been kept up to date with things since then
- When I have phoned VOCAL about an issue, they have contacted me in the same day, by returning my phone call

Reassurance

- Although I didn't use your services it was always nice to know that if I had needed your support it was there. Very sadly my mum passed away last year.
- Always good to know that you are at the other end of the phone for info
- At the moment I have had no need to contact anyone but I know you are there if I need anyone
- I find VOCAL a wonderful support and always at the end of the phone to answer any problems I may have

- I have not contacted VOCAL for any reason but it is good to know you are there to help
- I have not contacted you as yet but good to know you are there!
- I was delighted to find somebody to reassure me I was not on my own
- It's reassuring and know that I can still call you up for any help
- Up until now have had no reason to call you, but nice to know you are there if I need you

GP referrals

- Amazingly good - starting with the people who answer the door and telephone. Such a relief that you existed, my general practice is a good one but didn't seem to know about you or at least very vague - Is it the same for other GPs?
- My doctor contacted VOCAL on my behalf I did not know it existed. But Andrea was very understanding and it was great to talk to someone.
- My GP registered me with you whilst discussing my husband's problem. I feel I am not ready as yet for your total support but may require your services in the future if his condition deteriorates.
- My GP sent my details to VOCAL. To date I haven't used the services that you provide but enjoy receiving information from you. I find it reassuring to know that you are there if I needed help or someone to talk to. I think you provide a very worthwhile service. Thank you.
- My husband died two years ago. Caring takes its toll and a doctor at my surgery told me about VOCAL which helped me greatly and the years I attended really lightened the load.
- VOCAL contacted me I believe through our GP practice

General comments on service

- Apart from regular information, no experience of services as yet/read all information sent to us and find this very helpful / would like to be kept informed **[mentioned 31 times]**
- At last it seemed I had found people who would give me some information - instead of having to ramble around the city asking questions and being told nothing!
- At present I am unable to attend courses but enjoy Book Club which has been set up at my local library – excellent

- I found the service I got was excellent **[mentioned twice]**
- I found VOCAL very good - it has helped me with some of my problems.
- I have only been in contact with VOCAL for a short time and they have been amazing.
- I visited with my son, and the lady took all my details. So far I have not required help.
- I was 'lost' - but VOCAL gave me all the help and information I needed.
- I was treated very well by VOCAL. Thank you.
- Just want to say a big thank you to everyone that supported me in the past, and for supporting my friends.
- Telephone conversations effective, but I've not found anything suitable in my area
- The very first meeting confirmed information I knew but was unsure of
- Very good to meet others in the same boat
- Very satisfied with all services
- VOCAL is a much needed service and should get more funding from the government.
- VOCAL's services are excellent. The team in charge deserves highest praise. We hope it will keep on providing its service to the community. They are praise worthy.
- When the situation became out of control, I ask for help
- Very helpful, they knew exactly what I was going through. I got the information I was looking for and supported me through a very difficult and confusing time.
- You have been a great help - can't thank you enough
- You were caring and helpful when I cared for my mum that I don't know how I would have managed without your help. My mum is now in a nursing home. Thank you so much for everything.

Feedback and critical comments

- At first, haven't been contacted, except for newsletters and invites to courses. Not had personal contact for a few years - do not have any person phoning or enquiring about situation.
- Good but not nearly enough, you should be running more courses, more counselling, more carer advocacy, etc. Why did you not provide these?
- Have contacted you on several occasions on problems with benefits but you could offer no help. Why? the benefits are also a huge part of the disability.

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| <ul style="list-style-type: none"> ▪ I attended a Stress management Course and could not cope with it. I left after one session - in tears, I found it so depressing. That was because I was so depressed. Personally felt that the course leader should have checked up that I was ok as it is all about care for carers. ▪ I found the service unsatisfactory because I did not receive any help ▪ I have always found VOCAL to be very helpful. But I do get a bit frustrated that when I phone there is usually nobody at the other end available. I also would like to be able to have a walk in shop. ▪ I have only phoned 5 times and only got a call back once out of 4 and I was answered by a person on the 5th ▪ I was removed from mailing list for some time. Proved difficult to be reinstated and receive the bulletins again. ▪ It's hard to say, when I first contacted VOCAL some years ago it was hopeful. They tried to get me a computer but could only raise half the amount through charities. I still don't have one and I can't access online things that could help my daughter and me - I can't even get her hair cut. ▪ I've never contacted VOCAL as you only seem interested in older people. (my husband is only 46 and I'm 49) ▪ My tutor listened, but unfortunately had no experience of dementia, I attended for 2 times but this did not assist me ▪ No follow up service ▪ Only use was enquiry about help to get someone upstairs. No information available. | <p>Subsequently found a service ourselves and passed details to VOCAL for their files. Attended one day information course on resources/services via VOCAL, not needed any so far but useful to know what is available.</p> <ul style="list-style-type: none"> ▪ Staff are off hand. If people are feeling vulnerable they want a listening ear, not feel that the person is only going through the motions ▪ Staff member was uncaring, elusive and defensive - not response needed! Glad she has gone - ineffective! ▪ Things I was offered did not suit the needs of my husband, as he is 70 in April he is not at all an old 70. He needs to be taken out, give me a bit of respite. ▪ Usually very helpful apart from once when I was told someone would call me back but they didn't ▪ VOCAL Midlothian were very supportive. However after trying to find Grannies Park and VOCAL Midlothian I felt frustrated as the area was deserted and was eerie. I wandered around and there were youths hanging about so I returned to the main street to ring Claire and explain. ▪ When I contacted VOCAL it was to make an appointment to speak to someone about my caring role and benefits. I was being faced with the prospect of having to give up my job to care for my severely disabled husband. I was informed that the centre was busy and there was a waiting list. I would be contacted when they could speak to me. I was advised to call the Citizen Advice Centre. I didn't feel this way very satisfactory. |
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2. Did the help that you received make a difference to you as a carer?

493 [81%] of carers answered this question:

Yes	416 [84%]
No	77 [16%]

Breakdown of how carers answered this question:

Area	Yes	No	Not answered
Edinburgh	313	50	86
Midlothian	74	20	24
Other area	24	5	7
Area not given	5	2	1

Carer age	Yes	No	Not answered
Under 60 yrs	170	23	32
61 - 79 yrs	165	41	56
Over 80 yrs	36	6	22
Age not given	45	7	8

Summary of comments

- 93% of carers provided comments to this question
- 38% said they felt more informed
- 11% said health had improved and they were less stressed
- 9% mentioned training courses
- 7% said they are reassured in knowing that VOCAL is there if needed
- 7% said they valued peer support
- 7% mentioned help with finance and benefits
- 6% carers noted VOCAL was a link or gateway to other services
- 6% felt they had more time for themselves
- Other themes which emerged in the comments included feelings of isolation and appreciation of professionals who listen and understood the caring situation.

2.1 Individual carer comments on the difference VOCAL made:

Confidence in caring

- I feel confident coping, me time is important to recharge my health has improved. I feel good about myself.
- I feel that I am more confident in caring for my wife knowing that if I need help and support it is there if and when I need it.
- I gained confidence to speak out and became more able to talk to health professionals. Any information session I attended was well presented and backed up with relevant hand outs. Good to meet others in similar circumstances.
- I got some confidence in myself to know someone is there to listen to you. Also helped when my child needed letter to forward to an appeal for school. Overall good.
- I have gained confidence in my caring role and in contacting medical, social service and official agencies.
- More confidence in being able to understand my husband's condition.
- More easier to handle the thing than before. More time for myself.

Courses and groups

- Attended a very informative course on continence - more informed.
- Enjoyed course run by VOCAL in 2010 which was most informative - have not used any of VOCAL's services since then.
- Excellently produced and run courses often with a speaker from outside agencies. Learned more from attending these re: my late husband's disease (emphysema) than I did from our own doctor.
- I am more informed but due to timing I have been unable to attend anything
- I attended a course for carers of people with dementia. It made a huge difference, equipping me for dealing with potential future problems (many of which have since occurred!)
- I attended training on how to deal with a stroke sufferer. I learned a lot. I was also able to provide details of VOCAL's activities to a friend whose mother was suffering from Alzheimer's. She contacted VOCAL and was provided with helpful information on support available.

- I did attend an evening course once, it enabled me to meet other carers and i did find it supportive but it was a while ago and I can't remember content
- I enjoyed the group sessions
- I have attended carers course at Victoria Hospital and Stress Course Currie High school.
- I have attended courses that have been informative and helpful.
- I have attended one of VOCAL's Stress Management Courses which I found very helpful. I hope to attend more in the future. I also received a carer's pass for Edinburgh Leisure Centres which I am really enjoying.
- I have enjoyed courses with you, and I look forward to Carers News.
- I have found the training courses very helpful and informative.
- I liked the little courses VOCAL runs. Its nice meeting people the same as yourself.
- I think that good information is given but for me although I know it is important to know what is ahead I personally would have rather had social interaction and only the occasional conversation about MS. I found it was hard to listen to other people's experiences and very sad. I handle my own situation by not dwelling on what's to come.
- I think the courses offered are excellent but I have been unable to attend any due to circumstances - the dates have not been convenient.
- I was told of different courses but I didn't have time to do them
- I went on a course a few years ago - 2 day session on how to cope with my son. Helped lots, met lots of new people.
- It first of all made me realise I was a carer as well as a husband. The courses certainly provided the information I was short of, giving me more confidence in my caring role. I don't get any more time for myself but I don't feel that I am being selfish when I make time for myself. My health has not improved due to my lack of motivation.
- Lots of information on courses. Staff excellent.
- My husband has managed to attend one session of a course to help people who are looking after someone with mental health problems. We wished to both attend all the sessions of this course but find that it is not

running this autumn - we need information and help please!

- Only because I've never really had the time to attend courses etc. Not really sure how VOCAL could help me other than attending courses.
- Really enjoyed the session I attended. It was very well presented and provided me with a lot of very valuable information.
- Specific courses for ailment and I used recipes received and still do
- Support group was excellent. There should be more available.
- The courses gave me an insight to what I may have to deal with, in the future.
- The courses gave me respite for 2 - 3 hrs. They helped by hearing of others in similar positions. They also suggested ways to ease obvious difficulties with Medics, City Services and health checks and tips were great help.
- The moving and handling course I attended helped me to avoid injury as my relatives condition deteriorated
- The presentation on the new welfare benefits changes was particularly relevant and informative for us. Information acquired gives a feeling of at least some control over situations which is always useful. Our son has only recently undergone the re-assessment and Sarah provided support with the completion of the form. Our son has been placed in the support group where he belongs which is a great relief to us. I also benefitted greatly from your excellent counselling service last year.
- Tom and I have not been to any courses except the Astley Ainslie tour. Tom and I both just look after each other as Tom is on oxygen in the afternoon and all night sleeping. Which means we only go out in the morning and then it depends on how we feel.
- Training and support is very good.
- Training sessions gave in depth knowledge of stroke. Power of Attorney information.
- Transition course for leaving school provided lots of information and options which I then used to discuss with school and social worker, or at least had knowledge of when they mentioned to me. Have also passed some of this info on to other parents of children nearing this phase.
- Unfortunately because I could not leave Bob for any length of time I could not make full use of VOCAL but found all the courses which I would have liked to attend sounded very

useful. My own mobility is a bit iffy so going would not have been easy, but I still think you are a great service for those who can benefit from it.

- Useful courses to help understand dementia and some behaviours /responses
- VOCAL are brilliant at carer training and income maximisation etc. but could do more to provide leisure/interest opportunities for carers
- Yes I found the course [unknown word]. Choices and changes very helpful. My health is much the same, a bit better regarding not as stressed.
- Yes knowing of all courses and help available.
- Yes. We appreciate the discussion at the Group and the information gleaned from the Group Leader and professional introduced by her.
- Yes. I undertook two courses one in Stress Management and one in dementia. I am starting to look after myself better and I am more focused.

Breaks from caring and time for self

- After contact with VOCAL, although I did not meet with the counsellor at Grannies Park. I felt they were there if I needed them. Claire kept in touch and was understanding and empathetic. I know it is difficult to find premises but as most carer are physically / emotionally / mentally tired, more central, easy accessible premises would be a great benefit.
- Basically I could do with more hours in the day!!
- Difficult question. Depends on what the person for whom you care wants. As a carer I would wish for time myself to do what I like.
- Don't get much time to myself
- Don't go to VOCAL. Husband disabled, can't get out of house.
- Excellent courses, encouraged me to take more care of myself, so I can care better for my sons
- Got respite which will give me some personal time as I am still recovering from a triple by pass at the back end of last year and from then until now I have been trying to cope day and night, which you can only do so long until you need help.
- Got some 'me time', Got all information necessary to make life more bearable. I am a much better person health wise.

- I am so looking forward to my short break away with my family and get away from my house
- I enjoy my Wednesdays to meet with my friends
- I received money for my holiday, as we are low income and in need for the money for the holiday. It was a great help to us all.
- I received some finance for a holiday away with my wife and children. This was a wonderful experience to see all the family to [unknown word] and my wife to enjoy the surroundings without my help at times.
- I took a bad ME relapse last year, could only sit up for 20 mins at a time. VOCAL organised an emergency sitter which gave both my parent support.
- I used to go to keep fit on a Tuesday morning at Liberton church for years, however I don't have time to do this at the moment, but I will restart if my husband gets into a care home nearer to home. I also dance Tuesday and Thursday evening, which I still do.
- I was able to see my grandson on a Wednesday and give his mum some help
- I was given a grant for a short break recently which was wonderful, nice and refreshing.
- It's good to know that VOCAL is there if I need to talk to someone. I've benefited from a grant to allow me to take a break.
- Quite happy with time for myself. As I play two half rounds of golf up the BRAIDS, twice a week all year even in winter time.
- Take time for myself often
- Very happy with money towards family short break. All looking forward to it very much.
- Very much so, helped to become more organised and have more time to myself.
- Was given help by an advocate to obtain respite
- We had 2 lovely holidays in Blackpool which were fantastic - this arranged through PRTC.
- When I needed a break at both times, I felt rested and it gave me the opportunity to continue on, I did not feel quite alone, the 2 breaks I did receive was a great time first to keep going. I do suffer a lot of health problems, it was greatly appreciated.

Carers health

- Excellent service, just talking to someone, health improved
- Health has improved as a result of leisure access card. Power of Attorney support made

the process easy and supported and cheaper than a lawyer. Training course on mental health caring excellent information source.

- Health is improving.
- Help over a long period especially since I myself had major health and mobility problems. 11 years ago 1st hip operation 1998. Finding things difficult to get much time to relax and read as full time carer for disabled husband.
- My health has improved, husband now in care home
- My health has not improved, I am suffering from stress
- My health is getting worse - I have a Hibabus Hernia, Hallux Ridgidus and a gall stone
- My health is improving slowly
- My husband has died sadly. He had Alzheimer's for many years. My health is improving and I now have time to go to your meetings I am 82 years. I must add that the meetings you arrange in ELC are a life saver for me as I now feel so dreadfully lonely and alone. I miss my husband so much we were married in 1948 and were always together with our family of 6 children, 5 girls and 1 boy.
- My overall health has improved, my well being has improved greatly, counselling helped me cope with stresses of family and advice on benefits helped
- Not at the moment but I am sure it will in the future. I have had a lot of health problems over the past 18mths but am feeling better now.
- Sadly for me my health has suffered triggering the need for my mother going into a care home permanently
- Yes it did I have been ill and in hospital - but I am getting better
- Yes when somebody phones me, I always get help with the advice the staff give me. My health at the moment is a bit worrying. I'm seeing the doctor.

Edinburgh Leisure card

- Had enquired about a leisure card and now have one and have started to go to gym so this is time just for me and is helping to make me more healthy.
- Have had a gym pass in the past and it was really good as I would not been able to afford to go without this. It gave me some me time. Thank you.

- I am enjoying the exercise benefits of reducing my stress and helping me to get fitter
- Use leisure card for swimming helps to relax

Emotional health and self esteem

- Advice and support helps my own mental health
- Counselling - helped me to get things into better perspective
- Counselling, also day courses
- Didn't feel so isolated, loneliness is unbearable sometimes, could do with more stress busting sessions - after 20 years it has really affected me. Are there any studies on the long term effects of stress - would like to be a guinea pig and find out more.
- Gave me information I needed. Less stressed.
- Generally feel more informed. Mental health improved from counselling sessions (10). VOCAL are very friendly, this itself makes a difference.
- Having got to the classes I feel I have a better attitude because I feel better in myself.
- I feel more valued as a human being, more self esteem
- I have been put in touch with the counselling service, which has been a HUGE benefit to me. I have also found out about various services, aids and benefits available to us.
- I have got into a routine and I feel much better
- I received 10 weeks counselling which helped me a great deal
- It has been good to share some difficult personal stuff and find that it is completely normal. I have been encouraged to continue to keep my own identity so easy to swallow up in caring. I have stopped smoking and take more time out for myself.
- Less stressed
- Made me feel more self assured/assertive. I went on to be a VOCAL advocate.
- Made me realise I need a break also.
- More able to think more positive about myself and look after my health for a change.
- My life is more relaxed. I was literally on the brink of taking a stroke with all the stress I was under. VOCAL took a lot of my burden with all their help for me and my husband.
- 'Piglet' book was good as was 'changing relationships'. The course led to my family working on meeting my needs as well as those of my wife. I have begun to use the gym at

local pool for the first time because of my leisure card from VOCAL.

- Received counselling - needed to wait quite a while but helped me not 'bottle up' my feelings and keeps things in better perspective. Feel a bit better supported.
- Relieves the stress of trying to fill in forms information as to what is available and help in obtaining moral support. Grant for a holiday that gives me something to look forward and is a calming thought.
- Removed a great deal of worry
- Stress issues addressed, information made available. I attended a few meetings and my health has improved with a leisure card.
- The counselling I received from VOCAL literally saved my sanity. A huge difference which has an ongoing beneficial effect - thank you!
- The counselling I received I can honestly say has saved my life. It has been the single most important point of support I have had during a very stressful and exhausting time.
- To re-iterate, I am at the beginning of the journey in to caring as none of the authorities are involved (very stubborn mother). I definitely feel benefit to my mental health as coming to VOCAL has been somewhere to ask about my worries and fears and also to offload to someone! Which has helped me mentally although consistent persecution from DWP is draining.
- Used counselling service - found this very helpful in coping with day to day activities and other things on my mind. Don't necessarily have more time to myself but have improved mood and don't feel so hopeless at times. Can't use a lot of services as I work during the day - caring at night so not got much time to attend.
- Vocal 'saved' me when I was struggling to cope when Dave had his stroke. Even though it was two and a half years after that happened, I did hear about Vocal in the Press. They also helped when I became depressed a year or so later. I felt everything was falling apart. Grateful thanks to Vocal.
- We felt more in control and able to organise actions without lots of messing about. Our stress levels went down and at every point the amount of time wasted was cut down considerably. Eg. when we were filling in Attendance Allowance the support cut our time down by a day. Even knowing about Attendance Allowance and Carers Allowance

let alone all the services - were all through VOCAL. Our stress management ability to look after ourselves and sense of clarity of role have all benefited.

- Yes, counselling, excellent
- Yes, took a load of pressure/stress off me. Also feel well informed as a carer

Feeling more informed and supported

- At the time I contacted VOCAL my aunt was in hospital very needing further care on being discharged. With information given, the chance to discuss issues I found this a great help.
- Attended workshop on guardianship - helped me to start to understand the process and implication involved.
- Certainly more informed and found I can cope better and I am NOT as stressed as before the course.
- Certainly more informed, plus there was things I did as a carer that I did not realise. You go on automatic pilot. I took something from every session we had in Johnston Terrace and Gracemount.
- Definitely informative, a great resource. Health could have improved but unfortunately I did not use the L.A. card I received nearly enough. Only lasted a year and couldn't find the time.
- Definitely more informed. Also, through training sessions found moral and practical support from other carers. More aware of self care (although easier said than done!). Good to know someone is there in and phone call when needed.
- Definitely more informed. I have been on courses at Johnston Terrace which have helped greatly. I get a few hours to myself a week, which I am grateful for. However my health and well being are much the same.
- Do feel more informed and relieved that my dad was going to have an interest outside his home and also company at a day centre.
- Feel I know more about entitlements. And have taken opportunities provided to improve my own health and wellbeing
- Feel more informed **[mentioned 14 times]**
- Feel more informed. Enabled to have a weekend break through getting information from care for carers.
- Felt more informed and supported. Helped get section 23 assessment for my son (after 4 letters to social work department).

- Find information sent by post helpful and keeps me up to date
- Found out things I didn't know about
- Good information about the school/adult services
- Greater knowledge, understanding and confidence
- Have found out what help can be available if required. I am lucky enough to have a lot of family and friends around, not be isolated.
- Have more information and know there is somewhere I can contact for advice. I have learned a lot from the VOCAL courses.
- Helpful personnel. Good advice. More informed. No improvement in health. Less time for myself (still manageable).
- I am more informed about things, I have found the help and support I received invaluable, as for my health it is just the same.
- I definitely feel more informed and I am glad VOCAL is there for the future when things may get more difficult.
- I definitely feel more informed and would not hesitate to encourage any other carers to make contact with VOCAL. Also the support is there at whatever level is required.
- I did feel much more informed as a carer, in general and in more specific terms. People who work in the front line dealing with various aspects of caring in community and nursing with infirmities and dementia I thought was very good. Meeting people in similar circumstances was very educating.
- I do feel more informed and it is good to know that I can contact Vocal for advice if required. I now have more time to meet up with friends as I have made use of one of the Agencies (regarding Sitter Service) recommended by Vocal.
- I do feel more informed especially being advised about certain information I was not aware of.
- I do feel more informed, which has helped in understanding both of the one's I care for. (49yrs + 73yrs)
- I do feel more informed. As regards more time to myself I do now, as my parents have both passed away. But at the time I had no time for myself and my health did suffer. I am trying to get back on track with myself but it has not been easy.
- I do more informed as a result of VOCAL's help. I now have possibilities of development.
- I feel more informed about areas that concern me and my situation.

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| <ul style="list-style-type: none"> ▪ I feel more informed about some things but the time for myself is more or less the same. It's still a juggling act and I'm undergoing problems at the moment. My health is actually suffering due to stress and a bit of anxiety over my caring situation at the moment. ▪ I feel more informed and not so alone, much more able to cope with things ▪ I feel more informed on where I can turn in my time of need. I also have more awareness of my son's ADHD. ▪ I feel more informed so the future looks better for me as a carer ▪ I feel more informed, am making time for myself. I got my confidence back and learnt to accept my role as a carer and that things have changed which has improved my health. Yes mentally as well as physically. ▪ I feel more informed, and I also feel I know that there is help available should I need it ▪ I feel more informed; have some time for myself but not a lot ▪ I feel no matter how many meetings I attend there is always something I learn. ▪ I feel you are more informed in what is going on ▪ I felt I was not alone. I was more informed and it was a while before I had help from Cross Reach so that I could get out with my husband, while someone really nice to look after mother. ▪ I felt more informed and encouraged ▪ I felt more informed and not 'alone' in my caring role ▪ I felt very supported and more informed. I do feel better and my health is ok, partly however because my daughter is much better. ▪ I felt welcomed and very informed and everyone was very helpful. I also attended some classes/meetings which were useful and I also passed an information to friends who needed help at that time and they were very grateful on receiving relevant information. Yes I have more time for myself now and my health has certainly improved. ▪ I have been able to have answers and help for everything I asked. The practical help was a saviour for myself and son. ▪ I have learned how to assist and prevent falls etc. Introduced to your lawyer, most helpful, and now have. P.O.A. I also feel if I need information I have your phone number. | <ul style="list-style-type: none"> ▪ I have more time, my health is improved and I am more informed. My husband is now in permanent long term care in Pentland Hills. I don't see him very often as it is quite a distance and two buses from where I stay. He is settled and seems happy enough. ▪ I was reassured that the emotions I was experiencing were common. I was given good advice and I have been less stressed. VOCAL has continued to keep me informed and I will follow up some of the courses. ▪ Info on care homes and talk with lawyer very useful. All in all a great service. ▪ Info on extra support available and the chance to network ▪ It's good for me to be more informed of things that are happening in my area ▪ I've more informed and appreciate the concern, being showed ▪ Keeps me informed of equipment available, gives me an understanding of problems/symptoms experienced by my wife and gives a comforting source for answering questions related to her illness. ▪ Keeps me up to date ▪ Knowledge that held out there! ▪ Mainly a matter of confidence - that I am well informed and would know where to turn if on unexpected problem were to arise. Also a useful point of contact will other carers to compare experiences. ▪ Met at GP surgery and given information on allowances and legal help - very useful as I was ignorant about some of these subjects. ▪ More information given than would have expected ▪ More informed and better awareness of options, benefits and services available. ▪ More informed and supported / aware of services out there. ▪ More informed and the ability to cope. Not looking for time, happy to meet my wife's needs. My health is good. ▪ More informed certainly. Reassured. ▪ More informed, but also enabled to actually do it. Having access to support has made a daunting task a real possibility and even a pleasure. THANK YOU so much for the work you do. I really do appreciate it. ▪ More informed, made me realise the importance of making a will and setting up a trust ▪ More informed, not necessarily helpful to my personal situation |
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- More informed. Course attended really useful. Have found VOCAL courses better than others I've attended.
- More informed. Got services I needed. More time for myself and other child.
- More informed. Have taken part in a few courses and enjoyed them e.g. music art visits.
- More time for myself, more informed, my health is not good at the moment on medication from doctors - arthritis in spine and osteoporosis in hip.
- More time to myself informed feeling a bit better
- Newsletter is very informative. My spare time is as status quo. My health is pretty good at this time, but do feel stressed at times.
- Partially, I feel better informed in some aspects although not entirely to help my daughters situation. I will be getting in touch with VOCAL to seek more information in the near future.
- Please see above - I certainly feel better informed and enjoy the knowledge that there is always someone there to turn to.
- Receiving the newsletter keeps me informed, what services are available.
- Someone listened and advised where to access more help when necessary. Found out more about how the 'system' works, i.e. what services were available immediately, when we really needed help - not having to wait to be heard. Health improved so could continue working.
- Sometimes [more informed], only by letter. on general. No [more time for self]. No [health improved].
- Support to me, more informed, information where to go and what to do, the departments to use
- The leaflets made me feel better informed **[mentioned twice]**
- The notes I have received from VOCAL is very helpful, as this is the only information I get, so I read these very carefully.
- Unfortunately I have not been able to make use of any of the services offered due to several different reasons. I do appreciate however being kept in informed via letters and newsletters.
- Updated knowledge I already had and informed me of courses, developments etc. It's easier to put things in perspective, armed with knowledge. My situation though time-consuming and tiring, is fairly straightforward and in comparison with people caring for v. Severely disabled and frail people, I feel I am lucky in that my experience caring for elderly residents in the 80s and my situation mean that I can cope fairly well. My husband, himself with long-term health probs, is very supportive and that makes all the difference. Other carers need the support and contact with others who understand difficulties, emotions, etc and 'time off' to recover from the mental and physical strain.
- VOCAL informed me about some sources of support and I feel that I can always ask them for advice and guidance
- VOCAL keep you well informed
- VOCAL told me what I was entitled too, told me my rights and was centrally much more informative than social work
- Yes definitely more informed. My health has greatly improved. I no longer support the relative I used to care for.
- Yes I did feel mine informed and my health started to take a bad turn because I came down with diabetics
- Yes I feel more informed about flexi working and benefits that can help me care for my brother
- Yes I feel more informed and know where to contact for appropriate info and help.
- Yes we are well informed and help as soon as it is needed.
- Yes, I definitely feel more informed -and- also comforted that I know I can revisit at any time for further help if needed. My husband's health has benefited. No I don't have more time for myself because my husband's health problems have grown. No. My own health has deteriorated because have nobody to help me.
- Yes, I do feel more informed but as my wife's health problem is Parkinson's - new situations to deal with are a challenge.
- Yes, I feel more informed but do not have time to read all the paperwork, as by evening am too tired to read it. No, I don't have time for myself, except when on respite. Health has improved as I had a bowel prolapsed op last summer (2010) but I do admit to being exhausted.
- Yes, in supplying much needed information
- Yes, quite well informed. A little bit more time for me. Still a lot of stress due to my husband's dementia but better than it was. Medication helpful.
- Yes. Well informed. Health has improved.

- Your info helped put me on the right track - never expected to be in this position and am ashamed to say had never looked in to the problems / obstacles which applied when you suddenly become a carer. Luckily am not too tied meantime (can leave husband a few hours meantime or on his own) but inevitable things will deteriorate as time goes on - so good to know that VOCAL is there even if it is only for moral support.

Finance and benefits

- A great help with filling in forms and what benefits are available
- Assisted me with help in filling in attendance allowance forms, courses I attended very helpful, also discussion with other people in groups who are in similar situations.
- Being kept informed will help in the future
- Better informed - attended session on changes to incapacity benefit
- Feel better informed about the changes to the benefit system. Have found it useful in the past to talk to other carers but you go home from a workshop and the work hasn't done itself.
- Feel more informed. Appreciated hearing about power of attorney and getting help setting this up grateful for support given.
- Financial advice
- Gave help regarding finance primarily
- Got money for signing course so was more able to communicate with son. Got leisure card which I used for a while. My partner uses his 4 times a week. This makes a huge difference.
- Help with filling in attendance allowance forms
- Helped complete forms for benefits
- I was given information on allowance I could apply for.
- It helped us with more money
- Just talking. Advice on claiming/reviewing benefits for my adult son.
- Making a will. Talking to other carers is always helpful.
- More informed about financial issues and planning for the future etc.
- My wife is 89, I am 88 and with saving dwindling away, the way was arranged for us to receive out carers allowance, some cake instead of bread.
- Not a physical difference, but having information is power! e.g. our Council Tax was

approx. halved. Now have Welfare and Financial Guardianship, have updated Wills and made provision for Discretionary Trust which we knew we had to do but Vocal's meetings made us get on with it!

- Now have POA, gym membership through carers of West Lothian and VOCAL
- Power of attorney, filling out forms to social services, DLA, etc. Life has its ups and downs. I'm stressed this week, for example.
- Received advice and information on trusts and power of attorney, guardianship which has proved helpful.
- Received information on benefits which was very useful but didn't actually make any difference to my "caring".
- Received information regarding attendance allowance which I did not know about, I applied and now helps with my expenses looking after my elderly mother. A big thank you to VOCAL staff for their help and support it has been very much appreciated. An excellent local service.
- She knew of all the help and benefits I could be claiming; knowing that my mum could claim exemption from paying council tax is saving her £150 per month! This money pays for ready meals (Wiltshire farm foods) and other 'luxuries'
- Such a huge change! Told of help available re benefits, guardianship, info etc.
- Thanks to advice given by VOCAL staff, we now receive attendance allowance, and a 25% reduction in council tax. I also attended the reading group, which I found most informative. However, due to holidays, I missed the last meeting, and I have lost the thread! I will contact Rachael, to get re-connected.
- Through VOCAL assistance and their contact with the office of the Public Guardian I was able to get Power of Attorney for my son. Without that help and advice I do not believe we would have been successful.
- VOCAL enabled us to get Power of Attorney which was very important
- Was granted Attendance Allowance! Enjoyed meeting other carers which made me realise there are others in a much more difficult situation than I am.
- Was helped to apply for DLA - enormous help!
- We are waiting until August, as her D.L.A. is up for renewal, hopefully I will get the carers. I don't have much time for myself, my health is fine.

- We have been granted the Attendance Allowance and it has been back - dated is May when cared for left hospital. VOCAL support was vital in filling in the form (Clair E. was marvellous). The Telecare meeting was very useful. VOCAL are helping me is apply for a 'Short Break' grant, so i can go to my son's wedding in D. in October. Bruce does not want to travel such a long way so is staying at home.
- We received I think the top allowance given by the Council
- Your help with form filling way excellent

Gateway and access to other services

- a) It has been useful (and stress relieving) to share information and experiences with other carers. b) Information on contacting services (eg. wheelchair service) has produced positive benefits. c) Getting to 'know one's rights' in the area of obtaining support is most helpful.
- After finding out about the Astley Ainslie "Smart Centre" we arranged a visit and got help towards choosing the best type of chair.
- Although I am not now a carer I would recommend VOCAL to anyone who find themselves in this position. For information regarding how to cope with everything it involves it was excellent they made it clear they were there to help you in every way possible e.g. hospitals, social work expenses etc. Thank you!
- Any information whether financial, services or resources that are available to carers will always make our roles easier.
- Given information and direction on son's transition from school. Helped keep me informed of what to expect from agencies and social work.
- Gives me access to things and services I may not be able to access. Great use of leisure card especially.
- Got to know about the entire scope of the carer's responsibilities and how to use the available services
- Helped by VOCAL to get help with care which we didn't know existed and has helped us greatly especially after my husband had a heart attack not able to do all the lifting he was doing.
- Helped me get a wheelchair for mum and a disabled car card
- Helped me to get the right treatment for my child

- Helped me with information to enable me to gain access to services like social care for my mother.
- I am more aware of the services available to carers
- I feel much more informed. The help from Irene in obtaining a trolley for moving things around after a hip operation was invaluable. She very kindly lent me one while I got one of my own.
- I had been carer to my young teenage son who suffers Epilepsy and learning difficulties for 16 years now and managed to get more help through various contacts which gave me time to myself.
- I was able to make contacts with the right people for the aids required. This allows me to have time for myself. My health is fine.
- Information provided allowed me to access other services. I appreciate the support given by VOCAL when I need it. As a carer it's easy to feel frustrated or isolated, staff seem to generally understand how carers feel. Still feel there should be a lot more awareness raised so that carers are fully supported financially, emotionally, and socially. (Although this is not a fault of VOCAL's - but our government!) If there was more recognition on the stress involved in being a carer I am sure services would improve.
- It helped me organise my son joining what was Midlothian Special Needs play scheme and is now run by Capability Scotland (I hope they continue to do excellent work). Also with contacts for Fragile X families.
- It was through Vocal that I heard all about the different kinds of dementia. I was able to understand how to deal with my husband's dementia and how to live in his world and be able to change the subject when situations got difficult. We also got so much valuable information regarding every aspect of available help from social workers, medication prompts and alarms from Telecare.
- Let me understanding what is out there for carers and person cared for.
- Life runs more smoothly when you have the right information and it makes for a calmer life.
- Made me aware of services available to carers and support. Also educated me in various illnesses. A greater understanding was achieved. Talking with fellow carers was very supportive.
- Made me aware of services available to carers in the area

- More aware of options and good for signposting
- More information you have - the more able you are to deal with the situation.
- Not exactly because my husband's dementia is worse. However the social workers are helping me a lot. Your lady put me in touch with them.
- Pointed me in the right direction to obtain more detailed information
- Provides information and contacts that we would not have been otherwise made known to us
- VOCAL gave me information on other services I could access

Isolation

- Feel isolated, can't be the only person in my age group who is a carer
- Felt less alone. Given very valuable encouragement and practical advice and phone numbers, forms etc.
- I am still caring for mum and at the moment am not coping well. I do attend a doctor - who is very helpful but I feel so lonely.
- I felt very isolated and stressed but through help from VOCAL I am a bit more together.
- I find speaking to non professionals (other carers) is helpful. It is really rewarding the help and understanding that VOCAL can give. it is also a big help meeting other carers as said before. It is a lovely life - at times - being a carer. I have lost so many friends over the years, lacking ability to 'get up and go'.

Listening ear

- After Matt went to Nursing Home I attended classes at Johnston Terrace which were very helpful. The most help I got was from speaking to Lisa at Gracemount either in person or on the phone while I was caring for my husband. It is really important someone listening while you feel so desperate.
- Firstly when you are going through a grave personal crisis and things are out of hand due to illnesses Vocal was a great support. Someone to care, listen and help you. I felt very, very supported (through Rachel) and cared for at a crucial time of my life.
- I knew nothing about mental health before it happened to my family. I could phone or visit VOCAL and just talk, cry or ask advice. I also met other parents with similar problems. I attended several courses run by VOCAL and

learnt more about the illness and how to deal with it.

- When someone came out to visit, it was nice to talk about things that had been on my mind. They helped to inform me about what I was entitled to and to start thinking about me. Almost like having older sister to listen and advise when needed.

Peer support

- Andrea was really helpful and as it was the first time I had support it was nice to know that help and advice was a phone call away.
- Being able to talk to other people, takes the pressure off and getting less stressed.
- Course on MS was very helpful. Also good to meet others who deal with similar problems.
- Enjoyed the courses, meeting and listening to other carers experiences
- I felt the carers courses helped me a lot in how to understand better especially understanding stress
- Information re: becoming legal guardians (financial and welfare) was invaluable. The solicitor who spoke to us was great. He then helped us much the whole procedure.
- It made one feel less isolated listening to other carers, and help could be given when needed
- It was good to meet other people in the same situation
- Joining the support group allowed me to meet people in similar circumstances. Make new friends and kept me informed to things available to me (financially, in my community and training courses).
- Learning how to make time for myself and meeting other people in similar circumstances and sharing their thoughts and ideas.
- Meeting other carers with their problems
- Most definitely, it allowed time away from caring to meet others who were experiencing similar situations and helped put things in perspective.
- Not so much the "help" but being given the opportunity to speak/mix with other carers to share views/concerns.
- Opened my eyes, and I found what I experienced at home was all documented. I.e. what I was going through had been done by everyone before me so what was happening to me was not new.
- Opportunity to meet other carers

- Other experiences are useful in putting together a perspective and it is helpful to know that there are others who are in a similar situation to oneself.
- Sharing time with other carers at the book club is extremely enjoyable and uplifting. Knowing that we are all doing our best, offering and receiving encouragement makes an enormous difference - something to look forward to.
- The main things were meeting with people in the same situation and finding out that feeling guilty was something everyone experienced and strategy to deal with it. In the end, though, it was the crisis engendered by the failure of my own health (breast cancer) that galvanised the medics to provide the professional help for my husband that I had been asking for over a long period of time.
- Up to date information was very useful. 2 courses and classes, the opportunity to meet carers helped me to feel less isolated.

Reassurance

- Also have point of contact when I need it and knowing there is staff there if I chose to go to it helps
- At least I know there is help and support available if I only had time to attend them.
- Going to do some courses. Confident that there is someone to call when I have unanswered questions.
- Helped with filling forms. Helped to meet people in the same circumstances and begin new friendships with other carers. Made one feel a lot more confident about oneself. You are not alone, they are at the end of a phone-line for you.
- I feel as though there is someone to turn to for support
- I felt help was at hand if the situation was worse than I could handle
- I felt like I had someone on my side. I had more info and I was prepared for the future.
- I felt someone understood what I was experiencing.
- I felt that if I needed help I could call on VOCAL
- I have been comforted by knowing I am not alone and VOCAL has shown me that. I learned where to look for help and not to try to do everything myself. This alone has benefited me personally.

- I know he is safe and enjoying himself for three hours every week.
- I know where to go to if I need any assistance/advice.
- I received a great deal of information, I have now realised there is support if and when required.
- Introduced me to local carer meetings. Due to all the available leaflets I do feel more aware of the help on offer. Just talking to someone who understands has helped me cope with feelings of stress.
- It cheered me to think that such help was available.
- It took a lot of strain from me knowing that VOCAL was there at hand.
- Just knowing there is an organisation that recognises the difficulties of being a carer makes a difference.
- Knowing that if I need answers I can call VOCAL and I will get the information I need. And if they don't have the answer they will get it for me. I will not need to call "round the houses" to get the answer.
- Knowing there is help from VOCAL's experts at the other end of the phone, is a great comfort, at my age.
- My husband has mood swings because of his stroke, and the information I receive from you lets me know there are other people in the same situation as myself which lets me know I am not alone.
- Nice to have someone there to help and understand all caring issues
- Now feel there is backup, support network there. Increase awareness, information
- Psychologically, a great help to know that you were there and could give advice I needed - a practical help with filling in forms in a nice, friendly place. People with more freedom than I had would benefit tremendously from the various talks - social possibilities. The only thing I was able to go to was of a very high standard - I should know - I was a sister tutor.
- Reassured me that I have a safe place to contact when I have more problems with my caring role. Learned lots to help me manage stress and know more about how to support my mother without taking over.
- Reassured us there was support
- The help I received has definitely made a difference, yes I am more aware of things now, I am working towards having time for myself, to improve my health. I feel a difference within myself knowing that I can

contact my local VOCAL if I have any worries - although they can't help at times, just talking it over with someone you can trust is a big big help.

- This enables me to go out to the shops without worrying
- To know that we are not alone. Other people to talk to who understand what it's like.
- We had a visit from your staff, mainly because the nurse at Stockbridge Health Centre suggested it. It did not change anything at the time but it was reassuring which we appreciated.
- Yes - in as much I know now that if the time comes I need more support - it is there! I've only to ask.
- Yes put me in touch with other carer. Realising you are not alone. Don't appear to have much time for myself.
- Yes. A little. No. Knowing you can get help is invaluable. I don't feel I am alone.
- You have a bit more confidence knowing you have someone to turn to if the need arises.

Comments about staff

- I have only been in touch with VOCAL for a matter of weeks, but the couple of phone calls that I have received have been helpful and made me feel better after talking to Claire.
- I was offered support from a personal planner, she ensured that she did whatever possible to help. I've been able to have more time to myself and my health improved a bit. Andrea is my support worker and she is very good at making things easier for me.
- Justine could understand some of the problems I had looking after my mother and was always giving my confidence a boost.
- Not as much information now as above since Lisa left but the staff at VOCAL office are very good
- VOCAL staff were sympathetic and informative. I also met other carers and it does help to feel that you are not alone in this dreadful situation. VOCAL has a range of information available and it's a great place to get advice from.
- Your staff are happy to help and it makes a difference. For example, I rang to try and find the contact number for Telecare, and someone found it and rang me.

General comments

- As my dad is still attending his day care centre every tues at least I'm reassured that he is having a good meal that day! Basically he isn't eating a balanced diet. I have written to his doctor concerning this problem for advice and help.
- Carer advocacy - only due to the last person that took my case on board, a big thank you to Mark at 13 Johnston Terrace, Edinburgh.
- Gave a forum to discuss any and all issues involved in caring.
- Gave me help I needed
- Have not used services for some time but when I did it was of benefit to how I cope.
- Have not yet use of VOCAL services, other than reading material.
- Haven't had to get help at present.
- Having a carer come in for 2 hours per week gives me some peace of mind as I live 50 miles away from my mother who lives in Edinburgh.
- Helped planning things better
- I do not have any problems but very aware that VOCAL could offer help
- I feel supported and have a lot of useful legal advice- among other things
- I feel supported whereas before VOCAL's help I was a floundering fish in a giant ocean
- I feel VOCAL have been and still are a great support, whether it is just information or a friendly chat, they are always willing to listen and help if they can.
- I felt I could ask questions and be told the truth
- I found the day I spent at VOCAL's offices of invaluable help. I came to Edinburgh from up North and didn't know where to turn for helps. Social care was almost impossible to get into but between a very helpful occupational therapist and yourselves life is so much easier.
- I had a clearer picture of the road ahead. (2 days after that I has a heart attack!!). I do feel a lot better now.
- I have arthritis and can't join your meetings as I can't manage the bus very well, but I am quite happy with all the mail sent regarding any help I might need
- I have learned to assume everything is all right unless I hear to the contrary - previously I was in a permanent state of concern and would phone to confirm if everything was OK. It doesn't work 100% of the time but it has

made a huge difference to the quality of my life - so THANK YOU very much.

- I have not as yet required any help however it is useful to receive information on events/courses
- I have only recently contacted vocal to enquire about services and help
- I have two days when my husband attends headway house and that is all at the moment, have carers in four times a day to help
- I haven't really had a lot of contact with VOCAL during my registered carers time, so I do not feel I can make to many comments. However my welcome pack was very useful.
- I received 65 hours help per week, that's one hour for every year of my husband's condition - not enough! While he is disgustingly fit and healthy, I am seriously under weight and stressed, worried and anxious and exhausted. GP offers pills, which have awful side effect. I'm coping at the moment but fear for the future. Setting up POA - see no.3
- I received regular update information for carer. Saved me time.
- I was never my mother's carer in the true sense of the word. My father really looked after her although they had my support some of the time. I dealt with the paperwork, doctors appointments etc. Mum suffered a stroke September 2010 and is now in a nursing home as you know. From the onset VOCAL have always been very supportive, willing to listen and help. No, I don't have much time for myself as I visit mum 3 or 4 times a week and my brother is in a care home and I visit him as often as I can. I am at my fathers flat on a Wed pm to do washing, ironing and housework. Mentally I feel drained (not every day but a lot of the time).
- In all my years being with my daughter, I have never thought I was a carer. In fact nowadays she may be mine at times. I cared for my husband for 18 years due to a stroke. I am very glad things may be improving for people.
- In the past, whenever I have needed help, the support and help were excellent.
- Its help to be listened to and understanding.
- Made me feel I had support and somebody who actually cared for my welfare. I'm sorry to say but I find many agencies - in particular medical and social dept are more interested in meeting target to and saving money than people.
- Managed to get action and a place at Canalside

- Me and my dad both help in house with my mother. My dad is 71 yrs of age. My dad helps my mum with showering etc. He does not get any help with doing this.
- More information about VOCAL help caring related to showers etc.
- No I do not really need any outside help at present. I also do not claim carers allowance as I am on incapacity benefit.
- Phoned back with answers as soon as they could
- Realising I am important as a carer
- Reiki helped too. Advocacy service is wonderful. A very useful service.
- She helped with things in the house and generally improved our lifestyle
- Sometimes, and other times hard
- Still waiting on social worker, sorting out care for my mum
- Telephone call was supportive. Due to nature of father's condition i.e. Extreme ups and downs there was no action I could take. As a family we are on standby for whenever he plummets and fund respite care privately. Father refused Vocal offer of weekly companion visits.
- This is a hard question to answer as life goes on daily
- VOCAL has made a massive difference to me like
- Wished I had known about them sooner
- Working ongoing progress. Thank you.
- Yes this is my second time around as a carer I did not get much help when I was a carer for late mum Mary and no help what so ever when Sue died not even from my day centre that I attend daily.
- Yes to all these questions. Thank you again.
- Yes, it was a big stepping stone, could not have done if without you!

Difficulties or no change

- As above - no, my health has got worse, I have less time for myself
- Have no time for myself and my health is definitely going downhill
- Husband retired medically, have less and less time, much more stress
- I am now unwell with myeloma
- I don't have much time to myself, as I have to stay with my husband. When I could join them, the workshops, but I can't leave my husband on his own.

- I had to put my husband into, to a care home as you cannot get 24 hours care, it has giving me a lot of health problems.
- I have not had the time to get involved in anything
- I still feel I need more time for myself, I my husband has contact with a person on a one to one basis it would help his confidence and also my health
- Indeed, I retired in March of this year aged 69. I could not attend courses due to work however now getting things in place for carers educational courses.
- Initially when I could visit VOCAL I found information very helpful. Now that I am tied to the house and only get out occasionally I find that days meetings are held I cannot attend.
- It is very difficult as my husband feels he wants me beside him most of the time. His walking is not good and memory also. I have on going neuralgia in the face and neck. Perhaps stress who knows? I found the map for wheelchairs users very interesting. As we have an electric scooter: but it is too heavy to put in our car. Knowing anywhere that hire electric scooters: parks: gardens: etc. would be very helpful.
- No more time for myself. But better able to adjust to a different life as a carer with a young family.
- No my job is more or less the same
- Not really, my husband is in chronic pain. His condition needs fluctuate so it is hard to plan too far ahead. I have employed activities, he does get respite through the services.
- Our circumstances have not allowed for time off and relief carers would be too challenging for my husband unless he was familiar with the individual. Friends and family have helped

and I feel less fraught and more relaxed - at time.

- Sorry but just couldn't find the time to attend meetings etc and had to constantly be in attendance. We had the carer attendant for a few weeks (council services) then was changed to 'call-in homecare'. This ceased after a time. My wife preferred to attend to herself.
- There was not really a lot they could do for me at this time.
- Things are just as it was at the beginning. I don't have time for myself. As everything I do is to suit his needs. He likes outdoor activities and I don't have time, to do that for him, also he's a recluse in his own home.

Feedback and critical comments

- I did not receive any help
- I went to an information session on future financial planning. My main criticism was that it was, for a lot of the time, monopolised by people who seemed to be, or to consider themselves, the 'in crowd', and who took up far too much time with their personal situations, so that the speakers didn't have enough time to talk about the wider picture. More energetic chairing would have helped a lot. That said, I did learn a few useful things
- I've never had any help from VOCAL as they seem to only help older people and older carers
- No - did not get any information requested
- The information / newsletter I receive has not been particularly helpful, there is never anything relevant or useful to me.
- Whenever I have contact or need a leaflet - they have always run out, at the printers etc. Not available, doesn't inspire confidence.

3. Which parts of VOCAL did you find most useful / least useful

3.1 Which parts did you find most useful?

425 [71%] of carers answered this question which was **comments based**.

Breakdown of how carers answered this question and key topics:

Area	Training	Financial	Peer support	Information	Counselling
Edinburgh	103	34	24	49	21
Midlothian	13	10	4	19	6
Other area	4	1	3	2	1
Not given	0	1	1	1	0

Carer age	Training	Financial	Peer support	Information	Counselling
Under 60 yrs	42	19	7	20	19
61 - 79 yrs	53	16	20	36	7
Over 80 yrs	10	8	3	7	0
Not given	15	3	3	8	2

Summary of comments

- 28% carers said training courses, groupwork and group meetings
- 15% said information and communications
- 14% said financial and legal support
- 8% said peer support and meeting other carers
- 7% said counselling
- 7% said Carers News

3.2 Individual carer comments on what they found most useful about VOCAL

Advice, support and activities

- | | |
|--|---|
| <ul style="list-style-type: none"> ▪ Advice/help/support [<i>mentioned 8 times</i>] ▪ Advice and help with forms [<i>mentioned twice</i>] ▪ Advice on a range of whom to ask for help and what benefits are available ▪ Advice on dementia ▪ Advice on what I could claim for ▪ Advice on which services are available. ▪ I can only say information over the phone, haven't been to any classes except for the Book group ▪ At the moment it's the practical help. ▪ Assistance helped to understand the illness and [unknown word] ▪ Having the card to keep | <ul style="list-style-type: none"> ▪ Help for the needy and elderly and infirm. ▪ I only use the carers Tuesday night service and I find very useful ▪ Book group at Leith Library ▪ C.A.B ▪ Card - Leisure card. Support letter for my child ▪ Information, Advice ▪ Information, advocacy ▪ Support group for family members affected by a relative alcohol addictions. ▪ Support group, training sessions esp PD sessions. Bereavement counselling. ▪ Support group ▪ Support groups once a month to meet and talk to other parents in the same situation |
|--|---|

- If I have appointments booked and as things happen I can take them to my sessions with Shirley and have not come away feeling less informed or more isolated - all good!
- Leisure Access Card, Website
- Leisure Card discounts various lectures etc. Newsletter
- Leisure Card, Fund Finder
- Leisure card, power of attorney and training course
- Information and leisure access
- Information about other agencies and Edinburgh Leisure card
- Info about carer's rights
- Info about social security
- Info on developments etc
- Supplying information
- Support and information
- I signed up for the Edinburgh Leisure card but have not had any opportunity to use it
- The information, to use people I'm caring for
- The information

Advocacy

- Advocacy *[mentioned once more]*
- Advocacy, help with benefits, getting out house really saved my life.
- Advocacy. Stress Management.
- As above. Also advocacy help, I think.
- The advocate

Breaks from caring

- Going away to, a weekend with VOCAL
- Holidays
- Once a week carer for mum
- Respite for person going to Canalside
- Taking Alex to Libertus for the day every Wednesday
- When informed of respite
- It gives me some free time to myself and as said above I can go out without worrying about my partner

Counselling

- Counselling Advocacy
- Counselling, Carers Group
- Counselling, Information sessions
- Counselling, Seminars
- Counselling, Support for me
- Counselling, emotional support at times of crisis, Support groups, Carer advocacy, TIME which was not available from the NHS

- Counselling, to be honest I haven't explored any other area and so cannot answer this correctly
- Counselling *[mentioned 3 times]*
- Counselling - still to happen. Legal and financial advice
- Counselling - waited over 8 months for an evening slot as I work full time. Had to go elsewhere
- Counselling, Group meetings, Help with claim forms
- Counselling service and knowing you are there for help
- Counselling service, seminars/workshops on a wide range of topics relevant to carers. Future financial planning, information support and stress management courses.
- Counselling service. Benefits advice
- Counselling, advice, training, contact, relaxation, stress therapy
- Have only used counselling service - found this most helpful although it may have been better to do for longer - perhaps with bigger gap in between appointments.
- At the moment I am on the list for bereavement counselling, this will be the most useful at this time for me. All the information that you have given me has been useful, thank you.
- Stress management *[mentioned 3 times]*
- Support and counselling
- Telephone counselling
- Without a doubt, the counselling has been the most useful for me personally. And the different courses I have attended have been very useful too.

Courses and groups

- Course for carers of stroke victims
- Courses and information *[mentioned 17 times]*
- Courses - particularly caring for someone with MS
- Courses and local contact
- Courses and phone, Enquiry information
- Courses for just about everything to do with caring
- Courses on Stress
- Information about courses for carers.
- Information about MS
- Advising of courses and assistance to dementia sufferer
- All of the courses I attended were helpful information wise. Most were connected

through British Lung Foundation and covered info from Physios, Macmillan nurses, occupational therapists. Also able to chat with other carers which was a good 'other side' to being there.

- A listening ear. The 'courses' VOCAL ran.
- Courses when run and it is useful to meet other carers
- Courses which informed me and which put me in touch with other carers in similar situations.
- Courses. Also the advocacy service, Mark Johnston was brilliant.
- Courses on the effects of stroke - continence care, and I hope to do one on "handling" in September
- Courses, Newsletter
- Courses, Website, Chatting to support worker
- Courses, Assistance getting carers assessment
- Counselling service last summer 2010
- Caring with confidence, MS carers course
- Classes that are run in the evenings.
- Apart from Edinburgh Leisure which I find very useful, I have also attended a talk on inheritance planning which was very interesting and useful.
- Have only used 'Looking to the Future' course which was a helpful start
- All the meetings I have attended have been most informative and helpful
- For me, the course at Royal Victoria Hospital about dementia and how to cope was very useful
- Group meetings, and just to know someone is there to help
- I have found all courses to be very helpful and have been a good learning curve for me.
- I have only used VOCAL once on a session on coping/accepting changes which occur when one's wife has Alzheimer's. The talk helped me greatly.
- I think the information sessions and sessions run for carers general wellbeing sound great.
- Information sessions.
- Information then meeting others. Courses, training, listening to knowledgeable people. Sharing experience.
- I went on an MS carers course and it was an invaluable experience - all of it was useful.
- I would be interested in attending courses (but have been unable to so far)
- Informative days/courses. Support from staff. Support from fellow carers.
- Information from the courses. Telephone contact. Relaxed atmosphere.
- Meetings and instructions how to protect yourself when dealing with husband.
- Meetings and help when needed.
- MS course
- MS course especially the taking care of yourself. Changing relationships, meeting others. Coping with stress / stress management.
- MS course, Diabetic course, Looking after myself
- Training and workshop events. Subsidised Leisure cards etc. Willingness of staff to help with any enquiry. Caring, professional staff.
- Training courses **[mentioned 3 times]**
- Training courses, carer support team
- Training courses, meeting other carers
- Training courses, special seminars and peer support
- The meeting which brought out everyone's problems and could connect with them
- The meetings was most useful meeting people who was in the same situation
- The MS course was very good
- The practical approach to dealing with MS in all it's aspects through the course - particularly in dealing with health and social care administrators
- The small groups where information was presented
- Workshops. Being able to source information from very helpful staff.
- Workshops/Courses, Advice
- Would like to attend course, One day when I have some spare time.
- The 3 C's course **[mentioned twice]**
- The courses arranged for carers are invaluable.
- The courses they provide and contact with other carers.
- The courses where one met other carers
- The different courses and meetings I attended and the staff were wonderful.
- The group meetings and learning new skills to cope with the person you care for.
- The group meetings at the VOCAL offices where talks on various relevant subjects took place.
- Taken part in a course in the past which I found interesting
- Seminar on various topics. Counselling. Support when needed. Advocacy, if needed.
- Seminars and various topics. Great for info and discussion.
- Seminars, Meeting others in similar position

- Relaxation class. Information to change to healthy diet & support. You always felt welcome at VOCAL.
- Short seminars on specific topics.
- Talks given by different people. To have people in similar situations to talk to and get advice from professionals.
- The information meetings
- The information on stroke patients
- Only been to that one session
- Parent/Carer Support Group, Group leaders knowledge
- I've been on 2 courses and found that all parts were useful if not at present certainly later on.
- Was a free course on computers at Niscux in Giles Street Leith I learned that I could do something that I thought I could not. I had fantastic tutors and brilliant fellow students. I loved it.

Financial and legal support

- Advice and information, given in talks, the chance to meet other people in similar situations, help with filling in DLA forms.
- Advice on who to contact for help (both practical and financial)
- Advised me about carers allowance
- Benefits / finance advice **[mentioned twice]**
- Benefits information. Strategies for coping
- Benefits. More Informed. Advocacy
- Being able to get keep in applying for George's attendance allowance
- Financial advice. Carers group.
- Financial help for a holiday,
- Finding out about benefits and having practical assistance to access them
- Help with direct payments
- Help with forms, courses and seminars
- Help with obtaining benefits and P of A. The fact that - for instance - Andrea was able to come out to the house to help me.
- Free courses - full of info. Power of attorney service
- Areas which concern answers to 'immediate' problems - when they arise eg DWP, national health, citizens rights etc.
- Did make use of your Power of Attorney and thought that was great and very helpful.
- Help about wills
- Assistance with arranging Power of Attorney.
- Guardianship
- I attended for classes (8 Wed. mornings) Feb/Mar 10, Very very useful, I also used your advocacy in April 2011 for Power of Attorney.

- Help regarding attendance allowance, local help groups, legal advice.
- Help with benefits advice. Short break information also help with assessment advice for me and the person I care for.
- Help with completing the 26p application for Attendance Allowance!!
- Have accessed info type services to date and these have been useful
- Information on allowances
- Information on benefits and it helped to know other people who were in the same situation as myself
- Information on rights and entitlements and courses
- Information on Telecare services. Legal services for power of attorney. Discussions with other carers.
- Legal - getting power of attorney, very helpful gentleman
- Legal advice **[mentioned three times]**
- Information about power of attorney, benefits and general rights
- Information about Power of Attorney and Attendance Allowance. Help with obtaining a trolley (as above). Guide on preventing falls.
- Information and guidance with regard to applying for carers allowance, training courses.
- POA service excellent, thank you
- Power of Attorney **[mentioned 3 times]**
- Practical advice (eg. Power of Attorney)
- Presentation on new ESA procedures
- The legal side of things. Legal guardianship etc. Knowing there are other people like yourself with similar problems. Meetings and sharing.
- The legal surgeries
- The help at the start, especially help with getting Carers Allowance so quickly and with getting all the support I needed. Regular information through the post.
- The help with Power of Attorney, Attendance Allowance, Understanding the problems with caring for somebody with dementia.
- The information given to me when I enquired about carers allowance but wasn't entitled to it.
- The one to one interviews at home and the courses. Getting help with power of attorney.
- Their assistance in sorting out Attendance Allowance and in getting Power of Attorney for myself
- They gave me advice on how to apply for a higher grade of attendance allowance for my husband

- Trusts and wills
- Wills and trust fund information, charity finding for son
- Sessions on finance and future planning
- Setting up power of attorney, courses offered, support given
- She helped to fill out forms, she guided us through all the social services documentation
- Talks on financial planning
- Talks on caring for carers needs. Legal advice and guardianship.
- Information about benefits, and consultation with lawyer about wills, trusts, etc.
- I've received help 2 years and that was helpful at the time I needed it, that was financial help for a break
- I used short break grant. I am interested in VOCAL workshops in the future

Gateway and access to other services

- Bath seat aero chambers, inhalers 2. Left handed walking stick. Hand held device for picking up items on floor.
- Befriender service
- How to deal with the hospital and the aids and package available
- Any problems VOCAL either told the answer or where I could find it myself
- All help given, showering my husband, also bathing and dressed for bed
- Help from Andrew to get the go ahead with our wet room and ramp - this has made a big difference to my husband.
- Helping out round house
- Explanation of how social services should work and assistance in getting that help
- Practical classes - falling, foot care
- Find out what help there is for people in my position
- Finding a day centre
- Info on funding for holiday
- Signposted for wheelchair
- Info re: nursing houses and related costs.
- Putting you in touch with agencies that can help specifically
- Telecare alarms etc. Services available to support someone in their own home as long as possible. Selecting a Care Home. Power of Attorney. Dealing with finance. The Dementia Cafe which was a great success as I could go with my husband. I am still in touch with them.

Information and communications

- Carers News, Access to Website, Carers Information Pack
- General information. eg. the newsletter
- I find the newsletter very interesting
- Access to information and events
- Details and services, Dates and times of meetings
- Details of services available
- All information has been useful
- All of the things VOCAL have sent me have been useful
- Getting latest news in newsletters.
- Gym, Information letters
- Having a knowledge that support is there is and when I should need it.
- Every bit of information is useful to me, as I said I get no other help, and even though it's just letters they are very interesting
- Getting information, may use the lawyer in future. Expect to find this useful.
- I receive update when there are any courses
- Info and newsletters. Also info about exercise programmes for myself, but don't have time at the moment. Usually too far away so therefore away from my mother for to long.
- Information in leaflets is very useful.
- Information on support available to carers-financial etc. and training.
- Information of services available. Power of attorney service, website to find answers to questions.
- Leaflets, newsletter, courses (learning), calls.
- Leaflets/Booklets, Courses, Seminars
- Information/leaflets, Classes, Meetings (meeting other people to talk to.)
- Carer advocacy and newsletter / regular info.
- Apart from initial package of information no other service used
- Keeping informed
- Information **[mentioned 7 times]**
- Information sent via post on training courses etc. quite useful, but it is very difficult for carers especially like myself who are unable to leave the person they care for to attend such training.
- Information updates and meeting others in similar (or worse) positions
- Newsletter. To know you are there if I need you.
- Newsletters, the way mail is sent out. The encouragement I receive when I phone the office.
- Newsletter very informative - thank you.

- Newsletter and E-mail newsletter
- Newsletter, Courses, Support and advice
- Mostly receive very informative "Vocal News".
- Literature and phone calls. Forums.
- Newsletter **[mentioned 6 times]**
- Newsletter and courses **[mentioned twice]**
- Information and newsletters
- Regular information **[mentioned twice]**
- Regular newsletters and good information of what is going on locally in whole area. Also link up with classes and other people in area with similar problems.
- Not used service really but like list of training dates
- That they keep you well informed about everything
- The continuing updates received through the mail
- The lists of courses etc, the activities
- To being always informed as to what is happening and what we should (as carers) be aware of all the cut backs being imposed
- To date workshops packs, carer information packs (first class)
- Up to date information
- Website

Staff and one to one support

- 1: 1 consultation re: financial services and training
- A member of your staff phoned weekly asking any help I required
- A point of contact for advice
- Access to friendly, easy to talk to staff
- Access to someone willing to listen
- Communication, location and result
- Contact by phone, in person, write letters, and attend meetings with you - support.
- Contact with a human being
- Contact with Jan
- Contact with others if needed
- Contacts and form filling
- All the phone help and support, which you can get advice on any problems you may have.
- All useful / helpful **[mentioned 3 times]**
- Always been helpful when I called
- Always having someone I can (if wish) to phone at VOCAL - if can't help at VOCAL will give me number etc of someone else. And phoning me back to see how I am getting on.
- Dalkeith, Midlothian staff are great and friendly and helpful
- Being able to speak to someone

- Having someone to turn to for support.
- Having someone to listen to
- Approachability of the staff - friendly and reliable
- Having a support worker, receiving counselling, getting financial help for a holiday, just knowing that VOCAL is there is very useful.
- Having Rachel there to talk to
- Having someone to talk in a crisis
- Having a named advisor as a point of contact from the start. An in-depth appointment with our advisor - Andrea. The training course for peer support.
- Good contact, Easily approachable, Friendly staff
- From the first call and each time I have called Vocal
- Face to face meetings
- Home visits, it enabled me to understand easier. Counselling- even though it didn't benefit me, it is good for others, a great support.
- Being within the local community, and not having to travel, always make time for me (even if they are busy), they contact me on a regular basis. Help to get me a little of me time - thank you!
- I cannot praise VOCAL enough! They have helped me through a crisis time with two parents with very differing needs. They have listened and advised. VOCAL have continued to keep me informed. If I need more support or advice I feel they are ready to help.
- I could talk to someone who cared
- Easy to contact
- Just getting things off my chest
- Just talking to someone on the phone as my. Outing on my own are limited.
- Just the way I was treated by the staff
- Knowing that I can pick up the phone and someone is there to help.
- One to one help at Pentland Medical Centre. Classes at VOCAL.
- One to one telephone support
- One-to-one availability information back-up. Meeting up with fellow carers.
- One-to-one counselling and support. Info about courses available.
- Person to person contact. Magazine.
- Phone support, Advice, Someone to listen, Practical support
- Phone
- I was kept most informed through telephone and E-mail

- If is all useful - they do a wonderful job.
- More respite, Clare very good - keeps me informed on things.
- Nice to know if I have any concerns I can pick up the phone and someone will be there to help or just listen to me
- Knowing that Vocal is there **[mentioned twice]**
- Knowing what help was available
- Talk on a one to one basis
- Telephone contact / help / advice **[mentioned three times]**
- That you were able to help over the phone
- The fact that someone would listen
- Rachael, Outreach Worker. Her role as listener, supporting me with form-filling and keeping me informed.
- Someone listening to what you have to say.
- Someone to talk to
- The staff. The information held. The pointers to further help.
- The support on the end of the phone
- The talk with Claire. Also the assistance given to complete the forms that were sent to us.
- Tips to prevent accidents. Ready information. Friendly voice on the phone.
- To be able to make contact by phone
- To be able to talk to someone that knows
- They are all excellent you keep us well informed. Thank you.
- Very able to talk through issues
- Visiting office
- Visits by your representative
- Your perseverance in helping
- Understanding of my predicament when Firrhill told my husband that they could no longer cope with his group

Peer support

- Learning about how other carers cope with all difference problems which arise

- Gives you the opportunity to meet with other people in similar circumstances and share information and ideas!
- Letting me know about the carers
- Meeting other people and listening to their problems and talking through solutions
- Meeting regularly with the group, literature provided and lunch!
- Meeting with other carers Interchange or info
- Meetings with other carers. Counselling with Karen.
- Information and just talking to people helps me. To just get on with things.
- Informed group leaders. Meeting other people in the same situation.
- Support from other carers very essential.
- Mostly knowing that there was an organisation that I could refer to for information and help. Also being able to meet with others in similar situations.
- Talking to other people with different situation from mine
- Talk at VOCAL's offices and meeting other carers
- Information about who to contact and for what (in relation to falls prevention). Contact with other carers.

Feedback and critical comments

- Newsletter, Setting up POA at the moment but have heard nothing since returning info in April. Would love to be able to attend courses but most courses depend on my receiving some form of care for my husband while I attend, which makes them inaccessible for me, as he can't be left on his own any more without access and there simply aren't enough carers to go round and friends melt away - very common and understandable.
- Need more info and services for under 65's.

3.3 Which parts did you find least useful?

179 [30%] of carers answered this question which was comments based.

Summary of comments

- 26% of carers said difficulty attending events. The reasons given include their caring situation, transport, work, having no time, lack of respite and the timing of meetings.

3.4 Individual carer comments on what they found least useful about service

Difficulty accessing services/support

Timing

- A lot of the courses are during the week and as I work full time I cannot attend
- Am unable to attend courses during the day time
- By my own choice I have no internet perhaps I could access info after hours!!!
- Some of the invites to meetings. I really appreciate all the help given but I feel day meetings would not benefit me
- Particular days of service

Timing due to work

- Access to counselling at the time needed when also working full time
- Courses always land on the days I still work
- Events held - difficult to find the time to attend as I work full time
- Many classes/seminars during day time - not good if you also work as well as care
- Training as I work f/t and training is mainly during the day
- The training courses are always held during the day on weekdays. I am not able to attend as I still work.
- The support for carers as I work and the meetings are mostly mornings, which I can't make.
- Focuses on care for older people. Less information for younger families (adolescents?) Workshops and training events at difficult times if working (part time 8.30-4pm), Location is difficult to park near.
- Most things seem to be aimed at the older carer who is not working as well as caring. I work and care for my husband so have no opportunity / time to attend meetings or groups

- Only due to my circumstances - all the other services as overleaf are excellent. Due to trying to be able to care, work a few hours each week and juggle everything else, was unable to be given the opportunity to attend training courses / stress management / exercise classes etc which I would have loved to attend.
- Only been able to attend training when I was on maternity leave as I work full time and never available evening / weekend.
- Summer camp - hours not helpful when I work full time

Lack of respite support

- Courses as I would like to attend but can get no support to get time out
- Courses for carers that I cannot attend as no sitter
- Details of courses as unable to attend unless sitter offered
- Training course I have to have someone to care for my husband to take advantage of these
- Nothing I can think of other than asking/expecting me to attend some meetings that I would like to attend but have no-one to look after my wife.

Transport

- Courses, as I am unable to travel to these.
- Most things are not in my area and I have difficulty travelling to venues.
- I am unable to access any of these because I am unable to travel to Edinburgh (I am disabled as well as my son), and have time constraints as my son can only attend school part time.

Due to caring role / lack of time

- Courses - great to know about but in my situation I don't have time to attend but v.useful for others who can attend!
- Courses. I would need several free hours to cover duration of course and transport to the venue.
- Leisure activities - no time for these!
- Not able to access courses as caring roles preclude me!
- Not able to attend sessions at VOCAL due to timing (usually over lunchtime). Doesn't fit with when I am needed to undertake caring duties.

Location

- Lots of outings, day meetings centred in Edinburgh which makes attendance a bit of a major expense.
- More city centre locations would be helpful
- Unfortunately they've either not been in an area I can get to or have been cancelled.
- Mostly of the meetings etc. were in the centre of town and the time and cost of attending was not feasible for us
- Some services would not apply in our case since we are not resident within Edinburgh.
- That most 'groups' and activities are in areas my mother would feel 'uncomfortable' in. She lives in Murrayfield.

Reason not given

- Courses, I can't go on them
- I do not find the courses useful as I would find it difficult to attend
- Not always to get in the courses on offer
- I am not in a position to complete courses at the moment

Courses, groups and meetings

- Course on falls
- Courses
- Courses - after 5 years I could do them myself
- Group sessions
- If I miss part of the course (1 day) I miss that particular subject that has been discussed. It would be nice to get a note covering what had missed.
- Cancellation of courses at very last minute frustrating
- The casual, unstructured format of meetings
- The group closing

- The organised class was cancelled and thus meant quite an effort was required to motivate myself alone
- With hindsight - the library club - but this was due to very few members turning up!
- 'Role play' where scenarios are given and you comment on how the characters might feel
- Although we look forward to assistance with [unknown word] I was a bit disappointed with one session of [unknown word]
- A lot of services seem to be for those caring with someone who has dementia

Communication and information

- Still have not received VOCAL pack which was supposed to have been given
- Phones
- The amount of info I have been sent - seems quite overpowering at times
- (Personally) - information regarding carers groups

Counselling and emotional support

- Counselling [*mentioned twice*]
- Counselling and never phoned back for appt. etc.
- Counselling service is terrible. Don't have a clue how to act with people who are carers - seem very inexperienced. Students? Get someone with caring experience.
- Counselling, which unfortunately I found difficult. As not easy to unburden, regret not lasting.
- Emotional support not required at the present time. Carers support groups not required at present. Healthy living information.
- Bereavement support to found. Marie Currie meets was beneficial.
- Stress management course [*mentioned twice*]

External agencies

- Carers assessment needs identified but not provided by council.
- It wasn't really useful it's just they say because of the care component and she really needs a carer.
- The problem is that because you are the voice of carers, you should have more power to get somewhere with social services but you don't.

Finances and form filling

- Difficult to say, I suppose lack of financial means
- Benefits
- Help with form filling in
- Having the limit specified
- I know it has to be done, but filling out all the forms!
- Completing forms (sometimes too long)
- No help with benefit problems

Lack of support/understanding

- No help provided
- Nothing to report - not seen anybody for at least 3 years, not even a general telephone call.
- Personally I feel a little bit isolated, as we had great support from the staff for our mental health group. Things are not as supportive as they used to be.
- Not feeling accepted - more interest to people with a person who needs more care.
- The time it takes to answer a query.

Peer support

- Courses, nice to meet with others in the 'same boat' but doesn't really solve the situation.
- I do not find it helpful when group members continually talk about the person they care for. For me carer support group is about the "carer".

Social activities and events

- Social activities [mentioned twice]
- Social meetings such as walks etc. but I work fulltime
- Carers day!!

Meeting individual needs

- Only workshops/meetings that did not apply to my own personal situation
- Services aimed at me personally, as I don't feel my caring tasks are stressful
- In my case, too much [information]

- Information received in the post tends to be unimportant to me. If I could receive relevant information i.e. mental health that would help.

General comments

- Cups of tea at meetings. In my opinion time wasted apart from getting to know others in various groups.
- Difficult to say as when I attended a course earlier this year I was already pretty well informed.
- As above only because I do tend to dwell on things and I want anytime away to be fun time and social talking. I face my situation every day and I do not run away. My person is brilliant and he is god's gift to our family.
- Because my daughter has mental health problems, we did not need help with physical needs.
- Haven't used any of the outreach groups (ie. caring for yourself etc)
- I did not feel I needed to take part in the social events.
- My husband did not like outside the house.
- Support services that assume that a carer we/I am suffering from mental health problems! I am unhappy about this situation I find myself in and grief struck. But assume this is a normal way to feel about the challenges ahead.
- Some services I don't require but others might - so difficult to comment.
- The assumption, not just by VOCAL, that we are carers because we are caring people who do it willingly. We are not given the choice outside of getting a divorce, losing our home and having to find a job that pays more.
- None that I can think of but I have had no need to use counselling and advocacy
- Not lived in Edinburgh long enough - all information and contacts very useful at present.

VOCAL’s services for the future

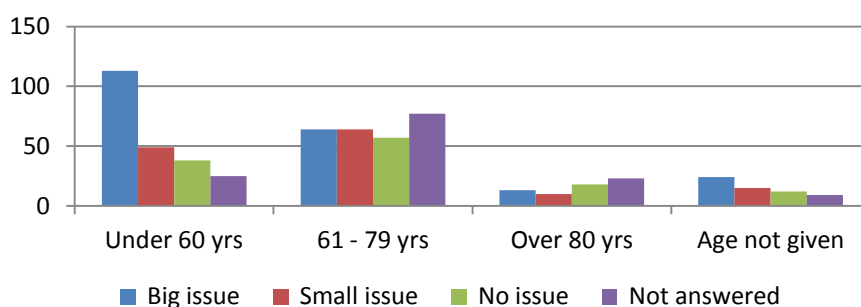
4. Finances: improving income, planning for future, managing debt

This question asked carers ‘How much of the following is an issue for you and / or the person you care for?’ and rated statements about **finances and future planning** against a scale of answers. The tables below outlines the responses to each statement based on age of the carer.

4.1 Improving your income (eg. accessing benefits, discounts, entitlements)

477 (78%) carers answered this question: 214 said ‘big issue’; 138 said ‘small issue’; 125 said ‘no issue’. **74%** (352) of carers who answered said improving their income was an issue.

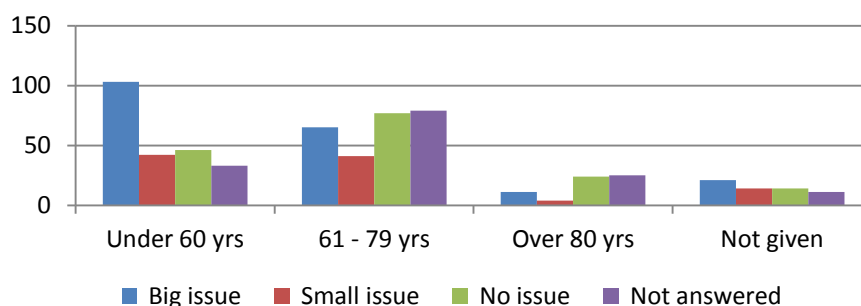
Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	113	49	38	25
61 - 79 yrs	64	64	57	77
Over 80 yrs	13	10	18	23
Age not given	24	15	12	9



4.2 Planning financially for the future (eg. power of attorney, trust funds)

463 (76%) carers answered this question: 200 said ‘big issue’; 101 said ‘small issue’; 161 said ‘no issue’. **65%** (301) of carers who answered said planning financially for future was an issue.

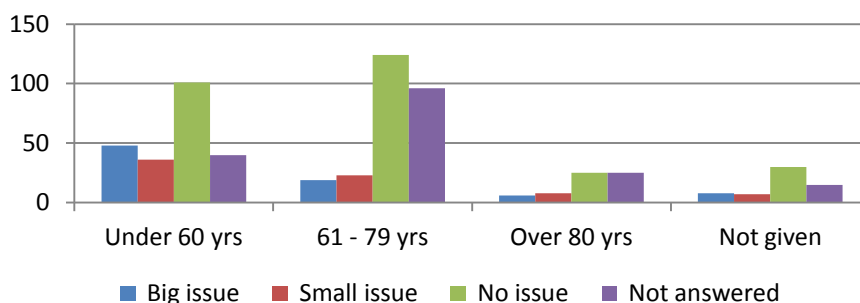
Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	103	42	46	33
61 - 79 yrs	65	41	77	79
Over 80 yrs	11	4	24	25
Not given	21	14	14	11



4.3 Managing or reducing personal debt

435 (71%) carers answered this question: 81 said ‘big issue’; 74 ‘small issue’; 280 said ‘no issue’. **36%** (155) of carers who answered this question said managing or reducing personal debt was an issue.

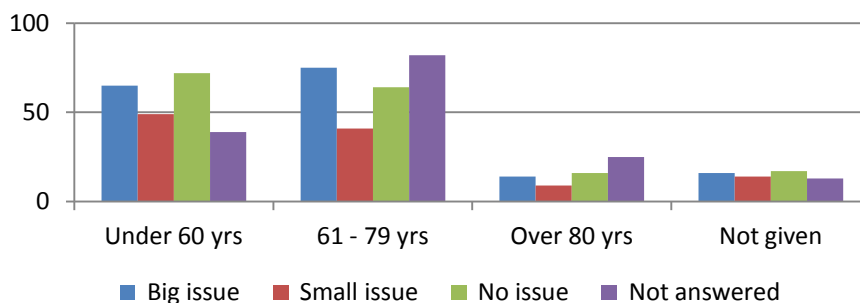
Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	48	36	101	40
61 - 79 yrs	19	23	124	96
Over 80 yrs	6	8	25	25
Not given	8	7	30	15



4.4 Paying/planning for long term home or residential care

452 (74%) carers answered this question: 170 said ‘big issue’; 113 ‘small issue’; 169 said ‘no issue’. In total **63%** (283) of carers who answered this question said paying or planning for long term care was an issue.

Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	65	49	72	39
61 - 79 yrs	75	41	64	82
Over 80 yrs	14	9	16	25
Not given	16	14	17	13



4.5 Individual carer comments on finances:

Improving income

- Applied for and now receiving attendance allowance for caring for my mother aged 89.
- Appreciate being informed of changes.
- As someone whose benefits were reduced, after losing an appeal, I feel I cannot pay bills etc. the same.
- As we are of the generation that saved for our retirement I find this hard, and I do not take respite as often as it is offered.
- As we are retired our income is simply related to state pension and any private we may have.
- At the moment not claiming any benefits or other entitlements.
- Being retired with various pensions and all the benefits entitled to, the above are not huge issues for me
- Benefits system is a minefield - difficult to get for husband since I work myself so he does not get much as far as I am aware.
- Constant worry of when funds/savings will run out to allow me to continue to act as a carer and not have to go back to work - alternative is to move outwith Edinburgh area to live.
- Had to give up work to be a full time carer.
- Have been fortunate to have financial adviser help.
- I am unable to work and became bankrupt as a result of caring - I am very pessimistic about my/our financial future.
- I am waiting to go to a tribunal for DLA, been refused twice.
- I find it stressful holding down a job and being a carer.
- I have given up employment for my parents, saving the government thousands and yet only get £55 a week to care for both my parents and struggle with money and bills.
- I still wonder why the carers allowance pay only £55, as I'm on my feet nearly 24/7.
- I think all carers should be allowed to earn more than £100 per week, I work part time (25hrs) therefore I am not entitled to receive my carers allowance even though the level of care is unchanged. There absolutely needs to be a realistic increase in the carers allowance to reflect the care provided to someone.

- I tried to get housing benefit for my son's house (that I own).
- Info from Vocal again about changes to benefits etc. is very useful.
- My husband's state pension and pension go to the home, he has no other money except his flat which I occupy.
- Our housing association has money advice which was more useful than VOCAL's support.
- She never gets a proper holiday. Can never access funding, VOCAL helping this year, but not again till 5 years have passed.
- The lady we got put us on the right road and we got full disability allowance. Thank you.
- The government financial help is enough till my husband or I dies.
- We are lucky to be financially stable and our son at the moment receives good benefits.
- Worried about gas and electricity rises in coming year.

Planning for the future

- I found going through these [planning for future, planning for long term care] a big nightmare.
- I had a lot of information, had already set up POA
- I have power of attorney over my husband's affairs. I don't feel a need for further help at the moment.
- If my father goes into hospital for a lengthy period or dies, care for my mother would be necessary and how to pay would be an issue.
- I have found the legal work has become prohibitly expensive - seven times more expensive than 12 years! (POA and wills)
- Accessing benefits and Power of Attorney has made it possible for me to have my aunt live with me in a house suitable for her.
- I have taken the appropriate steps to secure my son's financial future (hopefully).
- Already have affairs and POA in place.
- Although my son is only 14 I worry about his future when I am not around.
- Am daughter brother has 'power of attorney'.
- As I am working full time above issues are less important. However I may need to review them in future.

- At the present time I have not thought any further than day to day.
- Can't afford legal fees for power of attorney.
- Eventually need to look into POA procedures.
- Have dealt with this in past. Mother was in care home but improved enough to come home again, we have POA for both parents.
- My health is failing and worry about who will care for my son
- My son is 26 - we have a lifetime of caring ahead of us.
- Not sure what will happen when I die.
- Not used above but will need to use soon as my son is getting older.
- Power of attorney is something that we as a family have been thinking about very seriously but something always craps up, but will need to make some changes soon.
- Would like some advice on best ways of saving money for our son.

Managing debt

- We have debt problems, my husband won't hear of me getting help from Christians against poverty.

Planning for long term care /self directed support

- Care home fees
- Concerned about being pushed into self directed support rather than council led services
- Direct payments for home based respite are virtually impossible to get.
- Give little thought to entering a care home
- Have left the last one blank [long term care] as this at the moment is too much for me to mentally entertain.
- I fear the home issue
- I have discussed this with my Financial Adviser as I wish my husband to be cared for at home: if I become unable to cope I would be require to pay for private care.
- I have not made arrangements for her care. I do not wish her to go into care. I have 2 sons (not married) but no family.
- I worry that we will have to sell mum's house to pay for her care when it gets too much for me.

- I would be concerned about long term home or residential care if required for me or my wife.
- Long term plan made, POA, plan for more care.
- My husband has now passed away but I was able to look after him at home with help until 6 weeks before his death.
- My mother is now in a care home (Feb 2011) however I still consider myself a carer, looking out for her care and financial benefit.
- My son is currently in the process of moving to supported accommodation
- No.4 [long term care] could be an issue eventually.
- Paying/planning for long term care - It would be good to know who this could be managed
- Planning for long term suitable supported accommodation is an ongoing issue.
- Planning for residential care in the future
- Planning/paying for long term care - constantly on my mind, worried.
- Residential care has to be available in the future.
- Taking over the financial concerns of my parents can seem very daunting, worrying - am I making the right/best decisions.
- The last point would/could be a problem depending on cost - but hope to keep my husband at home!
- The person I care for is settled in a home with support and benefits as required.
- Our needs will alter as time goes on. For example - residential care may be needed.
- We are planning to stay with our family and won't leave our home until it is absolutely necessary.
- We sold our house and live in rented accommodation and have funds to see us through, but care home costs of +£3000 per month would be a big problem.
- We want our daughters to stay in the family home but finding help with care in the home is difficult - both financially and practically.
- Would be a big issue if need for residential care arose.

General

- When caring for someone for the first time and faced with the situations as above can be very daunting.

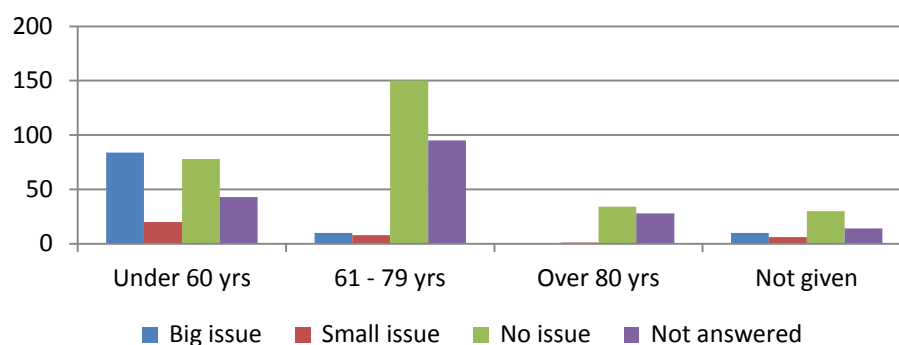
5. Employment and training

This question asked carers ‘How much of the following is an issue for you?’ and rated statements about **employment and training** against a scale of answers.

5.1 Remaining in paid employment

431 (70%) carers answered this question. 104 said ‘big issue’; 35 ‘small issue’; 292 said ‘no issue’. **32%** (139) of carers who answered said retaining paid employment was an issue.

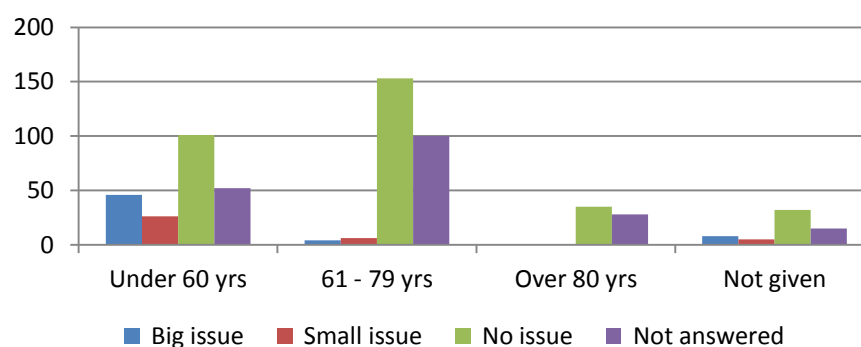
Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	84	20	78	43
61 - 79 yrs	10	8	150	95
Over 80 yrs	0	1	34	28
Not given	10	6	30	14



5.2 Entering (or re-entering) paid employment

416 (68%) carers answered this question. 58 said ‘big issue’; 37 ‘small issue’; 321 said ‘no issue’. **23%** (95) of carers who answered said entering or re-entering paid employment was an issue.

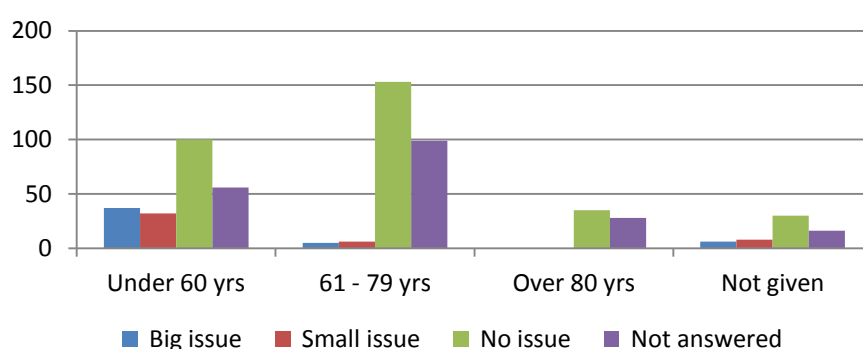
Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	46	26	101	52
61 - 79 yrs	4	6	153	100
Over 80 yrs	0	0	35	28
Not given	8	5	32	15



5.3 Accessing training or volunteering to lead to paid employment

412 (67%) carers answered this question. 48 said ‘big issue’; 46 ‘small issue’; 318 said ‘no issue’. In total 23% (94) of carers who answered this question said accessing training or volunteering to lead to paid employment was an issue.

Carer age	Big issue	Small issue	No issue	Not answered
Under 60 yrs	37	32	100	56
61 - 79 yrs	5	6	153	99
Over 80 yrs	0	0	35	28
Not given	6	8	30	16



5.4 Individual carer comments on employment:

Caring role preventing work

- Can't return to work as no one else to look after
- Due to caring for 3 family members!
- Forced to give up work due to caring responsibilities
- I am my wife's full-time carer, so not currently employed
- I have had to give up full time work to care for my son
- I will never be able to work as my wife needs round the clock care.
- I wish to be at home for my daughter as she is in the house so much. I wish benefits reflected real life/costs. Cameron is targeting disabled people in a very negative way.
- If I get full time work, there is no one to look after my cousin
- If I was to get employment to help financially I would lose my allowance and have to cut my hours for caring
- Left employment to care for 2 persons - family. Care full time for 2 family members - had to give up work due to cost of nursing

- homes - once savings run out real worries will set in. Only entitled to 1 x carers allowance despite above
- My mother needs constant care/no option of working
- Not suitable - caring for dementia, COPD and other illnesses
- Recently stopped working
- Would like to get back into work. Childcare is massive problem as no family to help and have absolutely no confidence at all about getting into employment.

Health issues

- Because of my ME, looking after my parents is enough at moment as I am still in poor health
- Due to ill health (long term condition) will be unable to work
- I would love to go back to employment, because of my PBC I get very confused and lethargic

- I took early retirement due to health issues - renal failure and I am now my Mother's full-time carer. I got Kidney transplant after 6 years on dialysis.
- I want to be able to get back to work but I have problems with my back. I will probably have to do some retraining.
- I am under doctors for mental health problems pulse I've just been diabetic and the two types of medication makes me very tired.
- In January my husband had his foot amputated. The next week I broke my arm! We stopped working - freelance typesetting and editorial services.
- Re entering employment depends on health conditions

Juggling work and caring

- Difficult at times to keep working / juggling care, get so tired and always so much to do.
- I am struggling to stay in paid employment as my husband's needs increase. He will not have help from outside agencies.
- I have had to get my hours for three days to two days, cannot get childcare for my son.
- I wish to remain in employment but this is becoming more accommodate my shift patterns. I therefore have to rely on my mother-in-law to care for my husband when I am working who also has health problems.
- I work 3 days week and care after work and on my days off.
- It is very difficult to find a job with enough flexibility around a carers lifestyle, most available jobs are in the very low income bracket.
- It is very important for me to continue working part-time with the NHS to care for my own family and 4 children.
- Remaining employment is a small issue however money is becoming more of an issue
- Work as part-time sub-postmaster
- Working part time and would like to remain so but caring is really beginning to impact on this more than I thought it would!
- Would like to continue working

Older carers

- At 71 I am unlikely to get paid employment - I really need most of my time for caring.

- I would like to retire - but rely on my income as pension with reduce income and I don't get state pension until age 63
- I'm 57 years - what sort of job - or who is going to employ me
- Retired, though may look for part-time work

Self employed

- Am afraid for future ability to remain self employed when caring responsibilities increase I will need more benefit advice
- I am self employed, at the moment this suits
- I am self employed, this is becoming more difficult
- Managing our time to make sure I can keep my self employed business running, while having the extra care tasks
- My main concern is finding a balance between caring and my self employed business

Training

- Could do with computer course, found out at college dyslexic
- I did volunteering before, I've done a few courses as well - some cut short due to family. I'd like to do some again.
- No time while caring. Would like to train massage.
- Paid employment that would allow me flexibility would be good, although I'd much prefer re-training so I could get a well paid job.
- VOCAL can help improve confidence apply for jobs.

Worry about the future

- At present I can continue working as we are managing with carers going in to see to my mother but I worry about the future.
- Could be an issue in future. Currently on IB.
- Could be concern in the future
- Not issue personally but may in future be for cared for persons
- No issue at the moment. Don't know about future.

General comments

- It is better for the carers well being if they can remain in some for of paid employment if possible - this is often dependent on employer if care at home can fit around this.
- Apart from financial benefit need an outlet to stay positive and stimulated

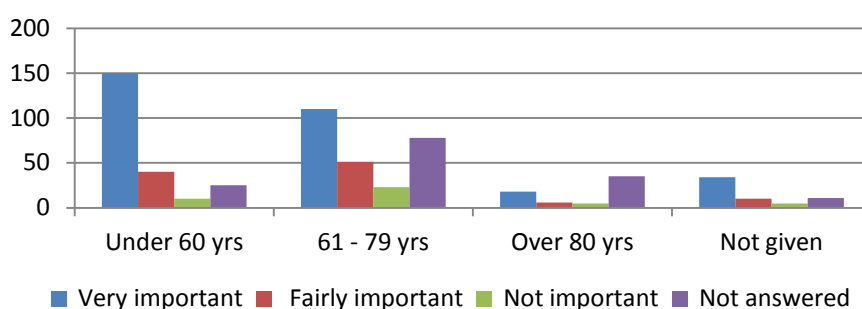
6. Carer services and support

Carers answered this question which rated services against a scale of answers. The tables below outlines the responses to each statement based on age of the carer.

6.1 Emotional support and counselling

462 (76%) carers answered this question. 312 said ‘very important’; 107 ‘fairly important’; 43 said ‘not important’. In total **91%** (419) of carers who answered this question rated emotional support and counselling as important.

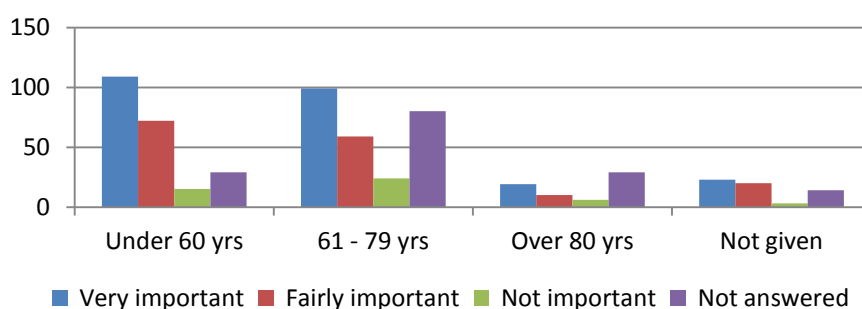
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	150	40	10	25
61 - 79 yrs	110	51	23	78
Over 80 yrs	18	6	5	35
Not given	34	10	5	11



6.2 Carer support groups

459 (75%) carers answered this question: 250 said ‘very important’; 161 said ‘fairly important’; 48 said ‘not important’. In total **89%** (411) of carers who answered this question rated carer support groups as important.

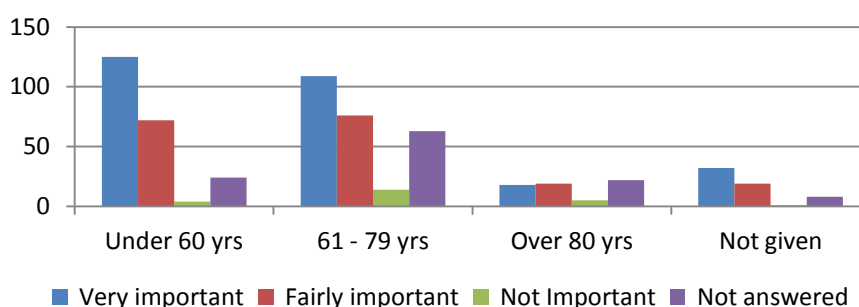
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	109	72	15	29
61 - 79 yrs	99	59	24	80
Over 80 yrs	19	10	6	29
Not given	23	20	3	14



6.3 Booklets, newsletters, regular information

494 (81%) carers answered this question. 284 said ‘very important’; 186 said ‘fairly important’; 24 said ‘not important’. In total **95%** (470) of carers who answered this question rated booklets, newsletters and regular information as important.

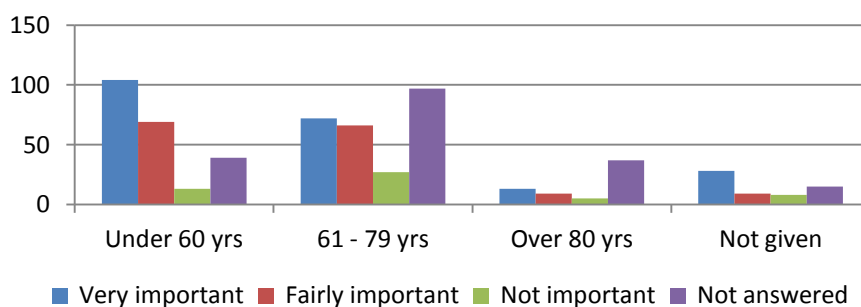
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	125	72	4	24
61 - 79 yrs	109	76	14	63
Over 80 yrs	18	19	5	22
Not given	32	19	1	8



6.4 Carer advocacy

423 (69%) carers answered this question: 217 said ‘very important’; 153 ‘fairly important’; 53 said ‘not important’. In total **87%** (370) of carers who answered this question advocacy as important.

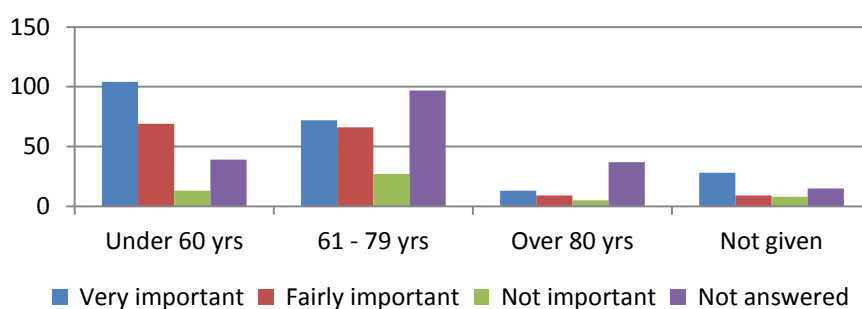
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	104	69	13	39
61 - 79 yrs	72	66	27	97
Over 80 yrs	13	9	5	37
Not given	28	9	8	15



6.5 A website for carers and support to find information online

430 (70%) carers answered this question: 226 said ‘very important’; 138 ‘fairly important’; 66 said ‘not important’. In total **85%** (364) of carers who answered this question rated a website for carers and support to find information online as important.

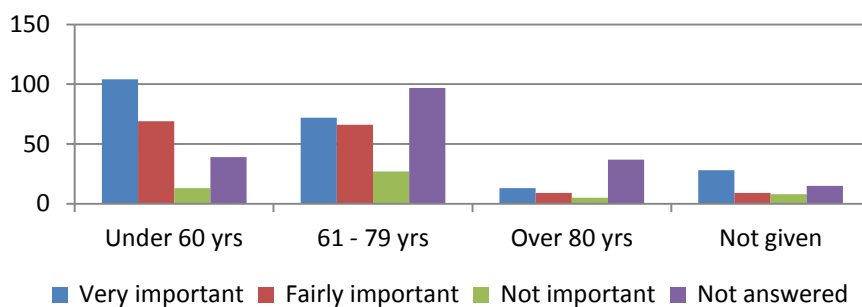
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	122	57	10	36
61 - 79 yrs	71	62	36	93
Over 80 yrs	10	4	11	39
Not given	23	15	9	13



6.6 Stress management courses

443 (72%) carers answered this question: 207 said ‘very important’; 157 ‘fairly important’; 79 said ‘not important’. In total **82%** (364) of carers who answered this question rated stress management courses as important.

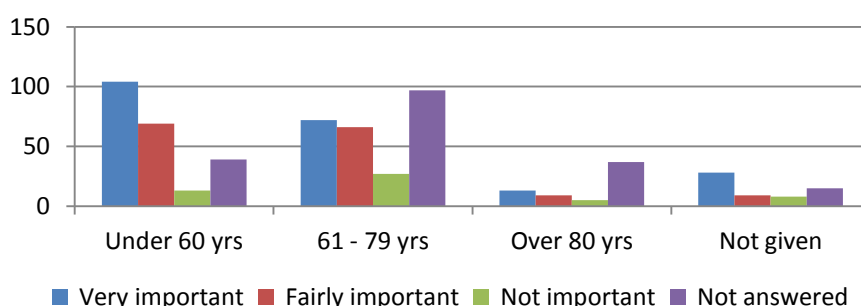
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	97	73	26	29
61 - 79 yrs	74	63	37	88
Over 80 yrs	11	9	8	36
Not given	25	12	8	15



6.7 Training and learning opportunities (eg. caring for someone with MS)

431 (70%) carers answered this question: 207 said ‘very important’; 123 said ‘fairly important’; 101 said ‘not important’. In total **77%** (330) of carers who answered this question rated training as important.

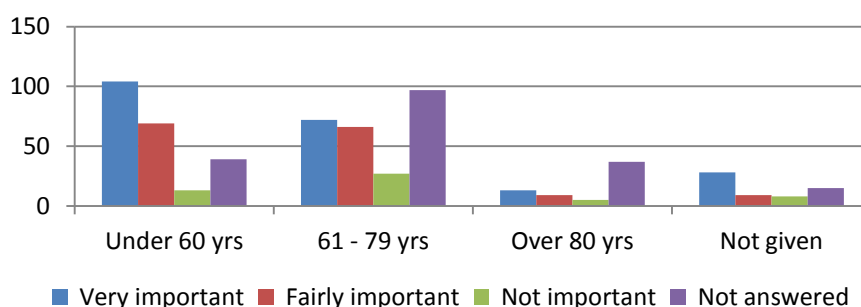
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	101	48	39	37
61 - 79 yrs	76	52	41	93
Over 80 yrs	12	7	10	35
Not given	18	16	11	15



6.8 Healthy living initiatives (eg. diet, exercise, weight management)

439 (72%) carers answered this question: 171 said ‘very important’; 177 said ‘fairly important’; 91 said ‘not important’. In total **79%** (348) of carers who answered this question rated healthy living initiatives as important.

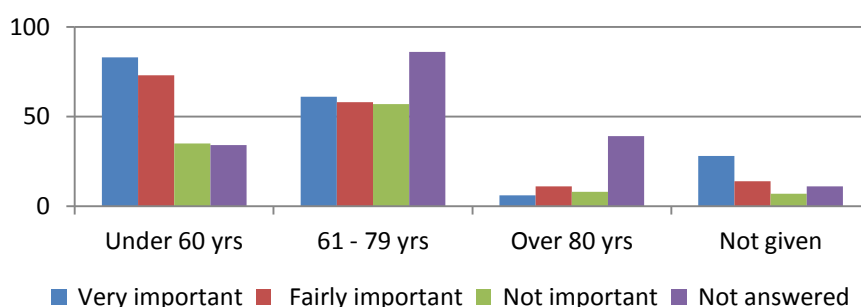
Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	81	73	37	34
61 - 79 yrs	62	73	39	88
Over 80 yrs	10	11	8	35
Not given	18	20	7	15



6.9 Social and leisure opportunities (eg. reading groups, gym buddies)

441 (72%) carers answered this question: 178 said 'very important'; 156 said 'fairly important'; 107 said 'not important'. In total **76%** (334) of carers who answered this question rated social and leisure opportunities as important.

Carer age	Very important	Fairly important	Not important	Not answered
Under 60 yrs	83	73	35	34
61 - 79 yrs	61	58	57	86
Over 80 yrs	6	11	8	39
Not given	28	14	7	11



6.10 Individual carer comments on services that are important to them

Access issues

- All are very important though finding the time to access them will need to be staggered for me
- Can't attend any event as never leave my husband for more than a couple of hours on his own
- Difficult to access exercise classes due to caring/family commitments
- Difficult to access some of these due to lack of time and opportunity
- Due to individual circumstances carers don't always have the opportunity to attend some of the services on offer.
- Full time carer - cannot make courses
- Have not got time to attend courses
- I cannot make full use of your service as I am my husband's carer and I am also getting disabled.
- I do not have time to attend courses, as Angus's condition requires full time caring.
- I don't leave my daughter for long periods of time - anything I have to 'go to' is not a reality for me.
- Lack of transport means I am unable to get to training opportunities
- Most of the above does not apply to me, as I have to stay with my husband 24/7. Don't get any help.
- My wife does not get out much
- No time to attend vocals courses
- Where do other carers get the time to be away from the person they care for? i.e. Social and leisure, when they also work.
- Unfortunately courses tend to start at 10am while the paltry amount of respite I receive starts after 10am
- Time for last two on list is a big issue [healthy living, social and leisure activities]
- Issue is around being able to have the time to attend/participate.
- Use leisure time to catch up
- Was not sure how to get there

Carers health

- As I am a diabetic, health living initiatives would be helpful
- I have been told I need to lose weight but my husband has the purse strings and buys unhealthy foods he needs to be spoken to

regarding this. He receives pension credit for us both, but I see none of it.

- Looking after health is top priority

Carer support groups

- I find carer support groups very helpful
- I see the support groups as important for some and up to a point, but I don't want to be a carer at all and if I can get away for 4 hours would rather be walking the dog or birding.
- I think support services for carers are very important. As carers we all have different needs depending on the person or persons that you are caring for.
- Support groups are wonderful

Emotional support

- A workshop on care homes, a workshop on pet therapy, a workshop to know / feel when you are 'not coping' - what are the signs. How to listen to your body and mind.
- I feel I can cope with my own health and emotional well being but am well aware not everyone can. My main concern is the well being and support for my daughter when I am not able to help or in the event of my death.
- I find it hard going, as I have no one to share with, I don't want to burden my friends and my sister doesn't want to know. Emotional support very important.
- I have never had any stress related problems but may require assistance later. Other than my wife with Alzheimer's we live fairly well, we walk daily, my wife can no longer read so TV plays a big part in our daily life.
- I receive a lot of emotional support and help from my friends and family and, due to hours received from Crossroads, I can arrange a sitter for my husband to allow me to meet friends.
- I think I am emotionally pretty strong and so wouldn't need a lot of these services but others would
- Receive emotional support and counselling from family and friends

Information

- As in my case, I did not know anything about dementia when my husband was diagnosed, so it was put into perspective for me with really helpful suggestions

- I appreciate the regular newsletters, information booklets and always read them. All the other items are very important, but I don't have time to take up the Vocal offers. Most of the support I need I receive through Church and family.
- There needs to be something for people to access info when they need it and different things may be needed at different times.

Social and leisure

- I enjoy swimming, cycling, walking, music and reunions with friends and ex-colleagues. Dare I say I like to get away from my caring environment.
- I have cared for my 2 autistic children for many years, have learned to cope by having support group of friends who have autistic children.
- I have good friends who I rely on for a listening ear
- I have some very good friends so walk with them and tennis if I can
- I would love to go the gym but I would not go alone and finding time is very hard plus very expensive
- I'm in the Leith book club, I go to Care for Carers classes, but I need more things to use. Also, you get feedback from carers you meet.
- Member of book group which has been great. Dance or exercise classes would be good too as a time to out for carers.
- It would help carers if they had access to free or by donation for massage and reflexology.
- Social and leisure opportunities are crucial to my health but it is hard to get out as often as I would like to.
- Social and leisure take a back seat now!
- Would be grateful got for any information on healthy living and social/leisure opportunities
- These services can be a lifeline at times. As a carer there is very little time to spend on myself, the Leisure Card was a brilliant support.

Short breaks / befriending

- I am interested in holidays where they can support me and person I look after
- My daughter would have benefitted from a befriender but none available

General comments

- Some things can (or even should) be provided by NHS / Social services
- Do not have computer / use internet **[twice]**
- These are all vital but I still meet people who are unaware of 'VOCAL' or 'Caire'

7. Can you suggest any areas for improvement for our services?

Summary of comments

- 39% (237) of carers provided comments for this question.
- 4% mentioned difficulty accessing services due to work, transport, their caring role, the timing of courses and events.

Financial and legal

- Dealing with the DWP. Paying for care
- Extra benefit definitely as my carers money all way get's spent on his house or him. I have no money left to get out and do things or get some new clothes etc.
- Have information about all finance money you are entitled to and discounts you are entitled to as well. Also how to claim a grant.
- Lower all areas which benefits and help with appeals CAB can't do it all
- More financial help from the government.
- More financial information about wills, benefits etc
- Help with wills etc. could be more prominently includable
- More support in accessing financial help and benefits planning out tax, inheritance and will management
- Only involved with Power of Attorney. Perhaps could be follow up with any carer applying for this - is there any other help could be useful.
- Power of attorney follow up as I thought they received my info and they were waiting for my info but in fact they lost it this taking 3 times longer to process

Fundraising

- Maybe throw out more opportunities for people to make financial donations to support VOCAL. Advertise that no funding comes from government. Thank you for the help I received.

General information and support

- If you can do monthly lectures about the important issues the carers could need or the difficulties they could overcome that will be a great help as well.
- It would be very good if someone could take care of a carers needs and coordinate their various entitlements. It has taken me approx 4 years to find that council tax can be reduced due to my wife's condition,

and this was only discovered due to a letter from the council.

Increase provision of services

- More education services for those who would take advantage - most carers have their focus on their loved ones but now and again they would be able and happy to accept help.
- More advocacy, life was 100% much easier when I had Sheena. As I am in do much pain awaiting hip op - I have done my best to complete form.
- More full-time staff!
- More help would be really appreciated
- More of it
- More pamper sessions, information on respite to care home also transport to visit and make an assessment, also buddies to go with carer to support. eg. push wheelchairs.
- More training courses - if funding allows!

Local support and services

- Make them accessible to people in West Lothian, or make it clear when people register with you that this area is not covered.
- I personally would like to see a drop in shop in Midlothian, as some days it would be very helpful to discuss things face to face rather than on the telephone, but I do realize the staff in Midlothian are very busy.
- Only thing I can think of is I would be more likely to get counselling if the centre was easier to get to - ie. local centres but this would probably cost too much - what about 'roaming' counsellors that go to the carer? Same with some of the courses - sound fab but too long being away from how to attend if you take travelling to and from the centre in to account.
- The new liaison with South Queensferry carers support is a great improvement as

sometimes it seems that outlying communities are forgotten.

More / better contact with carers

- A visit from someone every year or six monthly would be nice, so I don't feel so isolated
- Face to face meetings with carers who sometimes feel they can't take anymore and need information urgently. To be told they can't be seen as very busy and there is a waiting list isn't really the response that carers need.
- Initially I would have appreciated personal contact although I did not have time for lengthy discussions. Meetings with social workers, OTs, demands of district nurses, carers etc, were time consuming and time was not available. This was a very frustrating experience for a new carer to the issues involved.
- It never feels as if anyone is ready to help quickly - people are not in that day, off sick, in a meeting, on leave etc. It all seems unfriendly and not what it should be about at all.
- Regular visiting by and for carers
- Returning phone call messages
- To be in touch with elderly and infirm there is always room for improvement.

Person-centred services/information

- I think there should be more bi-lingual staff in all offices and areas of VOCAL - especially younger BME people who have knowledge of issues within the community.
- A more person centred approach - less defensive and more organised for counselling service - not working for clients
- Keep the varied courses etc. - much appreciated!
- For me the lack of experience of dementia was my real problem
- Support group for a specific mental illness i.e. Bipolar, Schizophrenia
- How about a "core package" aimed at carers in specific circumstances e.g. aged, child, dementia. Overall, I think the services are excellent.
- I would like information on developments made for people with mental health disorders

- I would like to get hold of a booklet with a simple exercise routine I could do to try to keep fit within the constraints of my full time caring duties, I have a DVD but can't find the time to watch it and learn what to do, then implement it regularly. A booklet (or even a sheet of paper) would suit me better. After 8 years as a carer I'm feeling more and more stiff and achy.
- I still feel like the first person to have to care for a terrapelgic. Where are the lists of respite options, where to get equipment, what aids others have found helpful.
- Identifying suitable respite care homes
- Remember people like my daughter - 17 yrs housebound. Try to find services like hairdresser for the housebound - this is a big deal and I can't go online to find anything.

Promotion and communication

- Attend special needs schools parent/staff specific evening arranged for you to inform carers little children still young of your resources whether staff, courses or information
- I see publicity for other carer organisations in Edinburgh now, is this new? And are you in competition with them for 'clients'?
- I think that VOCAL could cross reference carers details with other groups to ensure that all carers received information VOCAL puts out in email information / alongside newsletters.
- Improve communication about cancellation of courses
- Information given out in newspapers for area and Dalkeith advertiser would help
- In my area we have Libertus, other parts of Edinburgh need to know VOCAL exists.
- Just letting know people know what help is available. If you knew from the on-set of things that help was there, that in itself is an uplift.
- More awareness of website
- More publicity maybe - it took me a while to find you!
- Only comments I have heard are that lots of carers have not heard about you. Need leaflets in GP surgeries, chemist, libraries etc. Practice Nurse to spread the word.
- Yes, advertise yourselves more - somehow / somewhere

Privacy

- One of the courses I attended was also attended by one of my neighbours. I didn't feel comfortable with that, so maybe that is something could be taken into consideration.
- Counselling could be better - felt intimidated as I knew the counsellor outside VOCAL and it was embarrassing.
- I can only think off more privacy, I realize this is not always possible. Because of vulnerable families.

Scheduling and delivery of events

- Access to training courses and follow up sessions outside of working hours.
- As above, the assumption that carers have time to spare.
- Because I work I cannot attend some of your courses during the day.
- Consider Saturday or evening talks/events, which will allow those who work full time to attend without having to take annual leave.
- Courses repeated with a choice of dates.
- Evening classes at weekends.
- Have some training sessions or meetings at night or weekends, as I work full time I miss out on meeting other carers and I would very much like to participate - as long as it is local, no travel outlay (finance).
- I would like to have a 'support' meeting say: Early evening. Apart from this that "VOCAL" is excellent.
- I would like to see more of the courses / workshops available on evening or weekends (as I still work full time)
- It is difficult for me to comment as I haven't actually used the services due to the fact I still work and don't drive, meaning accessing support groups etc. is more difficult. I do appreciate information sent through. Thank you.
- Meetings are easier to attend if they are not too long. 2-3 hours is best.
- More flexible hours for training courses to cater for working carers.
- More information sessions at varying times workers not able to attend during the day
- More on respite, practical support in regard to this. More aimed at carers who also work. Personally I would like access to regular reduced cost therapies. ie. massage, reflexology etc as I know this is

of benefit to me especially if taken regularly.

- None. You do a wonderful job. Some of your training classes are on days and evenings I have something else on.
- Perhaps there could be a 'creche' to enable carers to attend support courses.
- Short courses ie. preferable to all day due to caring commitments.
- Some of the courses offered are interesting but I could not manage whole days.
- Somehow or other assisting with a day carer to allow myself to attend some more meetings, to learn more of what is expected of me as a carer.
- Summer/holiday camps that match FT working hours.
- To make more courses available in other areas.
- Take the training to carers not the other way round.
- Try to offer some evening or weekend training.
- Wider / more flexible time for those of us that have small children and no respite or family help.
- Would you be able to send information on training course via email? I would like to have them well in advance to organise my diary. More events in evenings and weekends.
- As I suggested already sometimes I miss 1 of the days of a 6 week course, its usually because mum requires my help. It would be great to get a print out of the information I've missed.

Short breaks and respite

- It would be beneficial if there was a service available, perhaps befrienders, who could spend a few hours each week with person who needs care to alleviate stress on carer
- More often if carers would go for a weekend trip without caring.
- Further to Q6. I wonder if you have ever surveyed carers re their experience of respite or sitter services?
- Try to arrange for the carer- even once a year or when the carer is in hospital, respite, but without the huge expense that it now costs for those who have spent their active lives saving for old age!

- Support carers by providing a befriending services to enable carers to sort out matters for the person they care for - which would help reduced stress and it would also give the carer the opportunity to attend some of the services on offer to maintain a healthy lifestyle which is very important.

Social activities / peer support

- How to support carers and clients who do not wish to 'socialise' as they have never been social?
- Entrance to swimming/fitness centres, Maybe this is something that could be expanded?
- Fun days - social outings, cookery classes, complimentary therapies, talks on benefits. Anything to get out of house.
- I rarely seem to see much for people caring for people like my son, i.e. young, physically able and with severe learning difficulties. That may be my fault and I know you have to cater for all kinds of care.
- I spoke to someone recently who was told there were no support group/social leisure groups for him. He is under 65 and caring for someone with severe mental health problems.
- More courses on keeping fit and well. Aqua fit/gym etc.
- Meeting local carers in similar situation may help. VOCAL could help people network with their agreement.
- Needs social and recreational daytime outings for the carers
- To arrange outings

Stress management

- Satisfied but so far haven't attended stress management courses, they have been cancelled due to lack of support, applied for 2
- Stress Management could include actual relaxation techniques

Transport

- Bus runs in Edinburgh to place that have electric buggies. I did ask Dunfermline Shopping Centre if they hired their e. bugs to go through the Glen (park) but they

don't. (It is a great comfort it feel that your good service is at the end of the phone).

Voice for carers / lobbying

- Any help with accommodation issues? Been on waiting list for 10 years (daughter) offered 5 totally unsuitable places so far, she knows what she wants, so do we.
- As above I think VOCAL should be a hub - directing carers to sources of support + social activities for both groups and for individuals. VOCAL needs to be more VOCAL! Against authorities. Enjoyed getting chance of reduced
- I think it would be interesting to lobby to govt. more. I know Vocal did the carers March. More leaflets/booklets as we are not online. More outings that I can go on with my daughter not leaving her behind (preferably afternoon outings as this is when she feels better). We would love to go on holiday again and are sad Pontins has gone. We can't afford holidays (my daughter is too old for Family Fund).
- Keep listening, lobbying and 'being there'.
- Making GPs appreciate alcoholic problems.
- Often there are times when I have ideas, suggestions, and complaints regarding eg. social services, GPs, attitudes towards carers. Lack of respect from these bodies. VOCAL could perhaps be more proactive in supporting us?
- Pushing for more help and respect for carers from social services. If possible I'd like to have more help from the social services in providing respite care to suit me. If possible VOCAL can mediate on my behalf, accessing help and respect from SS can improve.
- Trying to keep improving services for carers, particularly financially, and improving carers rights. More subsidised schemes/benefits i.e. Leisure Card, travel card, cinema card, days out cards? Be allowed to being fulltime education without losing carers allowance. Carers allowance should reflect the "job" being done, millions of pounds are being saved by the government as carer are paid a pittance to care for someone.
- Possible to have carers employed by the Council and commercial carer companies contracted to the Council made aware of the existence of Vocal.

- To keep on trying to get Carers Allowance to people over 65

General comments

- Talks to other smaller carer groups
- Yes you could try to help people of all ages not just people aged 60 and over.
- You used to be completely independent and that's the way it should be otherwise vulnerable people who need help can sometimes feel isolated and unsure of whom they can trust.
- A 0800 number might be good
- Personally I found when my husband's dementia made him take an unexpected turn for the worse and had to go to hospital then was told he needed a nursing home as he could no longer walk, stand, feed himself and his memory is very little. I was, I felt, very alone and no one was there to advice or support (I needed the help from someone who knew what to do. I was at the mercy of the social worker who just wanted him into a nursing home.

Positive feedback

- I am happy with all aspects of VOCAL. I have attended lots of courses and made friends with lots of people with similar problems.
- I believe you have a very high quality service so do not see room for improvement
- I cannot think of anything specific except to say - just be there as always, you are a lifeline for a lot of people including myself. Thank you!
- I can't think of any ways you can improve on what you are doing. I just wish I as person were able to attend your courses.
- I have found many courses I have been on most beneficial. Always hearing of something new. Always learning from other participants. Don't know of any areas for improvement, the service is excellent!
- I have taken voluntary courses in the past and enjoyed these meetings. I think VOCAL is an excellent place for into and support. Long may it continue.
- My parents and my GP were insistent that I speak to you. At the time I was not sure you could help me. Since phoning you I have been given information, reassurance and help when I didn't know what to do. I cannot think of any improvements you could make to your excellent service.

- I like the way VOCAL can make you feel the most important person to have phoned today, a service offered to each and every call.
- A very accessible service when the need arises - always nice to know you are there!
- I am most impressed with every area I have encountered.
- I believe you provide an excellent service **[additional 35 similar comments]**
- I feel you are very accurate with your information. I appreciate hearing from you. You take time out to make time for people like myself and my situation.
- You provide a valuable service - much appreciated. Attending courses made me realise there are carers in a very difficult and demanding positions than my own.
- On the few occasions I have contacted your service I have been dealt with quickly, understanding, thank you
- Personally I am very happy with the service that you have given me. There has been plenty of information. Andrea I would like to thank very much for the help she had given me and support over the phone. The carer service is excellent to my mind.
- Please carry on the good work you are doing. What is important is knowing someone is at the end of the phone if you are alone when the crisis hits. Thank you for what you did for me and mine.
- Retain the same standards and level of services
- Simply being available meets all my needs at present
- Vocal put me on the right path as a carer for my husband. Even when he had to go to a Nursing Home in the last weeks, the advice you gave me helped us to find a very caring and really lovely home where he was well cared for and happy. Thank you again for your help.
- Volunteers do an excellent job - very well done. I often recommend VOCAL to other carers, I meet through Parkinson's life.
- We have only limited involvement with VOCAL services. However, our experience has been perfectly satisfactory. We have good support from our family. For which we are very grateful.
- We have found the services VOCAL provides to be invaluable and we honestly cannot think of an area with room for improvement. Thanks for your support - please keep up the good work.

Appendix 1: Example of Survey Form

Form 1: Getting your views about VOCAL's services now and in the future

Some information about you (please note this survey is completely anonymous):

Do you live in: Edinburgh Midlothian Other _____
Please select your age range: under 60 yrs 61 - 79 yrs Over 80 yrs
Is the person you support over 60 years old? Yes No

Your experience of VOCAL's carer services:

1. How did you find the response(s) that you received when you contacted VOCAL?

Excellent Good Satisfactory Unsatisfactory Can't say

Comments

2. Did the help you received make a difference to you as a carer?

Yes, please give some examples below. No

Comments Eg. Do you feel more informed? Have you more time for yourself? Has your health improved?

3. Which parts of VOCAL's service did you find most useful, and which least useful?

Most useful

Least useful

Please turn over to complete the final part of this form

VOCAL's services for the future

4. How much of the following is an issue for you and/or the person you care for?

Please tick any that apply

	Big issue	Small issue	No issue
Improving your income (eg. accessing benefits, discounts, other entitlements)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Planning financially for the future (eg. power of attorney, trust funds)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing or reducing personal debt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paying/planning for long term home or residential care (self directed support, care home fees)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

5. How much of the following is an issue for you?

Please tick any that apply

	Big issue	Small issue	No issue
Remaining in paid employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Entering (or re-entering) paid employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accessing training or volunteering to lead to paid employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

6. How important are the following support services for carers?

Please tick any that apply

	Very important	Fairly important	Not important
Emotional support and counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Booklets, newsletters, regular information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer advocacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A website for carers and support to find information online	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress management courses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Training and learning opportunities (eg. caring for someone with MS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healthy living initiatives (eg. diet, exercise, weight management)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social and leisure opportunities (eg. reading groups, gym buddies)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

7. Can you suggest any areas for improvement for our services?

Comments

Thank you for taking the time to complete this form.

Please return in the FREEPOST envelope provided (VOCAL, Freepost 3172, Edinburgh, EH1 0XG)



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HAPPY TO TRANSLATE

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