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Carer Survey

Edinburgh report 2015

A study of carers' views on the economic impact of caring, barriers to a life alongside caring, support received from VOCAL and priorities for future developments.

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Contents

Executive Summary

In Edinburgh 37,859 people support a family member, relative or friend who is elderly or has a long-term condition or disability. The value of their care has been estimated at £771 million – providing significant savings for City of Edinburgh Council and NHS Lothian.

VOCAL supports and empowers carers to ensure they are resilient, have choices, care with confidence and in good health and have a life of their own. The organisation delivers carer support through two carer centres in Edinburgh and Midlothian and through staff based in local communities.

VOCAL has a strong record of strategic planning for the future to provide high quality support and standards of service to carers and partners working with carers. Since 2011, VOCAL has commissioned a survey of carers every two years.

To strengthen support for carers now and for future generations, VOCAL actively seeks carer views and engagement to determine what support might be important to carers in the future.

VOCAL shared the findings from the 2013 survey with NHS and local authority partners to inform the development of the Edinburgh and Midlothian Carer Strategies. In response to carers' views, VOCAL increased support for carers who combine paid work and caring and now offers more support and opportunities for carers in their local communities. VOCAL also invested in a new carer centre in Midlothian and develops similar proposals for Edinburgh.

In October 2015 VOCAL launched its third and largest survey to date. Again, questions focussed on carers' experiences, the quality of VOCAL support and priorities for the future developments.

Method

Questionnaires were mailed to 6,965 carers. The survey was again advertised on the VOCAL website and promoted through carer networks; and in addition for the first time this year via social media. A total of 940 responses were received – a response rate of 13.6%, higher than for 2013 (13.2%) but still slightly lower than for 2011 (14%).

Three quarters of respondents (75%) came from Edinburgh and a fifth (20%) from Midlothian. These proportions are very similar to the 2013 survey (72% and 18%) and 2011 survey (74% and 19%)

This report focuses on the 728 responses to the survey received from Edinburgh carers.

- In 2015 there were 728 carer responses, up from 567 in 2013, a 28% increase in the response rate.
- 45% of all respondents had been in touch with VOCAL within the previous six month; 84% identified themselves as current carers, 10% as former carers and 6% as having both current and former carer status.
- The majority of respondents were female (77% vs 22%). Under half (43%) were aged under 60 years of age, over a third (38%) were aged 61 to 79 years and 8% were aged over 80 years. Older carers (61 and over) comprised a similar proportion of respondents in the 2015 survey (46%) as in 2013 (44%).
- The majority of respondents (95%) classified themselves as white and 3% as from other ethnic minority groups.
- Almost a third (31%) of those receiving care were aged 80 and over. 57% were aged over 60 compared to 51% (2013). This year the proportion of people receiving care aged 60 and under was smaller (2015, 38%; 2013, 42%).
- 75% of carers provided care for one person, 14% for two people and 3% for three people.

- Carers provided care for people with physical health problems (42%), with long term conditions (36%), dementia (36%) and less than a quarter for those with mental health problems (22%). 17% of carers provided care for someone with a learning disability.

Carer Identification

- Carers were asked who first helped them realise that they were a carer. 55% said that they realised this themselves. The GP surgery (15%), social worker or occupational therapist (10%), family and friends (12%) were also important in helping carers to recognise their role.
- 70 carers (10%) named other agencies which helped them realise that they were a carer. Of these 2% (14) specifically named VOCAL either on its own or alongside another agency. Others mentioned a wide range of individuals, organisations and agencies: care staff, local authority and NHS staff, memory clinic, third sector support groups, benefits agencies and leisure groups.
- Some 22% carers said they were referred directly to VOCAL by an individual or agency.

Economic well being

- Almost half of carers (47%) reported that caring had affected their finances. A third (36%) had had to reduce hours or give up paid employment. Altogether 27% (179) were affected in both of these ways; 56% (374) were affected in one of these ways.
- The financial issues of importance to the greatest proportion of carers were accessing benefits and allowances (58%) and planning for the future (48%).
- More than a fifth (22%) of carers commented on finance related issues including: balancing caring and employment, benefits and other entitlements, funding care, breaks from care, considering future care and legal and financial arrangements.
- Working whilst caring was a struggle and some carers had reduced hours or given up work altogether to accommodate caring. There was concern how this would affect their long-term financial position. Flexible working was important for carers in employment while others wanted support to get back into employment after caring.
- Those who were caring for adult children but also other carers expressed concern about what would happen to the person they cared for if they were not longer able to care. Some were making plans to for the future.

A life alongside caring

- Lack of time was the primary barrier to carers maintaining a life alongside their caring and was mentioned by 1 in 5 carers. Caring was all consuming and carers felt they were always ‘on call’. Any free time was circumscribed by set periods of respite.
- Specific routines and caring tasks to meet the cared for person’s needs meant the carer was tied to the house most of the time. Particular routines e.g. feeding, drug compliance and giving medication meant carers were committed to particular times of day, every day and often all day.
- Difficulties in maintaining employment whilst caring was a recurrent theme. Carers spoke of not having enough time to care and having little or no time for themselves. Work did offer a space away from caring for some.
- Some carers were caring for more than one person and sometimes across generations. This brought its own stresses and strains with often conflicting demands. Help from a supportive family helped ease the strains of caring.

- Around 1 in 6 carers said lack of support and respite care was a barrier to them having time to themselves. Some carers did not know what help was available while others spoke of the lack of available, appropriate or quality care.
- Lack of money was a barrier for some carers. Financial help from government was felt to be missing or inadequate and there were concerns regarding potential local authority cost cutting. Paying for sitters, extra carers, respite or private care was expensive.
- Guilt and worry was a primary emotion expressed by around one in ten carers.
- One in ten carers felt caring took a toll on their own physical and mental health. Some were unable to relax or lost sleep because of constant anxiety. Stress due to caring affected mental health or could exacerbate existing conditions.
- More than 1 in 10 felt their family life and social life was affected by caring. Carers could become socially isolated and lose contact with activities they used to enjoy. Activities and social contact were felt to be good for well-being.

Using technology

- In 2015, 80% had used the Internet within the previous seven days; 83% had used the Internet within the last three months, an increase from 2013 (76%).
- The proportion never using the internet had decreased to 14% (2013, 18%).
- As in the previous survey, older carers were less likely to use the Internet but over half (56%) of carers over 80 years had used the Internet compared to 33% in 2013.
- The majority (69%) of carers, and a larger proportion (83%) of those using the Internet in the last 7 days said they were confident using the Internet.
- Over a third of carers used the Internet to contact family and friends online (38%) or to get information and support (37%); 15% had saved money via the Internet.
- Non Internet users said they had no time to learn or use it, could not see how it would help or could not afford to pay for it.
- The majority of people who said they used social media were also Internet users.

Shaping services and support for the future

- Carers thought that VOCAL should develop more opportunities for breaks from caring (41%), services with a greater focus on both physical and emotional health (40%), help with practical tasks (33%). More emotional support (32%); and a carers' centre in their own local area (32%) was called for by almost a third of carers.
- Suggestions for specific support included; creative activities such as art classes, nature walks, visits to galleries etc., computer classes, opportunities for places to take teenagers with disabilities and exploring transitions.
- Other suggestions focussed on working more closely with other agencies and the development of the carer voice:
- VOCAL should encourage more active citizenship so that carers would have more involvement in shaping and planning services
- more help for carers to understand social care processes and structures, care packages and the 'politics around care'.

- VOCAL should do more to influence Edinburgh Councillors or the Scottish Parliament on the provision and cost of care.

Carers' experience of VOCAL

- In 2015 a new question discovered that carers found out about VOCAL via a very wide range of services, professionals and individuals including: NHS general practice and hospital services, community health services, family and friends, social services staff, support and voluntary sector groups, information services, school, the work place, advertising, the internet and directly from VOCAL
- As in the 2013 survey several aspects of VOCAL's response was rated very highly. An overwhelming majority of carers (94%) rated VOCAL's overall response as 'excellent' or 'good'.
- Similarly most carers rated as excellent or good the friendliness of VOCAL's response (96%), and the ease of getting in touch with VOCAL (94%).
- Carers reported that the people they came into contact with at VOCAL were approachable, supportive, encouraging, informative and listened to them. Carers also felt reassured that VOCAL was there when needed.
- Information and 'training courses and seminars' were the services that most carers found useful (73% and 40%). Other services mentioned by around a third of respondents were meeting other carers/carer support groups (34%) and help with POA/legal issues (32%).
- There were a range of very positive comments on VOCAL, its services and staff. VOCAL staff were said to be friendly, helpful and professional.
- As in 2013, the benefits of attending training courses and seminars were commented on and meeting other carers on training courses and in carer support groups was also of great benefit. Again as in 2013, some carers could not attend courses/training most commonly due to the timing of courses. For some, courses clashed with their caring responsibilities for others they worked during the day and wanted more courses in the evenings and weekends.
- Financial and legal services such as help with Power of Attorney, applying for benefits and finance/grants for short breaks were all found useful by carers.
- Two thirds of carers (66%) reported that the help they received from VOCAL made a big difference to them, the same proportion as in 2013. Another fifth of respondents (21%) said it made a small difference – an increase of 4 percentage points on the same figure in 2013. This continues the upward trend in the number of carers reporting that VOCAL's help made a difference to them (84% in 2011, 85% in 2013 and 87% in 2015).
- The comments on how VOCAL's help had made a difference covered similar topics to the two previous surveys. These included: reducing feelings of isolation; being listened to in a non-judgemental and supportive way; giving carers the confidence to cope; peer support; recognising their own needs, practical help e.g. help with Power of Attorney, completing benefit forms; information; help with respite.
- Seventeen carers (3%) said the help they received from VOCAL made no difference to them. Of these, one felt the legal service recommended by VOCAL was 'extortionate', another felt a lot of VOCAL's information related to dementia and older people, a third carer reported that the course she attended was 'not a success'. Finally there were two complaints from carers who found out too late about the benefits and support they could have had.

1. Introduction

1.1 Background

In Edinburgh and Lothian over 72,000 family carers, partners and friends support someone with a long-term condition or disability or an older person. According to the 2011 Census, 37,860 people care in Edinburgh, 8,240 in Midlothian, 9,480 in East Lothian and 16,650 in West Lothian[1].

VOCAL delivers carer support through two carers' centres in Edinburgh and Midlothian, and through staff based in the community. The organisation has a strong record of strategic planning for the future to provide the best quality standards of service to carers and partners working with carers. Since 2011, VOCAL has committed to undertaking a survey of carers every two years.

To get service provision and support for carers right now and for future generations of carers, VOCAL actively seeks carer views and engagement on VOCAL's services and what support might be important to carers in the future.

In 2011 VOCAL carried out the first survey of carers using their services. 611 carers participated in the survey – a response rate of 14%.

In response to carers' views expressed in the 2011 survey, VOCAL extended opening times, broadened the range of interventions and provided more meetings and courses held in the evening and at the weekends.

In June 2013 VOCAL invited around 5,500 unpaid family carers in Lothian to give their views on carer experiences, inviting external researchers to undertake the survey to ensure objectivity and professional research standards. 714 carers from Edinburgh and Midlothian replied to the survey – a response rate of 13.2%.

VOCAL shared the findings from this survey with NHS and local authority partners to inform the development of the Edinburgh and Midlothian Carer Strategies. In response to carer's views VOCAL increased support for carers who combine paid work and caring and now offer more support and opportunities for carers in their local areas. This survey also informed VOCAL's investment in a new Carers' Centre in Midlothian and the range of services delivered from there to carers across Midlothian.

In October 2015 VOCAL launched its third and largest survey to date. Almost 7,000 carers in Edinburgh and Midlothian were invited to participate. Again, questions focussed on carers' experiences and the quality of VOCAL services. There were also questions on future support including the role of GPs, employers, health and social care services in identifying and supporting carers.

VOCAL will use findings from the survey for its new business Plan 2016-2021 to improve their own services and to work with partners in the NHS and local councils to improve the range and quality of carer support.

1.2 Method 2015

The survey was organised by VOCAL who undertook the operational elements of the survey and data input. Two external researchers - Anne Birch and Christine Sheehy - designed the questionnaire (in partnership with VOCAL), analysed responses and wrote the final report. Both researchers brought the experience of conducting and analysing the 2013 survey to this process.

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[1] Scotland's Carers www.gov.scot/Publications/2015/03/1081/downloads

In early October 2015 a personal letter and invitation from VOCAL'S Vice Convenor of the Board of Directors was issued to all active carers on VOCAL's contact list to participate in the survey. Carers were asked to complete a short questionnaire and return it to VOCAL using a FREEPOST reply envelope.

In addition the survey was also published on VOCAL's website (as in 2013) and also promoted via social media (new in 2015).

In addition the survey was widely advertised through Edinburgh and Midlothian's network of carer support agencies.

A reminder email was issued to all carers a month later and the survey was advertised again via the VOCAL newsletter, e-bulletin and social media. The survey was also made available to carers attending groups and training events during the survey consultation period.

Respondents were given four weeks (by 6 November) to return the completed questionnaire but as last time VOCAL extended the period for inclusion of returned questionnaires to include as many responses as possible in analysis.

A prize draw was offered to encourage participation in the survey. Respondents were invited to provide contact details to enter the draw but could return completed questionnaires anonymously if preferred.

All data from the completed questionnaires was entered into an Excel spreadsheet. All comments were read and coded according to a coding frame developed for each question which invited comments. Respondents' comments were selected to present the full range of respondents' views and to further illustrate the findings of the study.

1.3 Response

A total of 6,965 survey packs were issued based upon addresses on the VOCAL carer contact list. Table 1-1 shows the response to the survey and comparison with the 2013 response.

Table 1-1 Response rate

	2015				2013
	Edinburgh	**Midlothian**		**Total**	**Total**
Mailed	5481	1484		6965	5498
Returned undelivered				74	78
Survey packs delivered				6891	5420
	Edinburgh	**Midlothian**	**Letter only**		
Replies	753	182	5	940	714
Response rate				*13.6%*	*13.2%*
Not included in counts	25	2	5	32	22
Total responses considered in this report	**728**	**180**		**908**	**692**

Reasons for not including returns in the numerical analysis are:

Questionnaire not completed – person cared for deceased	9
Ceased to be a carer – individual now in residential care or other reason	5
Blank questionnaire	12
Marked ‘not a carer’	1
Arrived too late	5

The response rate of 13.6% is comparable to previous surveys – slightly higher than for 2013 (13.2%), slightly lower than for 2011 (14%).

Completion of the questionnaire varied across the survey. Carers did not always fill in all parts, perhaps reflecting their situation, the level of interest or familiarity with particular topics.

85% (772) individuals opted to provide contact details to enable them to take part in the prize draw, 15% (136) made use of the option to reply anonymously.

1.4 A new approach to reporting findings in 2015

The 2011 and 2013 survey reports included all returns in one survey report, not seeking to report separately on findings from Edinburgh and Midlothian carers.

In 2015 VOCAL decided to produce two separate reports – focusing on carers using the Edinburgh and Midlothian Carers Centre and services respectively. Although this limits the possibilities for making comparisons with previous years it offers the opportunity for greater focus on carers’ experiences and views at a local level.

The VOCAL Edinburgh report will focus on the 728 Edinburgh centre replies. Limited comparisons to previous years for the Edinburgh centre will be made where possible. (Where comparisons with the 2013 survey are made the data used are Edinburgh plus East and West Lothian and ‘other’ areas. For ease of reference these areas are referred to simply as Edinburgh in the report).

The separate VOCAL Midlothian report will focus on the 180 Midlothian replies and comparisons will be available against the 2013 Midlothian only report.

Table 1-2 shows where carers completing the survey are resident. Additional detail on the full dataset of Edinburgh and Midlothian responses across the three survey years can be found in the Edinburgh report appendices.

1.4.1 Where carers live

Table 1-2 shows that the majority of all respondents (75%) came from Edinburgh. The number of Midlothian carers replying to the survey has grown again and now represents one fifth (20%) of returns. Similar numbers of carers replied from East and West Lothian.

In 2015 just two returns were from carers outside these areas (Scottish Borders) and they completed the VOCAL Edinburgh questionnaire. In 2013 the ‘other’ category had included carers who lived further afield (Borders, Falkirk, Fife (Dunfermline, Letham, Cupar), Glasgow, Dunoon, Banchory and Kirkwall), but cared for people in the Lothians.

The new method of adding postcodes to questionnaires has improved identification by carer location.

Table 1-2 Carer local authority area

	2011		2013		2015	
	No.	**%**	**No.**	**%**	**No.**	**%**
Edinburgh	449	*74*	495	*72*	682	*75*
Midlothian	119	*19*	*125*	*18*	*180*	*20*
East Lothian	36	*6*	*19*	*3*	*20*	*2*
West Lothian			*17*	*2*	*22*	*2*
Other			*12*	*2*	2	*0*
No data	8	*1*	*24*	*3*	*2**	*0*
TOTAL	**612**	*100*	**692**	*100*	**908**	*100*

*Postcode not printed on questionnaire

1.5 Profile of respondents and those they care for

This section presents the characteristics of those carers who responded to the survey.

The majority of respondents identified themselves as current carers (611, 84%), one in ten as former carers only (73, 10%) and a minority as both a former and current carer (44, 6%). This pattern is very similar to 2013. Three respondents, who identified themselves more as Power of Attorney or only concerned with finding out about this, were included as current carers as they answered a range of questions.

Table 1-3 Carer status

Carer status	2013		2015	
	Edinburgh		**Edinburgh**	
	No.	**%**	**No.**	**%**
Current carer	487	*86*	611	*84*
Former carer	46	*8*	*73*	*10*
Both	34	*6*	*44*	*6*
TOTAL	**567**	*100*	**728**	*100*

1.5.1 Age and gender of carers

43% (310) of Edinburgh carers responding to the survey in 2015 were aged between 20 and 60 years. Older carers (61years and over) comprised a similar proportion to 2013 (46% vs 44%). The proportion not giving their age was larger (12%) than in the previous survey (10%).

Table 1-4 Carer age group

Carer age group	2013		2015	
	Edinburgh		Edinburgh	
	No.	%	No.	%
20-60 years	263	*46*	310	*43*
61 to 79 years	206	*36*	274	*38*
80 and over	44	*8*	58	*8*
Age not given	54	*10*	86	*12*
TOTAL	**567**	*100*	**728**	*100*

As in 2013, female carers responding to the survey in 2015 outnumbered male carers 4:1 (Table 1-5).

Table 1-5 Carer gender

Carer gender	2013		2015	
	Edinburgh		Edinburgh	
	No.	%	No.	%
Male	114	*20*	161	*22*
Female	444	*78*	562	*77*
Transgender/ticked both	1	*0*	0	*0*
Gender not given	8	*1*	5	*1*
TOTAL	**567**	*100*	**728**	*100*

Edinburgh female carers tended to be younger than male carers; 46% female carers were aged 20 - 60 years compared to under a third (32%) of male carers (Table 1-6). A higher proportion of male carers were in the oldest age group compared to females (19% vs 5%).

Table 1-6 Edinburgh Carers gender by carer age group 2015

Carer age group	Male		Female		Not given		TOTAL	
	No.	%	No.	%	No.	%	No.	%
20-60 years	51	*32*	258	*46*	1	*20*	310	*43*
61 to 79 years	50	*31*	224	*40*	-	*0*	274	*38*
80 and over	31	*19*	26	*5*	1	*20*	58	*8*
Age not given	29	*18*	54	*10*	3	*60*	86	*12*
TOTAL	**161**	**100**	**562**	**100**	**5**	**100**	**728**	**100**

1.5.2 Ethnicity of carers

The overwhelming majority of respondents (95%) to the survey classified themselves as white although there were a small number of respondents in each of the other ethnic categories (3%)[2] (Table 1-7).

Table 1-7 Carer ethnic group

	Edinburgh	
	No.	%
White	689	*95*
Asian, Asian Scottish, Asian British	15	*2*
Caribbean or Black	2	*0*
Mixed or multiple ethnic group	4	*1*
African	3	*0*
Arab	2	*0*
Other ethnic group	1	*0*
Not given	12	*2*
TOTAL	**728**	*100*

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[2] The 2011 census shows 4% of people in Scotland classify themselves as from minority ethnic groups - an increase of two percentage points on the 2001 census. In the City of Edinburgh 8% of the population classify themselves as from a minority ethnic group, Source: 2011 Census. http://www.scotlandscensus.gov.uk/en/news/articles/release2a.html accessed 16/01/2016

1.5.3 Edinburgh carers by sector

The locality of Edinburgh residents is shown by city sector in Table 1-8. Further analysis of the response by sector can be found in the appendices.

Table 1-8 Response by sector of residence (Edinburgh)

Sector	No.	%
East	127	*19*
North West	208	*30*
South Central	172	*25*
South West	175	*26*
TOTAL	**682**	

1.5.4 Age of people receiving care

Table 1-9 shows the number of people receiving care in each age group.

In 2015 almost a third (31%) of all persons cared for were in the 80 and over age group slightly more than in 2013 (29%). 57% were over 60 compared to 51% (2013). There has been a 4 percentage point increase in those cared for aged 61-79 years from 22% (126) in 2013 to 26% (189) in 2015.

In 2015, the proportion of people receiving care aged 60 and under was smaller than in 2013 (38% vs 42%).

Table 1-9 Age group of person receiving care

Cared for age group	2013		2015	
	Edinburgh		Edinburgh	
	No.	%	No.	%
Up to 17 years	58	*10*	75	*10*
18-25 years	38	*7*	47	*6*
26-54 years	113	*20*	128	*18*
55-60 years	28	*5*	26	*4*
61-79 years	126	*22*	189	*26*
80 and over	167	*29*	227	*31*
Age not given	37	*7*	36	*5*
TOTAL	**567**	*100*	**728**	*100*

Of carers aged 80 and over, 71% (41) were caring for someone aged 80 and over (Table 1-10).

Of carers aged 20-60 years, 55% cared for people aged 60 years and under. 41% cared for people aged 61 and over a quarter (25%) looked after people aged 80 years and over.

Table 1-10 Age of person receiving care by age group of carer

Age group of person receiving care	20-60 years		61 to 79 years		80 and over		Age not given		TOTAL	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Up to 17 years	66	*21*	3	*1*	-	*0*	6	*7*	75	*10*
18-25 years	35	*11*	7	*3*	-	*0*	5	*6*	47	*6*
26-54 years	53	*17*	56	*20*	4	*7*	15	*17*	128	*18*
55-60 years	20	*6*	2	*1*	1	*2*	3	*3*	26	*4*
61-79 years	51	*16*	112	*41*	6	*10*	20	*23*	189	*26*
80 and over	79	*25*	80	*29*	41	*71*	27	*31*	227	*31*
Age not given	6	*2*	14	*5*	6	*10*	10	*12*	36	*5*
TOTAL	**310**	***100***	**274**	***100***	**58**	***100***	**86**	***100***	**728**	***100***

1.5.5 Number of people receiving care

Carers mostly cared for between one to three people. A number of people noted other additional caring roles within the immediate or extended family or with neighbours. Some cared for both of their older parents alongside caring for a partner or child. Some managed their own or another's children alongside their own caring responsibilities.

> *I also support my other daughter with babysitting my two grandchildren.*
>
> *Dad (plus 2 children).*
>
> *All the time one [age 51], half week, 2 others [age 82 and 86].*
>
> *Main carer for my son, but also help my brother who has Asperger's + used to help care for my mum.*
>
> *[one aged 20] 24/7 (and 86 from a distance).*

We asked carers to identify the condition/disability experienced by the person they provided care for (Table 1-12). For all carers, 42% identified caring for people with physical health problems, 36% with long term conditions, 36% with dementia and 22% with mental health problems. Less than a fifth (17%) cared for someone with a learning disability.

Amongst current carers, 12% cared for a child with additional needs. Conditions mentioned in the 'other category' included '*autism spectrum disorder*', '*multiple conditions*', '*Parkinsons*' or were problems related to ageing of the cared for individual.

Twenty-seven carers (4%) chose not to specify the care grouping to which the individual(s) receiving care belonged. The majority ticked one or two conditions, and less than a sixth (14%) ticked three or more conditions as occurring within the individual(s) they cared for.

1-11 Number of individuals cared for

Number of cared for	Carer	Former carer	Carer & Former Carer	Total	%
1	493	23	32	548	*75*
2	87	3	10	100	*14*
3	23	-	-	23	*3*
4-6	4	-	-	4	*1*
None	1	28	2	31	*4*
No data	3	19	-	22	*3*
TOTAL	**611**	**73**	**44**	**728**	**100**

Table 1-12 Number of carers by condition/disability of person receiving care

Condition	Carer	Former carer	Carer & Former Carer	TOTAL	%
Physical health problem	265	22	19	306	*42*
Dementia	217	25	23	265	*36*
Long term condition	229	17	16	262	*36*
Mental health problem	132	15	14	161	*22*
Learning disability	116	1	8	125	*17*
Child with additional needs	72	1	2	75	*10*
Other	35	6	2	43	*6*
Drug or alcohol problem	29	5	7	41	*6*
TOTAL	**611**	**73**	**44**	**728**	***100***

1.6 Equalities

The Equality Act 2010 promotes equal opportunities for specified groups including: age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

We asked carers to comment on whether they had any equalities issues relating to their caring role. Thirty six respondents (5%) chose to comment in this section.

General comments concerned disability, particularly mental health.

> *People who have mental illness are discriminated against and abandoned (e.g. ESA assessment process).*
>
> *Disability (mental health problems).*
>
> *Me - no. My husband yes - disability - sensory impairment.*
>
> *Ignorance of mental health issues shown by various agencies .*
>
> *Where is the constructive help for sick disabled? There is no equality for sick and disabled in Scotland. How much money do you think I've saved the government in 33 yrs. of caring??*

Several carers noted that they themselves had a disability.

> *I am a disabled person within the meaning of Section 1 of the Disability Discrimination Act 1995*
>
> *I am disabled myself but could manage my caring roles ok, although more advice would have been nice.*
>
> *I have severe depression which classifies me as disabled.*
>
> *My MS is a major issue for me as a carer*

There were comments related to age (and carer disability).

> *Perhaps age!!*
>
> *I have been ambulant disabled since childhood but worked till retiring age. I would like to see an increase in attendance allowance to help people who elderly also disabled.*

There were five comments concerning the assumption that caring was automatically more a female than male role. These women felt taken for granted both within the family and by the state. One male voice felt his caring ability was not appreciated by the professional sector.

> *Yes- the assumption seems to be that being female and the wife that you are automatically the best person to be caring for the vulnerable person. Not so in my case. I would have been much better out in the work place with husband in professional care.*
>
> *Lack for regard and consultation shown by supported accommodation organisation for role of family in caring. Expectation that daughters fill in gaps.*
>
> *Gender. That I the daughter, carry all the responsibility. My brother doesn't even Facebook or ask how mum or I are.*
>
> *As a daughter the caring role falls to me alone. Two brothers take no responsibility re. my mother's failing health, yet they are appreciated more by her and will have equal share in any inheritance. It does not seem fair!*
>
> *As a male carer it is assumed I am somehow less well equipped to look after my mother than a female. I have heard so often people in the sector telling me I should put my mum into a care home where she would be miserable. Due to my gender and own health issues!*

A lesbian couple felt their marital status was not recognised.

> *We are a lesbian couple and sometimes find it difficult as people assume we are friends or sisters rather than a married couple.*

There were three comments in relation to race.

> *Yes. Disability and race. Some professionals are very disrespectful!*
>
> *My [cared for person] is mixed race + has autism.*
>
> *Person I look after is racially prejudiced - was common for her generation.*

As with the last survey, although not a protected characteristic, these carers felt they faced inequalities in relation to employment.

> *Equality issues I experienced at work related mainly to a lack (or apparent lack) of a carers policy and support managed through a policy – e.g. missed training, etc.*
>
> *I have had difficulty increasing my hours at work because people are aware that I have commitments outside work.*
>
> *Yes – penalised financially as a family member. Have had to make choices re work + not getting required support even though working + keeping others in work i.e. Direct Payments processing! + managing 6 staff.*

1.7 Contact with VOCAL

We asked carers when they had last used any VOCAL services (other than receiving the magazine Carer News). More carers (45%, 324) had used VOCAL in the last six months than in 2013 (42%, 288) (Table 1-13). Just under a third, (32%, 231), had used VOCAL more than a year ago (a similar figure to 2013). 2% (16), of carers said they had never used any VOCAL services (they did, however, opt to receive Carers News for information).

As might be expected, the pattern for those who were former carers was different to carers. Only 22% of former carers had been in touch with VOCAL in the last six months.

Table 1-13 When did you last use VOCAL services? 2015

	Carer		Former carer		Carer & Former Carer		TOTAL	
	No..	%	No..	%	No..	%	No..	%
Within the last 6 months	289	*47*	16	*22*	19	*43*	324	*45*
7-12 months ago	109	*18*	13	*18*	3	*7*	125	*17*
More than a year ago	170	*28*	41	*56*	20	*45*	231	*32*
Never	15	*2*	0	*0*	1	*2*	16	*2*
No data	28	*5*	3	*4*	1	*2*	32	*4*
TOTAL	**611**	***100***	**73**	***100***	**44**	***100***	**728**	***100***

2 Carer Identification

2.1 Who helped you to realise that you are a carer

We asked carers “Who first helped you to realise that you are a carer?” All but five respondents answered this question. Although we asked people to pick just one option many chose to tick two or more. Figure 2-1 below therefore presents data for all options chosen.

Figure 2-1 Who first helped you to realise that you are a carer?

Over half of carers (55%) said that they realised themselves that they were a carer. The GP surgery (15%), social worker or occupational therapist (10%) were also important in helping carers to recognise their role. Family and friends (12%) were important too.

Seventy carers (10%) carers named other agencies which helped them to realise that they were a carer. Of these, 2% (14), specifically named VOCAL either on its own or alongside another agency.

> *A worker from VOCAL came to my work to talk about the services VOCAL provides, and I realised I was a carer.*
>
> *VOCAL - during a course I was on people helped me realise.*
>
> *VOCAL as I didn’t consider myself a carer. I was just doing what most grannies would do.*
>
> *Realised when seeking advice from VOCAL, advocacy + social work.*
>
> *GP & VOCAL!*
>
> *With help and guidance from GP and various agencies (VOCAL, Eric Liddell Centre, etc).*

Other individuals, organisations and agencies specifically mentioned included:

Care staff	Home carer Carers
Local authority	Social work department CHAI advice from Council
NHS/Memory clinic	Memory Loss Clinic Leith Memory Hospital March Hall
NHS staff	Mental health nurse Community educational psychologist CPN
Support groups	PASDA, Alzheimer Link office, Support in Mind. The Action Group Norton Park. Chest, Heart and Stroke Scotland Turning point Into Work
Information	Radio programme Leaflets in a shop window
Benefits	Benefits agency

2.2 Direct referrals to VOCAL

Carers were asked if any of the people or organisations detailed in the previous question made a direct referral to VOCAL on the carers' behalf. 95% (695) carers answered this question.

Table 2-1 Direct referrals to VOCAL

Referred to VOCAL	No.	%
Yes	153	*22*
No	460	*66*
Don't know	82	*12*
TOTAL	**695**	***100***

Two thirds (66%) of those carers responding to this question reported that they were not directly referred to VOCAL. Just over a fifth were referred (22%).

Table 2-2 shows which organisations were most likely to refer individuals they helped identify as carers onto VOCAL. Social Care Direct were most likely to do this followed by a social worker or occupational therapist. However, these findings must be treated with caution due to the small numbers in some of the categories.

Table 2-2 Referrals to VOCAL

	Yes	No	Don't know	Not answered	TOTAL	% referred
Someone at Social Care Direct	7	1	6	1	**15**	*47*
Social worker or Occupational Therapist	30	33	9	1	**73**	*41*
Organisation supporting the person you care for	17	26	9	0	**52**	*33*
Family member or friend	26	53	10	1	**90**	*29*
Someone at your GP surgery	31	62	14	3	**110**	*28*
Someone at the hospital	9	26	6	1	**42**	*21*
Someone from another organisation	13	46	8	3	**70**	*19*
I realised myself	71	265	41	23	**400**	*18*
Someone at work	1	8	1	0	**10**	*10*

A follow up question went on to ask how long people had been caring at the point they were directly referred to VOCAL. 90% of carers (655) responded to this question although only 153 carers said they had been directly referred. Clearly, the majority of respondents to the follow up question read the question as “how long have you been caring?”

However, if the responses to this question from the 153 carers who said they had been directly referred are considered, it is clear that the point of referral bore little relation to length of time caring. Referrals took place at all stages of caring (Table 2-3).

This finding must be treated with caution, as it is not clear whether these respondents provided information on the length of time they had been caring overall as most respondents did or on the length of time they had been caring at the point of referral.

Table 2-3 Length of time caring at point of referral

Length of time caring	No.	%
Less than 2 years	51	*33*
Caring for 2-5 years	48	*32*
Caring more than 5 years	48	*32*
Don’t know	5	*3*
TOTAL*	**152**	***100***

* 1 respondent did not give length of time

2.3 Employment

Carers were asked whether they were in paid employment, studying, both in employment and studying or neither. 98% (714) carers answered this question.

Of those, 27% were either in employment or studying (Table 2.4). Ten carers said they were self-employed.

Table 2-4 Employment/studying status of carer

Employment/studying status	No.	%
In paid employment	182	*25*
Studying	7	*1*
In employment and studying	7	*1*
Neither	518*	*73*
TOTAL*	**714**	***100***

* Includes 10 carers who were self-employed

Those who responded that they were employed and/or studying were asked whether a list of statements relating to their employment/study and caring were important to them. As the number of those studying, or studying and in employment, were so low the figures for all those in employment and/or studying are considered together.

Table 2-5 Statements important to carers in employment and/or studying

	No.	%
Asks me about my caring responsibilities	90	*46*
Has someone I can speak to in confidence about my caring role	64	*33*
Has a carers policy	65	*33*
Helps me to access information and support related to my caring role	30	*15*
Links me into local carer support	20	*10*
Has a carer support group	16	*8*
TOTAL*	**196**	

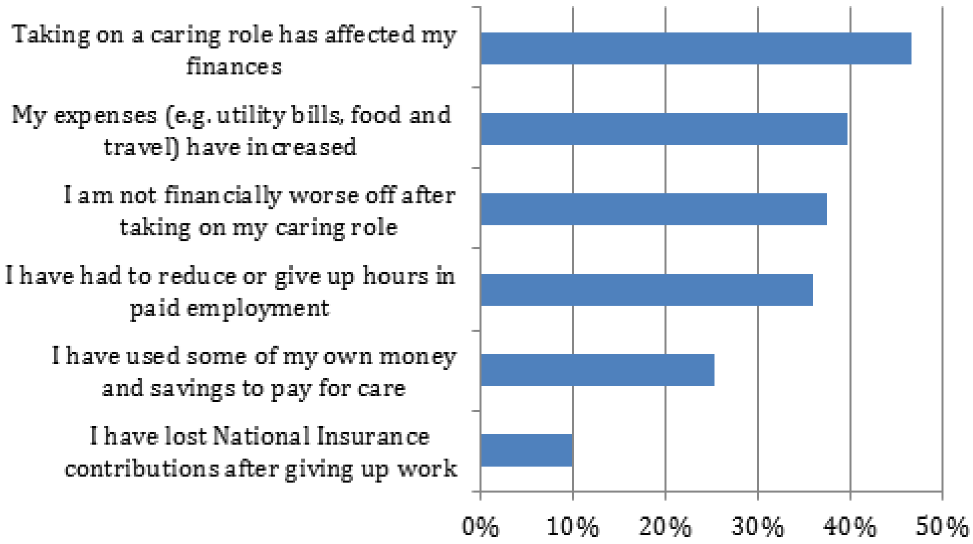
Almost half (46%) of those carers in employment and/or studying reported that it was important that their employer/college asked them about their caring responsibilities. A third of carers said that their employer/college had a carer's policy and the same proportion that there was someone they could speak to in confidence about their caring role. Other support in terms of information, links to local carer support and provision of a carer support group were important to fewer carers.

3 Economic well-being

This section of the survey asked about how caring has affected the carers' financial position and then went on to explore which issues relating to finance were important to respondents. These questions are different from those in the financial well-being section of the previous survey which focused more on financial planning and so direct comparisons are not possible.

The first question in this section asked carers to select which statements relating to their financial position applied to them (Figure 3-1). Carers could select more than one option.

Figure 3 1 Statements relating to carer's financial position since taking up caring



A total of 668 carers (92%) responded to this question on their financial position since taking up caring.

Almost half of carers (47%) who responded to this question considered that their caring role had affected their finances. Approximately a third (36%) said that they had had to reduce or give up hours in paid employment. Altogether 27% (179) were affected in both these ways; 56% (374) were affected in one of these ways.

In contrast, over a third (38%) reported that they were not financially worse off as a result of their caring. A quarter of carers (25%) who responded had used some of their own money and savings to pay for care.

3.1 Financial issues important to carers

Carers were asked to select from a list the financial issues which were important to them. There was also an opportunity to report other financial issues, outwith the list, that were important to them. 91% (655) of carers responded to this question.

Table 3-1 Financial issues important to carers

	No.	%
Accessing benefits and allowances	382	*58*
Planning for the future (Power of attorney, wills)	314	*48*
Reducing energy and utility bills	270	*41*
Funding to pay for breaks from caring	225	*34*
Remaining in paid employment	146	*22*
Flexible working arrangements	138	*21*
Managing debt	83	*13*
Reducing number of hours at work	63	*10*
	655	

Figure 3-2 Financial issues important to carers

Accessing benefits and allowances was the issue most important to the greatest proportion of carers (58%) and planning for the future (e.g. Power of Attorney, Wills etc.) was important to just under half (48%) of carers (Fig 3-2).

We asked carers to identify other issues that were important to them. More than a fifth, (22%, 147) provided additional comments. The issues highlighted related to balancing caring and employment, benefits and other entitlements, funding care, breaks from care, considering future care and legal and financial arrangements.

Recognition of their caring role was important to some carers and not necessarily recognition in financial terms:

> *Being recognised financially for the support I give unpaid.*
>
> *Finding a way to get 'tangible' acknowledgement/ reward for the extensive caring, over and apart from a Carers Allowance.*

Two carers appeared to want to maintain a more independent position regarding their caring.

> *I sort things myself - so no need of VOCAL. The above are N/A.*
>
> *Maintaining care within family, and access to all services, social and medical.*

One carer was of the view, expressed many across different sections of this survey, that knowing VOCAL was there was a source of reassurance to them.

> *Again just knowing VOCAL's support is also there for the future of our economic well-being to help us with any problems yet to arise is priceless.*

An important issue for some was ensuring the cared for person was as happy, secure and comfortable as they could be. This meant not only providing the basics but also some extras to improve the quality of life for both carer and cared for.

> *Keeping me and my mother (person I care for) as well, positive and happy as possible.*
>
> *Being able to provide the little luxuries in life, to improve the standard of life for my brother - he only has me.*
>
> *Budgeting. Being able to have a healthy diet also enough to access entertainment occasionally.*

Help with more practical issues was needed for example, making modifications in the home to allow the cared for person to live at home and making daily life easier for the carer and cared for person.

> *Just help with things that would make life more easier on a daily basis.*
>
> *Getting help to make our home safe for my wife, i.e. hand rails, walk in shower/wet room.*
>
> *Getting help with cleaning and gardening as I don't have much spare time for these things.*

3.1.1 Combining paid employment with caring responsibilities

Employment issues highlighted included having to reduce working hours to accommodate caring responsibilities or having to give up work entirely. In contrast another carer reported that they had to increase their working hours to cover the increased expenses due to caring.

> *I had to give up paid work. I could no longer juggle both.*
>
> *Having had to give up work because of additional caring responsibilities (at a distance) I feel strongly that help to support carers continuing in education and employment is not only essential for the well-being of them and their families, their future and Scotland's economic development.*
>
> *Increasing my working hours in order to meet the financial commitments.*

In one case a carer had to reduce their working hours in order to receive Carers' Allowance although this did not affect their financial position overall.

> *Being self-employed I have had to cut my working hours in order to receive Carers' Allowance, but overall not worse off.*

Carers who were in work were finding this a struggle and some recognised that flexibility at work was important in helping carers both to stay in work and manage their caring responsibilities. However, in one case although flexibility had helped one carer stay in work the strain of their caring had become too much for them.

> *Because I'm 47 (was 45 when I got on board with VOCAL) I worry about staying in the game as a worker. Difficulty for me in particular was that I worked in caring/ therapy – incredibly hard to keep doing at work when one is also doing this at home! Burnout...*
>
> *More important to have flexibility at work as time goes on. Take half day then make up time.*
>
> *Until 2 weeks ago I had been employed for 36 years. I gave up work as I could no longer cope with work and caring for my son as he got older (and I older as well!). Flexible working arrangements were hugely important to me for 12 years – sadly I could no longer keep working even with a degree of flexibility.*

Some carers were looking for work or study opportunities and a few were trying to develop a business to fit with their caring responsibilities.

> *Would like to study, or get back to work.*
>
> *I would have liked to develop my holiday letting/ Airbnb business but have not been able to as being a full-time carer used up all my energies.*

At the end of their caring role a carer may find themselves in the position of looking for paid employment.

> *I am now actively looking for paid employment in order to pay my bills and debt, plus affording to feed and clothe myself for the moment I am not only a widow and penniless, but soon homeless if I cannot find paid work soon.*

For one carer it was important that her son whom she cared for could find employment so that he could lead and independent life in the future.

The longer term impact of reducing working hours or giving up work altogether, was a concern for some carers. They worried about how this would affect national insurance contributions and pensions and therefore their long term financial position.

> *Planning for my future: reducing hours has affected my pension; unable to save due to money being swallowed up in care costs.*
>
> *It is important to me to try and find employment (part-time) and try to sort out NI contributions (lost 2 years contributions to date) - this is proving difficult.*

In contrast, in the view of one carer, questions about employment were irrelevant as their caring was a full-time occupation:

> *Question 12, 13 are irrelevant. I know my husband and children rely on me only. Why are you obsessed with work? Caring is 24hr day job.*

3.1.2 Benefits and other entitlements

Carers raised a number of issues around benefits. For some it was important that they knew what benefits were available and what they were entitled to. Others were concerned with the length of time it took to get benefits and the effect on other members of the family covering costs until the benefits were sorted out.

> *Being told about benefits you are entitled to and how to apply for same!!*
>
> *We have Attendance Allowance - don't know if anything else applies as we are both retired.*

> *Benefits and allowances all take so long to get processed. Also don't like that the Attendance Allowance provided can't be used if I or family members want to use it to take mum out. Only if we can get support worker but can't find one due to language barrier.*
>
> *My main problem was that it took almost 9 months to sort out my daughters correct benefits. In the meantime I had to top up her rent/ food + living cost from my own earnings.*

An important issue to one carer was the benefits lost to the family when a child turned 18 and lost benefits:

> *I have been trying to raise the issue of our household losing £2000 a year since my daughter turned 20 (3 years ago) and I lost the component part of income support for having a child with additional needs and child benefit.*

3.1.3 Paying for care

Paying care home fees and other aspects of care was a concern for several carers along with finding good quality and appropriate care:

> *I am concerned about funding my mother's nursing home if her house does not sell quickly.*
>
> *I am not sure if I can afford long-term care.*
>
> *Help towards paying the monthly home help bill to the Council.*
>
> *Finding additional support for my autistic daughter from a service provider with the appropriate knowledge and understanding of her requirements.*
>
> *Difficulty obtaining suitable care for hours required. Agencies seem to take a long time to recruit appropriate person, as different people every day is unsuitable.*

Lobbying for excellent care services to be provided at affordable prices was important to one carer.

Paying for therapies and diagnosis was a concern for some:

> *Funding to pay for our child's therapies.*
>
> *Less waiting times on services (CAHMS currently 40 weeks), less having to fight for everything. Had to pay for additional testing on my autistic son. He was diagnosed dyslexic – Council no longer do testing, but not all autistic kids are dyslexic.*

3.1.4 Short breaks and respite

Several carers raised the importance of receiving regular breaks and short-term respite. Some carers wanted help with funding such breaks others wanted information on breaks.

> *Paying for a befriender to take my husband out and keep him company while I do some shopping.*
>
> *Finding ways to get cheap weeks not far away as too tired to plan breaks.*
>
> *Would like to access additional support for breaks or sitter. Information on breaks.*
>
> *Help when I have to work by my child is unwell or is having a hard time coping at school*

Concerns were also expressed regarding reduction or withdrawal funding for clubs attended by people being cared for and thus providing respite for carers and clubs for carers themselves.

3.1.5 Balancing caring and carer's health

A handful of carers were aware of the importance of maintaining their own health both physical and mental to enable them to continue caring and to ensure they had a life of their own.

> *At present maintaining a balance of caring and looking out for my mother (who is residing in a residential home) and looking after myself.*
>
> *Balancing a caring role (for husband) while maintaining own independence. Not losing sight of myself.*
>
> *Time for myself, without work and caring responsibilities.*

Some also wanted to be able to share or reduce their caring role, to have more time for themselves or other members of the family e.g. to support son and daughter in law with a premature baby.

> *Help to reduce, or make easier my caring role for the sake of my own health.*
>
> *Having someone to share burden.*

Some carers, particularly those looking after younger children wanted more help with childcare.

3.1.6 Planning for the future

Those caring for adult children but also others looking after other adults expressed concerns about what would happen to the person they cared for if they were no longer able to carry out this role. Some had already made or were planning arrangements for such an eventuality:

> *Who would take care of my son if something were to happen to me?*
>
> *Setting up emergency plans in the event of my inability to meet my cared for person's needs.*
>
> *Will be using legal surgery again soon because I was diagnosed myself with MS and would like to have a will so I can leave things for my son.*

Some carers felt that they were in a good position as they were retired with good pensions and with wills and POA in place and so had no worries about finances. However one did recognise that they this was partly due to not needing 'outside care'.

> *I am retired with a good pension. I have no financial difficulties.*
>
> *None above, we are well off with good pensions. Power of Attorney and wills completed.*

4 A life alongside caring

We asked carers “What are the barriers to having time to yourself and a life alongside your caring? 81% (590) respondents answered this question.

The primary barrier mentioned by around one in five carers was lack of time; due to the ‘*always on call*‘ nature of caring and the particular and unpredictable nature of caring.

4.1 Lack of time

The all-consuming nature of caring meant carers had little time to themselves inside or outside the home. Organising and providing care to ensure the individual was comfortable could involve being available twenty-four hours a day, seven days per week; and running one or more households. Many carers said quite simply ‘*lack of time*’; ‘*I’m always on call*’.

> *Impossible. It’s an hour to hour, day in day out.*
>
> *There is always something needing to be done - prepare food and make ready meal, chase up doctors and medication, write down ‘what is in my head’ for his care.*
>
> *So much time caring that spare time is spent catching up on day to day issues/ bills + chasing up stuff for daughter - therapy/ hospital etc.*

For some caring meant loss of time to themselves in the house and loss of privacy; it was necessary to leave the house to get time for themselves.

> *I have not time to myself at all - no privacy - I am a 24/7 carer.*
>
> *I need to leave the house to get time for myself - as my husband is at home all the time, and very dependent on me (emotionally as well as practically).*

Any free time or opportunity to go out was limited to a few hours or circumscribed by set periods of respite. Carers spoke of not being able to be away at mealtimes, for more than a few hours, not a full day, not evenings, not overnight. Any time available might not fit with the kinds of activities that carers might like to do themselves.

> *I live with my sister, for whom I am carer. I can go out for a few hours, but do not feel I can leave her overnight.*
>
> *My wife goes to Monday Club (Portobello) for three and a half hours with lunch, this give me time to myself.*
>
> *Main barrier is preparing meals. VOCAL courses tend to overlap meal times for instance.*

When the cared for person could no longer be supported at home and was admitted to residential or supported care the carer still continued to spend a lot of time travelling to visit or trying to organise something better.

> *My husband is now in a care home and I feel I cannot go on holiday and not go in every day to see him.*
>
> *Despite my son living in supported accommodation and having a good number of hours support, I have seen him last Thursday, Sunday, Monday, Wednesday, Thursday and tomorrow!*
>
> *I have put my son in residential home that promised everything and have given nothing. I am spending all my time trying to get something better than a zoo!*

4.2 The particular and unpredictable nature of caring

Specific routines and caring tasks to meet the cared for person's particular needs could mean the carer was tied to the house most of the time. Carers could find themselves committed to particular times of day, or all day every day (e.g. for feeding, drug compliance checking, to give medications at a particular time).

> *The person I care for requires TOTAL care including feeding/drinks so cannot be left for more than a couple of hours.*
>
> *Only my husband and I are able to change our son's cannula, and if it's pulled out it needs replaces immediately. Family have refused to train so a lack of people to take on his medical needs prevent us from anytime away longer than an hour or so.*
>
> *With my wife's condition being progressive MS I find that I cannot leave the house for more than an hour and a half at a time. [She] is in a lot of pain at the moment through wheelchair sore on her left side buttock. I have to keep raising and lowering the bed and putting [her] on her side to relieve the pain. [She is on morphine related drugs]*
>
> *I work at caring 24/7 - for my wife + don't have any time. Apart from getting a nap for an hour or so in the afternoon.*

Carer time could be determined by routines for attending day-care and hospital etc.

> *Being on a strict timetable Monday - Friday, putting daughter on her bus to centre each morning, I have to leave home in time for her coming home again.*
>
> *Coordinating respite for the two people I care for (different respites). The time slot 1-2 hours not great as by the time you drop off the cared for, get home or do a bit of shopping, it's time to pick up!*
>
> *I do get a bit of time to myself on a Tuesday, he goes to Headway in [location] until 3 o clock. On a Thursday he goes to a stroke club for 2 hours in the afternoon.*

Where individuals were psychologically dependent upon the carer they refused to be cared for by anyone else. This was a particular difficulty where the individual had dementia and/or their care needs were escalating. Some carers could feel under tremendous emotional pressure to be there all the time. There was a sense that the individual was reluctant for them to be out even for a very short time and would be 'clock watching' until the carer came back.

> *Due to the change of number of circumstances my son is so attached to me that he wanted to stay with me all the time in home, which is limiting all of time for myself.*
>
> *My wife's persistence on shadowing me everywhere I go and her adamant refusal to allow someone to come in and sit or stay with her.*
>
> *As mum's health deteriorates I have no time for myself – everything is centred around mum's needs – she is unable to be left alone at any point.*
>
> *I cannot leave the person I care for now as their health is deteriorating more and I am required constantly, even at night have to get up 3-4 times. It is difficult to be on call 24 hours.*
>
> *I have support staff but if my daughter is upset then she only wants me!*
>
> *My husband watches the clock if I go to have lunch with other widows. He has recently been in the eye hospital so I cannot leave him as he needs me to put in his drops and gel to keep the eye free from infection.*
>
> *Emotional blackmail is the main problem. Father goes into 'meltdown' if he thinks I'm going away ... Anywhere!*

> *Lack of time, having the energy, person I look after won't accept respite care, the person I look after won't engage with the available services, lack of other relatives to relieve me, person has virtually no close friends I can ask to help, emotional blackmail – gets very upset when knows I am going away and makes negative comments.*

Carers were unwilling to leave the individual on their own when there were potentially significant risks. These included lack of mobility and potential for falls, and concerns about particular behaviours.

> *I can't go out for any length of time without worrying about [XX] setting off the fire and smoke alarms or she might fall.*
>
> *My wife tries to do things but she is always stumbling over. So I do not go out, unless she promises to stay in bed, as she has fallen over twice already.*
>
> *My husband drinks as soon as left alone.*

Plans, even if made, often had to be cancelled. The individual's care needs might be erratic, fluctuate from one day to the next, from hour to hour and there was a sense of '*not knowing what situation I will have to react to next*' and having to drop everything and '*be available at a moment's notice*'.

> *Care agency staff and other medical visits to the home prevent me from making appointments or arrangements to go out in advance.*
>
> *One barrier is the unpredictable nature of dementia - just when you think all is well there is another crisis to deal with.*
>
> *When my husband won't go out in his wheelchair, or wants to sleep.*

Even where there were no current issues people were looking ahead to the future when caring might demand more of their time. It was hard knowing that an illness or disability was progressive, that there would be no improvement. One spoke of it as being 'hard to think for two'.

> *No barriers yet, just more difficult to include my mother in family/ occasions.*
>
> *Always knowing things will not improve, and I always have to be here.*
>
> *At the moment workable. There will be a time in the future when I shall require to use VOCAL for help.*

In some situations when carers did go out, they took the individual and responsibility of caring with them.

> *I have to be there most of the time and she is not able to go out on her own. If I go out I have to make sure she wears her Council Badge to press for emergency. I usually take her out by my car for shopping and some help from my family.*
>
> *Always have to carry along my brother anywhere I go, either home or abroad, since he can't be left alone.*

4.3 Balancing employment and caring

A recurrent theme was the difficulty of maintaining employment whilst caring; both not having enough time to offer the cared for person and leaving no or little opportunity for anything else. However work could also offer a space away from caring.

> *I am in full time employment, my caring role is to support my elderly mother to care for my father who has dementia, I don't have a lot of time to support her.*
>
> *It's hard to find time for myself being a carer and working full-time it takes a lot out of me. I would love to have some time for me but it never works out that way.*

> *Very busy caring and when my son is being 'cared' for by others I have to work.*
>
> *I am a single parent working full-time, I get 3 hours of respite per week. I have no time for myself.*
>
> *Only have time to myself when at work.*

Changes in employment, loss of a wage earner or reduced hours meant less income coming in but some carers felt this was the right thing to do. In some cases a partner worked longer hours or away to compensate for loss of income.

> *Finances – things are much tighter with only one earner in the household!*
>
> *I left my work in [retail] to care for my dad. I only worked 16 hours there as I have an 11 year old daughter and I'm a single parent, so my money did drop and I now receive my benefit to live on but I know I'm doing the right thing looking after my Dad.*
>
> *My partner works very long hours and often away to compensate for me not working (because I am caring), so I don't get a break.*

4.4 Family relationships and family support

Caring for more than one person

A carer could be caring for any combination of partner, sibling, one or two parents or other older relative, own children or grandchildren. Sometimes stress arose caring across generations and balancing conflicting demands.

> *I have to look after son with autism as well as support a husband through illness and addiction when leaves little time for self.*
>
> *Looking after a 92 year old father and stroke husband, time is difficult.*
>
> *I get no time to myself as I now care for my husband as well as my grandson.*
>
> *I feel stressed a lot of the time. I also have grandchildren to care for. It can cause conflict.*
>
> *I have no time for myself or my family. My parents have priority over everything I miss my grandchildren especially.*

A carer might be supporting one parent in the parent's or their own home whilst also visiting the other parent or family member in residential care.

> *My father's social anxiety, and emotional reliance on me, the need to keep my parents in contact with each other (my mother has dementia/ is in a nursing home 300 miles away), teenage children, work commitments, lack of money, time and opportunity.*

Importance of family support

Having a willing and supportive family eased the impact of caring on the carer and enabled them to have some time to themselves.

> *Fortunate in having family who share responsibilities, although I always organise everything.*
>
> *I am blessed to have a loving caring family who appreciate I need time out, and they sit with my husband to allow this.*
>
> *My sister and wife also help with caring duties, so the time I spend with my mother doesn't impact greatly on the time to myself.*

Where family support was not available carers felt the responsibility of being the sole carer, main carer or legal guardian. Family members might be few or live at a distance away. Tensions in the family and lack of understanding about the caring role could make life more difficult.

> *The expectations by my family that this is my duty.*
>
> *Being sole carer in the family, so it was all my responsibility to see to my father's house, finances, paperwork, his wellbeing and carer + to alleviate his distress at dementia diagnosis.*
>
> *The main barrier is time. My daughter relies on me heavily and does not like going to spend overnights at her dad's. We are a very small family, so there is a lack of respite/ other human resources to give me 'time off'.*
>
> *Family misunderstanding - being only family carer with a child, 2 jobs, travel with work - not fully understood by other family carers or persons [parent] I care for, upsetting.*

Relationship with partner

People felt no barrier to time for themselves where they were still able to do things with their spouse/ partner and felt it was their choice to care.

> *No real barriers, as we do lots of things together (cared for and carer). Having very similar likes and dislikes, we rub along fairly nicely, thank you.*
>
> *I didn't have any barriers as my husband, we were out everywhere together.*

However caring for a partner/spouse could put a lot of strain on the relationship. This was ameliorated where the cared and cared for person were learning to do new things together. It also helped when the cared for partner recognised that the other needed a break.

> *Sometimes it is difficult to build the fun time into your life when you know your partner cannot share it.*
>
> *Getting time for the things I used to do on my own and with friends - but three and a half years down the line I am getting used to doing new things together while we still can!!*
>
> *We have to pick things that we can both do - so I opt out of most of the walking group outings because cared for cannot cope with them.*
>
> *At present my husband resists help from others but this is changing slowly, and he is accepting that I need time to myself in order to enjoy our life together.*

Where the carer cared for another adult or child this could also 'take a toll' on the relationship with the partner, affecting the amount of and quality of time spent with the partner. There could be a consequent loss of privacy, intimacy and emotional support.

> *Loss of freedom of moving about, loss of privacy and intimacy with husband.*
>
> *As parents we always have an adult 'child' with us wherever we go. We always have another adult with us on holiday, social events, etc. We are never a couple.*
>
> *I am lucky as [sibling] has respite provided. But I find it hard though even with that to juggle time with my husband and children's needs. I can't really discuss my worries and stresses with my husband as he would push perhaps for alternative housing for [sibling] if he thinks it is causing me problems.*

4.5 Lack of suitable support and respite care

Around one in six carers said lack of support and respite care was a barrier to them having time to themselves.

A small group did not know or did not have time to find out what help was available. Queries concerned: overnight help so the carer could be away; processes for accessing respite care and especially at short notice; eligibility of working people for services.

Carers spoke of the lack of availability, appropriateness or quality of respite care. There was insufficient support or respite care in general; also a lack at short notice, for emergencies or to cover the carer's own needs such as going to hospital.

> *Lack of support - no day-time care for mum 5 days a week.*
>
> *Extreme lack of staff available in East Lothian carers' organisations available to provide a sitter/companion service for my Dad. Also my elderly Mum who also cares for my Dad is going through here own health problems at the moment - so I'm often looking after both of them. Also, there's no appropriate Day Centre in Musselburgh for my Dad with moderate-severe dementia.*

Carers said there was a lack of support and services to meet the needs of people with some specific conditions or needs. Situations mentioned included: no support group for a child without a definitive diagnosis; alcoholism plus physical problem; complex problems; younger people with dementia; aspects of Aspergers.

In some instances there was no appropriate care to meet linguistic and cultural needs.

> *Don't know what is available. Need support worker to take and use the allowance as my mum can't speak English so it has been very hard to get a carer and still wanting someone for the weekend and help to get out and about.*
>
> *Not enough carers to care 24 hours – Polish language – for no stress for my mother.*

Where respite care was available there were issues about its quality. There were comments about the lack of dependability, continuity and regularity of care packages. There were anxieties about costs, local authority funding restrictions and reductions in respite:

> *Quality of available services/agencies particularly evenings and weekends is poor and expensive (+ lacks continuity).*
>
> *Care professionals not really caring, just doing a job. Changes to care packages too long to implement. Frequent changes of carer. Have to repeat care support professionals role 3x/day.*
>
> *Lack of consistent, reliable respite care and on-going care. Even daily covers require us on hand as Mum's dementia makes the myriad of new faces confusing to her.*
>
> *Social Care Direct responses to requests for respite care are too slow so that forward arrangements for the carer cannot be made.*

The parents of children with special needs missed out in two ways: lack of care for their children and lack of access to making the kind of connections and friendships often made via children's mainstream childcare or school involvement.

> *No available special needs babysitters.*
>
> *As my daughter grew older and heavier (wheelchair user) - friends who had helped could not do so any longer, so only break was when my daughter in respite carers at home helped but not for overnight.*
>
> *Caring for a child means that nay person who is paid to care for your child must be/have a level of training. Therefore finding suitable respite carers is a barrier.*
>
> *Not able to access mainstream childcare including friends. Lack of after school care for children with additional needs.*
>
> *I only get 2 nights a month respite, my social life has disappeared. Most of my friends don't have small kids and it makes going out difficult.*

The lack of the right kind of support also meant that the individual missed out suitable company.

> *Finding suitable friends/ respite carers for my daughter.*
>
> *Visitors to entertain my husband when I am working at home. Men are not naturally good at visiting and it makes such a difference to the patient.*

The impact of lack of support and care meant that the carer was not able to get away for a holiday or to have a holiday to suit and include all family members. They could not visit grandchildren or travel to visit distant relatives.

> *It is not possible to be away for longer than a short weekend!*
>
> *Would like a holiday. Haven't had one for 21 years.*
>
> *Can't find a package of respite that meets different family members 'needs. Can't go on holiday as my son suffers poor health.*
>
> *I can't afford to go see my parents in Hong Kong because no other people to look after my daughter.*

A few said they would have to resort to paying privately for help.

> *My partner is entirely dependent and needs constant supervision and company, therefore only when I pay a befriender do I get time to myself. Cannot always ask friends.*

4.6 No spare money

Carers' household income could be decreased and outgoings increased and often there would be no spare cash to do anything for themselves. Financial help from the Government was felt to be missing or not adequate. Carers worried about the threat of potential local authority cost cutting and lack of or restricted funds for respite. The Self Directed Support system was a challenge to navigate. Any available money would go towards getting better care or respite for the cared for person. Paying for sitters, an extra carer, day or short break respite or private care was expensive.

> *Also living off Carer's Allowance the financial situation is an absolute nightmare.*
>
> *Lack of suitable and affordable sitter to care for my daughter. I am anxious about cost-cutting by our local Social Services.*
>
> *Council SDS support means I need to do more work in order to receive minimal respite. Private respite providers double the cost under new SDS system, cost is a big issue.*
>
> *Cost of private care to allow me to leave the house.*
>
> *I need childcare if I want to go out. This can be expensive. Choice of childminder restricted due to PVG/disclosure checks.*

For some, caring carried extra expenses including travel costs and wear and tear on carers own transport. Thinking ahead to potential future expenses, such as funerals was an extra headache for families with ageing parents.

> *After travelling expenses (bus), shopping, paying bills - not enough money to do what I want.*
>
> *I am an only child and I am the principal carer for my dad who has Parkinson's with 11 years difference between my parents I am holding back spending the estate as I am anxious about money and don't know how to pace the spending as it needs to cover both lives.*
>
> *I find that now that I am retired and being my son's, who is now 22 years old, sole carer that I am aware that my disposable income is very limited as I need to plan for our future and keep money for that purpose (i.e. funerals) I have to spend money wisely.*

Carers found that there was no spare cash to allow them to do things for themselves such as attending a class, having a social life, following hobbies or having holidays.

> *I struggle to get a break to myself. I have an 11 year old son with ADAH and a 4 year old who was born with bowel problems and still suffers greatly, we do not manage to get time or breaks away as I can't afford it as I'm in education.*
>
> *I can't afford to have a social life anymore.*
>
> *I can't afford to go on holiday or short break because I do not have any person who can stay with my son. I can't afford to start any job or study for the above reason.*

4.7 Guilt and worry

Guilt was a primary emotion expressed by around one in ten carers. There was a sense that they were expected to undertake this role; of "*responsibility expectation and obligation*".

They felt guilty for leaving the cared for person when they knew that the individual could not do what they wanted to do themselves. There was discomfort at being out if they knew the individual would feel unhappy or unsettled until the carer returned. They felt guilty for not having time to spend with other family members. Even where carers got time for themselves they could not always enjoy it. They felt they should be doing other tasks, such as housework, rather than having time for themselves. They felt a constant sense of 'being on call' and worrying about the individual's health, safety and well-being. There was the emotional strain of the individual being always 'on my mind' and a lack of trust in other people to undertake the caring role.

> *Guilt over having fun while a loved one is fading away.*
>
> *Worrying about how the people I care for will react to me doing something that means I have to leave them to their own devices.*
>
> *Constantly thinking of how to do the best for my parent – is she in the right place, is she getting sufficient/ appropriate care etc, my mind is always 'whirring'.*
>
> *It's the emotional strain of having an autistic child.*

4.8 Health

Around one in ten carers felt that constant caring took a toll on their own physical and mental health.

> *The fact that I feel like there is no time at all to properly look after myself and so I feel very drained and unappreciated ALL THE TIME!*
>
> *I don't want time to think, better to be busy because it's too bleak and sad to think.*

Physical health problems

Carers experienced not being able to relax or lack of sleep because of the constant anxiety and being on call. They felt physically exhausted, constantly tired and lacked strength and energy as a result of the endless tasks to do. Where carers had their own existing or developing health conditions, it made caring harder. Carers spoke of their own long-term conditions (MS, COPD, cancer), mobility problems and ageing.

> *I have also for many years now had very little sleep during night due to my husband's painful nights and bad mobility. Therefore I try to catnap during day to compensate for lack of sleep.*
>
> *Time pressures - having to provide 3 meals a day, do all caring, attend to personal hygiene etc, etc.*

> *No mental energy left - absorbing my partner's anxieties - alleviating them used it all up.*
>
> *Having to 'make do and mend' and often injuring myself having to do jobs that are now beyond me.*
>
> *Caring is very hard. Takes most of my time. I am old myself. I keep caring for my wife (78 yr. old) and my daughter (learning difficulties) out of love.*

Mental health problems

For some the constant stress was affecting their mental health or exacerbating existing conditions. Carers spoke of changes in self-esteem and confidence as well as stress, anxiety, and depression and difficulty in concentrating.

> *I am a carer to my 2 sons and supervisory guide for my daughter, the work is not hard but constant – this affects my self-esteem, my ability to concentrate therefore studying would be difficult for me. I am not interested in talking to others with similar situations.*
>
> *I suffer from depression and sometimes feel I need someone to look after me too.*
>
> *I used to get so entangled in my worries that I had no energy left do things for myself. Fortunately this has got much better after the counselling and workshops.*

Lack of energy to keep up the fight

The nature of the felt permanent responsibility, of being the sole carer, of being a single parent with a caring role meant that individual carers felt they had to 'fight' to get anything for themselves as they focussed upon providing the best possible care and experience for the cared for person. Getting time for oneself required confidence and energy which might not always be available.

> *Have to fight to get time to myself. Very demanding caring role.*
>
> *Insufficient time and money, constantly being on call to make decisions for mum! There is no real support from Social Work and Local Authority, I have to fight for everything!*
>
> *Time factors, I have reduced my hours at work but still running 2 households and spending increased number of hours caring for my mum. I am not good at asking for help.*

4.9 Social life

More than one in ten felt their family and social life was affected by caring. Carers could become socially isolated and lose contact with activities they used to enjoy doing. Maintaining or starting activities required determination.

Increasing social isolation

Carers spoke of being exhausted, and too tired either to plan anything for themselves or to enjoy activities if they did get out. There was a loss of interest in social contact and social skills; sometimes a lack of confidence and being scared to meet people, loneliness and isolation. One spoke of social embarrassment felt because of the cared for one's behaviour.

> *It's hard to keep up social interactions and I feel like a broken record on some aspects of life right now.*
>
> *I have time to myself when children are at school. But I'm isolated when I have my son with me because his behaviour is unpredictable, so going out is difficult.*
>
> *Guilt. Gradual decline in social skills. Inability to commit to any outside experiences or relationships.*

Rural living and having to travel from outside Edinburgh could contribute to isolation.

> *I live in an isolated rural area with no public transport. All meetings and courses are in town so no*

> *way for me to attend. I sometimes feel rather isolated.*
>
> *Living in South Queensferry it is not easy to attend any course which are not held locally therefore contact with others is restricted.*
>
> *Need to have activities nearer to home.*

Loss of activities

People were unable to maintain the activities and hobbies they used to pursue or to take up new one. There was a sense of neglecting their own needs and putting '*life on hold*'.

> *Understanding and having the confidence to pursue my interests. I was spending all my time supporting, and neglecting my own needs.*
>
> *My life revolves around caring for my husband. I don't have much time for my hobbies, sewing, crafting, reading, going out. He gets very upset and agitated when I'm not in the same room. He has lost interest in his hobbies. He has visits to Day Centre 2x a week.*
>
> *Not really knowing what to do – it's been so long since I started.*
>
> *I am full time carer (24/7) with only 2 respite periods/week. So am unable to pursue my previous hobbies, interest, exercise etc.*
>
> *No money to do night classes, feel scared to go out and mix now.*
>
> *As I have less income coming in, tendency not to participate or meet up with friends (not isolated at all, and have made/ met good friends with other parents with disabled children).*

Even basic things to take care of their own health and well-being were difficult.

> *Lack of time to myself. I need someone to sit with my husband if I am not there, even going to the hairdresser or dentist is a luxury.*

Activities and social contact are good for well-being

Carers spoke of having to learn to get time for themselves; that juggling all responsibilities was worth it and that good planning could help.

> *I have had to work hard to create outside interests for myself and also to be a carer at the same time.*
>
> *There are barriers (juggling everyone's needs) but a good routine has enabled me to free up time for myself.*

A range of activities were mentioned as important for the carers' well-being; including exercise, being with friends and meeting other carers.

> *I go singing once a week, I don't have driving lessons no more but hope to start up again soon, have stopped go out before to look after mum.*
>
> *During fishing season I get out about twice a week for about three hours a day.*
>
> *I find I have to plan for my free time. I go swimming, have different classes to attend and keep up with my friends, all are extremely important for my sanity.*
>
> *I found the CAIRE Project became important because I was having a day a week when I didn't need to make a decision or think about cooking and met some lovely carers. I had started attending an art club in Blackhall, but this year I only managed 3 meetings.*

5 Using technology

People use the Internet for many reasons: for information, to find services, keeping in touch with friends and family and shopping online. Carers who don't have access to the Internet often miss out on important information, financial savings and social opportunities.

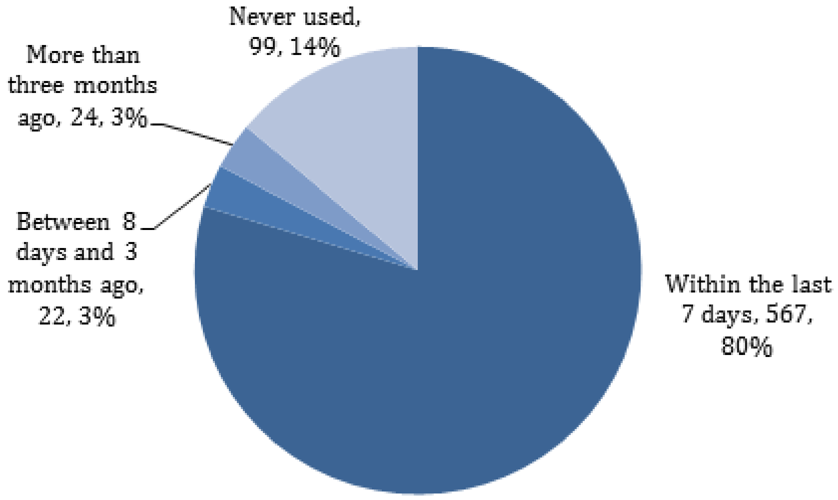
We wanted to find out whether more carers were using the Internet now than in 2013 and what they were using it for.

Some people have easier access to or prefer to use mobile phones and tablets rather than traditional desktop computers and laptops. We were interested to see if carers were using social media such as Facebook, What's app or Twitter.

5.1 When did you last use the Internet?

We asked carers when they last used the Internet[3]. 98% (712) carers responded to this section of the questionnaire.

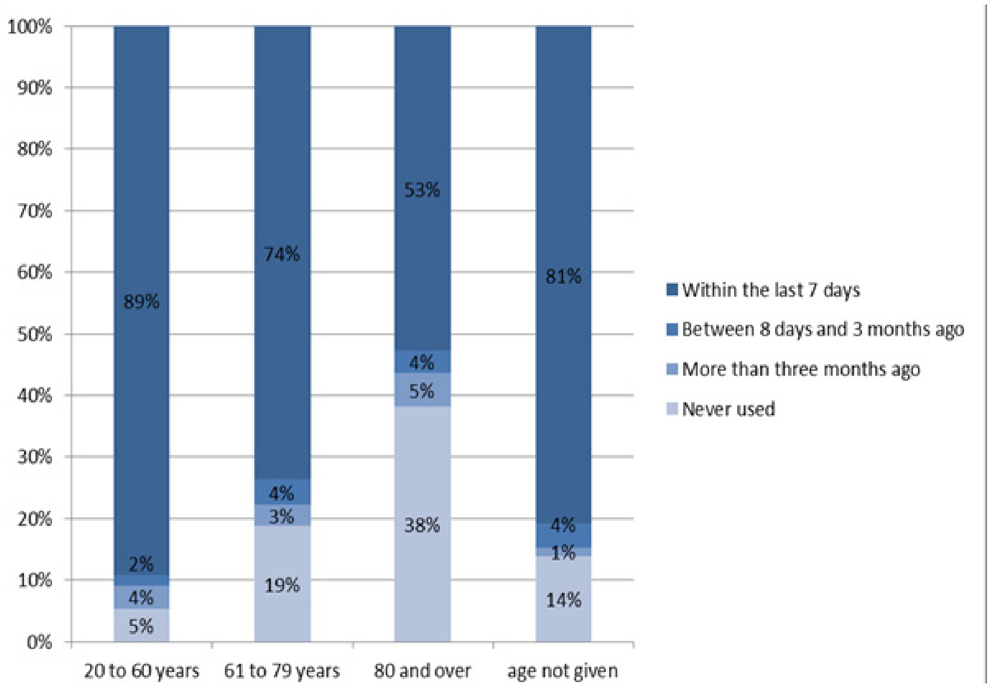
Figure 5 1 When did you last use the Internet? (%)



We found that 80% of carers had used the Internet within the last seven days and a further 3% within the last three months. (Figure 5-1) This is an increase on the three quarters of carers (76%) using the Internet within three months at the last survey. A smaller proportion (14%) had never used the Internet at all compared with last time (18%).

[3] This question was drafted to be in line with the question used by the Office for National Statistics (ONS) Internet Access Quarterly Update, Q1 2014. This found 13% of the adult population had never used the internet. Age is a key factor as to whether an individual is likely to have used the Internet. Almost all adults aged 16 to 24 years (99%) had used the Internet. In contrast, only 37% of adults aged 75 years and over had ever used the Internet. http://www.ons.gov.uk/ons/dcp171778_362910.pdf

Figure 5 2 When did you last use the Internet by age group



As might be expected use of the Internet varied with carer age. Most of those in the youngest age group (91%) and those aged 61-79 years (79%) had used the Internet within the last three months; for those over 80 years over half (56%) had used the Internet within this period. This was a definite increase from the last survey (33%). However over one in three carers (38%) aged over 80 years have never used the Internet.

5.2 Using the Internet

We asked carers how confident they were using the Internet. We also asked why they did or did not use the Internet. 95% (688 of 728) answered this section.

The majority 69% said they were confident using the Internet and as might be expected a larger proportion of those who had used the Internet in the last seven days (83%) were confident in using it.

Over half (52%) of those who had used the Internet over 3 months ago and almost a third (30%) of never users said they lacked confidence in using the Internet.

Well over a third of all carers used the Internet to contact friends and family online (38%) or to get information and support (37%). A handful commented that they got information via another family member using the Internet rather than using it directly themselves.

15% had saved money using the Internet.

Of those who had never used the Internet, 58% said they had no time to learn or use the Internet; 12% could not see how using the Internet would help and 17% could not afford to pay for the Internet.

Table 5-1 Confidence and reasons for using or not using the Internet

	Within the last 7 days	Between 8 days and 3 months	More than 3 months ago	Never used	No response	TOTAL
	%	%	%	%	%	%
I am confident using the Internet	*83*	*19*	*24*	*3*	*13*	*69*
I lack confidence using the Internet	*14*	*67*	*52*	*30*	*75*	*19*
I contact family and friends online	*44*	*19*	*14*	*3*	*13*	*38*
I go online to get information and support	*43*	*24*	*14*	*3*	*13*	*37*
I have saved money using the Internet	*18*	*5*	*5*	*0*	*0*	*15*
I don't see how using the Internet will help	*2*	*0*	*14*	*12*	*0*	*3*
I can't afford to pay for the Internet	*2*	*0*	*19*	*7*	*25*	*5*
I have no time to learn/use the Internet	*2*	*24*	*33*	*58*	*13*	*10*
TOTAL	***562***	***21***	***21***	***76***	***8***	***688***

5.3 Use of social media

We asked carers whether they used any social media. 57% (418) answered this question indicating that they used at least one form of social media.

The majority of people who said they used social media were also Internet users. Only a small number of non-Internet users reported using social media.

Table 5-2 Use of social media by frequency of use of Internet

	Within the last 7 days	Between 8 days and 3 months	More than 3 months ago	Never used	No response	TOTAL
Facebook	290	6	2	5	4	307
WhatsApp	142	4	0	3	0	149
Twitter	44	0	0	1	0	45
Other	36	1	1	4	1	47

Other social media used by carers included Instagram (5), Linkedin (3), Viber (2), Instag/viver (2) and Reddit (1).

Some of the responses to ‘other’ in this question included modes of accessing the Internet (phone, I-pad), search engines (Google), applications such as Skype, Messenger and Internet sites (Pinterest).

6 Shaping services and support for the future

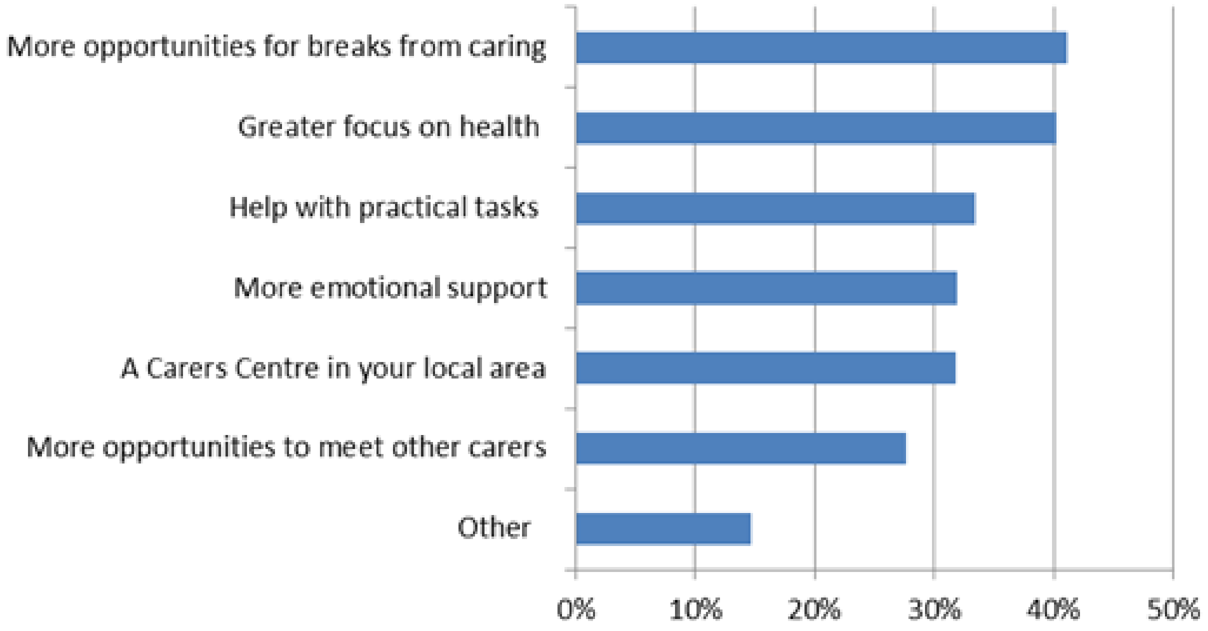
In order to inform VOCAL'S new five year business plan carers were asked for their views on the services and support that VOCAL should be delivering and developing in the future.

A total of 620 (85%) of carers responded to this question either selecting one of the options provided or commenting on services they would like to see in the future.

The service selected by most carers who answered this question was 'More opportunities for breaks from caring' (41%) followed closely by 'Services with a greater focus on health both physical and emotional' (40%). (Figure 6-1) A third (33%) of carers wanted help with practical tasks. 'Services providing more emotional support' was selected by 32% of carers, the same proportion that wanted 'A carers' centre in their local area'. Ninety carers (15%) provided comments on other services they would like VOCAL to develop.

The response to this question by sector of residence for Edinburgh residents can be found in Appendix 1.

Figure 6-1 Services and support VOCAL should be delivering in the future



Carers wanted respite for short periods to give them a break away from caring, to provide opportunities to meet other carers and to give the cared for person some additional interest e.g. befriending and short holidays for both carer and cared for.

> *Breaks for caring are a lifeline.*
>
> *Have quite a good life balance at present! Looking for holidays we can enjoy as a family - that's quite difficult.*
>
> *Information on what respite opportunities are available, especially for the cared for person.*
>
> *It's too easy to on focus your duties and forget about you. It's important to have a date in the diary (for you) meeting other carers or keep fit classes work for me. Respite is my lifesaver as it charges my batteries for the next round.*

> *Sharing experiences with other carers helps relieve the stress burden, as would more breaks.*
>
> *I assume this is for the person being cared for - such services would be great as it gives the carer a break, safe in the knowledge the person has someone else keeping them safe during this 'break'.*

However one carer was sceptical about being able to have a break, claiming never to have had a break in 16 years of caring:

> *Respite care seems to be a great concept but not a reality.*

Those who selected services with more focus on health were aware of the importance of maintaining their own health but some wanted courses on particular topics and more specific support as below:

> *A course on understanding depression. I heard other carers talking about a course on dementia - something similar for depression.*
>
> *I would appreciate lessons on CPR in case it was needed.*
>
> *More services for carers with learning disabilities. More support for older carers who have a long-term medical condition or disability that affects their caring role and ability to cope, and affects their own health.*

More emotional support was important for some carers:

> *Emotional support because of my own mental health problems and loss of support of CPN due to changes in way services now provided.*
>
> *Telephone support really good as no time to go to groups. Befriending - support that Council don't provide - many folk don't fall into their 'tick box category'.*

Carers who were getting older themselves wanted help with practical household tasks as they were finding such tasks harder to manage. Other specific tasks that carers wanted help with ranged from gardening to decorating and hairdressing. Three carers wanted a list of reliable, trustworthy tradespeople who would charge reasonable prices.

Those who wanted a Carers Centre felt that more people would access a local centre as it meant less travelling time and it would also give carers an opportunity to meet other carers.

> *A carers' centre in my district would be excellent in order to meet other carers and be informed about help available.*
>
> *Even small local connection may make it more accessible to people.*
>
> *Most of the courses were not in my area, making it difficult for me to leave my husband for over 4 hours.*

Those who were new to VOCAL services felt they could not offer any suggestions for future services and support as they were not sure what VOCAL had to offer currently.

Some reported that they were happy with the services that VOCAL were already providing.

> *All the above are helpful and valuable. Happy with the service. Try to be independent, but use any support if I need to.*
>
> *I think Vocal do an excellent job and it would be difficult to expand further.*
>
> *No other charity provides this support especially if the person you care for has no specific diagnosis.*
>
> *Sorry I don't know, seems good to me as it is.*

A few carers indicated that they wanted more help in a number of areas that VOCAL already provided help e.g. financial and legal issues, information on benefits and other services available for carers.

> *Advice on dealing with DWP - specifically getting financial support from DWP.*
>
> *Advocacy role – both negotiating with other agencies to progress e.g. benefits, assessments, and with carer and person cared for to assess needs, explain help available, etc.*
>
> *Legal advice and help.*
>
> *It would be good to know what is available when (if) my wife comes home.*

Others wanted additional help in these areas:

> *Extra money for being a carer.*
>
> *I would like VOCAL to get Virgin Media to give carers discounted Internet.*

Other areas suggested by individual carers in which VOCAL could develop specific support and services included:

- Creative activities: Art, nature walk, art gallery trips, Days out: North Berwick, Peebles etc.
- Use of technology i.e. computer classes
- More opportunities for places to take teenagers with disabilities
- Exploring transition - school to adult services, home to residential care away from home, home to nursing home/ long-term care.

It was suggested courses and groups could be held in the evening or weekends for those who worked or would find it easier to attend at these times.

> *More evening or weekend events for carers who also have to work during the day.*
>
> *Using VOCAL centres to people working and caring that could be accessed after working hours.*

Working with carers and other agencies

There was a range of suggestions for how VOCAL should work with carers and other agencies and how they should seek to influence the local authority and Government.

One carer felt that VOCAL should collaborate more with other service providers (e.g. Alzheimer's UK, Lifecare) so that they could pool resources and 'fight' together for carers. While another wanted VOCAL to help improve information flows between the NHS and the Edinburgh Council of Carers for all types of carers.

Other suggestions focussed on the development of the carer voice:

- VOCAL should encourage more active citizenship so that carers would have more involvement in shaping and planning services
- more help for carers to understand social care processes and structures, care packages and the 'politics around care'.
- VOCAL should do more to influence Edinburgh Councillors or the Scottish Parliament on the provision and cost of care for example:

> *…. help getting the issues over effectively to Edinburgh Councillors the effect of their decision making i.e. the mass privatisation of home care and how agencies across the city are very often short-changing clients i.e. regularly 30 minutes equates to 15 as they 'cram' cases.*
>
> *Speaking to the Scottish Parliament about link between inflation and cost of care; training and pay of carers from agencies and impact of this on agency charges; link between the above and pay for those in paid employment - my pay (hourly rate, excl. tax) is only £2 more than hourly rate of care.*

> *My son has had great difficulty in gaining paid employment over the years. Could VOCAL influence this aspect which indirectly has affected my life considerably?*

Another wanted VOCAL to encourage carer identification while one carer complained that they had not had a carers' assessment.

Other suggestions for how VOCAL should develop services

Other carers wanted VOCAL to work in different ways as the comments below demonstrate:

> *Represent all disabilities. It appears alcoholics and drug abuse you support in abundance. I hope to see big improvements as a charity.*
>
> *Vocal needs to concentrate on simple practical help for carers and should have staff visiting the carers not the other way around. Everything you seem to do puts Vocal at the centre. You must put carers at the centre. I have had more help and advice from the Red Cross.*

Another carer felt that VOCAL should do more to promote itself and its work:

> *Promote your excellent work by speaking at least every 2 or 3 years at a parents evening at every special school. Too many parents never hear of you.*

Finally one carer was interested in being involved in the development of the new business plan:

> *Doing well but always good to write or re-write a plan - I would be interested in information or input of such a plan.*

7 Carers' experience of VOCAL

7.1 How carers found out about VOCAL

In 2015 a question was included in the survey for the first time, which asked carers how they found out about VOCAL. A total of 625 carers responded to this question. Carers found out about VOCAL from a variety of sources (Table 7-1).

Table 7-1 How carers found out about VOCAL

NHS: General practice	Information services
NHS: Hospital services	School
NHS: Community health services	Workplace
Personal communication: family, friends	Advertising
Social services: social worker/care support worker	Internet
Support/ voluntary group	Directly from VOCAL

Over a third of carers reported that they found out about VOCAL via the NHS. General practice was most frequently mentioned route through which carers found out about VOCAL. In some cases carers mentioned their GP surgery without specifying whether it was an individual or from another information source (e.g. a leaflet or poster). However, the majority indicated that their GP told them about VOCAL. A few carers reported that other primary care staff including the practice nurse or practice manager told them.

Carers who found out about VOCAL via hospital services were not always specific as to whom or which hospital service told them about VOCAL. Occupational Therapists were the single most frequently mentioned health professional. Memory Clinics were also mentioned by a number of carers.

Where 'a doctor' told carers about VOCAL it was not always clear where the doctor was located.

Some carers found out about VOCAL via the community health services including the Child and Adolescent Mental Health Services, Health visitors, link workers, mental health nurses and community psychiatric nurses.

Personal communication via either family and/or friends was mentioned by about a sixth of all those that answered this question and in a few cases it was another carer who told them about VOCAL.

The local council, specifically Social services were another source of information about VOCAL with social workers the most frequently mentioned. Social workers in other settings were also mentioned:

> *Social Worker from Royal Edinburgh Hospital.*
>
> *Through kinship social worker.*

One carer reported that a care support worker told them about VOCAL while another said it was their husband's care service.

Many carers said they found out about VOCAL via specific support groups relating to the disability experienced by the cared for person. Alzheimer's were frequently mentioned but other organisations such as the Red Cross, Kinship Carers, North Edinburgh Drug Advice Centre (NEDAC), Headway, Parkinson's group, PASDA (supporting families of adults with autism), Mid and East Lothian Drugs (MELD), Support in Mind, Lothian autistic society were also mentioned.

Local community centres and carers' groups were another source of information about VOCAL.

Generic information services e.g. Citizens Advice Bureau (CAB) or the local public library were the source of information on VOCAL for a few carers while others found out about VOCAL through information services which served specific user groups. These included:

- Kindred – (for children with special needs)
- FAIR – (for people with learning disabilities)
- Multiple sclerosis helpline
- McMillan Cancer Advice

Carers of children with special needs often found out about VOCAL from their child's school or from other parents in the school.

Carers who were in paid employment reported that they found out about VOCAL from colleagues at work or because of the type of work they did:

> *Through former work in SWD.*
>
> *Previously worked with Age Concern.*
>
> *From a workmate.*

A small proportion of carers found out about VOCAL through various forms of advertising, this included leaflets and posters and newspapers. No carers mentioned that they found out about VOCAL using social media specifically although the Internet was important to some carers.

Some carers had seen the VOCAL office and called in to ask about services:

> *Pass office regularly.*
>
> *Walked in VOCAL Carer Centre.*
>
> *Walking pass centre.*
>
> *Worked in the area of the office.*

A number of carers could not remember how they found out about VOCAL and some of these felt they had always known about the organisation:

> *Can't remember - known about them for a long time.*
>
> *Can't remember. Aware of it long before I was a carer.*
>
> *General knowledge.*
>
> *Have known for years*

7.2 Quality of VOCAL's response

In order to gain an understanding of carers' satisfaction with the services provided by VOCAL, carers were asked to rate various aspects of the response they received when they contacted VOCAL. This included the friendliness of the response, how easy it was to get in touch with VOCAL and whether they received as much information as they needed. Carers were asked to rate the response on a scale ranging from 'excellent' to 'very poor'. In addition carers were asked to rate VOCAL's overall response. Table 7-2 details the aspects of VOCAL's response carers were asked about and how carers rated them.

Table 7-2 Rating of VOCAL's response

	Excellent	Good	Fair	Poor	Very poor	Can't say	
	%	%	%	%	%	%	No.
Friendliness of response	*75*	*21*	*1*	*0*	*<1*	*3*	698
Ease of getting in touch with VOCAL	*67*	*27*	*2*	*<1*	*<1*	*3*	702
Doing what they said they would	*64*	*25*	*4*	*<1*	*1*	*6*	687
Getting as much information as needed	*61*	*31*	*4*	*<1*	*<1*	*3*	691
Knowledge of staff and volunteers	*53*	*32*	*7*	*1*	*<1*	*7*	685
Getting information about other groups/ organisations	*51*	*29*	*7*	*<1*	*1*	*12*	682
VOCAL's overall response	*70*	*24*	*3*	*<1*	*<1*	*2*	691

Of those who answered these questions 96% of carers rated the 'friendliness of response' as 'excellent' (75%) or 'good' (21%). Less than 1% (3 carers) felt the response from VOCAL was 'very poor'. The 'ease of getting in touch with VOCAL' was rated at a similarly high level (94% 'excellent' or 'good').

The next three aspects of VOCAL's response were also highly rated by carers as 'excellent' or 'good': 'doing what they said they would' (89%), 'knowledge of staff and volunteers' (85%) and 'getting information about other groups and organisations' (80%). However, again 12% carers felt they could not comment on this last element of VOCAL's response (can't say or no response) probably because they had not asked for this sort of information.

'Getting as much information as you needed' appears to have been rated less highly this year (62%) with only 31% saying this was excellent. In the 2013 survey 90% rated this aspect as 'excellent or good'.

Between 4-6% carers chose not to answer the options for this question. This may indicate that, at least in part, they had no experience of VOCAL's response.

VOCAL's overall response

When asked about VOCAL's response overall, 94% of carers who answered this question rated the response as 'excellent' (70%) or 'good' (24%). This is similar to the result from the 2013 survey. This suggests that VOCAL is maintaining its high quality response to carers.

7.3 VOCAL's services

VOCAL provide a wide range of support, activities and services to cater for the needs of their users. Carers were asked to indicate which ones they had found useful from a list of services offered by VOCAL. There was also an opportunity to mention other services not included in the list. Space was given to allow further comments on the services.

Table 7-3 shows the proportion of carers responding to the survey who found various services offered by VOCAL useful. Carers could select more than one service.

Table 7-3 Carers finding services useful

Service	No.	%
Information (including carer information pack)	533	*73*
Training courses and seminars	292	*40*
Meeting other carers/carer support groups	244	*34*
Help with Power of Attorney/legal issues	236	*32*
Financial planning and benefits advice	192	*26*
Help to look after yourself	177	*24*
Help with managing your caring role	156	*21*
Social/leisure and health activities	133	*18*
Counselling	118	*16*
Help to plan support	129	*18*
Help with accessing short breaks and respite	98	*13*
Website	96	*13*
Family support (Addictions)	48	*7*
Advocacy	43	*6*
Other	7	*1*
TOTAL	**728**	

The options in this survey were slightly different to the previous one. However, where the options were directly comparable, the proportion of carers in Edinburgh finding the services useful were greater by between 1 to 6 percentage points for every category compared to the 2013 survey with the exception of information and counselling which remained the same (This comparison is for Edinburgh only respondents in 2013).

Many of the comments on the services in response to this question were general comments on VOCAL, its services and its staff. The majority of these were positive comments with several carers commenting on the range of services offered by VOCAL.

> *All services were excellent. VOCAL is really a one-stop shop, can't imagine where else could provide their services.*
>
> *The wide range of services under one roof is helpful to carers and makes it easier to find out what is necessary/ available and to access it.*
>
> *VOCAL has been a great service for me and mum who I care for, anything we have asked of VOCAL they have really helped in every way they can.*
>
> *VOCAL was/is a lifeline. The service and staff helped me negotiate a very difficult time in my life, i.e. caring for an elderly parent with dementia.*
>
> *I'm really pleased the way VOCAL has been developing over the years. It's always been good, but it's getting better + better. Keep up the good work!*

Many carers commented on the friendliness, helpfulness and professionalism of VOCAL's staff:

> *Friendly response gives me confidence that if we have a problem (either of us - wife (88) or me (84)) we can ask for help.*
>
> *Any service used has been very professional and very helpful.*
>
> *Any services I have used have been excellent, also very helpful and understanding. Always prepared to listen as well.*
>
> *Extremely friendly and caring staff. They always rang back when they said they would.*

However there were some comments that indicated that carers were unhappy with the service they received from VOCAL and one felt VOCAL did not offer the right sort of support in a crisis.

> *I find VOCAL of no use to me - as I find I have learned to 'fight all my own battles'. Those who really need help don't get it + those who are the loudest at complaining get all the help in the world.*
>
> *I only call when I need help and it can take a long time before the phone is answered. Quite often the person I speak to cannot help.*
>
> *VOCAL services is based on information pack; training courses and seminars (every carer's does not have time). The lack of real support for the carer's crisis.*

Carers living in East Lothian were disappointed that some services were not available to them.

Information

As in the previous surveys, the service mentioned as useful by the largest proportion of carers of all ages was information (including the carer information pack) (Table 7-3). Over two thirds (73%) of carers reported that they found this service useful. Although several carers said they received the carers' information pack other individuals found specific information provided by VOCAL very useful to them.

> *Found information pack helpful and interesting.*
>
> *It was very helpful to learn more about my husband's diagnosis and how best to care for him in the future.*
>
> *Specific accurate information about how/ where to get a record of dates of hospitalisation that are acceptable by the Department of Benefits, Work and Pensions, who would not take my word about when my mother was in and out of hospital. Now resolved.*
>
> *I was helpfully signposted to other services and in fact specific ones contacted on my behalf. I found this invaluable.*

Some carers had only received the carer information pack to date but indicated that they might use other services in the future.

7.3.1 Training courses/seminars

The training courses and seminars run by VOCAL were found useful by over a third (40%) of carers and 16% had found counselling useful. The comments suggest that carers generally got a great deal out of the courses they attended and as in many activities run by VOCAL, meeting other carers was an important element of attending activities:

> *Excellent dementia awareness course. Has helped in so many ways. Really helpful and understanding staff. Good to meet other carers*
>
> *Personally I found the telecare seminar very useful when my mum was still living at home.*
>
> *Brilliant dementia training course - very useful info and conveyed in an appropriate/interesting way. Though 1 session wasn't useful for East Lothian folk.*
>
> *I have attended a number of seminars, all of which have been very useful. I have learned a lot through attending VOCAL courses.*
>
> *Through the training it was good to meet team and other carers in same position.*

However not all the comments on courses were so positive. One carer felt they had received little support from VOCAL as both the courses they had enrolled on had been cancelled and the information they had asked for had not been sent to them.

Counselling

Several carers commented on the counselling sessions they had attended. The majority were positive about the courses but one carer found it 'awkward' as the counsellor had children at the same school as the carer.

> *I found the counselling service excellent and very helpful.*
>
> *I have found all the services I've used to be really effective and of benefit, particularly counselling.*

7.3.2 Accessibility to training courses/seminars

Although there was a small increase in the proportion of carers saying they had attended courses offered by VOCAL compared to the previous survey 40% vs 35% as in the last survey a number of carers indicated that they would like to attend such activities but were unable to do so for a variety of reasons. Most commonly this was because of the timing of the courses etc. For some their caring responsibilities meant that they could not attend courses which started too early in the day, for others they could not attend during the day at all as they were working.

> *Please note as a carer of 3 people no help. I cannot attend any meetings, I am sole carer. Isolated, no help forthcoming from GP or anyone else.*
>
> *Some of the courses look good but they almost always start when I am letting the carer in. Otherwise it's a full-time job and if I sit down I fall asleep.*
>
> *Unfortunately most of carers courses are am, and my husband is not active, dressed etc, until late morning.*
>
> *It has always been a comfort to know it is there. If only you would run courses in the evenings.*
>
> *The only comment I would like to make is the training courses are mainly during the week. I work school hours so find it very difficult to attend.*

7.3.3 Social/leisure activities

The proportion of those finding social/leisure activities useful increased by four percentage points between 2013 and 2015, 12% vs 16%.

> *Loved the relaxation therapy groups and craft group days.*
>
> *Very enjoyable leisure activities - art gallery visits and gym.*

7.3.4 Financial and legal services

Over a quarter of carers (26%) found the financial services including applying for benefits offered by VOCAL useful and almost a third (32%) found legal services such as help with POA useful.

A few carers provided further comments on each of these two areas. Most of these were positive with carers finding these services 'very helpful' or 'excellent'. Some carers also commented on the help they had in applying for benefits and short breaks:

> *XX was fantastic on benefits advice. XX was fantastic on Better breaks application.*
>
> *I would like to add that when I applied for Short Break possible grant, the help I was given by a Vocal employee was outstanding. The gentleman who I only know as XX helped run through the questions with me and highlighted helpful info on the form. He was extremely caring and kind.*

However some carers had poor experiences of these two services. In two cases the carers were not specific about the problems they experienced:

> *I tried to get help with Power of Attorney documents I was preparing myself but felt as if I was having to drag the information out of your staff. After having failed to get the POA documents approved I returned to Vocal to get advice on how to proceed and was told to start all over again. I ignored this advice and called the Public Guardian.*
>
> *Unfortunately we had a very negative experience when we attended re Power of Attorney for our daughter but we have used the legal contract for future use.*
>
> *Not very helpful with financial issues. Felt let down.*

7.3.5 Reassurance

Although some carers were not currently using or had ever used any VOCAL services, they felt very reassured to know that VOCAL was there if and when they needed their services.

> *Knowing VOCAL is always there if needed.*
>
> *Just knowing VOCAL is there at the end of a phone is good solid support at all times.*

7.4 Difference VOCAL's help made to carer

Carers were asked what difference the help received from VOCAL made to them as a carer. Table 7-4 shows how carers rated the difference the help from VOCAL made to them and how this compared to a similar question in the previous surveys.

In the 2015 survey, 95% (688) carers responded answered this question.

Table 7-4 Difference help received made to carer 2011, 2013, 2015

	2011			2013		2015	
Help made a difference?	**No.**	**%**	**Help made a:**	**No.**	**%**	**No.**	**%**
Yes	416	*84*	**Big difference**	348	*66*	456	*66*
			Small difference	98	*19*	147	*21*
No	77	*16*	**No difference**	22	*4*	17	*2*
			Can't say/ Not applicable	66	*11*	68	*10*
TOTAL	**493**			**529**		**688**	

In 2015, of those who answered this question, two thirds (66%) said that the help they received from VOCAL made a 'big difference' to them as a carer. This is the same proportion of Edinburgh carers who chose this option in the 2013 survey. There was a small increase in the proportion that said VOCAL made a small difference to them 21% vs 19%.

In the 2011 survey the option 'can't say/not applicable' was not available to respondents. This may be why there was a higher proportion selecting the 'no' option.

Difference help made by age group of carer

Those in the oldest age group (80 and over) were less likely than the other two groups to say that the help form VOCAL made a difference (big and small difference combined) (Table 7.5). A larger proportion of this group also reported that they couldn't say whether it had made a difference. Although this group also were also slightly more likely to say that VOCAL's help made no difference, the number of carers in this age group is low so caution must be used in making this comparison.

Table 7-5: Whether help received made a difference by age group of carer

Help from VOCAL made:	20-60 years	61 to 79 years	80 and over	Age not given	Total
	%	%	%	%	%
A big difference	*71*	*62*	*60*	*65*	*66*
A small difference	*19*	*25*	*15*	*23*	*21*
No difference	*3*	*1*	*4*	*4*	*2*
Can't say	*7*	*12*	*21*	*7*	*10*
N	***299***	***260***	***48***	***81***	***688***

7.4.1 How help from VOCAL made a difference

The ways that VOCAL helped carers were similar to the reasons given in the previous two surveys. This help can be grouped broadly into

- emotional support for caring,
- information and practical help in the form of training courses
- financial and legal help including completing forms.
- Short breaks and respite

For many of those who said that VOCAL had made a big difference to them it was having someone to talk to about their caring responsibilities, who was a good listener and who had an understanding of what the carer was experiencing that carers found valuable. Some carers commented on the kindness and empathy of the people at VOCAL they spoke to and how this lifted their spirits. In some cases the staff at VOCAL were the only people they felt they could talk to about their caring.

> *I cannot over emphasise how important and comforting it is to speak to VOCAL workers who know about and understand the life of a carer without going into detail each time.*
>
> *I have no other person to which I can talk freely with now, therefore great to be getting 'listening time' with VOCAL.*
>
> *Speaking to someone on the phone – made me feel like a person listened to. Gave me hope.*
>
> *This was a very lonely sad journey for me, and I had someone who listened and supported my making difficult decisions and coping with loss.*
>
> *Your staff are excellent – knowledgeable, helpful, supportive, caring.*

Knowing that VOCAL '*were there*' if needed was reassuring and made many carers feel that they were not alone. Some had only minimal contact with VOCAL but felt reassured that they could get in touch with VOCAL if needed.

> *It is really good to feel you are not alone.*
>
> *Often when faced with what you consider a huge problem all the stress can be wiped away simply by chatting to someone with knowledge on the subject.*
>
> *The help I received from VOCAL helped me so much in coping with my husband's dementia. I felt so reassured. I was not coping alone.*
>
> *On first contact I was made aware that I did not have to deal with everything alone. It was a great relief.*

For many the support they received from VOCAL increased their self-confidence and made them better able to cope with their caring responsibilities.

> *I was able to put a plan in place to help my husband reduce his drinking (not enough yet), and find better ways of discussing problems with him.*
>
> *Many ways. I was not coping. I did not know how to be a carer but put my all into it. This affected my mental health, relationships with family and friends.*
>
> *The help and advice my husband and myself got from our counsellor helped us to cope with our situation and realise how to come to the final solution with a good result, which we hope will continue.*
>
> *VOCAL gave me the confidence to become a carer and gave me the information to do so successfully.*

An important element of helping carers cope better with their caring responsibilities was helping them recognise that they were a carer: that they had their own needs for example in making time for themselves and looking after their own health both physical and mental. For some the support from VOCAL helped them not 'feel guilty' if they took time out for themselves.

> *I realise that whilst I was a carer, I mattered too, and that it was okay for me to have as good a life as I could.*
>
> *It made me feel like a person again and not just a carer.*
>
> *The help that I received enable me to recognise my carer role, but also that it was important to look after myself and make time for myself. This had helped me to manage my situation and change some of my thought patterns.*
>
> *They taught me not to feel guilty when I took timeout to relax and meet up with friends instead of being a 24/7 carer.*
>
> *VOCAL have been a god send to myself and my family, I don't know what I would have done without VOCAL. Keeping myself focused on my caring role and plenty of help for my mum and dad, thank you so much for all your help and advice. Excellent.*
>
> *I did not realise I was a carer – I was just a mum doing what I could. Finding out there was understanding and support made a huge difference, and meeting others helped me get a perspective.*
>
> *Helped me understand how to deal with the challenges.*
>
> *The help I received made me realise that I was not alone and the feelings and struggles I had were normal and ok. I learned how to think about my own health and wellbeing which would help me to be a better carer and reduce stress and anxiety levels. I have learned how to change my approach to caring for my loved one and become a better and stronger person by attending smart meetings.*

Information

Information on options available to carers and the person receiving care including benefits, legislation and assessment were helpful for many carers. Similarly, informing carers of what services were available, how to access these and in some cases referring carers on was valued by some carers. For some the information and support provided allowed carers to take the next steps necessary to help with their caring.

> *It helped me understand new legislation and how to deal with my son in various ways when his behaviour was hard to cope with – seeing that others are in the same position as us helps too.*
>
> *I got the information I needed to ask for extra help for care with my parents-in-laws, and they also helped with form filling in. Excellent.*
>
> *As a XX citizen living in Scotland VOCAL was vital in assisting with information and advice and actively contacting organisations which assisted in my caring role. Without VOCAL I would not have managed on my own.*
>
> *I was given advice as to who to contact in order to get an assessment and general guidance on the whole procedure.*
>
> *More understanding of how the social care and support system works. More confidence in speaking up to ask for support.*
>
> *We now have the befriending service full time and Direct Payments are provided by the Council. We were unaware Direct payments could be given for a befriending service until VOCAL informed us.*

Information provided by VOCAL helped carers understand the condition experienced by the person they cared for. This made a difference to many carers. It helped them cope better and enabled them to be more prepared for what might happen in the future as the condition developed.

> *It helped me understand more the problems I had in dealing both with dementia and mental health problems and put me in touch with other helpful groups.*
>
> *Meeting and listening to other carers and what they have to cope with, this helps me to understand more. Being a lot more understanding and tolerant with my husband.*
>
> *Provided information so I had a better understanding of the issues, this alleviated my anxiety. I was better able to provide support and space for them to decide what action was in their best interest. Better understanding as to when external support was required.*
>
> *Now we understand very well how to deal and look after our son suffering from learning disability. All that was due to the great help we received from VOCAL that was prepared and introduced in excellent way. Thank you VOCAL.*

Practical advice

In addition to the emotional support and information that made a ‘big’ difference to carers the practical advice offered by VOCAL was also very important to many carers.

Training courses/activities

Many carers reported that the training courses offered by VOCAL were very informative and helped them understand the condition the person they cared for was experiencing. In many cases, carers reported that meeting other carers on training courses who were in the same situation as themselves was very beneficial.

The various support and activity groups organised by VOCAL were also appreciated; they were enjoyable and helped carers do something for themselves. Again meeting other carers facing similar challenges and exchanging experiences was very important.

> *I know the theory but found it hard to apply it to my situation. The training/ seminars helped to bridge the two! Activities were good too.*
>
> *I did a small course and learned a lot about PIP, which has helped my niece, and will help my son and myself when the time comes to switch benefits.*
>
> *The provision of training course and workshops has given me all the information I require. It has also helped me meet other carers and we can support each other. The activity groups are fun and relaxing, giving me a much needed break! The staff are all so friendly and helpful, and can’t do enough for you, and this included people brought in to run courses.*
>
> *I enjoy time out from caring to access courses and workshops. Essential information is learned via legal surgery re. guardianship and issues re. wills etc.*
>
> *I attended a course on ‘transition’ for my son many years ago and it was excellent, very informative and a chance to meet other carers in a similar situation.*
>
> *Free training helped me plan for what was coming.*
>
> *Realised that I was a carer, attended courses which helped me cope better as a carer and identifying routes to help guide me through the social services.*
>
> *It helped me realise that I was not alone, and that there were ways of helping me manage my caring role. Also going to art gallery visits with other carers gave me other things to think about other than caring for a while, but also time to share my role with others who understand, and who were happy to share good advice.*

> *Realised that I was a carer, attended courses which helped me cope better as a carer and identifying routes to help guide me through the social services.*

In other cases VOCAL facilitated access to a range of therapies e.g. reflexology, massage, yoga and gym sessions and swimming:

> *I attended gym sessions which was good for my health but I also enjoyed meeting other carers.*
>
> *Getting information on a swimming card 'saved me'.*

Counselling

Carers were very positive about counselling provided by VOCAL, in relation to both the personal benefits of the counselling and the quality of the counsellors.

> *Counselling excellent, just having someone to listen to you is so good, and the small classes are good.*
>
> *Massive life changing help in the form of counselling. It has taken me from despair to taking control of my life for really the first time.*
>
> *I went initially to access counselling, but I got much more than that! I've been given information to help in my carer role and help and access to activities that would help support me.*
>
> *Professional counselling aimed at carers, identifying problems and suggesting remedies.*

Support with financial and legal matters

Many carers used VOCAL to help them with applying for Power of Attorney (POA), Guardianship, setting up a will and with navigating their way through the benefits system.

Assistance with setting up Power of Attorney (POA) was the service most frequently mentioned by carers:

> *Power of Attorney matter concluded very effectively. Also had knowledge could go back to VOCAL if had any other queries.*
>
> *Power of Attorney information was explained very well indeed and queries were answered well and quickly.*
>
> *Gave help and advice needed for Power of Attorney and Guardianship.*
>
> *Free legal surgery. The half hour with the solicitor was very useful and helped me to have a better understanding about Power of Attorney.*
>
> *Person I care for was reluctant to prepare Power of Attorney or will, didn't see the need for them. With VOCAL's help in explaining why so important, and making it so easy, we now have Power of Attorney in place, and in process of preparing a will.*
>
> *I accessed a legal firm through VOCAL, to get legal guardianship for my son.*

Practical help in applying for benefits made a difference to carers. This included VOCAL informing carers about what benefits they might be entitled to, navigating the benefits system and then going on to help them to complete the relevant forms (e.g. Attendance Allowance, Carers Allowance, pension credits). This help was important to carers who were often in difficult stressful situations and unable to cope with the bureaucracy.

> *I got help immediately with an increase on my husband's Attendance Allowance from XX who made me feel at ease filling in the form, I feel I could talk to her about anything.*
>
> *I was very grateful for help in applying for pension credits in respect of my wife.*

> *The help I received from VOCAL was extremely beneficial knowing that VOCAL was there to support me through benefit advice and filling out the necessary paperwork. Seemed overwhelming especially during the bereavement of a family member.*
>
> *Unable to manage DWP documents and communications prior to VOCAL.*
>
> *Someone helped with legal and financial aspects, which is complicated (and more so when you are elderly and confused). The government and councils have made it so difficult to access services and benefits. When you are struggling to do the simplest tasks like cook and keep yourself clean 30 page booklets are completely unachievable and upsetting.*

The difference this made to carer's lives and the people they cared for was clear:

> *Help to apply for Attendance Allowance. Able to use taxis now for shopping and visits to bank and barber.*
>
> *We were able to get Attendance Allowance for my father-in-law, which took the pressure off him by being able to get him help around the house.*
>
> *XX was a great help in filling in Attendance Allowance form and general advice. She also told us about paying less in Council Tax. The extra money has really helped in that we have a gardener come every 2 weeks and can get windows cleaned. It allows little treats like going occasionally for a meal or just a coffee.*

VOCAL helped carers to apply for finance/grants from other sources of funding. Such funding allowed carers and families to purchase other goods and services that improved the quality of their lives. These included a wide range of things like employing a support worker/sitter, discounts on gym membership, football tournament, a greenhouse, a bread making course and table and chairs.

> *We are all able to sit together for evening meals as I got a table and chairs from the grant.*

Short breaks and respite

VOCAL were able to provide some carers with short periods of respite e.g. a sitter for a couple of hours a week to allow them time to for themselves or to go out as a family. Other carers were able to access holidays with VOCAL's help. Both these short regular periods of respite and longer holidays away from caring made a big difference to carer's ability to cope with caring and to look after their own mental health.

> *Allowed me 2 hours to go out, leaving a sitter with my husband, thus giving me peace of mind that he would be looked after.*
>
> *A support worker came to take my son out on a regular basis for a few hours. It was an invaluable chance for me to spend time with my other son and husband without pressure of being a carer all the time. It was also so important to know XX was safe and having a good time without me. This couldn't have happened without VOCAL's support and funding.*
>
> *Counselling and short breaks fund helped me to recharge my batteries and gave me a break from caring.*
>
> *Getting a break at low point just boosted my spirits.*
>
> *Has enabled me to take my dad away on short breaks and have the money to pay for it.*
>
> *VOCAL gave me the money so me and my children could go on holiday for a break..*

Help made a small difference

Those who said the help from VOCAL made a small difference to them mentioned many of the same aspects of VOCAL's service as those who considered the help they received had made a big difference to them e.g. having someone to talk to, not feeling alone, information particularly signposting to other services and sources of help, attending training courses, legal advice and help with setting up POA, information and advice on accessing benefits, recognising themselves as a carer and meeting other carers.

For carers newly in contact with VOCAL there had been little time for this to make much difference; indeed some felt they would have benefitted more if they had known about VOCAL's services sooner.

> *It gave me options which I'm not yet ready to exercise, but the information is there for when I am!*
>
> *It's only a small difference as I have only just started receiving help. But even knowing help is out there is huge!*
>
> *The course on MS was very informative but would have been of greater use to me had I heard about VOCAL and attended a course while my son's disabilities were less severe.*
>
> *I think if we had received the training earlier it would have had a bigger impact. This was not through anything VOCAL could have done other than more visibility of website.*
>
> *It took about 6 months before POA was sorted out. I received this the day before my mother died.*

VOCAL's help was felt to make little difference where there was delay in access to other agencies'.

> *Edinburgh Social Work backlogs mean despite VOCAL's advice, I've not yet been able to obtain additional support.*
>
> *I am still trying to access services for the person I care for, this seems to be ongoing and has been for 12 years.*

A few carers felt less positive about their experiences of VOCAL:

> *VOCAL put me in contact with solicitor (XX) who have drawn up a revised will, reviewed deed of trust, revised Power of Attorney. All at considerable cost to me. VOCAL put me in touch with an alcohol referral unit which was no help – my (cared for person) has subsequently died.*
>
> *The initial Las/VOCAL counselling was a very useful chance to talk. I had to cancel the second sessions as I felt uncomfortable with the counsellor and have got a part time job.*
>
> *One person (carer) in the group took over the Training course.*

Help received from VOCAL made no difference

Seventeen carers (3%) reported that the help they received from VOCAL made no difference to them as a carer and eight of these went on to make a comment. Five of these comments are detailed below. The remaining three carers reported that they had no contact with VOCAL or did not require any help.

> *A solicitor came out to visit - but the estimate for services was extortionate + unaffordable - so no use at all.*
>
> *As explained overleaf, my partner is 45. I am 43 and we have two small children. A lot of the information relates to dementia and older people which I understand but there is little mention of other types of carers.*
>
> *Attended a 'stress' course - not a success. Felt more stressed afterwards.*
>
> *I asked for help with mother's pension when she passed away. Got told nothing can be done because I was not her spouse. They did what they could and I never for respite. Was always late in applying. I*

> *paid for myself for a holiday, I was a nervous wreck.*
>
> *I cared for my partner for almost 13 years. I never knew anything about Carers Allowance until speaking to another carer at one of your courses – the wife of the person she cared for! I never dreamed that the government would give you money for looking after a family member! A member of your staff worked out that I could have claimed almost £28000. Because I had 'managed' without the money I couldn't claim anything retrospectively.*

The carers who felt they could not say whether VOCAL's help had made a difference to them had mostly not used the service but three submitted the following comments demonstrating very different reasons as to why VOCAL had not made a difference to them:

> *Haven't had any help from VOCAL. Only phoned once. The person I spoke to made me feel guilty – stressed something I considered inappropriate. Also the person I care for does not live in the VOCAL area (I do) and they asked why I was approaching VOCAL and not an organisation in the person being cared for's area. I haven't been back in touch.*
>
> *Have attended on VOCAL meeting. But it was for Dementia sufferers mainly. My wife has (XX condition) which appears not to require the same treatment as EAI sufferers.*
>
> *I haven't acknowledged the role of carer as I have only thought of myself as a wife as I have always been caring all my married life and this dementia is still mild to moderate and my husband has always been difficult and doesn't think he needs any help.*

8 Appendix 1

8.1 Comparison tables for all responses 2011 (where available), 2013 and 2015 VOCAL surveys

Table 8-1 Carer status

Carer status	2013						2015					
	Midlothian		Edinburgh		TOTAL		Midlothian		Edinburgh		TOTAL	
	No.	%	No	%	No	%	No	%	No	%	No	%
Current carer	104	83	487	56	591	85	150	83	611	84	761	84
Former carer	11	9	46	8	57	8	21	12	73	10	94	10
Both	10	8	34	6	44	6	9	5	44	6	53	6
TOTAL	**125**	**100**	**567**	**100**	**692**	**100**	**180**	**100**	**728**	**100**	**908**	**100**

Table -8-2 Carer age group

Age group	2011		2013						2015					
	TOTAL		Midlothian		Edinburgh		TOTAL		Midlothian		Edinburgh		TOTAL	
	No	%	No.	%	No	%	No	%	No	%	No	%	No	%
20-60 years	225	37	59	47	263	46	322	47	74	41	310	43	384	42
61 to 79 years	262	43	43	34	206	36	249	36	61	34	274	38	335	37
80 and over	64	10	12	10	44	8	56	8	19	11	58	8	77	8
Age not given	60	10	11	9	54	10	65	9	26	14	86	12	112	12
TOTAL	**611**	**100**	**125**	**100**	**567**	**100**	**692**	**100**	**180**	**100**	**728**	**100**	**908**	**100**

Table 8-3 Carer gender

Carer gender	2013						2015					
	Midlothian		Edinburgh		TOTAL		Midlothian		Edinburgh		TOTAL	
	No.	%	No	%	No	%	No	%	No	%	No	%
Male	31	25	114	20	145	21	42	23	161	22	203	22
Female	93	74	444	78	537	78	136	76	562	77	698	77
Transgender/ticked both			1	0	1	0	1	1	0	0	1	0
Gender not given	1	1	8	1	9	1	1	1	5	1	6	1
TOTAL	**125**	**100**	**567**	**100**	**692**	**100**	**180**	**100**	**728**	**100**	**908**	**100**

Table 8-4 Age group of person receiving care

Cared for age group	2011		2013						2015					
	TOTAL		Midlothian		Edinburgh		TOTAL		Midlothian		Edinburgh		TOTAL	
	No	%	No.	%	No	%	No	%	No	%	No	%	No	%
Up to 17 years	195	32	17	14	58	10	75	11	16	9	75	10	91	10
18-25 years			7	6	38	7	45	7	7	4	47	6	54	6
26-54 years			12	10	113	20	125	18	26	14	128	18	154	17
55-60 years			5	4	28	5	33	5	19	11	26	4	45	4
61-79 years	306	50	38	30	126	22	164	24	48	27	189	26	237	26
80 and over			38	30	167	29	205	30	48	27	227	31	275	30
Age not given	114	18	8	6	37	7	45	7	16	9	36	5	52	6
TOTAL	**615**	**100**	**125**	**100**	**567**	**100**	**692**	**100**	**180**	**100**	**728**	**100**	**908**	**100**

Table 8-5 Carer ethnic group (2015)

	Midlothian		Edinburgh		TOTAL	
	No.	%	No	%	No	%
White	169	*94*	689	*95*	858	*94*
Asian, Asian Scottish, Asian British*	3	*2*	15	*2*	18	*2*
White & Asian, Asian Scottish, Asian British*	2	*1*	-	-	2	*0*
Caribbean or Black	-	-	2	*0*	2	*0*
Mixed or multiple ethnic group	1	*1*	4	*1*	5	*1*
African	-	-	3	*0*	3	*0*
Arab	-	-	2	*0*	2	*0*
Other ethnic group	3	*2*	1	*0*	4	*0*
Not given	2	*1*	12	*2*	14	*2*
TOTAL	**180**	***100***	**728**	***100***	**908**	***100***

* Respondents ticked both White and Asian, Asian Scottish, Asian British categories

8.2 Analysis of response by sector (Edinburgh respondents only)

Table 8-6 Age of carer by Sector

	East		North West		South Central		South West		TOTAL	
Carer age group	No.	%	No	%	No	%	No	%	No	%
20 to 60 years	59	*46*	81	*39*	64	*37*	81	*46*	285	*42*
61 to 79 years	41	*32*	90	*43*	70	*41*	63	*36*	264	*39*
80 and over	12	*9*	15	*7*	15	*9*	15	*9*	57	*8*
Age not given	15	*12*	22	*11*	23	*13*	16	*9*	76	*11*
TOTAL	**127**		**208**		**172**		**175**		**682**	

Table 8-7 Carer gender by sector

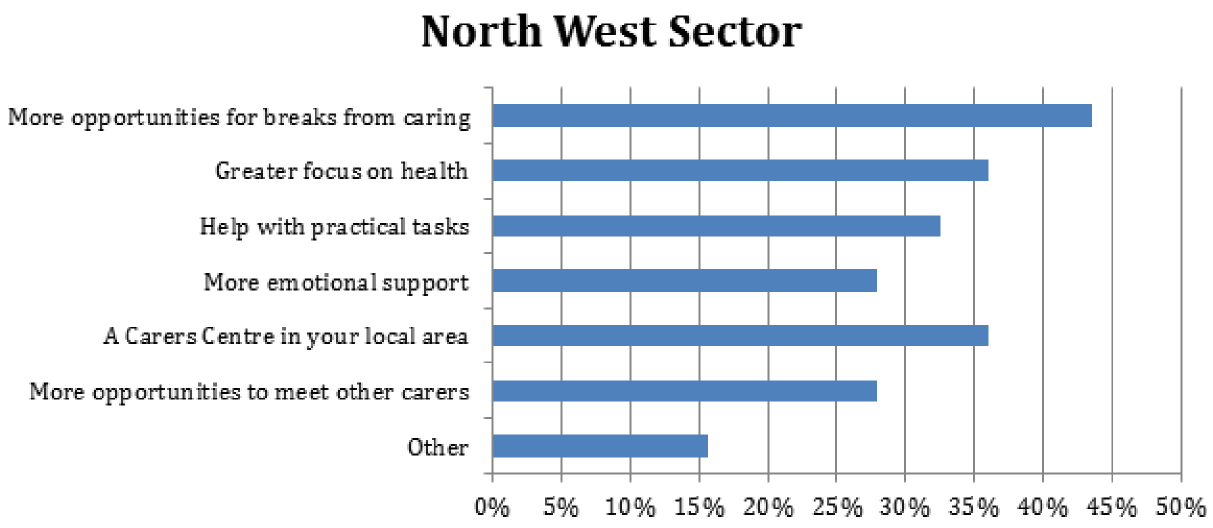
	East		North West		South Central		South West		TOTAL	
Carer gender	No.	%	No	%	No	%	No	%	No	%
Male	28	*22*	43	*21*	38	*22*	42	*24*	151	*22*
Female	97	*76*	165	*79*	133	*77*	131	*75*	526	*77*
No data	2	*2*	0	-	1	*1*	2	*1*	5	*1*
TOTAL	**127**		**208**		**172**		**175**		**682**	

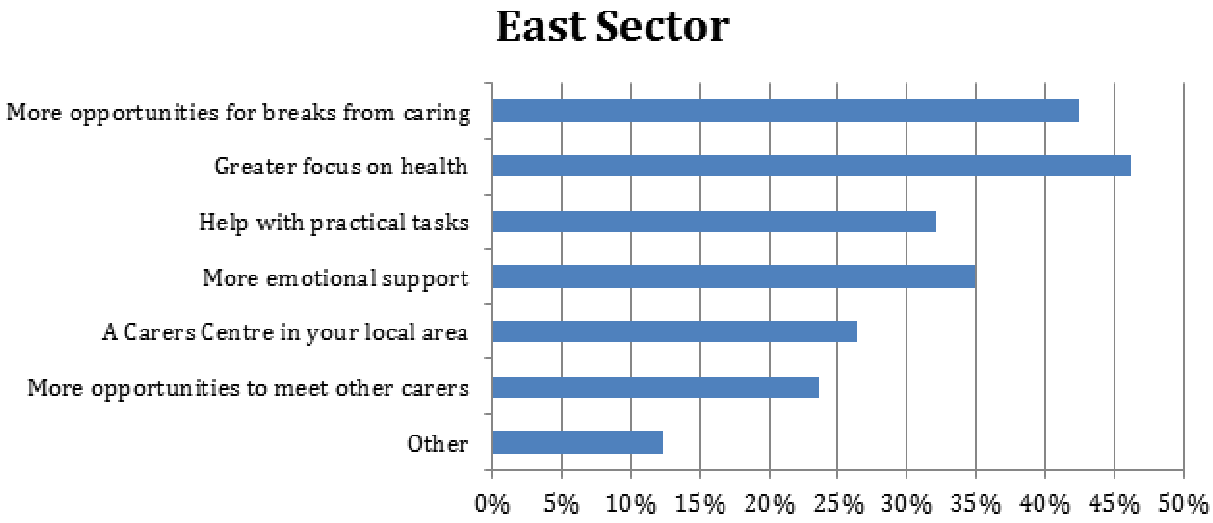
Table 8-8 Age of person cared for by sector

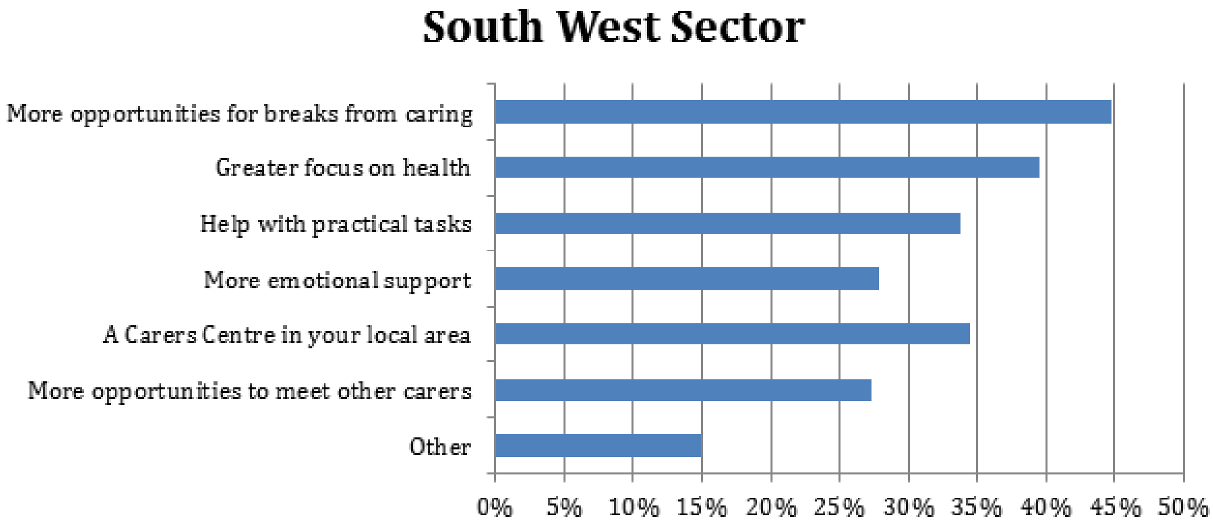
	East		North West		South Central		South West		TOTAL	
Age of cared for	No.	%	No	%	No	%	No	%	No	%
Up to 17 years	10	*8*	24	*12*	16	*9*	21	*12*	71	*10*
18-25 years	7	*6*	13	*6*	10	*6*	13	*7*	43	*6*
26-54 years	23	*18*	40	*19*	24	*14*	31	*18*	118	*17*
55-60 years	5	*4*	2	*1*	11	*6*	6	*3*	24	*4*
61-79 years	34	*27*	50	*24*	45	*26*	50	*29*	179	*26*
80 and over	41	*32*	71	*34*	56	*33*	45	*26*	213	*31*
Age not given	7	*6*	8	*4*	10	*6*	9	*5*	34	*5*
TOTAL	**127**		**208**		**172**		**175**		**682**	

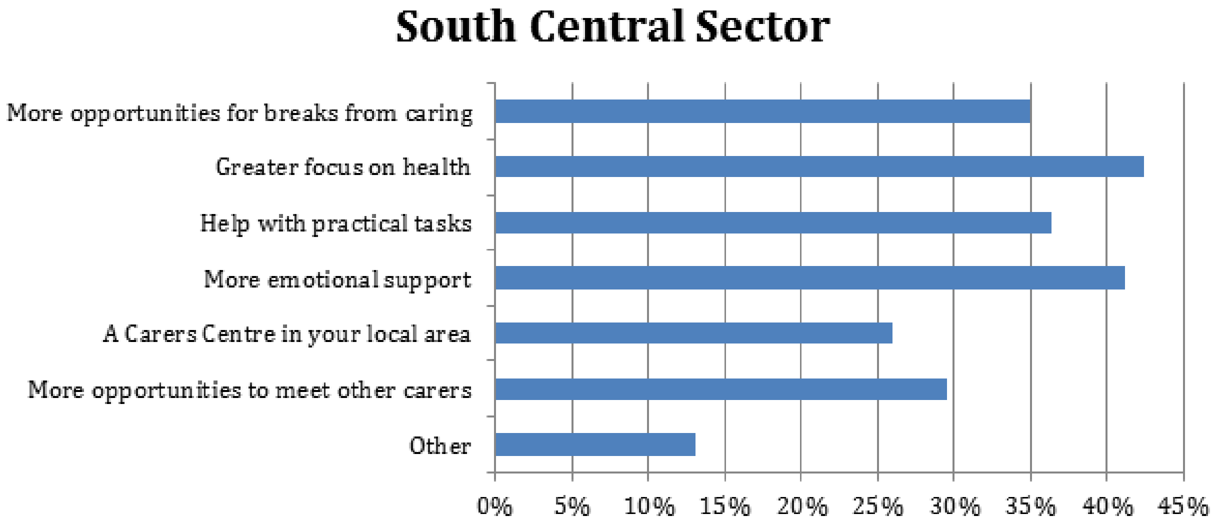
Table 8-9 Services and support VOCAL should be delivering in the future by sector

	East		North West		South Central		South West		TOTAL	
	No.	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
Other	27	*16*	13	*12*	23	*12*	19	*23*	82	*14*
More opportunities to meet other carers	48	*28*	25	*24*	42	*24*	43	*42*	158	*27*
A carers centre in your local area	62	*36*	28	*26*	53	*26*	38	*53*	181	*31*
More emotional support	48	*28*	37	*35*	43	*35*	60	*43*	188	*33*
Help with practical tasks	56	*33*	34	*32*	52	*32*	52	*52*	195	*34*
Greater focus on health	62	*36*	49	*46*	61	*46*	62	*61*	234	*40*
More opportunities for breaks from caring	75	*44*	45	*42*	69	*42*	51	*69*	240	*42*
TOTAL	**172**	**100**	**106**	**100**	**154**	**100**	**146**	**154**	**578**	**100**




East Sector
More opportunities for breaks from caring
Greater focus on health
Help with practical tasks
More emotional support
A Carers Centre in your local area
More opportunities to meet other carers
Other
0%
5%
10%
15%
20%
25%
30%
35%
40%
45%
50%


South West Sector
More opportunities for breaks from caring
Greater focus on health
Help with practical tasks
More emotional support
A Carers Centre in your local area
More opportunities to meet other carers
Other
0%
5%
10%
15%
20%
25%
30%
35%
40%
45%
50%


South Central Sector
More opportunities for breaks from caring
Greater focus on health
Help with practical tasks
More emotional support
A Carers Centre in your local area
More opportunities to meet other carers
Other
0%
5%
10%
15%
20%
25%
30%
35%
40%
45%

9 Appendix 2

Survey Questionnaire

vocal
working with carers

VOCAL EDINBURGH CARER SURVEY 2015

Please complete this survey and return it to VOCAL in the FREEPOST- envelope provided.
Address: Freepost RTJZ – RBZT – LHGH, VOCAL, 8-13 Johnston Terrace, EH1 2PW

Your experience with VOCAL

1. Are you?

- A carer ☐1
- A former carer ☐2
- Both ☐3

2. Do you care for someone in this group? *(tick all that apply)*

Physical health problem	☐1	Mental health problem	☐1
Child with additional needs	☐1	Learning disability	☐1
Long term condition	☐1	Drug or alcohol problem	☐1
Dementia	☐1	Other (please state)	☐1

3. How did you find out about VOCAL? ____________________

4. When did you last use any VOCAL services?
(other than receiving Carer News)

- Within the last 6 months ☐1
- 7-12 months ago ☐2
- More than a year ago ☐3

5. Please rate VOCAL's response(s):

	Excellent	Good	Fair	Poor	Very poor	Can't say
The ease of getting in touch with VOCAL	☐1	☐2	☐3	☐4	☐5	☐6
Friendliness of response	☐1	☐2	☐3	☐4	☐5	☐6
Getting as much information as you needed	☐1	☐2	☐3	☐4	☐5	☐6
Getting information about other groups/organisations	☐1	☐2	☐3	☐4	☐5	☐6
Knowledge of the staff and volunteers	☐1	☐2	☐3	☐4	☐5	☐6
Doing what they said they would	☐1	☐2	☐3	☐4	☐5	☐6
Overall, how would you rate VOCAL's response?	☐1	☐2	☐3	☐4	☐5	☐6

6. Which VOCAL services have you found useful? *(Tick all that apply)*

Information (including carer information pack)	☐1	Help to look after yourself	☐1
Help to plan support	☐1	Financial planning and benefits advice	☐1
Meeting other carers / carer support groups	☐1	Counselling	☐1
Training courses and seminars	☐1	Family support (Addictions)	☐1
Help with accessing short breaks and respite	☐1	Advocacy	☐1
Help with Power of Attorney / legal issues	☐1	Social/leisure and health activities	☐1
Help with managing your caring role	☐1	Website	☐1
Any other service, can you say what?		…………………………	☐1

Any further comments on the services?

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

- Yes, the help I received from VOCAL made a **big** difference ☐1
- Yes, the help I received from VOCAL made a **small** difference ☐2
- The help I received from VOCAL made **no** difference ☐3
- Can't say/not applicable ☐4

Please tell us how and why?

Carer Identification

Many people with a caring role don't automatically think of themselves as a 'carer'. As a result they often miss out on vital information and support. Most people who contact VOCAL do so because a family member or friend referred them, but health, social care and employers have a crucial role to play too.

8. Who first helped you to realise that you are a carer? *(Tick one)*

I realised myself	☐1	Someone at your GP surgery	☐6
Family member or friend	☐2	Someone at the hospital	☐7
Social worker or Occupational Therapist	☐3	Someone at your work	☐8
Someone at Social Care Direct	☐4	Someone from another organisation	☐9
Someone at an organisation supporting the person you care for	☐5	*please say which:* ____________	

9. Did any of the above make a direct referral to VOCAL on your behalf?

Yes ☐1 No ☐2 Don't know ☐3

10. At this point of referral were you:

Caring for less than 2 yrs ☐1 Caring for 2-5 yrs ☐2 Caring more than 5 yrs ☐3 Don't know ☐4

11. I am . . . *(please tick one)*

In paid employment ☐1 Studying ☐2 Both ☐3 Neither ☐4

If you are employed or studying which of the following are important to you? *(Tick all that apply)*

My employer / college . . .

- asks me about my caring responsibilities ☐1
- helps me to access information and support related to my caring role ☐1
- has someone I can speak to in confidence about my caring role ☐1
- has a carer support group ☐1
- has a carers policy ☐1
- links me into local carer support ☐1

Economic Well-being

12. Which of the following statements apply to you? *(Tick all that apply)*

Taking on a caring role has affected my finances ☐1
I have used some of my own money and savings to pay for care ☐1
I have had to reduce or give up hours in paid employment ☐1
I have lost National Insurance contributions after giving up work ☐1
My expenses (eg. utility bills, food and travel) have increased since I started caring ☐1
I am not financially worse off after taking on my caring role ☐1

13. Which of these issues are important to you? *(Tick all that apply)*

Accessing benefits and allowances ☐1
Reducing energy and utility bills ☐1
Funding to pay for breaks from caring ☐1
Reducing number of hours at work ☐1
Managing debt ☐1
Planning for the future (Power of Attorney, Wills) ☐1
Remaining in paid employment ☐1
Flexible working arrangements ☐1

Other, please say what . . . .

A life alongside caring

14. What are the barriers to having time for yourself and a life alongside your caring?

I find the barriers to having time to myself / life outside caring are: *(please say below, eg. don't know what is available, I can't afford to, no barrier)*

Using technology

15. When did you last use the Internet? *(Tick one)*

Within the last 7 days ☐1
Between 8 days and 3 months ago ☐2
More than 3 months ago ☐3
Never used ☐4

16. Which of the following statements apply to you? *(Tick all that apply)*

I am confident using the internet ☐1
I lack confidence in using the internet ☐1
I don't see how using the internet will help ☐1
I have saved money using the internet ☐1
I can't afford to pay for the internet ☐1
I go online to get information and support ☐1
I contact family and friends online ☐1
I have no time to learn/use the internet ☐1

17. Do you use social media? *(Tick all that apply)*

Facebook ☐1
What's app ☐1
Twitter ☐1
Other (please state) ☐1

Shaping services and support for the future

Over the coming months VOCAL will write a new five year Business Plan. It will set out directions for the organisation to support carers to build carer resilience and health and wellbeing. We would like to hear your thoughts about the services and support VOCAL should be delivering and developing in the future.

18. What other services and supports do you think VOCAL should develop and why?

Greater focus on health (physical & emotional) ☐1
More emotional support ☐1
Help with practical tasks **(eg.** household, shopping, gardening, hairdressing) ☐1
More opportunities to meet other carers ☐1
A Carers Centre in your local area ☐1
More opportunities for breaks from caring ☐1
Other *(please say what in box below)* ☐1

And finally some questions about you

19. Are you? Male ☐1 Female ☐2 Identify as transgender ☐3 **20. Your age:** ☐☐☐

21. How many people do you currently care for? ☐

22. Age(s) of the person(s) you care for: ☐

23. Which group best describes your ethnic group or background?

White ☐1
Asian, Asian Scottish, Asian British ☐2
Caribbean or Black ☐3
Any other ethnic group, please state: .... ☐7
Mixed or multiple ethnic group ☐4
African ☐5
Arab ☐6

24. Equalities

The Equality Act 2010 promotes equal opportunities for specified groups including: age, disability, gender re-assignment, marriage/civil partnership, pregnancy/maternity, race, religion and belief, sex and sexual orientation. Do you have any equalities issues relating to your caring role?

Thank you for completing the questionnaire

To be entered in the prize draw please provide your contact details below:

Name: ____________________
Address: ____________________
Telephone: ____________________ **Email:** ____________________

We may wish to talk to some carers in the future to discuss issues relevant to carers.
If you are willing to be contacted to help us in this way please indicate this by ticking this box ☐

Any information you give us will be treated in the strictest confidence.

For office use Ref Loc

VOCAL company reg: SC183050 Registered Charity: SC020755

HAPPY TO **TRANSLATE**

You can get summary versions in Braille, large print, easy read and audio if you ask us - call VOCAL on 0131 622 6666.

PQASSO QUALITY MARK level 2 Charities Evaluation Services

NHS Lothian

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Private limited company (Scotland): SC183050