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Carer Survey Report 2013

A study of carers' views on changes to health, social care and benefits services and on services and support received from VOCAL (Voice of Carers Across Lothian).

October 2013

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Acknowledgements

VOCAL would like to thank all carers who took the time to respond to this survey. We are also grateful for the professional support of researchers Anne Birch and Christine Sheehy who helped us with the development of the survey and undertook the full analysis of returns.

Like carers, they went beyond the call of duty to ensure carers views and opinions are adequately reflected to aid future planning of carer support in Edinburgh, Lothian and across Scotland.

Executive summary

VOCAL regularly invites feedback from carers on the quality of the support and information it provides, as well as views on changes to welfare and priorities for future services. VOCAL carried out a survey in 2011 of carers using their services. In response to carers' views expressed in this 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 the summer of 2013 a similar survey of all those on the VOCAL database of carers was conducted. The survey had two main purposes. It provided an opportunity for carers to comment on recent and imminent changes in the way carers receive services and support (including carer's rights, Self-Directed Support, economic well-being and using technology). It also sought carers' feedback on their experiences of VOCAL and the difference this made to their caring.

Questionnaires were sent to 5,498 carers. The survey was also advertised on the VOCAL website and promoted through carer networks. A total of 714 responses were received – a response rate of 13.2% which is slightly lower than the response rate achieved for the 2011 survey (14%).

- 42% of all respondents had been in touch with VOCAL within the previous six months and 85% identified themselves as current carers, 8% as former carers
- The majority of respondents were female (78% vs 21%). Just under half (47%) were aged under 60 years of age, over a third (36%) were aged 61 to 79 years and 8% were aged over 80 years. Older carers (61 and over) comprised a smaller proportion of respondents in the 2013 survey than in the 2011 survey (44% vs 53%).
- Almost three quarters of respondents (74%) came from Edinburgh and almost a fifth (19%) from Midlothian. These proportions are very similar to the 2011 survey, 72% and 18% respectively.
- The majority of respondents (93%) classified themselves as white and 3% as from other ethnic minority groups.
- Almost a third (30%) of those receiving care were aged 80 and over. More than a half (54%) were aged over 60 years of age compared to 50% in 2011. In 2013, the proportion of those receiving care aged 60 and under was greater than in 2011, (41% vs. 32%).
- 70% of carers provided care for one person, 15% for two people and 3% for 3 people.
- The majority of carers provided care for people with physical health problems (44%), 41% with long term conditions; and around a quarter for those with dementia (27%) or mental health problems (24%). A fifth (20%) of carers provided care for someone with a learning disability.

Carers' Assessments

Carers' assessments are recognised to be helpful for carers and practitioners to identify key priorities for carer support and as a gateway to appropriate services, provided the process is supportive and inclusive. In future, carer assessments may take on even greater importance to support carers early in their caring role and to target services to those in greatest need and in complex caring situations.

- Carers were asked who they would be most comfortable with carrying out a carers' assessment. Someone from the local carers centre was the most popular choice (58%), followed by someone from the health service (25%), and then someone from an organisation supporting the person receiving care (23%).

- Only 9% chose someone from the council and 4% suggested other organisations. Twenty five respondents mentioned VOCAL specifically
- The knowledge, understanding and, in some cases, specialist skills of the assessor were considered more important than the agency that the assessor came from. It was also felt that an assessor should be caring and understanding of carers' needs.
- Some carers had already had experience of carer's assessments.
- More than half of carers considered that information and advice, emotional support, condition specific training, regular breaks from caring and counselling should all be provided by right and free of charge for carers. Just under half (47%) would like advocacy and 46% would like moving and handling training to be available by right and free of charge.
- A third of carer's comments related to the need for financial support and/or advice including welfare rights advice and benefits assessment; filling in forms. Free leisure cards and funded breaks were also mentioned frequently.
- Specific advice or training to help carers support the needs of the person receiving care was also mentioned.

Self Directed Support

Self Directed Support (SDS) aims to give people who require care and their carers greater choice and flexibility in how they receive support. Under new legislation, all those eligible to receive support must be offered SDS and, for the first time, carers can be offered SDS.

- The majority of carers (63%) felt they knew little or nothing about SDS and 90% felt it was 'very' or 'fairly' important that they got help and support in understanding and choosing SDS options.
- There were fears about how SDS might affect current levels of benefits, quality of care and the availability of services from carer organisations.
- Carers did not feel well informed about SDS and wanted to know more about it and how it might affect them. Carers were concerned about the responsibility and time needed to manage a Direct Payment. Some carers felt that the introduction of SDS might be used as a means of cost cutting for local authorities.

Economic well being

- More carers indicated that they were interested in aspects of financial planning now than in the future, 82% vs 51%. For example, maximising benefits was important to a larger proportion of carers now rather than in the future.
- When asked about the aspects of financial planning important to them, 89% of respondents chose 'planning for the future (i.e. Power of Attorney, wills and trusts)', 74% maximising allowances, and 39% combining paid employment with caring responsibilities.
- About 14% indicated that they felt that were on top of financial issues and 9 of these carers mentioned that VOCAL had helped them in this.
- Carers wanted support on where to get help on financial matters, entitlement to benefits, pensions, childcare and related financial matters.

- There were views on how this support should be delivered including leaflets, newsletters, one to one help, at home, and via courses/seminars. Views were also expressed that the support should be regular, free and not just ‘on line’.
- Combining employment with caring was an area that some carers wanted support. Issues included giving up employment to care; support to get back into employment; concerns for the person receiving care if the carer returned to work. A number of carers wanted financial support for their caring role.
- Topics mentioned in financial planning for the future included financial advice regarding going into paid care, power of attorney, cost of legal advice and financial help with respite.

Using technology

- Three quarters of carers (76%) had used the internet within the last 3 months. 18% of carers had never used the internet. Older carers were less likely to have used the internet.
- More than a third of carers (37%) expressed interest in obtaining support to use the internet if this were offered. Those who had last used the internet more than three months ago and ‘never’ users were more interested in potential support.
- Carers favoured support at home (19%); via the local library (15%); at a local carers centre (12%).
- Carers who had never used the internet were likely to say this was due to access such as cost of equipment and/or broadband; a lack of motivation in using the internet e.g. lack of time or energy to tackle computers; no perceived need or interest in getting familiar with computers; a sense of being ‘too old’ to bother and the carer’s own incapacity.
- Those who had used the internet sometime in the last 3 months indicated that they had problems similar to ‘never’ users in accessing the internet as above but they also had less confidence in using computers.

Carers’ experience of VOCAL

- An overwhelming majority of carers (93%) rated VOCAL’s overall response as ‘excellent’ or ‘good’. Older age groups rated VOCAL’s overall response more highly than younger age groups, 98% vs 93%.
- Similarly over 90% of carers rated as excellent or good the friendliness of VOCAL’s response, knowledge of staff and volunteers, ease of getting in touch with VOCAL and getting as much information as needed.
- 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, advice and support and training courses and seminars were the services that most carers reported as finding useful (70%, 62% and 35% respectively). Other services mentioned by around a quarter of respondents were carer support groups and seminars (28%) and help with POA/legal issues (27%).
- Carers commented that the information provided by VOCAL helped keep them up to date and was provided in terms they could understand although a small number felt they were overwhelmed with information. Practical help, for example with applying for benefits was mentioned by some as was being able to talk to someone in times of stress.

- 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. However some carers reported that they could not attend training courses etc for a number of reasons including; timing of courses, physical access (access to building, distance to course).
- Two thirds of carers (66%) reported that the help they received from VOCAL made a big difference to them and another 19% said it made a small difference. This was a slight increase in the number of carers in the 2011 survey reporting that VOCAL's help made a difference to them (84% in 2011 to 85% in 2013).
- The comments on how VOCAL's help had made a difference covered similar topics to those in the 2011 survey. These included: helping carers to recognise their own needs as carers and normalising their feelings about caring; reducing feelings of isolation; being listened to in a non-judgemental and supportive way; giving carers confidence and empowerment; peer support; practical help e.g. help with Power of Attorney, completing benefit forms; support in dealing with other agencies including advocacy; information; help with understanding the condition of the person receiving care.
- Twenty-seven (4%) of carers said the help they received from VOCAL made no difference to them. Of these, seven reported a poor experience when dealing with VOCAL. Two of these were because VOCAL failed to get back to the carer when they said they would, two felt the service was not specialised enough to help, one was never able to get the right person; two did not like the way they were treated by VOCAL personnel.

Conclusions

The comments received across the survey illustrate a very wide range of caring situations and a wide variety of carers' responses to these circumstances. Carers expressed the difficulties, challenges and associated overwhelming emotions of stress, pressure, anxiety and concern, experienced by many of them, as they sought to manage sometimes exhausting caring responsibilities. Often there was little time or energy to negotiate contact with external agencies and systems.

VOCAL provided the information, advice and support to help carers juggling the caring role with household responsibilities, maintaining their own health and wellbeing, financial worries and, for some, remaining in or finding suitable employment. The study also suggests that carers have strong views regarding carers' assessments and concerns regarding their lack of knowledge of SDS.

1 Introduction

1.1 Background

In Edinburgh and Lothian over 92,000 family carers, partners and friends support someone with a long term condition or disability or an older person.[1]

VOCAL seeks to provide high quality services to carers to support them in their caring role. Services include advice and information (including a regular newsletter and e-bulletin), training courses, emotional support and counselling, peer support groups, carer advocacy and a range of specialist interventions such as benefits and legal surgeries. The VOCAL Carer Support Team work with carers on a one-to-one basis to help them identify issues affecting them, and to provide the best quality outcome to them now and in the future.

VOCAL delivers carer support through two carers' centres in Edinburgh and Midlothian, and through staff based in the community.

VOCAL wishes to learn more about carer satisfaction with the services they provide and about the issues that are important to carers living in Edinburgh and Midlothian. With this aim in mind, in 2011 VOCAL carried out a survey of carers using their services. This survey achieved a response rate of 14% (611 carers). 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.

VOCAL are committed to undertaking a survey of carers every two years and in June 2013 launched the largest carer survey undertaken in Lothian to date, inviting around 5,500 unpaid family carers to share their views. The 2013 survey again focussed on carer experiences of VOCAL; it also provided an opportunity for carers to comment on recent and imminent changes in the way carers receive services and support: covering carer's rights, new legislation on Self Directed Support, economic well-being and using technology.

VOCAL aims to use findings from the survey to improve their own services and to work with partners in the NHS and local councils to improve the range and quality of support for carers.

1.2 Method

In June 2013, the VOCAL Carer Survey was posted to all carers on VOCAL's active contact list . In addition the survey was widely advertised on VOCAL's website, through Edinburgh's and Midlothian's network of carer support agencies and local voluntary organisations' councils (Edinburgh Voluntary Organisations Council and Midlothian Voluntary Action)

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

Respondents were given seven weeks to return the completed questionnaire. 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.

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[1] Lothian 92,777; Edinburgh 47,404; Midlothian 14,192; East Lothian 13,095; West Lothian 18,086. Caring Together: The Carers Strategy for Scotland 2010 – 2015. Source: The Scottish Household Survey 2007-08. ,. http://www.scotland.gov.uk/Publications/2010/07/23153304/30

The survey pack, issued direct from VOCAL, included an introductory letter from the Vice Convenor of the Board of Directors, and a short questionnaire (Appendix 2), and a FREEPOST reply envelope.

All data from the completed questionnaires was entered Into an Excel spreadsheet. Quantitative data was analysed using SPSS (Statistical Package for Social Science). 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.

The survey was organised by VOCAL who undertook the operational elements of the survey. Two external researchers - Anne Birch and Christine Sheehy - were responsible for designing and finalising the questionnaire (in partnership with VOCAL), organising data input, analysing responses and writing the final report.

1.3 Response

A total of 5,498 survey packs were issued based upon addresses on the VOCAL database. Fig 1-1 shows the response to the survey.

Figure 1-1 Response rate

Survey packs issued	5498
Returned undelivered	78
Survey packs delivered	5420
Responses received	714
Response rate	13.2%
Not included in numerical analysis	22

Reasons for not including returns in the numerical analysis are:

Figure 1-2 Reasons for non-inclusion of response

Questionnaire not completed – person cared for deceased	8
Spoiled questionnaire	1
Blank questionnaire	3
Marked 'not a carer'	2
Response by email only, specific questions not answered	2
Arrived too late to be included in analysis	6

Where appropriate the comments from these twenty responses have been taken into account in analysis of written comments.

The response rate of 13.2% is slightly lower than the previous survey in 2011 (14%) although more efforts were made to reach more carers

There was a varying degree of completion of the questionnaire across the survey, perhaps reflecting the level of interest or familiarity with particular topics.

552 (77%) individuals opted to provide contact details to enable them to take part in the prize draw, 162 made use of the option to reply anonymously.

1.4 Profile of respondents and those they care for

This section presents the characteristics of those carers who responded to the survey. Where possible comparisons are made to respondent characteristics in the 2011 survey.

The majority of respondents identified themselves as current carers (591, 85%), less than one in ten as former carers only (57, 8%) and a minority as both a former and current carer (44, 6%).

1.4.1 Age and gender of carers

Almost half of the carers responding to the survey in 2013 were aged between 20 and 60 years, 44% were over 60 years of age (Table 1-1). Older carers (61 and over) comprised a smaller proportion of respondents in the 2013 survey (44%) than in the 2011 survey (53%).

Table 1-1 Carer age group

Age group	2011		2013	
	No.	%	No.	%
20-60 years	225	*37*	322	*47*
61 to 79 years	262	*43*	249	*36*
80 and over	64	*10*	56	*8*
Age not given	60	*10*	65	*9*
Total	**611**	***100***	**692**	***100***

Female carers responding to the survey in 2013 outnumbered male carers 4:1 (Table 1-2).

Table 1-2 Carer gender 2013

	No.	%
Female	537	*78*
Male	145	*21*
Identify as transgender	1	*0*
Gender not given	9	*1*
Total	**692**	***100***

Female carers tended to be younger than male carers; over half of female carers (51%) were aged 20 - 60 years compared to under a third (33%) of male carers (Table 1-3). A higher proportion of male carers were in the oldest age group compared to females (18% vs 6%).

Table 1-3 Carer gender by carer age group 2013

	Male		Female		Trans gender		Not given		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
20-60 years	48	*33*	273	*51*	1	*100*		*0*	322	*47*
61 to 79 years	61	*42*	186	*35*		*0*	2	*22*	249	*36*
80 and over	26	*18*	30	*6*		*0*		*0*	56	*8*
Age not given	10	*7*	48	*9*		*0*	7	*78*	65	*9*
Total	**145**	***100***	**537**	***100***	**1**	***100***	**9**	***100***	**692**	***100***

1.4.2 Ethnicity of carers

The overwhelming majority of respondents (93%) 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 1-4).

Table 1-4 Carer ethnic group

	No.	*%*
White	646	*93*
Asian, Asian Scottish, Asian British	8	*1*
White & Asian, Asian Scottish, Asian British*	6	*1*
Caribbean or Black	1	*0*
Mixed or multiple ethnic group	4	*1*
African	1	*0*
Arab	2	*0*
Other ethnic group	2	*0*
Not given	22	*3*
Total	**692**	***100***

* Six respondents ticked both White and Asian, Asian Scottish, Asian British categories.

1.4.3 Where carers live

Table 1-5 shows a very similar geographic distribution of carers who responded in the 2011 and 2013 surveys. The majority (74%) came from Edinburgh and 19% from Midlothian.

Some respondents lived further afield, but care for people in the Lothians. Places mentioned in the 2013 survey included Borders, Falkirk, Fife (Dunfermline, Letham, Cupar), Glasgow, Dunoon, Banchory and Kirkwall).

Table 1-5 Carer local authority area

	2011		2013	
	No	%	No	*%*
Edinburgh	449	*74*	495	*72*
Midlothian	119	*19*	125	*18*
East Lothian	36	*6*	19	*3*
West Lothian			17	*2*
Other			12	*2*
No data	8	*1*	24	*3*
Total	**612**	***100***	**692**	***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 26/09/2013

1.4.4 Age of people receiving care

Table 1-6 shows the number of people receiving care in each age group.

Almost a third (30%) were in the 80 and over age group and more than half (54%) were over 60 compared to 50% in 2011.

In 2013, the proportion of people receiving care aged 60 and under was greater than in 2011, (41% vs. 32%).

Table 1-6 Age group of person receiving care

	2011		2013	
	No.	%	No.	%
up to 17 years	195	*32*	75	*11*
18-25 years			45	*7*
26-54 years			125	*18*
55-60 years			33	*5*
61-79 years	306	*50*	164	*24*
80 and over			205	*30*
Age not given	114	*18*	45	*7*
Total	615	*100*	*692*	***100***

Older carers (80 and over) were more likely to be caring for older people (70%). It is most likely to be their spouse, (Table 1-7). For the younger age groups of carers, 20-60 and 61-79, although over a quarter of them (24% and 29% respectively) were looking after older age groups, over 80s, sizeable proportions were caring for those in younger age groups: over a third of 20-60 year old carers were caring for under 25s whilst 24% of 61-79 year old carers were caring for 26-54 year olds. In both these cases they were likely to be looking after their children.

Table 1-7 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	69	21	4	2		0	2	3	75	11
18-25 years	41	13	1	0		0	3	5	45	7
26-54 years	55	17	59	24	3	5	8	12	125	18
55-60 years	23	7	5	2	2	4	3	5	33	5
61-79 years	47	15	96	39	9	16	12	18	164	24
80 and over	77	24	72	29	39	70	17	26	205	30
Age not given	10	3	12	5	3	5	20	31	45	7
Total	**322**	**100**	**249**	**100**	**56**	**100**	**65**	**100**	**692**	**100**

1.4.5 Number of people receiving care

Carers mostly cared for between one to three people (Table 1-8). A number of people noted other additional caring roles within the immediate or extended family or with neighbours:

> *I also help my older brother who has high-functioning aspergers.*

I keep an eye on two or three elderly neighbours and help out if I can.

2 year old child and grand daughter.

Table 1-8 Number of individuals cared for

Number cared for	Carer	Former carer	Carer & Former Carer	Total	%
1	452	9	25	486	70
2	94	1	10	105	15
3	16	0	3	19	3
4-6	2	0	0	2	0
None	0	4	0	4	1
No data	27	43	6	76	11
Total	**591**	**57**	**44**	**692**	**100**

We asked carers to identify the condition/disability experienced by the person they provided care for (Table 1-9). The majority identified caring for people with physical health problems (44%) or long term conditions (41%); dementia (27%) or mental health problems (24%) were relevant for about a quarter of carers and learning disability for a fifth (20%). One in ten of current carers cared for a child with additional needs. Conditions mentioned in the 'other category' included 'autism', 'Parkinsons', 'Age related Macular Degeneration' (AMD), 'stroke' and 'head injury'.

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

Table 1-9 Number of carers by condition/disability of person receiving care

Condition	Carer	Former carer	Carer and former carer	Total*	%
Physical health	273	13	21	307	44
Long term condition	258	8	16	282	41
Dementia	160	17	11	188	27
Mental health problem	141	5	17	163	24
Learning disability	131	2	5	138	20
Child with additional needs	75	2	0	77	11
Other	61	3	7	71	10
Drug or alcohol problem	29	5	10	44	6
Total	**591**	**57**	**44**	**692**	**100**

* Carers could tick more than one condition.

1.4.6 Contact with VOCAL

We asked carers when they had last used any VOCAL services (other than receiving the magazine Carer News). Just over 42% had used VOCAL in the last six months (Table 1-10).. Just over a third, 34%, had used VOCAL more than a year ago. Thirteen respondents (2%) 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 26% of former carers had been in touch with VOCAL in the last six months.

Table 1-10 When did you last use VOCAL services?

	Carer		Former carer		Carer and Former carer		Total	
	No.	%	No.	%	No.	%	No.	%
Within the last 6 months	251	42	15	26	22	50	288	42
7-12 months ago	111	19	15	26	6	14	132	19
More than a year ago	193	33	25	44	14	32	232	34
Never	12	2		0	1	2	13	2
No data	24	4	2	4	1	2	27	4
Total	**591**	**100**	**57**	**100**	**44**	**100**	**692**	**100**

1.4.7 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 five respondents (5%) chose to comment in this section.

Most comments were short and not all made it clear how they were affected in relation to their caring role. Several carers noted that they themselves had a disability:

> *I myself am registered disabled in both hands due to complications of diabetes.*
>
> *I have a disability myself under the Equality Act 2010.*
>
> *I am visually impaired.*

Although not a protected characteristic some felt they faced inequalities in relation to employment:

> *Inequality as carer when in paid employment.*
>
> *Yes, I always have a fight trying to get my [parent] treated equally and not disadvantaged by [parent's] disability. Additionally my employer is very unreceptive to my request for flexibile hours.*
>
> *Being female, staying in work has been a challenge. Finding suitable childcare is an ongoing issue.*
>
> *Gender – I earned £30,000 before I had to stop to care for our [child]. We have also saved society at least £200,000 because we have cared for our [child] at home and kept [child] out of hospital – UNFAIR.*

2 Carer's rights

2.1 Carer's Assessment

In future carers may require a Carer's Assessment in order to receive services and support as a carer. The purpose of the assessment is to look at what support carers need in their caring role. It also explores maintaining carers' health and well being and how carers balance caring with other areas of their lives such as employment or social activities.

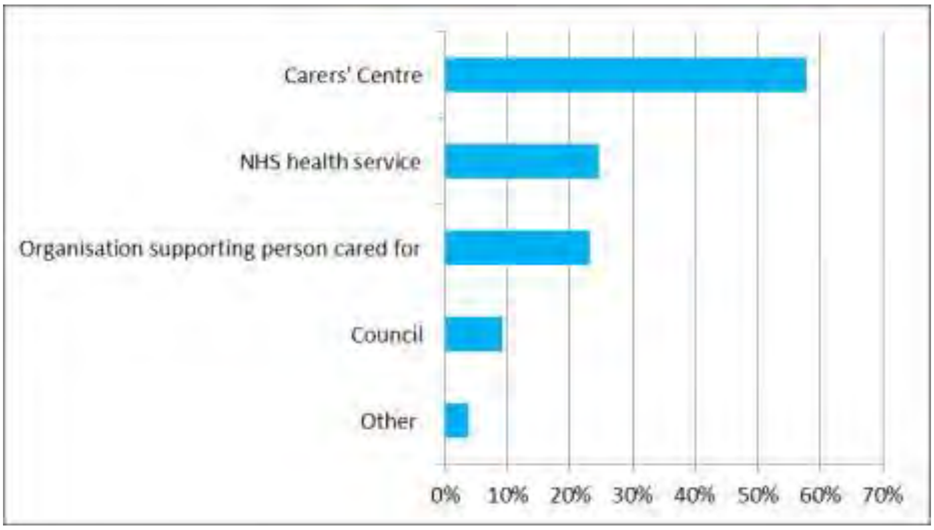
We asked carers who they would feel most comfortable with to carry out a Carer's Assessment. 94% of carers answered this question.

Table 2-1 Organisation carer is most comfortable with to carry out a Carer's Assessment

	No.	%
Someone from your local Carers' Centre	375	58
Someone from NHS health service	160	25
Someone from an organisation supporting the person you care for	150	23
Someone from the Council	59	9
Someone from another organisation	24	4
Total*	649	100

**Number may sum to more than 649/ 100% as carers could tick more than one option.*

Figure 2-1 The organisations that carers are most comfortable with to undertake a Carer's Assessment



Carers could choose one or more organisations that they felt comfortable with to carry out a Carers' Assessment. The majority (74%) chose just one of the main organisations, a further 14% chose two organisations, 4% chose more than that.

The most popular choice, by more than half (58%) was for someone from the local Carers' Centre to carry out the assessment and three quarters (76%) of these listed it as their only choice:

> *never had a carer's assessment but would prefer no.3 [carers' centre]*

Twenty five individuals mentioned VOCAL specifically, even referring to staff by name:

> *from somewhere like VOCAL if they were funded to do that.*
>
> *Past experience VOCAL courses and NHS and some council staff found to be very good.*

Other specific Carers Centre organisations mentioned included: Eric Liddell Centre, Care for Carers, Carers of West Lothian, Help the Aged or Age Concern, Hemihelp, RNIB, Woodburn Day Care Club, the Red Cross.

The second most popular choices were someone from the NHS (25%) or from the organisation supporting the person receiving care (23%). Comments in relation to potential NHS based assessors included a handful of suggestions that doctors/GPs do the assessment or specialist nursing staff:

> *Difficult - the NHS have also been very helpful so probably them or the Carer's centre.*
>
> *That it should be a specialist nurse with adequate training.*
>
> *Learning Disability nurse.*

Specific organisations mentioned which supported the person cared for included Marie Curie, Action for Children, Parkinson's UK, City of Edinburgh Council LAC Team or Headway, VOCAL and Alzheimers Early Onset Service, community nurses for disability.

Less than one in ten carers (9%) favoured someone from the council:

> *I found Midlothian Council social work dept very helpful.*
>
> *social services, from whom we already get support.*
>
> *Possibly social worker but as you are not allocated one for any time it's difficult for them to know you.*

4% (24) ticked 'another organisation' and these included:

> *Independent organisation without targets.*
>
> *National Autistic Society.*
>
> *PASDA as they actually understand the condition and others typically haven't specific expertise in autism.*
>
> *Simpson House.*

Seven people said they had already had a carer's assessment, four noting specifically social work involvement:

> *Have had a carer's assessment from a very insensitive social worker. Eventually got a very good and helpful social worker who put a package in place to help my [child] (and me!).*
>
> *Social Worker has arranged to do this in 2 weeks so already decided for me!*

Four current carers felt they just 'can't say, 'don't know', 'not sure'.

Carers who did not specify a particular agency, saying 'don't mind', 'any of the above', tended to highlight the knowledge, skills and qualities they wished to see in the person carrying out the assessment. 'Any' agency was felt acceptable as long as the assessor demonstrated appropriate knowledge and understanding:

> *were informed and caring.*
>
> *was qualified.*
>
> *who specialises in this area i.e. has specialist skills and knowledge of carers' needs.*

understand some of the problems of carers.

The attitude of the assessor was key:

> *It's the quality of the assessor that counts. Someone wise, knowledgeable and compassionate from any organisation.*
>
> *It depends on the attitude of the assessor.*
>
> *Someone who actually "cares" ie has done it!*
>
> *Would feel they have my best interests as a carer at heart.*
>
> *someone who truly understands the problems of the person you care for; [says 'NO' to council].*
>
> *whoever it is they should have a duty of confidentiality as they well have access to information on person cared for.*

The potential effect on the carer themselves was important:

> *Would prefer not to have to do any assessment. As a carer you sometimes feel your life/time isn't your own without having to give even more of yourself away.*
>
> *Never had experience of such an assessment. What is important is strengthening of oneself.*

A few comments indicated experience of finding assessment unhelpful and a desire to have a change of agency:

> *Certainly not the council social workers I have just, and still am going through my carers assessment with them and have lost all faith in them. Total nightmare.*
>
> *Feel the NHS or social work dept not the right people from experience.*
>
> *Someone from a carers centre like VOCAL. I had a bad experience with a carers assess from social worker. It was not supportive - one of the worst experiences ever.*

More than one assessor would enable a shared judgement to be made:

> *I think only one source might not be enough and more than one might be preferable.*
>
> *I think the judgement should be shared. Not just one person.*

Another wanted reassurance about funding to back up assessment:

> *Find carer assessments pointless - no funding services to back up need.*

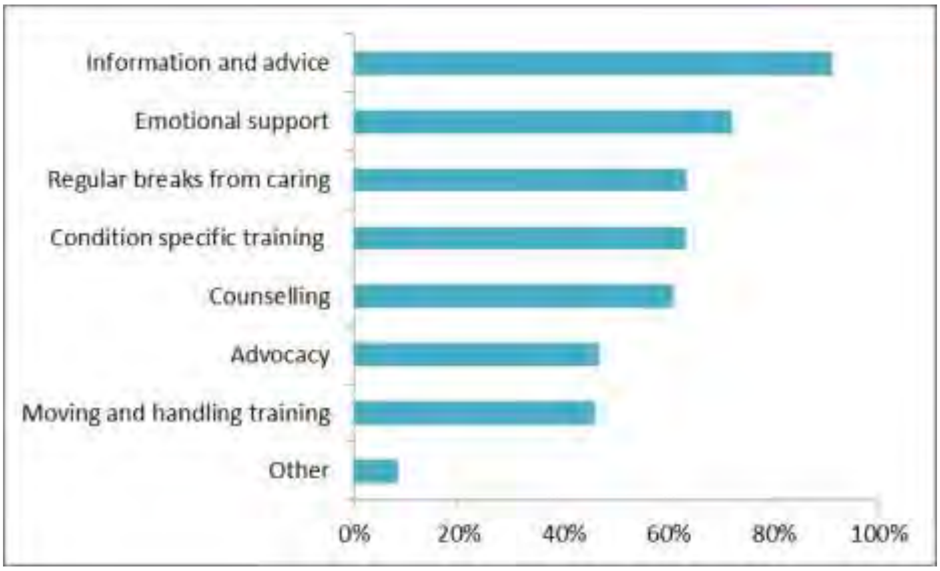
A small number of responses indicated quite a depth of feeling:

> *I couldn't complete it because if I wrote how I felt I think I would cry.*
>
> *nobody seems to care now as it has been 3 years since X has her stroke I get no help from anybody.*

2.2 Services which should be available to carers free of charge

We asked carers what services and support do you feel should be available to carers by right and free of charge. 97% (670 respondents) answered this question.

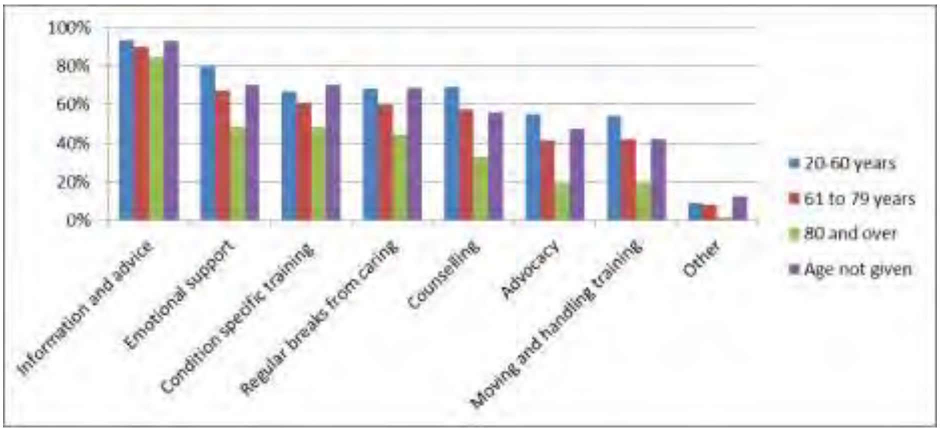
Figure 2-2 Services and support which should be available to all carers by right and free of charge (% of all carers)



The majority of carers said that information and advice (91%, 612) and emotional support (72%, 483) should be available. Around two thirds indicated condition specific training (63%, 425), regular breaks from caring (63%, 425) and counselling (61%, 409) to be important. Just under half would like advocacy (47%, 313) and moving and handling training (46%, 309) to be available. One in ten (9%) made other suggestions.

In these responses, information and advice was of equal importance across all age groups. A smaller proportion of the oldest age group chose any of the options (Fig 2-3 Table 7-8). For example counselling was important to two thirds (69%) of those aged under 60 years and to a third (33%) of those aged 80 and over.

Figure 2-3 Services and support by carer age group (%)



Eighty people provided additional comments. Where all options were chosen this might be reinforced with a comment that all were required ‘anything that helps’, ‘everything that a carer needs should be free’.

Around a third of comments concerned the need for carers to receive some form of financial support or advice. This ranged from welfare rights advice and benefits assessment for both the carer and the person receiving care including help with filling out forms, to subsidised or free services and specific benefits or payments. The services most frequently mentioned concerned free leisure cards and facilities or funded breaks:

> *Legal and advice financial.*
>
> *Some financial supports on a loan basis which could be paid back once the carer has got back on their feet.*
>
> *More help paying for things for carer like vouchers for haircuts, shoes and discount from phone people like Virgin media so carers can access internet - it is too expensive.*
>
> *Carers allowance should not be stopped when the carer becomes a pensioner.*
>
> *Regular breaks…etc - if this means free respite to enable a break yes.*
>
> *I would love the local authority to offer free/discounted gym memberships for carers. It would be a great way to deal with stress.*
>
> *free bus passes, as for what we receive is just £59 just doesn't cover all the travelling I need to do, if there were free bus passes there would be more chance travelling on a bus and not taxis.*

A couple of lone voices suggested that some carers may be more able than others to pay for services:

> *Breaks: perhaps these could be subsidised rather than free for those who could contribute financially.*
>
> *A lot is available free of charge already.*

Caring can take up a lot of time and practical support would be helpful for some:

> *Help with cleaning as very difficult to keep home tidy when caring takes up much of your time.*
>
> *Changing to a domestic role especially for carers unused to running a house and providing nutritious meals.*

Help was also needed to deal with ‘the system’:

> *I care for someone less than the hours needed to get support/money/respite. However, as caring has a significant effect on my life and interacts with my impairment, there should be support for people like me.*
>
> *help to organise breaks.*
>
> *Computer work. Assertive course as you deal with a lot of arrogant professionals.*
>
> *Assistance in getting extension for son etc.*

Carers wanted specific advice or training to support the needs of the person receiving care:

> *Terminal cancer.*
>
> *How to feed when there is a problem swallowing.*
>
> *There should be an opportunity for carers to access help for the cared for - like physiotherapy.*
>
> *Specific support groups mental health addictions in your area/region.*
>
> *someone who can talk directly to the person who is being cared for.*
>
> *Information on how the person you care for has been affected by affliction as early as possible in detail for lay person to understand.*

> *Emergency helpline 24/7*

Carers also wanted specific services or support to improve their own quality of life and well-being. Respite, breaks or sitting services would help as would leisure opportunities for carers:

> *remembering that the carer is important too and opportunities to maintain carer's health to be fit to look after my child.*
>
> *Sitting service, if person being cared for cannot be left. Simply to do food shopping, go to bank etc.*
>
> *Training in recognising and treating the mind/body imbalances in life which reflect stress of caring.*
>
> *Peer support from trained peer carers.*
>
> *leisure activities i.e. swimming/yoga, exercise classes etc.*

Assessment and support should be available as a matter of course, on a regular basis:

> *regular follow ups regardless of care or needs.*
>
> *Reassessment as needs change.*

Support was also needed for when the carer stopped caring and moved to a different role:

> *support when the caring has stopped. What do you do next?*

There were also some clear calls for general recognition and respect for the role they were undertaking:

> *Just notice we are there.*
>
> *Recognise paperwork that has to be done for cared for person (phone calls, organisation).*

3 Self directed support

Self directed support (SDS) aims to give carers and those they care for greater choice and flexibility in how they receive support. Individuals, assessed as needing support, can choose to:

- continue to receive services arranged by their local authority,
- purchase services offered by their local authority
- purchase services from a private provider or
- a combination of all three options.

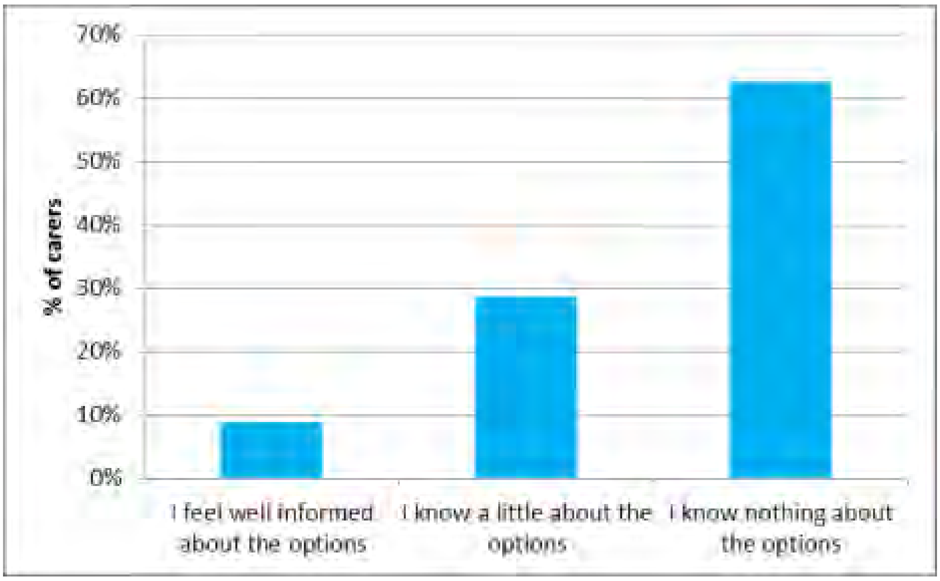
A form of SDS, Direct Payments (DPs) has been available for several years however, legislation passed in the Scottish Parliament in 2012 ensures that all those eligible to receive support must be offered SDS and, for the first time under this legislation, carers can be offered SDS.

Carers were asked how informed they felt about the options for SDS and how important it was that they received help and support in understanding these options. They were also invited to express any concerns they may have about how these changes might affect them as a carer.

3.1 Knowledge of SDS

A total of 673 (97%) carers responded to the question on how much they knew about the options for SDS. Of those responding to this question, almost two thirds (63%) reported that they knew nothing about the options (Figure 3-1), 29% knew a little about the options and less than 10% felt well informed.

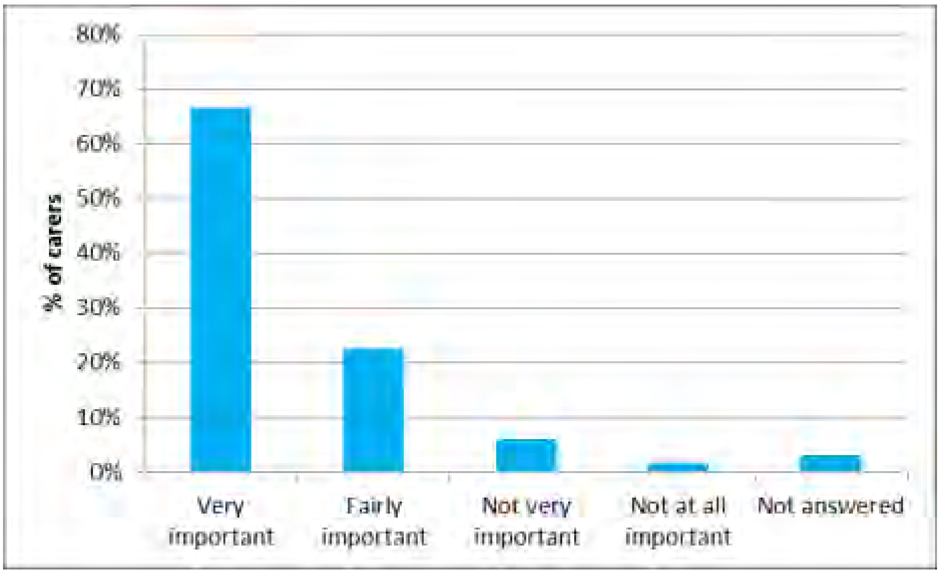
Figure 3-1 How much do you know about the options for Self Directed Support?



3.2 Importance of help and support in understanding SDS options and making choices

Not surprisingly over two thirds (67%) of these respondents felt it was 'very important' and almost another quarter (23%) felt it was 'fairly important' (Fig 3.2) that they got help and support in understanding and choosing options.

Table 3-2 How important is it to you that you get help and support in understanding these options and making choices.



3.3 Concerns regarding SDS

A range of comments were expressed by those who felt well informed about SDS (19 carers commented). A small number of carers were positive about SDS and some of these had had some experience of DPs:

> *Personally, at this point, I have no concerns as it is a great option to have. I have taken a front seat by becoming a member of the Core Group, organised by the council, in this report.*
>
> *No concerns, all positive.*

In one case the person receiving care already had a DP so the carer did not anticipate that there would be 'much change'.

Concerns expressed amongst those who felt well informed about SDS included concerns about how this might affect finances, benefits such as carers'/attendance allowance and the quality and hours of care that the person receiving care currently received. There were also concerns regarding assessments which one respondent felt were 'stressful and depressing' and left carers in 'despair'.

Some well-informed respondents had doubts as to how well-informed local authorities were about SDS and how effectively they would implement it:

> *I gained further clarity from XX at VOCAL re SDS. In my experience, there is little joined up approach from social services in their overall knowledge of how claiming e.g. direct payment works, so I feel there needs to be education for those who supply the services in how SDS will affect carers etc.*
>
> *That local authorities will not use it effectively.*

The remaining concerns amongst those who considered themselves well informed were not having enough information and support about SDS to enable them to make decisions and even if they had enough information whether they had the time to work through all the options:

> *Not having sufficient advice and support to make such significant decisions. Fear of having to do it all ourselves.*
>
> *I have been 'well-informed' of SDS but I am so busy with coping with our combined responsibility ties that I am unable to understand the complexities involved.*

Others reported that they did not have any concerns although some thought this might change once the new arrangements were introduced.

Amongst those who considered they knew a little or nothing about the options for SDS there was a widespread view that they did not know enough about it to express any concerns:

> *Not aware so therefore cannot comment.*
>
> *No concerns, just lack of knowledge - will check a website above however.*
>
> *Until I fully understand the changes, I cannot at this time comment.*

Some were concerned about their lack of knowledge and others wanted more information to be able to understand how SDS for carers might affect them and their caring role:

> *Not sure as I am not as well informed as I would like to be.*
>
> *As I know nothing about the proposals I am concerned about their effect on my role and opportunities as a carer.*
>
> *With other priorities, I have not kept up to date with current changes and this lack of knowledge adds to my concerns.*
>
> *I have not received any info on direct payments and how they will affect me, I hope information will be provided soon as the future is unknown and a worry.*
>
> *Not knowing anything at all at present I would be concerned about everything related to caring.*

Those who felt that they knew a little about SDS expressed the same range of concerns as those who felt they were well informed. These concerns included how SDS would affect them financially, with respect to the benefits they were receiving, the impact on carers particularly in relation to increased bureaucracy and paperwork and the time needed for this. It was felt that the introduction of SDS would mean increased stress for carers:

> *Anxious that present levels of ILF award may be reduced.*
>
> *Feel will probably lose out like all recent government actions.*
>
> *Yet more paperwork! More time spent being assessed = more stress/time to fit in even more to a hugely demanding day.*
>
> *More time completing paperwork and therefore time with my parents is compromised.*
>
> *It sounds as if it could be more bureaucratic with the carer having to organise things.*
>
> *This is worrying on top of normal caring responsibilities e.g. organising, arranging, managing, paperwork.*
>
> *Ongoing concerns about being an 'employer' and the stress and extra pressure this inevitably brings.*

One carer already had some experience of the red tape that might be involved:

> *I've tried Direct Payment and it was such a hassle. With a little creative thinking it could be a great thing but at the moment it's like putting a harness on a horse to run in a field.*

There was also a concern that there would be a lack of support and clear information to help carers decide on options:

> *As usual I assume that "more options" equals more difficult decisions with precious little or obscure official advice and probably ending up worse off.*
>
> *Being little informed and therefore unable to make right decision. Having time as a carer to become informed.*
>
> *All sounds fine but still need to kow what help and support is best in the first place as I am not trained as a Mental Health Nurse.*
>
> *I think SDS in theory is a good idea from others dictating what can and can't be done, as long as this doesn't turn into a long and difficult path of trying to find out information and the right person to help.*

The time needed to '*pore through masses of literature'* was a concern for some and one carer felt that help and support was needed in the form of direct communication with someone rather than being given a lot of information to read and digest:

> *As I feel mentally exhausted from juggling work and care responsibilities, plus several friends have mental health problems so I don't feel I have energy to read about changes, so I need help to understand the changes from 1:1 support or a talk. I can cope with infor via safe people, just reading info is exhausting.*

Some carers although feeling they knew little or nothing about SDS knew enough about what it might entail to comment that they did not want the additional responsibility that SDS might bring:

> *Do not want to be responsible for a budget or finding a service, on the face of it, it sounds a good idea with more choice, feel it could turn out to be very stressful though with lots of things able to go wrong.*
>
> *Self funding by Direct Payment seems complicated with contracts etc to arrange.*
>
> *That this SDS is forced on carers, that we have the pressure of employing someone to help i.e. for personal care, and that person doesn't turn up, or is sick etc and you may not have anyone to help. I also worry about the extra paper work, keeping records when you have little time to yourself as it is. I feel it is extra pressure.*
>
> *Pressure to take on SDS while already overloaded caring for 2 young adults with very different needs and both highly demanding.*

Others were doubtful as to the ability and willingness of the Social Work Department to implement SDS and make it work:

> *I hope these changes will help us carers but quite frankly if it's the Social Work Department overseeing the changes I don't have much hope. If my experience right now with this department in trying to set up Direct Payments, god help us. I have found the whole process a total stressful situation. Who wants more stress - not me.*
>
> *Hopefully the implementation of Self Directed Support will offer more choice to support service users and their carers. My worry is that individual councils will drag their heels over the introduction of SDS.*

There was a view that SDS might be a way for the local authority to save money and some were fearful that the amount and/or quality of the care already received might be compromised:

> *Basically it seems to be a cheaper option for the Council and has many pitfalls for carers. I receive a direct payment in lieu of services my wife cannot use but it does not increase annually and I have no idea how the amount is calculated.*
>
> *Changes usually mean doing more with less resources and calling it a 'new initiative'. I fear this is another example.*
>
> *is this all to be needs led or cost led?*
>
> *With all these services they need to be run with well-being of the people they are set up to help in mind. Not to be constrained by constant reminders to save cash and cut corners.*
>
> *I fear the quality of care and finances will be greatly affected.*
>
> *Potential reduction in support hours is also a concern.*

Related to this was also a view that resources were not available to make significant changes for carers:

> *Not expecting carers to suddenly get support as I doubt the resources are there.*

Not all respondents were as sceptical about the introduction of SDS for carers:

> *At the moment I am not too sure about this but I am open to considering it if it seems a better option. I am about to have a reassessment of my needs as a carer and expect to have to decide if it would work for me once I know the outcome.*

From some of the comments it appears that some carers are fearful that SDS might mean that VOCAL and other organisations and the services they provides may not be available to them once SDS is in place:

> *At present I enjoy being able to contact the carer's centre VOCAL to help me. I am concerned that the future might not be as simple as that!*
>
> *Don't know what the changes are but would not like to lose support I have in VOCAL, Care for carers, LAC, Craighall Day Centre.*
>
> *Not sure I can answer this but I would certainly like the carers charities still to continue.*

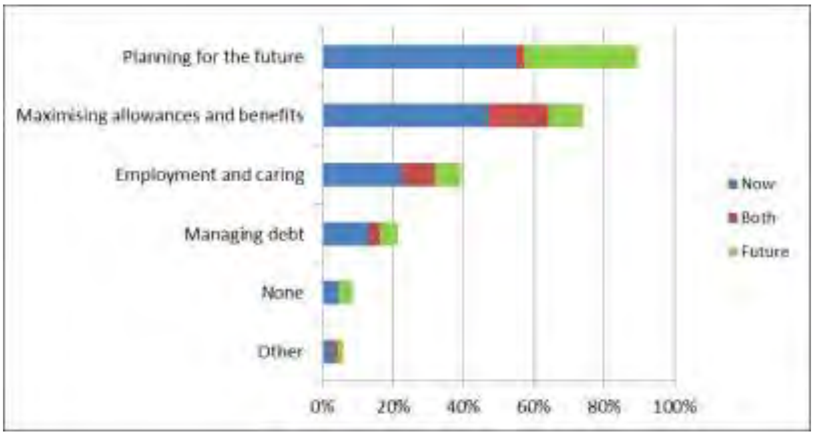
4 Economic well-being

Caring costs and has a price, but carers and families should not be worse off as a result of their caring role. Planning ahead for the future – to stay in work, maximise income and plan for affordable long term care – is the key to economic wellbeing.

We asked carers to indicate which of a number of aspects were most important to them, now and in the future. 92% of carers answered this question and more carers 82% answered questions concerning aspects of current financial planning than answered the same questions in relation to the future 51%.

The aspects important to most carers answering this question were planning for the future (e.g. Power of Attorney, Wills and Trusts) (89%) and maximising allowances and benefits (74%); followed by combining paid employment with caring responsibilities of importance to over a third (39%), managing debt (21%), other (6%) (Figure 4-1).

Figure 4-1 Aspects of financial planning important to carers (%)

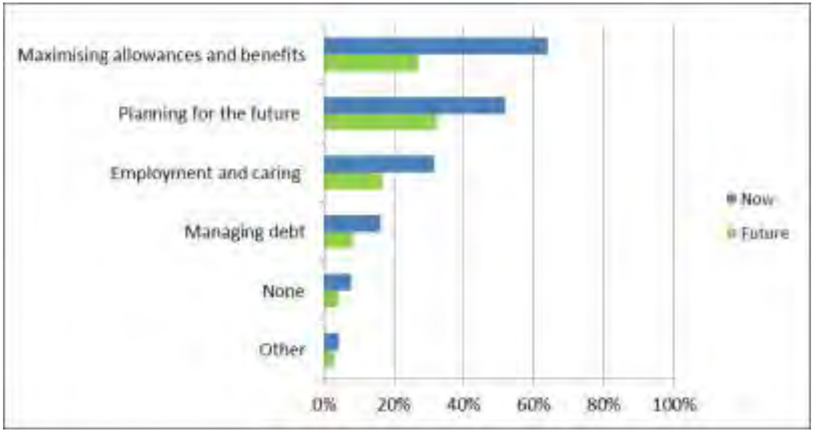


The pattern varied somewhat for carers considering what was of importance now rather than in future (Fig 4.2). Maximising allowances and benefits was of importance to a larger percentage now (64%) than planning for the future (52%).

Overall 9% of carers said financial planning was not important to them now (8%) or in the future (4%) and this is explored further below.

The other aspects noted of relevance, both to the carer and those receiving care included: taking account of ageing and death, changing circumstances and financial income, tax, pensions and benefits. These and other aspects are explored in more detail in the following section.

Figure 4-2 Aspects of financial planning important to carers now and in the future (%)



We asked carers how they could best be supported in the aspects of financial planning they had identified.

More than half, (56%, 388) provided additional comments. These in the main related to arrangements carers had already made, advice, information and support, balancing caring and employment, understanding changes in benefits and legislation, maximising entitlement and benefits, legal help, considering future care and legal and financial arrangements.

Thirty five carers mentioned VOCAL / local carers' centre specifically as a source of support in this area.

It is interesting to note that one in seven carers (14%, 52) felt they were on top of financial arrangements and nine said VOCAL had already '*sorted*' this area for them:

> *VOCAL has provided these services (to) us through PASDA and they meet my needs. For me, knowing that an organisation exists that has me as a carer at the centre, rather than as an inconvenience is very reassuring.*
>
> *We have already put a future plan into place. We have been paying 2 mortgages for over 2 years and have had a huge financial dent in our savings and income. We are always out of pocket sustaining our [child's] life and we've had to fight all the way. We do without to make sure [child] is happy.*
>
> *My [spouse] is now in full time care and Midlothian Social Work services have given good advice.*

However carers were mindful that this situation might easily change and they might need to review their arrangements:

> *I am managing on my present finances but should this change because of government changes I would require some advice, I don't have the time or energy to pore through government legislation. Carers are very much left to their own devices by the government.*

Information, advice and support

As for previous questions, carers detailed many aspects of information, advice and support which would assist them in financial planning. These ranged across the format of such information (leaflets, newsletters, step-by-step guide), to the content (in-depth, comprehensive, on choices, who to contact, benefits, eligibility, entitlements and criteria, budgeting, pensions) and ease of accessibility (readily available, regular updates, free, in one place, not just-on-line, jargon-free):

> *Having access to information and having places like VOCAL who have people who know about the various aspects to financial planning and who are able to chat with you.*
>
> *More info about companies doing this type of thing.*
>
> *information on how to get financial assistance for purchasing necessities for myself/person I cared for i.e. contacts/charities to approach.*
>
> *Info available on internet so I can access when it's convenient for me, Advice line/support, face-to-face if I have questions or am looking for support.*
>
> *By being given up to date information about benefit rules, eligibility criteria etc.*

Carers varied in the way they wished to receive advice and support (good communication, telephone call, one-to-one) and in who they wished to receive it from ('talking it over with an adviser', 'informed people'):

> *The services of free advice from professionals which VOCAL offers.*

> *I would contact VOCAL who would point me in the right direction of someone who could help if they didn't have somebody who was an expert in that field.*
>
> *getting advice and help to manage the out going costs against income as it is not always easy to match things.*
>
> *Advice for person with mental health problems to help budget properly.*

Carers needed advice on entitlements, benefits and pensions both for themselves and for the person receiving care. They needed support to be available as and when required and importantly in advance of being needed. There were many difficult feelings associated with this subject and concerns about changes in benefits and legislation:

> *If you are entitled to benefits, you should not have to fight for them.*
>
> *Proper information on allowances and benefits, not just as-and-when you find out and ask for it. My family have become much worse off due to raised costs and financial cuts and I am expected to find money I do not have!!*
>
> *As long as my son is happy I will work and care for him don't like the fact of all these changes in his money, it can be very upsetting for me, wish they would leave things as they are. (Just let us get on would be the best support).*
>
> *More a government issue: they should realise that people with severe mental health illness (or physical). Should not be subjected to the stress of constantly being assessed/re-assessed for welfare benefits when it is evident that their condition is not going to change. This causes me, as a carer, the greatest amount of stress - what will happen to my son in the future?*

Some carers were just too overwhelmed and stressed by their current caring role to even begin to tackle this subject:

> *Can't face going to any of these places at present. Visiting VOCAL will have all the answers.*
>
> *the person I care for is not stable at present and it is very hard to plan for the future.*

Around one in twenty carers spoke of wanting a full review of all benefits and entitlements, help to understand their full financial circumstances and how to make the best of them. Only a handful spoke specifically about help to get out of debt:

> *Individual assessment in confidence with knowledgeable person in all areas rather than a different person or company for each area.*
>
> *some assistance in getting me able to plan my finances better, ideas and help to get me out of debt - managing it in a way I can cope with, also I would like to work again, but I don't know how I can do this as I am not sure what the rules are.*
>
> *Just to be debt free and not have any money worries. Things are hard enough just now hopefully things will get better.*

Just a handful of people mentioned child and childcare related financial issues:

> *my child eats a lot of time and [child] takes up a lot more money than normal children.*
>
> *School holiday cover needed 9-5 but very, very expensive.*
>
> *If there was a service you could call on for support when working to look after your child - jobs are limited due to child care issues.*
>
> *Advice for benefits/support offered for teenagers. Advice on POA. 'Childcare' for teenagers during holidays.*

A handful of carers said that having someone to visit to give advice and support ‘at-home’ would be beneficial for several reasons. It would be easier, when already stressed as a carer, to find time to talk in the privacy of one’s own home, with all one’s paperwork more readily to hand:

> *someone to come and explain everything to me as I do not understand a lot.*
>
> *I could be better supported if someone was available for home visit as most of the information needed is here at home. e.g. bank statements, council papers and pension papers plus is all on hand.*
>
> *24 hour care is so mentally and physically draining, that further research and form filling (which most people dislike when they do have the time) are the extra hassle/step too far. A house visit by benefits expert with them pro-actively arranging a meeting.*

Other carers wanted to take a proactive stance to getting the information and advice they required by attending a range of group activities: courses, seminars, workshops, training:

> *More information, more classes geared towards young people e.g. cooking classes.*
>
> *maybe a one-off course/information session as to what financial help is available to carers and what the criteria are.*
>
> *I would like to either go on a course or one to one with someone. Benefit changes mean that the only info I receive is guessing.*
>
> *Attending seminars on them and help with form filling.*

Combining paid employment with caring responsibilities.

More than one in ten of carers answering this question focussed on the difficulties of combining paid employment and caring:

> *My mum requires round the clock care. I work full time but because we are only entitled to personal care, I am finding it increasingly difficult to juggle and may have to reduce work hours to manage and will reduce earnings as a result.*

When the stress of caring became too great or practical problems became insurmountable people had taken early retirement or given up employment:

> *I have had to stop working - any help and advice came too late.*
>
> *I gave up a full time job to give my mother more of my time. My health was suffering due to long hours at work then at Mum's. I have no pension (private) & at 59 do not expect to collect a state pension till I'm nearly 66. I have travelling expenses but rely on my husband for finance.*
>
> *Caring for someone fulltime is a very expensive business. You have to give up employment in order to carry out your caring duties. This hurts you financially and emotionally and affects your own mental health.*

Some carers had more supportive employers:

> *Still being supported by my work but may not always be the case - if I go onto sick pay we will be severely short of funds.*
>
> *I have been lucky, in that, my employer (Royal Mail) are supportive. If however they decided to make me stick to a strict time scale I would suffer a great deal. If the government could force employers to take a more supportive role with the carers in their workforce it would help a lot of people.*

However others felt their job was continually at risk, that they might be overwhelmed with a crisis:

> *there is no support available and wasn't at the time I needed it when I put my job at risk so many times, when I was caring for my daughter, and so many times of crisis. It was a nightmare.*

Carers wanted information on just what they were entitled to should they consider getting back into part-time work, on just what choices were available to them:

> *Would like to know how many hours I could make go out to a wee part-time maybe 16 hours a week and how and if it would affect all my benefits i.e housing etc.*
>
> *How can I combine caring for my father with a part-time job, so I can get back into the job market - haven't "worked" for years.*

Others were despondent that they might be permanently unemployed or worried if they returned to work, what would happen to the person they cared for:

> *Planning for the future has been dealt with by the Family Solicitor and the trust left by my mother. At the moment I am on Employment Support Allowance with not much chance of any employment taking me on with my medical history far less being able to fit in caring for an increasingly elderly and frail father. I have difficulty in believing in a future and while financial planning takes a back seat, I know it should be important.*
>
> *Caring role is full time. Too busy and tired to find work - tried working part time last year for a year but ended up exhausted and had a break down. Can't understand why I lose my carer's allowance when I qualified for my state pension. Worked all my life for my pension but having an elderly person at home is COSTLY.*
>
> *I am at present unemployed, I fear what will happen to my sister if I am not there to help care for her when I do find employment. I can only work part time as I need to help my sister.*

Several felt that benefits should more closely fit carers' needs and that specific funds should be given for the caring role:

> *Not losing my carer's allowance would make a big difference to me. I work 17 hours a week yet do not qualify for carers allowance as I am just over the threshold. Yet my carer responsibilities are still the same. It should be paid like child benefit or as long as DLA is being paid to the person you care for.*
>
> *Originally I was in paid employment and caring for my wife without support of benefit. As my own health deteriorates I will need more help in the future both financially and physically. I am now 58, if my wife loses her benefits under the new P.I.P system we will be in dire straits!!!*
>
> *My carers allowance stopped when I took on a job as I earn slightly more than the £100 a week threshold. However, the time I care for my daughter did not change …… This frustrates me!*
>
> *If the Direct Payment was more versatile I could use my free personal care in "block" form when I am at work (now reduced to 16hrs/week). At present I pay Alzheimers Scotland £160 per week. Is it worth it?*
>
> *I have to work for a living as well as care for my mother who stays with us. I would like, as would others, to get a salary for this role. This would perhaps encourage more families to look after family in their house as opposed to homes.*

Planning for future care

Carers spoke of needing advice to plan for their own future care, as well as that of their child, spouse or parents:

> *Both of us do not want to go into a home and pray we will get help to stay in our own home. We both have occupational pensions as well as state pensions. We already get help which we pay for from Attendance allowance for my husband to 2014.*
>
> *More advice on best ways to invest money to benefit my son in future to ensure he has the financial support he needs and that it is managed in a way that benefits him and not others.*
>
> *I want simple - clear - explanation of my financial liabilities should my wife have to go into long term care. I don't have it.*
>
> *My mum will be going into permanent care soon, dad will be living at home. We are concerned about what assets/savings dad may have to relinquish to ensure mum is cared for. Understanding of options really.*
>
> *Discussion with a financial advisor in how to manage my parent's finances effectively yet ensuring they are not drained dry if/when a care home is needed. Also advice on Care/Nursing homes.*

Legal issues (POA, wills, trusts)

Carers also wanted information and advice related to legal issues including wills, trusts and power of attorney:

> *Legal advice on what would be best financially for my youngsters. Should I invest in a flat for them or as they require it, support from social work would this make them worse off?*
>
> *I have POA for my mother and in the process for my husband's grandfather. I worry I don't have a will myself for my children. I work part time round my caring role which is a juggling act and stressful, never easy but I want to work. Finding time for yourself is the most difficult of all.*
>
> *Have power of attorney, wills arranged but would like information on trusts, as my daughter's future worries me as she won't be able to continue in the P/Time job for many more years. She is only 36.*
>
> *I have already applied for power of attorney, but my mother may need more care in the future. In the future I would need to know which benefits my mother would be eligible for.*

Several remarked upon the cost of getting legal advice:

> *Perhaps with a short list of local solicitors who have some empathy with the issues.*
>
> *Need to have quotations in advance from solicitors or their fees can be very expensive.*
>
> *I had a will made but it was very expensive. Some templates on your website would help.*

Respite and other support

Other measures to be financed to support carers that were mentioned included respite and practical help at home.

> *Respite so that I can continue to manage. Holiday clubs etc. during school holidays.*
>
> *Regular 'breaks' from caring responsibilities and more financial assistance from X Council.*
>
> Practical help at home so I have the energy to work in addition to caring.

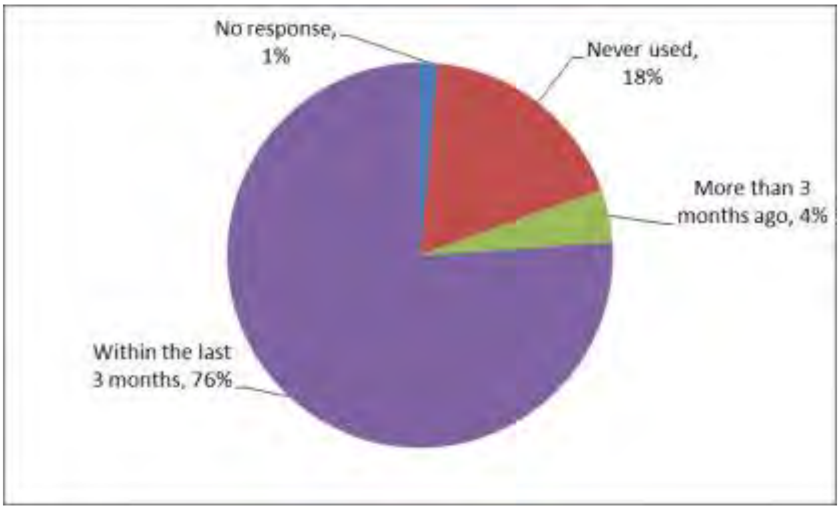
5 Using technology

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.

5.1 When did you last use the internet?

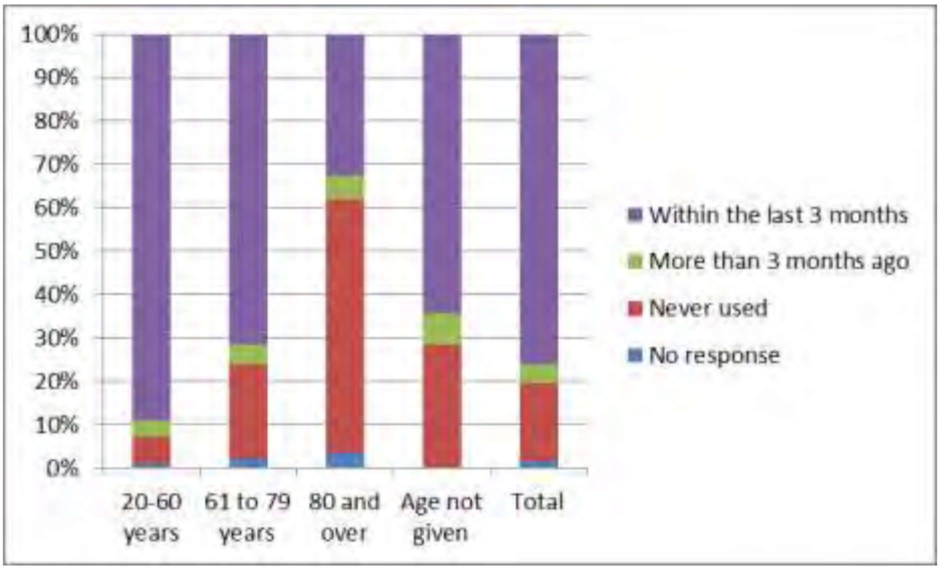
We asked carers when they last used the internet[3]. 98% (677) carers responded to this section of the questionnaire.

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



Three quarters of carers (76%) had used the internet within the last 3 months and a further 4% more than 3 months ago but at least 18% had never used the internet at all (Figure 5-1).

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



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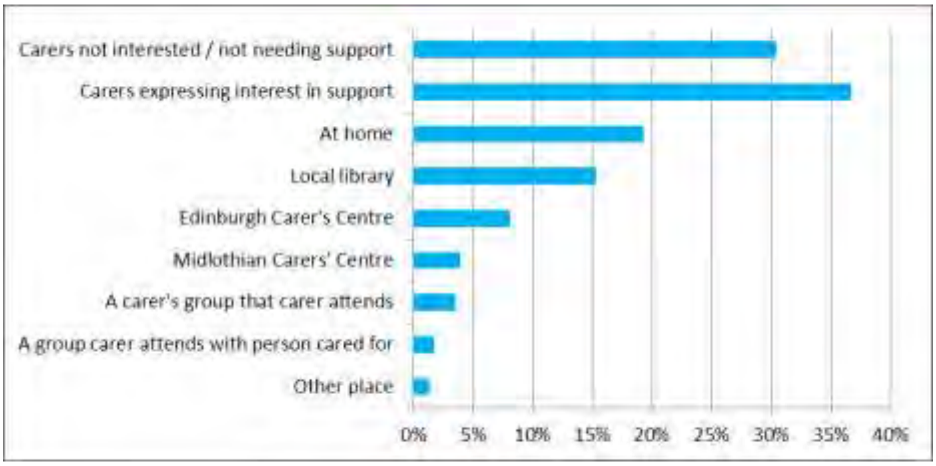
[3] This question was drafted to be in line with the question used by the Office for National Statistics (ONS) Internet Access Quarterly Update, Q1 2013. This found 14% of the adult population had never used the internet. Age is a key factor as to whether an individual is likely to have used the Internet. Almost all adults aged 16 to 24 years (99%) had used the Internet. In contrast, only 34% of adults aged 75 years and over had ever used the Internet. http://www.ons.gov.uk/ons/dcp171778_310435.pdf

As might be expected use of the internet varied with carer age; most younger people (89%) and those aged 61-79 years (72%) had used the internet within the last three months; but for those over 80 years only one out of three (33%) had done this and well over half (58%) had never used the internet (Table 7-9, 8-10).

5.2 Where would you like to be offered support to use the internet?

We asked carers where they would like to be offered support to use the internet. More than a third of carers (37%, 248) expressed interest in obtaining support to use the internet should this be offered. Almost a third (30%, 206) said they were not interested in or did not need support.

Figure 5-3 Carers interested in internet support and preferred location (%)



As might be expected a larger proportion of those who had last used the internet more than three months ago (67%, 20) or 'never' users (45%, 55) were interested in potential support (Table 5-1).

Table 5-1 Internet use by location for support (%)

	Within the last 3 months	More than 3 months ago	Never used	No response	Total
	%	*%*	*%*	*%*	*%*
At home	*17*	*33*	*20*	*70*	*19*
Local library	*14*	*27*	*19*	*20*	*15*
Edinburgh Carer's Centre	*7*	*23*	*6*	*40*	*8*
Midlothian Carer's Centre	*4*	*7*	*4*	*0*	*4*
A carer's group that you attend	*3*	*7*	*3*	*0*	*4*
A group you attend with the person you care for	*2*	*7*	*2*	*0*	*2*
Other place	*1*	*7*	*1*	*10*	*1*
Total expressing interest	*32*	*67*	*45*	*90*	*37*
I am not interested / don't need support	*32*	*13*	*29*	*10*	*30*
N	**515**	**30**	**122**	**10**	**677**

Support at home was of most interest (19%) and this included 100 individuals who already used the internet and 31 who never used or did not specify how often they used the internet already:

> *At home is essential as I have an adapted computer for my sight problem.*

Support via the local library was the second most popular option (15%, 104) and was again of more interest to less experienced users.

8% (55) of carers expressed interest in getting support at the Edinburgh Carers' Centre and 4% (27) at the Midlothian Carers Centre.

24 individuals indicated they would like support to be offered at a carers group they attended already, and three quarters of them (18) had used the internet within the last three months. Fewer people showed interest in getting internet support at a group they attended with the person they cared for (2%).

Other potential locations included:

> *College courses/ schools.*
>
> *have ticked home but would like to know what sites could be useful , also VOCAL.*

109 carers provided further detail about their use of the internet and comments were fairly evenly split between issues of access, motivation and skills.

Those who had never used a computer were more likely to mention difficulties with access: not having a computer at home, not having broadband or the internet, having old equipment which needed replacing or not being able to afford it:

> *I do not own a computer.*
>
> *No equipment, poor access to use.*
>
> *Don't have broadband.*
>
> *ancient system - painful for my back to sit for long.*
>
> *computer kaput and can't afford to buy a new one.*
>
> *I am not clued up with it and cannot afford internet at home.*

The 'never' users were also more likely to mention factors associated with motivation to use computers and the internet. These included a lack of time or energy to tackle computers, no perceived need or interest to get familiar with computers, a sense of being 'too old' to bother or carer's own incapacity:

> *do not have the time or inclination to learn.*
>
> *too busy caring to take time out to learn but would like to.*
>
> *Have not embraced the computer and have no wish to do so!*
>
> *I don't know how! I am age 88 now.*
>
> *I used university computers until 2001 but have not used one since I became visually impaired in 2004.*

Some had general fears for example about 'confidentiality', and there were a small number of outright statements of 'dislike':

> *Do not trust confidentiality.*
>
> *limited in my knowledge, concerned re internet vulnerability.*
>
> *I hate using it!*

Carers who had never used the internet or used it infrequently were likely to mention that family and friends accessed the internet for them:

> *3 sons have internet and support me .*
>
> *Any internet use my son lives near by and carries it out.*
>
> *never used directly but obtain benefits of internet indirectly though my daughters internet.*
>
> *not computer literate and friend helps.*

Some who were interested did not know where to go to find out about computers or get support.

Less frequent users mentioned issues to do with knowledge and confidence:

> *Don't know how and a bit scared to try.*
>
> *not very good at computing.*
>
> *I registered with my local library - all I got sent was a self-teach package. NOT what I needed. Disappointed.*

For carers who had used computers within the last three months comments were also likely to relate issues of access and motivation; however they also related to level of skill in using computers / internet:

> *I cannot afford the Internet altho' we have a computer from Pass it On.*
>
> *mostly when I have time - I am too tired to concentrate.*
>
> *Only use twice a week as do not have my own computer.*
>
> *I don't shop on the internet but I do look up advice.*
>
> *I feel nervous of prompts and changes and finding my way around the internet.*
>
> *Do not know enough about extent of its use.*

There were even offers to help other carers get going with the internet:

> *I could offer support in internet use having recently retired.*
>
> *I do not need internet support and use internet daily but this may help others.*

6 Carers' experience of VOCAL

6.1 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 6.1 details the aspects of VOCAL's response carers were asked about and how carers rated them.

Table 6-1 Rating of VOCAL's response

	Excellent	Good	Fair	Poor	Very poor	Can't say	
	%	%	%	%	%	%	N
Friendliness of response	77	19	1	0	<1	2	656
Knowledge of staff and volunteers	61	29	4	1	<1	5	634
Ease of getting in touch with VOCAL	63	31	3	<1	<1	2	646
Doing what they said they would	64	25	3	1	1	5	635
Getting as much information as needed	62	28	3	1	1	4	649
Getting information about other groups/organisations	54	28	4	1	1	12	618
VOCAL's overall response	70	23	3	1	1	3	650

Of those who answered these questions almost three quarters (77%) of carers rated the 'friendliness of response' as 'excellent', with another fifth (19%) rating it as 'good'. Less than 1% (2 carers) felt the response from VOCAL was 'very poor'.

The next four aspects of VOCAL's response, knowledge of staff and volunteers, ease of getting in touch, doing what they said they would and getting as much information as needed' were all rated very similarly by carers. Around 90% of carers rated these aspects of VOCAL's service as 'excellent' or 'good'. Ease of getting in touch with VOCAL was the most highly rated of these features of VOCAL's response, 94% of carers rating it as 'excellent' or 'good'.

Just over half of carers (54%) rated information about other organisations as 'excellent' but in this category a larger proportion (12%) of carers felt they could not comment on this element of VOCAL's response (can't say or no response) probably because they had not asked for this sort of information. It is also of note that 11% (74) of all carers did not answer this question at all a much higher proportion than the other questions in this section (typically 2-5% of carers). This may also indicate that, at least in part, they had no experience of this element of VOCAL's response.

VOCAL's overall response

When asked about VOCAL's response overall, 93% of carers who answered this question rated the response as 'excellent' or 'good'. This is an increase of 6 percentage points on the comparable figure in the 2011 survey in which 87% of carers rated VOCAL's response as 'excellent' or 'good'. This suggests that VOCAL has further improved its high quality response to carers.

VOCAL's response by age group

Table 6-2 shows the proportion of carers rating the various aspects of VOCAL's response as 'excellent' or 'good'. There is little difference between the age groups in how they rated VOCAL's response with all aspects achieving a high rating. Those in the oldest age group, 80 and over, rated friendliness of response, knowledge of staff and volunteers, doing what they said they would and overall response more highly than the other groups. However they rated getting as much information as needed and getting information about other groups less highly.

Table 6-2 Rating of VOCAL's response by age group of carer (Excellent and good)

	20-60 years	61 to 79 years	80 and over	Age not given	Total*
	%	%	%	%	%
Friendliness of response	95	96	98	98	96
Knowledge of staff and volunteers	90	89	92	93	90
Ease of getting in touch with VOCAL	93	94	93	96	94
Doing what they said they would	86	91	95	95	90
Getting as much information as needed	90	92	86	95	91
Getting information about other groups/organisations	80	81	81	93	82
VOCAL's overall response	91	94	98	97	93

Note: Between 618 to 656 carers responded to these questions

6.2 Carers' views on VOCAL's response

Later in the questionnaire (Q.6) carers were asked to comment on the usefulness of VOCAL services. Some of these comments related more to the quality of VOCAL's response and so these comments are reported on here. It should be noted that it was not always possible to distinguish whether respondents were referring in their comments to staff or volunteers.

VOCAL staff and volunteers

Many of those who commented found the people they came in contact with at VOCAL were approachable, listened to them, were supportive and encouraging:

> *Everyone is so helpful, always make time if you need to talk - I think they (are) all 'angels in disguise'.*
>
> *Outwith the services I would just like to mention how helpful, considerate and understanding the VOCAL staff have been on every single occasion I have been in contact. Thank you.*
>
> *Staff are caring and listen and don't make you feel you're a nuisance.*
>
> *Extremely helpful, friendly staff, nothing is a bother.*
>
> *I found all VOCAL's staff and volunteers gave really useful, understandable and reassuring advice and help.*

> *Most informative and very helpful if info not available at time then they get back to you ASAP - superb!*

Some also commented on individuals who had helped them with particular enquiries or situations:

> *XX at Dalkeith is a great support to me; I don't know how I would cope without her. First class.*
>
> *I have only recently accessed VOCAL services and do not know more than 2 staff , XX has been absolutely fantastic, really out-standing, very informative, supportive, encouraging and always does what he says he will do.*
>
> *I was very impressed with the Power of Attorney service. XX was helpful, supportive and gave me all the advice I needed. I fully recommend this service.*

However, some carers had a more mixed view of those they dealt with at VOCAL and found the response from VOCAL varied according to who they spoke to:

> *Depends on who you get to speak to XX and XX are very good. Others need to do what they say they will or have done.*
>
> *Not found all staff to be great.*

A small number of carers also found that the person they spoke to was not as well informed as they would have expected although in the second case below a satisfactory outcome was achieved eventually:

> *Could do with a worker who knows the legal issues with social work/education.*
>
> *Staff were helpful but due to sickness absence they changed throughout inquiry and this was a bit disjointed. Often staff did not know answers to questions which I would have considered common and undertakings to call back were given obscure and dragged on. However, in the end we did get a small contribution to taking our daughter abroad and help with equipment hire/carer costs.*

There were also a small number of carers who said that staff did not get back to them with information or that they did not do what they said they would. For example

> *Either nobody gets back to you or it is weeks before they do - makes you think twice about phoning VOCAL.*
>
> *I received a phone call from VOCAL approximately 1 year ago, during which I mentioned the need for financial advice for future care of both my very elderly parents. I have not yet received an appointment with the financial advisor. I am only available Friday afternoons as I work full time.*
>
> *Person didn't call when said they would. I waited in an hour, I didn't hear for over a week.*

There was one other instance of an individual who had attended a VOCAL course in 2011 and despite a number of attempts to be put on VOCAL's mailing list did not receive any further contact until early 2013.

One respondent had a suggestion as to how to improve VOCAL's staff response to gay people:

> *When I popped into your office the member of staff apologised twice for asking if I was gay or transgender for your statistics and seemed embarrassed asking. I told her I was gay then she said "I'm sorry". It might be helpful to organise training for your staff from Edinburgh LGBT centre and vice versa to develop communication skills and exchange expertise.*

Views on VOCAL's overall response

There were many positive comments on VOCAL overall with carers describing VOCAL and the services they provided as 'excellent', 'very helpful', 'a life-saver' and 'invaluable'. The comments below give a further flavour of how carers view the response and services they received from VOCAL:

> *Very accessible, quick responses. Geared to my needs as a carer and as a person, unlike my experience of the formal health services.*
>
> *VOCAL services were a godsend and gave me hope and renewed strength. Recognition at last of carers' needs. Allowed me to recharge and so be much stronger to pull my relative through their illness.*
>
> *I have lot of support from VOCAL I do not know what I would do without your service.*
>
> *All services were excellent at a time when support and help was most needed. They were there when it felt in most need of support and advice.*
>
> *VOCAL offers a much-need, comprehensive service to carers.*
>
> *Your advice has meant more than words can explain, instead of worrying over an issue I know that someone at VOCAL can give me good advice to make the best decision. I have recommended you to many other carers and I know they feel the same, well done.*

6.3 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. Comments were also invited on the usefulness of services and on services which were not useful.

Not all carers had used all the services and some indicated that they were not aware of all the services that were available:

> *Didn't know that VOCAL offers counselling services, maybe it should be better promoted along with social/leisure activities.*

Reponses to this question are a reflection of the most widely used of VOCAL services – some of the services may be just as useful to individuals but may only be appropriate to some carers e.g. advocacy, family support (addictions). There may also be an issue of some of these services not being immediately available to all those who want to use them e.g. counselling:

> *I am on waiting list for counselling they have been really good at helping me with a lot of things.*

Table 6-3 shows the proportion of carers responding to the survey who found various services offered by VOCAL useful.

Table 6-3 Carers finding services useful

Service		
	No.	%
Information (including carer information pack)	487	70
Advice and support	427	62
Training courses and seminars	244	35
Carer support groups/meeting other carers	196	28
Help with POA/legal issues	185	27
Financial planning and benefits advice	124	18
Counselling	94	14
Social/leisure and health activities	85	12
Help with accessing short breaks and respite	75	11
Website	79	11
Advocacy	44	6
Family support (Addictions)	22	3
N	**692**	

Services by age group

There was some variation in whether carers found services useful by age group (Table 6-4). Carers in the oldest age group, 80 and over, were less likely than younger age groups to say that advice and support, carer support groups/meeting other carers, training courses and seminars, social/leisure and health activities and the website were useful. Information, advice and support and help with accessing short breaks and respite were more likely to be found useful by the youngest age group (20-60 years).

Table 6-4 Services found useful by age group

Service	20-60 years	61 to 79 years	80 and over	Age not given	Total
	%	%	%	%	%
Information (incl carer information pack)	72	66	68	83	70
Advice and support	65	60	48	63	62
Training courses and seminars	35	37	27	37	35
Carer support groups/meeting other carers	23	35	18	37	28
Help with POA/legal issues	25	31	29	19	27
Financial planning and benefits advice	17	19	18	22	18
Counselling	16	12	16	8	14
Social/leisure and health activities	13	12	4	15	12
Accessing short breaks and respite	12	8	7	17	11
Website	14	10	2	12	11
Advocacy	6	6	4	11	6
Family support (Addictions)	2	6	0	2	3
Total	**322**	**249**	**56**	**65**	**692**

Information

As expected the service mentioned as useful by the largest proportion of carers of all ages was information (including the carer information pack). See Table 2.3. Over two thirds (70%) of carers reported that they found this service useful. This was closely followed by the proportion of carers (62%) who found the advice and support they received from VOCAL useful.

Those who found the information useful particularly valued being kept up to date with new developments such as benefits changes:

> *I like the VOCAL information pack as it keeps me up to date with everything*.
>
> *Even though you might not use any of their services, they still keep in touch by email which I found very useful.*
>
> *Information pack very helpful and re-assuring re (the) future.*
>
> *Being kept up to date with information.*
>
> *I found the services very helpful - information re the causes and effects of a stroke.*

The quality and accessibility of the information provided was also commented on by some:

> *I feel the information is pitched at the right level and gives a good background/awareness of issues in caring for someone and how to get help/support.*
>
> *All issues very well presented. Topics fully researched and discussed.*
>
> *Very helpful, put us at ease right away, all information given in terms we could understand.*

A small number of carers felt that they were sent too much information and that it would be better if the information was more targeted. However one respondent held the opposite view feeling that all information should be sent and the receiver could decide what was useful or relevant to them:

> *Although finding the information useful in part, I felt overwhelmed by the deluge of newsletters, courses, invitations to this, that and the other. It is useful as I finally get round to gradually processing it but the information overload is not helpful. It isn't just VOCAL it is a problem that we're all getting used to.*
>
> *Yes (as taken from info pack) but I think it's better to tell people everything on offer and let them decide what they want, as you have done.*

6.3.1 Support

Almost two thirds (62%) reported that they found the advice and support they received from VOCAL useful. This support took a range of forms including practical help with completing forms, advice on benefits and support when people were feeling stressed and/or isolated:

> *Would not have received attendance allowance without VOCAL's help.*
>
> *I haven't really been to any meeting with VOCAL yet, but have telephoned them for advice on benefit and employment. They were very helpful.*
>
> *Assistance for completion of claim form greatly appreciated.*
>
> *It has been very benefic*ial in times of isolation and stressful situations to have someone to talk with.

6.3.2 Training courses and seminars

In this section although the majority of the comments relate to training courses some relate to other services such as counselling and other activities. It is not always possible to determine to which service the comment is relating.

The training courses and seminars run by VOCAL were found useful by over a third (35%) of carers and 14% had found counselling useful. It was clear from comments that several carers had attended several courses and seminars and had generally got a great deal out of them:

> *Think the seminars and courses offered are excellent.*
>
> *Seminars have all been extremely worthwhile, presenters are knowledgeable and supportive. I have felt more positive after each one.*

Courses/seminars mentioned by individuals for particular praise included the counselling course, ‘stress management for carers’, ‘Council adaptations’, life coaching, ‘caring for feet’, legal issues and a course on wheelchair manouvering. Several carers also mentioned the advice and support they had with setting up Power of Attorney.

Many carers commented on the value of meeting other carers in the same or similar positions as they were themselves and the benefits from talking about their situation. Over a quarter of carers said that they found carer support groups and/or meeting other carers was useful and this is borne out by comments:

> *Training course made me aware of other carers and to be able to discuss and exchange different problems and access info and help where appropriate.*
>
> *Helped me not to feel isolated, meeting other carers in similar situations and finding we had things in common.*
>
> *Meeting other people whose experiences similar to my own was reassuring.*
>
> *Meeting others in similar situation and sharing experiences etc was very useful.*
>
> *For someone who is hard of hearing misses a lot as he/she cannot get what others are saying.*

However, it is worth noting that for one respondent (see comment above) that their disability meant that they did not get as much out of the peer support from other carers as might have been possible.

Although comments on particular courses were mostly positive there were a few negative comments on the same courses/services. For example, a small number of carers (4) reported that they did not find counselling useful but they did not elaborate any further. Similarly one respondent reported that they did not find the workshop on changing relationships useful.

6.3.3 Accessibility to training courses/seminars

Although a third of carers (35%) had taken advantage of the courses, seminars and other activities on offer from VOCAL, other 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 and for another group who were caring for children, they needed courses which fitted into the school day:

> *I would like to attend training courses but I can't make 10am because of my caring responsibilities.*
>
> *Not many events are run in the evening and I found getting to the office at 6.30pm quite difficult as I work full time.*
>
> *There seems to be an assumption that carers don’t work and they are free to attend courses during the day - I cannot.*
>
> *Not managed to access services as would have liked as many do not fit in with school times.*

For some carers their caring responsibilities preclude them from attending courses at any time of day without incurring a financial penalty:

> *The services would be useful if I could access them. I work almost full time and look after the person I care for in the evenings, which means it is almost impossible to attend the courses etc. unless I take leave or pay for carers, both of which I can't afford financially.*

Although the timing of courses was reported most commonly as the reason why carers could not attend courses other reasons people gave for not attending were:

Physical access to courses: There were two individuals who had attended courses but had difficulties due to their disabilities. Although this was not due to access to the VOCAL building itself, the barriers encountered prevented further attendance at courses:

> *Have used VOCAL for one training course in Edinburgh but I am disabled myself so unable to drive from Livingston or I would use the service a lot.*
>
> *I am a carer who has to use a wheelchair, the Edinburgh centre was wheelchair friendly and staff helpful - but parking locally was totally unsuitable (especially high kerbs) so I cannot access your help again.*

Distance to course: The location of activities was also an important factor in whether people felt able to attend courses or activities. Those living outside Edinburgh felt they were at a disadvantage:

> *Not enough groups/social activities/chance to go on training programmes in Midlothian.*
>
> *With the local office being in Edinburgh it is impossible to attend any meetings there. The book group in our local library is handy, and nice to meet others.*

Age/gender appropriate services: Two carers felt the support and activities were not appropriate for them:

> *Social/leisure and health activities are more geared up for older people or women.*
>
> *Would like a support group for carers 20-35 years, feel we are under-represented.*

For some, they find leaving the person they care for is difficult at any time either because they do not feel confident in leaving the person receiving care or because there was no-one available to allow the carer to attend :

> *I haven't really taken advantage of all that VOCAL offer as I find it difficult to leave my mother with people I've not met.*
>
> *Up 'til now I didn't manage to use any services. I have difficulties in getting transport and I didn't have any "baby sitter" for my husband.*

Waiting to get on to courses and in some cases course being cancelled was raised as an issue by a few carers:

> *All excellent services on offer. I was very disappointed that a course I was booked onto was postponed due to low numbers: 'caring for a child with a learning difficulty – looking to the future….'*
>
> *I asked for help (someone to talk to ?) when at the end of my tether but was put on a waiting list then some weeks later received a letter asking if I still needed it since the service was so busy. By then my crisis had passed and I just kept going.*

6.3.4 Family support (addictions)

A small percentage of carers (3%, 22 carers) indicated that they found the Family Support (Addictions) service useful. Although several of these carers reported positive experiences using

VOCAL services, three were very positive about the particular help and support they had received from this service:

> *Family Support (Addictions) - a fantastic, supportive service.*
>
> *Found the support of the Family Support (Addictions) absolutely wonderful after my daughters marriage folded due to her husband's drink problems. XX supported her and I for roughly one and a half years. We will be forever grateful for the help we received.*
>
> *I am a former carer, having looked after my brother who had an addiction to alcohol. He died in 2010 and I continued to use the support group until 2012. XX was a huge source of support to me and has helped me to get through the pain of my brother's death.*

In contrast one respondent commented that they did not find the Family Support (Addictions) useful but did not elaborate any further.

6.3.5 Publicity

Two carers felt VOCAL and its services should be better advertised:

> *More publicity for e.g. in care homes, would be helpful.*
>
> *Should be better advertised. VOCAL are there to help.*

6.3.6 Other services

Some carers mentioned other services VOCAL had provided. These included the grants service, helping to find a play scheme for one child and access to football for another, massages, life coaching, reflexology, paying for driving lessons and day groups dealing with problems experienced by carers. It is not clear from some of these comments whether these are services directly provided by VOCAL or whether carers access these services through or with the help of VOCAL.

6.3.7 New or additional services

A few suggestions were put forward for VOCAL to provide additional services – these included courses at different times, for different target groups or different geographical areas (this respondent lived in Edinburgh):

> *some courses etc only applicable in certain areas - would be really useful to run similar courses in other areas with any relevant changes/amendments.*
>
> *1/2 day weekend courses would be very useful.*

6.3.8 Reassurance

Some carers reported that although they may not be currently using or have ever used any of the services they felt very reassured knowing that VOCAL was there when they needed it:

> *I don't need VOCAL too much at the moment but I have peace of mind that there is that safety net for me when I do need help.*
>
> *Comforting to know support is available if so required.*
>
> *Knowing that people are there to help and that I am not alone.*

6.4 Difference VOCAL's help made to carer

Carers were asked what difference the help received from VOCAL made to them as a carer. Table 6.5 shows how carers rated the difference the help from VOCAL made to them and how this compared to a similar question in the 2011 survey where carers were asked whether the help received made a difference to them and were given two options to choose from, 'yes' or 'no'.

In the 2013 survey 93% (641 carers) answered this question compared to 81% (493 carers) in the 2011 survey.

Table 6-5 **Difference help received made to carer 2011 and 2013**

2011			2013		
Help made a difference?	No.	%	Help made a	No.	%
Yes	416	84	Big difference	423	66
			Small difference	122	19
No	77	16	No difference	27	4
			Can't say/ Not applicable	69	11
Total	**493**			**641**	

In 2013, 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. The proportion of carers who said VOCAL's help made a difference (big or small), in 2013 was very similar to the proportion in 2011 who reported that it made a difference in 2011 (85% vs 84%).

In the 2011 survey the option 'can't say/not applicable' was not available to carers. This may be why there is 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 6-6). A larger proportion of this group also reported that they couldn't say whether it had made a difference.

Table 6-6: **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	63	70	66	72	66
A small difference	22	16	14	15	19
No difference	5	4	2	2	4
Can't say	10	10	18	11	11
N	**313**	**231**	**44**	**53**	**641**

6.4.1 How help from VOCAL made a difference

Almost two thirds of carers (449, 65%) commented on whether help had made a difference to them. The reasons carers gave for the ways that VOCAL helped them as carers were similar to the reasons given in the 2011 survey.

Many of the comments were about VOCAL helping them cope as a carer, recognising their own needs as a carer in making time for themselves and looking after their own health. Normalising the way they were feeling about their caring role was also important, particularly for some new to their caring role. For many, VOCAL was a lifeline for them in stressful situations and in helping them continue in their caring role:

> *Having couselling set aside 1 hour a week for myself and from that and my regular weekly "chats" I realised how much I was needing space away from my mum (Alzheimers) and three kids as I was grieving for my dad who had died with kidney failure. It allowed me the time to realise that I was reacting "normally" and that I was exhausted.*
>
> *I felt quite low in spirit, but when I contacted VOCAL, everyone was very friendly and helped me to understand that some of the feelings I had about my caring role were normal.*
>
> *I was at the point of not knowing how to go forward and almost unable to continue caring.*
>
> *In many ways really in particular meeting up for a coffee and chat for counselling when I wasn't coping very well. The support and understanding pulled me through.*
>
> *It made me feel like I was a person and not just my husband's carer again, also helped me to meet new people and learn new skills. Really enjoyed the courses, and as they are free it means I can go as finances are stretched.*
>
> *It's helped me to actually view myself as a carer and that it's ok to be called that when your dealing with your daughter. At the time I was so low and just needed someone to off load to. They made feel "normal" and my feelings are ok.*
>
> *Let me know someone cared for me as a carer.*
>
> *I feel totally burnt out as had been struggling on my own for so long. VOCAL's recognition of the issues I face gave me the ability to carry on with recharged batteries. I am unsure if my relative would have survived if I had not had that fresh energy to fight for them.*

Other factors mentioned in helping carers included not feeling so isolated, knowing that VOCAL were there if needed and being listened to in a non judgmental and supportive way:

> *Knowing I can contact someone when circumstances change gives a great sense of security.*
>
> *We felt 'on our own' - as we always have done till we heard about VOCAL services.*
>
> *I did not feel alone and abandoned.*
>
> *It made me feel less alone in my caring for my husband and kept me from leaning quite so heavily on my only daughter and my son-in-law. I did not feel as if I was being judged but supported.*
>
> *It is great to have the listening ear of someone who is unbiased and also to receive their expertise and you know you can trust them. They share your burden so making it much more bearable; and all with a smile and a kind word. Thanks to VOCAL.*
>
> *Having someone who was not in the medical field listening and understanding what our needs were and sharing with someone who was non-judgemental was a big help.*

Several carers commented that the help VOCAL provided increased their’ confidence in how they were caring and in dealing with other agencies and some said the help ‘empowered’ them in their caring role:

> *It took away some of the worry. Gave me confidence in what I needed to do.*
>
> *VOCAL staff hugely helpful in terms of knowledge and honest advice which propels you forward into tackling things I was struggling with and feeling alone with. VOCAL staff are hugely helpful in empowering me as a carer in decision making and give me confidence in my multifaceted caring roles.*
>
> *I was assisted in applying for attendance allowance & I attended a course for carers on dementia & learnt new information, ideas & now feel empowered to deal with my father's dementia.*

Peer support

As already mentioned in previous section support from other carers which carers met while attending courses, seminars and training was also mentioned as an important way of helping carers. Meeting other carers dealing with similar or more difficult situations and learning from other carers as to how they coped:

> *The carer support group made me realise that I was not on my own. I was able to share thoughts, get practical advice and had a group of people to talk to who understood the difficulties and were not judgemental. And all this was done in a very free and easy group setting, open and honest.*
>
> *Talking with other carers helped to confirm what I was endeavouring to achieve as regards my own health was the right way to go.*
>
> *Apart from the support the VOCAL staff provide I find meeting other carers a great help to me. You realise you are not alone and can learn so much from them. I have found the courses I have attended at VOCAL a great help.*

However for one carer although finding attending support groups very beneficial one still had to return to the caring situation which can remain unchanged:

> *It is good to go to the carers' support group because the people you talk to understand what we are going through. We usually feel better at the end of a group meeting but then you have to return home where you find that nothing has changed at all.*

Practical help

As well as the emotional support that many carers mentioned a great many also referred to the practical help they received. Setting up Power of Attorney (POA) was most frequently mentioned but help with other legal issues such as setting up Guardianship arrangements and wills were also mentioned by a few. Some carers mentioned that they had had problems with understanding what was involved in POA, Guardianship etc. but VOCAL were able to explain in terms they could understand and refer them to advisors/solicitors who could draw these documents up for a small charge. Some had been wrestling with setting up a POA for some time:

> *By providing a service that helps with power of attorney issues. It helped me as a carer with an issue that is difficult to deal with. The whole process was easier to deal with, with total support at all stages.*
>
> *The advice given regarding Power of Attorney and whether was needed or not was clear and easy to understand. Having looked at numerous websites on this topic and getting more and more confused by legal jargon. It was great to speak to someone in person to answer all our questions.*
>
> *When applying for power of attorney for my dad and mother-in-law we didn't know where to start and received amazing help and support.*

Other practical help which made a difference to carers was help with completing forms for benefits. This help could start with VOCAL making carers aware of what benefits may be there and what they are entitled to and then going on to help in completing forms. In some cases carers had previously been turned down for benefit but with VOCAL's help in presenting their case they had been successful in attaining benefit:

> *I had previously applied for monetary support but was turned down. VOCAL helped me to complete these forms more accurately.*
>
> *Through help given to fill in a DLA form for my son, I started to understand how I need to explain the needs he has to the DWP.*

> *The help getting my mum on to benefits has helped to pay for additional care and practical help so has freed me a bit as a carer and allowed me to recharge my batteries, wheewh!*

Similarly some carers mentioned that VOCAL had helped them in dealing with other agencies and professionals to present their case or outline what their carer responsibilities were (carers' assessment) which, in some cases led to them to being successful in receiving services e.g. respite/breaks, subsidised leisure card/gym membership:

> *I met with a social work manager at the carers conference and he managed to get the ball rolling on my ongoing battle with social work.*
>
> *The information provided by the staff is helpful and gave me the confidence to demand the support I am entitled to from social services.*
>
> *Gave me confidence, felt prepared. Useful advice when communicating with professionals who care for my mother.*
>
> *Through VOCAL I was made aware (and subsequently obtained) a payment from Edinburgh District Council to improve carers well-being. The payment will pay for my membership of a local fitness club (my first time in 8 years) and this will make a big difference to my quality of life with long-term health benefits as a bonus.*
>
> *Also helping me to complete the assessment was great as I wasn't very good at describing what I did as a carer.*
>
> *Arranged a little respite for myself which was hugely appreciated and helped me along a lot.*
>
> *Help with leisure activities has made a huge difference. As I can afford to go to the gym/classes using a subsidised leisure card. Support with short breaks/funding applications have been very beneficial to our family situation.*

Some carers also had help of advocates:

> *The advocacy I received along with welfare rights (VOCAL put me in touch with them) helped me win my tribunal to keep receiving income support - which allowed me to see mum as much as I did.*
>
> *The advocacy we received was very good in the preparation and lead up to a meeting at school. Unfortunately the advocate took ill on the day of the meeting. The meeting went ahead but in hindsight we should have cancelled it. This was not attributed to the services given by VOCAL.*

Referral to other agencies which could help also important for some in getting perhaps more specific help e.g. for children with additional support needs:

> *Thanks to VOCAL who gave me a list of youth groups, my daughter now attends the Yard and also Kindred (when they have funding). She has made lots of friends and is a lot happier.*
>
> *I contacted 1st hand and received befriending service for my son.*

Information

Information on options available to carers and the person receivng care including benefits, legal arrangements, carer's assessments, housing etc. were helpful for some carers. Several mentioned that these options had not been mentioned by the statutory services they had been in contact with. Several also mentioned that VOCAL were important in updating them on changes in the benefit system which enabled them to apply for more support:

> *Being better informed of options and choices available, what entitlements/expectations should be met by other agencies e.g. social work etc.*
>
> *It opened my eyes and awareness to what I could expect when I began as a carer.*

> *It gave me the information I needed about the change of law for children with additional needs at that time which enable me to make sure my child was adequately supported in school by asking for what I knew he was entitled to.*
>
> *Gave me up to date information on benefit changes.*
>
> *VOCAL was the first place where I found the right information. They put me on the right track.*
>
> *They help me access information that otherwise would have been difficult for me to obtain.*
>
> *The information XX gave me regarding my rights as a carer has been invaluable. Him guiding me towards the L.C.I.L has helped very much with regard to problems I am having with social work department and Direct Payment info. I now have an Independent Living officer supporting me with this. Thank you XX for your advice.*

Understanding condition

For some, gaining information and understanding of the condition the person receiving care was experiencing and how this might change over time, 'being forewarned' was considered extremely useful in increasing confidence in providing care for that person. Practical support in caring for the person was also valuable:

> *They are trained to not judge - something that most of we carers have had from family and friends. Plus the drug scene is changing constantly and it keeps me with the knowledge on how to deal with this and understand what is going on.*
>
> *Gained a lot of knowledge about addiction and support from the family support groups and the help that's available.*
>
> *I learned more about communication with an autistic condition.*
>
> *1. when my wife was diagnosed with dementia, attendance at a VOCAL dementia course gave me the knowledge and confidence to care for her without undue stress. 2. visit to the dementia centre at Stirling University, organised by VOCAL, provided valuable insight and information on a range of aids.*
>
> *Made me aware of the difficulties that I can expect as my husband has dementia. Also what service I may need to contact in the future.*

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. advice and help with setting up POA, information and advice on other legal matters, SDS, care homes, other organisations and services e.g. telecare, getting time for themselves, help with accessing breaks and respite.

Help made no difference to carer

Twenty seven carers reported that the help they received from Vocal made no difference to them as a carer and 15 of these went on to make a comment. Seven of these reported unsatisfactory or poor experiences in their dealings with Vocal. In two of these cases people did not get back to the carer when they said they would, two felt the service was not specialised enough to help, another was never able to get the right person and had a low opinion of the counselling service and the remaining two did not like the way they were treated by VOCAL personnel:

> *Advocacy worker promised certain action, never materialised despite several reminders. [X worker] Midlothian never responded to messages.*

> *I contacted a worker at the family addictions service. We arranged to meet, I felt she judged me when I had told her I has a bad experience at third sector agency]. […]. About a month later I received a questionnaire asking what activities I would be interested in for a summer programme. I completed this, sent it away and that was the last I heard from them. I was so disappointed as I was struggling so much and really needed the support. I have now been attending counselling at [external counselling agency] for nearly two years and am so grateful as I can now manage my life.*
>
> *I went to Vocal last week, the adviser was completely unaware of the updates, and even she promised to update but she was completely an ignorant person, she made me feel down from her attitude. Although I have the recommendation from big organisations like [third sector organisations] but my worker reflected that Vocal are not really helpful or specialised in this part. Sorry my experience was really bad.*
>
> *When I consulted about how to deal with alcohol addiction I recollect that I was given some general, non-specific advice. I would have welcomed firm advice such as help to make an appointment with a named specialist..*
>
> *I never seem to get to the right person e.g. people on holiday, off sick, no available etc. - left feeling there is no point in contacting Vocal. Counselling service is awful - people do not have a clue about being a long term carer and the stress.*
>
> *The service needs to be much more flexible in terms of visiting carers in their own home as many, like myself, are unable to attend appointments in town because of caring responsibilities and the unpredictability of the role. Very helpful over the phone. The person who visited didn't know any more than I did and so was no help really. Staff need to be made more empathetic and this one wasn't . She felt more like an administrator.*

The remaining relevant comments (6) about Vocal not making a difference included two where the respondent: had not used the service or not had time to read information and wanted face to face contact, three where there was no success applying for benefits and one where a disabled carer found the training/meetings on offer were too far away.

7 Appendix 1

7.1 Tables by local authority area

Table 7-1 Rating of VOCAL's response by carer location (excellent or good) (%)

Response	Edinburgh	Midlothian	East Lothian	West Lothian	Other	Not answered	Total
	%	%	%	%	%	%	%
Friendliness of response	96	95	100	94	100	100	96
Knowledge of staff and volunteers	90	90	94	81	100	91	90
Ease of getting in touch with VOCAL	94	90	89	94	100	100	94
Doing what they said they would	90	84	100	94	100	90	89
Getting as much information as needed	91	88	100	88	100	90	91
Getting information about other groups/orgs	83	78	83	67	90	80	82
VOCAL's overall response	94	87	100	94	100	96	93
N	**471-446**	**109-117**	**17-18**	**15-17**	**10-11**	**20-23**	

Table 7-2 VOCAL services found useful by carer location (%)

Service	Edinburgh	Mid Lothian	East Lothian	West Lothian	Other	No data	Total
	%	%	%	%	%	%	%
Information (incl carer information pack)	73	60	79	60	67	67	70
Advice and support	61	62	74	65	50	67	62
Carer support groups	30	26	26	6	25	46	28
Training courses and seminars	38	22	37	18	42	46	36
Accessing short breaks and	10	10	0	12	8	30	10
Help with POA/legal issues	26	26	26	53	25	25	27
Financial planning and benefits advice	20	10	26	12	0	17	18
Counselling	16	10	11	6	17	4	14
Family support (Addictions)	4	0	5	0	0	8	3
Advocacy	5	7	16	12	0	25	6
Social/leisure and health activities	14	6	21	6	8	17	12
Website	12	10	5	24	8	8	11
N	**495**	**125**	**19**	**17**	**12**	**24**	**692**

Table 7-3 Whether help received from VOCAL made a difference by carer location

Help from VOCAL made:	Edinburgh		Midlothian		East Lothian		West Lothian		Other		Not answered		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No	%
A big difference	302	65	75	67	11	58	12	75	8	80	15	75	423	66
A small difference	90	19	24	21	3	16	2	13	2	20	1	5	122	19
No difference	19	4	5	5	2	10	1	6	0	0	0	0	27	4
Can’t say	53	11	8	7	3	16	1	6	0	0	4	20	69	11
Total	464	100	112	100	19	100	16	100	10	100	20	100	641	100

Table 7-4 Organisation carer is most comfortable with to carry out a Carer’s Assessment by carer location

	Edinburgh		Midlothian		East Lothian		West Lothian		Other		Not answered		Total	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Carers’ Centre	268	57	66	57	14	82	9	56	6	60	12	63	375	58
NHS	116	25	32	28	4	24	5	31	2	20	1	5	160	25
Supporting organisation	114	24	22	19	4	24	4	25	4	40	2	11	150	23
Council	38	8	15	13	3	18	2	13	0	0	1	5	59	9
Other organisation	15	3	5	4	1	6	1	6	0	0	2	11	24	4
Total	472	100	115	100	17	100	16	100	10	100	19	100	649	100

7.2 Tables by carer age-group

Table 7-5 Organisation carer is most comfortable with to carry out a Carer's Assessment by age group (No.)

	20-60 years	61 to 79 years	80 and over	Age not given	Total*
Carers Centre	177	136	28	34	375
NHS	82	53	10	15	160
Supporting	85	43	12	10	150
Council	26	24	6	3	59
Other organisation	13	5	2	4	24
Total	308	232	52	57	649

Table 7-6 Organisation carer is most comfortable with to carry out a Carer's Assessment by age group (%)

	20-60 years	61 to 79 years	80 and over	Age not given	Total*
	%	%	%	%	%
Carers Centre	57	59	54	60	58
NHS	27	23	19	26	25
Supporting	28	19	23	18	23
Council	8	10	12	5	9
Other organisation	4	2	4	7	4
Total	100	100	100	100	100

Table 7-7 What services and support do you feel should be available to carers by right and free of charge? (No.)

Service	20-60 years	61 to 79 years	80 and over	Age not given	Total
Information and advice	297	218	44	53	612
Emotional support	255	163	25	40	483
Condition specific training	213	147	25	40	425
Regular breaks from caring	218	145	23	39	425
Counselling	221	139	17	32	409
Advocacy	176	100	10	27	313
Moving and handling training	173	102	10	24	309
Other	29	20	1	7	57
Total	319	242	52	57	670

Table 7-8 What services and support do you feel should be available to carers by right and free of charge? (%)

Service	20-60 years	61 to 79 years	80 and over	Age not given	Total
	%	%	%	%	%
Information and advice	93	90	85	93	91
Emotional support	80	67	48	70	72
Condition specific training	67	61	48	70	63
Regular breaks from caring	68	60	44	68	63
Counselling	69	57	33	56	61
Advocacy	55	41	19	47	47
Moving and handling training	54	42	19	42	46
Other	9	8	2	12	9
Total	100	100	100	100	100

Table 7-9 Last internet use by carer age group (No.)

	20-60 years	61 to 79 years	80 and over	Age not given	Total
Within the last 3 months	284	177	18	36	515
More than 3 months ago	12	11	3	4	30
Never used	20	54	32	16	122
No response	3	5	2	0	10
Total	319	247	55	56	677

Table 7-10 Last internet use by carer age group (%)

	20-60 years	61 to 79 years	80 and over	Age not given	Total
	%	%	%	%	%
Within the last 3 months	89	72	33	64	76
More than 3 months ago	4	4	5	7	4
Never used	6	22	58	29	18
No response	1	2	4	0	1
Total	100	100	100	100	100

Table 7-11 Last internet use by location for support (No.)

	Within the last 3 months	More than 3 months ago	Never used	No response	Total
At home	90	10	24	7	131
Local library	71	8	23	2	104
Edinburgh Carer's Centre	37	7	7	4	55
Midlothian Carer's Centre	20	2	5	0	27
A carer's group that you attend	18	2	4	0	24
A group you attend with the person you care for	8	2	2	0	12
Other place	5	2	1	1	9
Total expressing interest	164	20	55	9	248
I am not interested / don't need support	166	4	35	1	206
Total	515	30	122	10	677

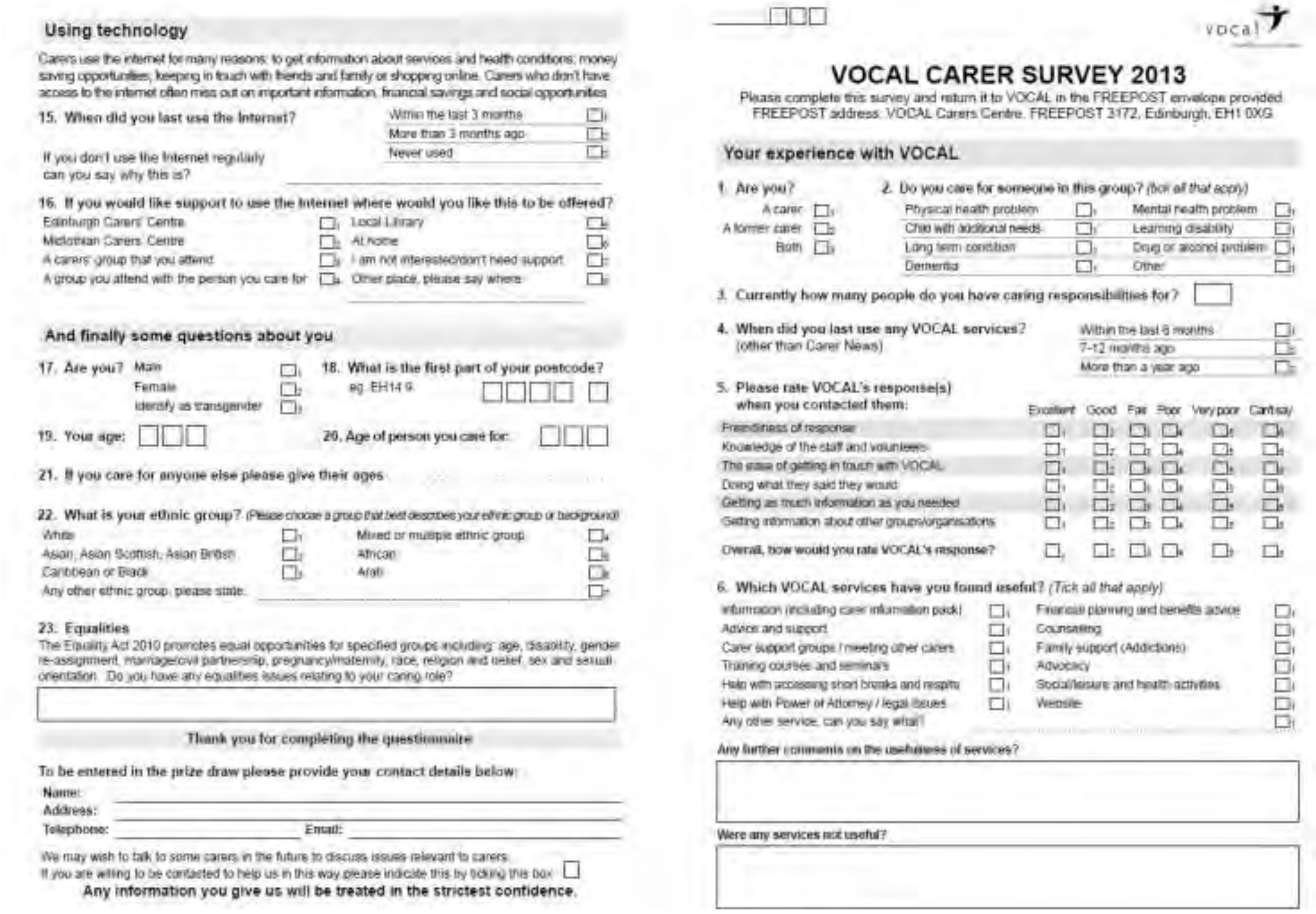
Table 7-12 Location for internet support by carer age group (No.)

	20-60 years	61 to 79 years	80 and over	Age not given	Total
	No.	No.	No.	No.	No.
At home	67	43	10	11	131
Local library	43	47	4	10	104
Edinburgh Carer's Centre	26	22	1	6	55
Midlothian Carer's Centre	14	10	0	3	27
A carer's group that you attend	10	8	1	5	24
A group you attend with the person you care for	6	4	2	0	12
Other place	4	2	1	2	9
Total expressing interest	109	95	17	27	248
I am not interested / don't need support	109	71	19	7	206
Total	319	247	55	56	677

Table 7-13 Location for internet support by carer age group (%)

	20-60 years	61 to 79 years	80 and over	Age not given	Total
	%	*%*	*%*	*%*	*%*
At home	*21*	*17*	*18*	*20*	*19*
Local library	*13*	*19*	*7*	*18*	*15*
Edinburgh Carer's Centre	*8*	*9*	*2*	*11*	*8*
Midlothian Carer's Centre	*4*	*4*	*0*	*5*	*4*
A carer's group that you attend	*3*	*3*	*2*	*9*	*4*
A group you attend with the person you care for	*2*	*2*	*4*	*0*	*2*
Other place	*1*	*1*	*2*	*4*	*1*
Total expressing interest	*34*	*38*	*31*	*48*	*37*
I am not interested / don't need support	*34*	*29*	*35*	*13*	*30*
Total	*100*	*100*	*100*	*100*	*100*

8 Appendix 2: Questionnaire



Using technology

Carers use the internet for many reasons: to get information about services and health conditions; money saving opportunities; keeping in touch with friends and family or shopping online. Carers who don't have access to the internet often miss out on important information, financial savings and social opportunities

15. When did you last use the Internet?

Within the last 3 months ☐
More than 3 months ago ☐
Never used ☐

If you don't use the Internet regularly can you say why this is? ______________________

16. If you would like support to use the Internet where would you like this to be offered?

Edinburgh Carers' Centre ☐
Midlothian Carers Centre ☐
A carers' group that you attend ☐
A group you attend with the person you care for ☐
Local Library ☐
At home ☐
I am not interested/don't need support ☐
Other place, please say where ☐ ______________________

And finally some questions about you

17. Are you? Male ☐ Female ☐ Identify as transgender ☐

18. What is the first part of your postcode? eg. EH14 9 ☐☐☐☐ ☐

19. Your age: ☐☐☐

20. Age of person you care for: ☐☐☐

21. If you care for anyone else please give their ages ______________________

22. What is your ethnic group? *(Please choose a group that best describes your ethnic group or background)*

White ☐
Asian, Asian Scottish, Asian British ☐
Caribbean or Black ☐
Mixed or multiple ethnic group ☐
African ☐
Arab ☐
Any other ethnic group, please state: ______________________ ☐

23. 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.

_______ ☐☐☐

vocal

VOCAL CARER SURVEY 2013

Please complete this survey and return it to VOCAL in the FREEPOST envelope provided
FREEPOST address: VOCAL Carers Centre, FREEPOST 3172, Edinburgh, EH1 0XG

Your experience with VOCAL

1. Are you?

A carer ☐
A former carer ☐
Both ☐

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

Physical health problem ☐
Child with additional needs ☐
Long term condition ☐
Dementia ☐
Mental health problem ☐
Learning disability ☐
Drug or alcohol problem ☐
Other ☐

3. Currently how many people do you have caring responsibilities for? ☐

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

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

5. Please rate VOCAL's response(s) when you contacted them:

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

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

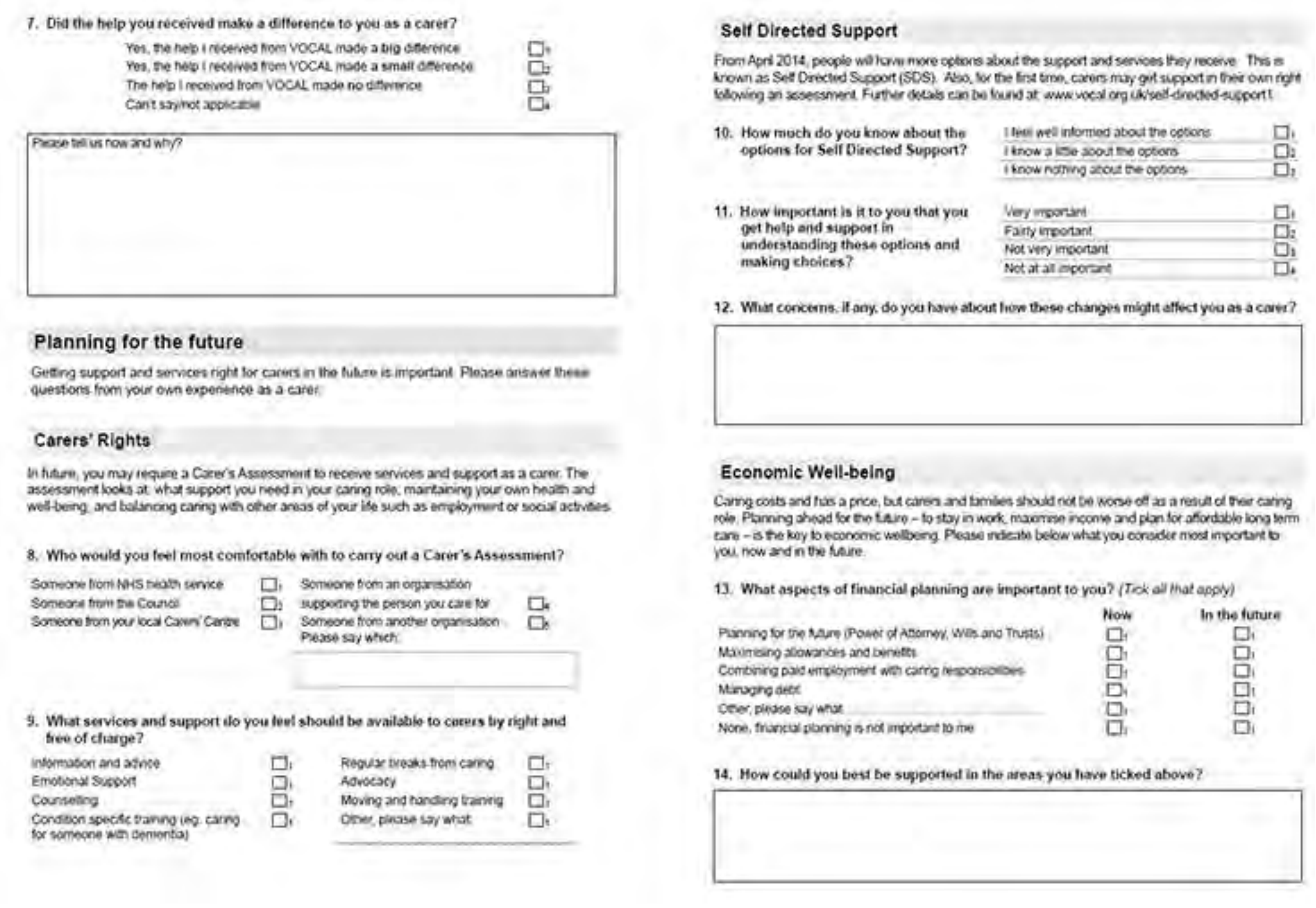
Information (including carer information pack) ☐
Advice and support ☐
Carer support groups / meeting other carers ☐
Training courses and seminars ☐
Help with accessing short breaks and respite ☐
Help with Power of Attorney / legal issues ☐
Financial planning and benefits advice ☐
Counselling ☐
Family support (Addictions) ☐
Advocacy ☐
Social/leisure and health activities ☐
Website ☐
Any other service, can you say what? ☐

Any further comments on the usefulness of services?

☐

Were any services not useful?

☐



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

Please tell us how and why?

Planning for the future

Getting support and services right for carers in the future is important. Please answer these questions from your own experience as a carer.

Carers' Rights

In future, you may require a Carer's Assessment to receive services and support as a carer. The assessment looks at: what support you need in your caring role; maintaining your own health and well-being; and balancing caring with other areas of your life such as employment or social activities.

8. Who would you feel most comfortable with to carry out a Carer's Assessment?

- Someone from NHS health service ☐
- Someone from the Council ☐
- Someone from your local Carers' Centre ☐
- Someone from an organisation supporting the person you care for ☐
- Someone from another organisation ☐ Please say which:

9. What services and support do you feel should be available to carers by right and free of charge?

- Information and advice ☐
- Emotional Support ☐
- Counselling ☐
- Condition specific training (eg. caring for someone with dementia) ☐
- Regular breaks from caring ☐
- Advocacy ☐
- Moving and handling training ☐
- Other, please say what ☐

Self Directed Support

From April 2014, people will have more options about the support and services they receive. This is known as Self Directed Support (SDS). Also, for the first time, carers may get support in their own right following an assessment. Further details can be found at: www.vocal.org.uk/self-directed-support1

10. How much do you know about the options for Self Directed Support?

- I feel well informed about the options ☐
- I know a little about the options ☐
- I know nothing about the options ☐

11. How important is it to you that you get help and support in understanding these options and making choices?

- Very important ☐
- Fairly important ☐
- Not very important ☐
- Not at all important ☐

12. What concerns, if any, do you have about how these changes might affect you as a carer?

Economic Well-being

Caring costs and has a price, but carers and families should not be worse off as a result of their caring role. Planning ahead for the future – to stay in work, maximise income and plan for affordable long term care – is the key to economic wellbeing. Please indicate below what you consider most important to you, now and in the future.

13. What aspects of financial planning are important to you? *(Tick all that apply)*

	Now	**In the future**
Planning for the future (Power of Attorney, Wills and Trusts)	☐	☐
Maximising allowances and benefits	☐	☐
Combining paid employment with caring responsibilities	☐	☐
Managing debt	☐	☐
Other, please say what	☐	☐
None, financial planning is not important to me	☐	☐

14. How could you best be supported in the areas you have ticked above?

VOCAL (Voice of Carers Across Lothian)
8-13 Johnston Terrace, Edinburgh, EH1 2PW
T: 0131 622 6666 **E:** centre@vocal.org.uk
W: www.edinburghcarers.co.uk

VOCAL is recognised as a Scottish charity: SC020755
Private limited company (Scotland): SC183050

HAPPY TO **TRANSLATE**

MOŻEMY **PRZETŁUMACZYĆ** আনন্দের সঙ্গে অনুবাদ করব

يسعدنا توفير الترجمة 很樂意翻譯 ترجمے کے لئے حاضر

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
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