

VOCAL Carer Survey 2015

EDINBURGH SUMMARY

A study of carers' views on the economic impacts of caring, the barriers to a life alongside caring and on services and support received from VOCAL (Voice of Carers Across Lothian).

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Summary

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

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

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

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

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

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

Method

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

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

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

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

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

Carer Identification

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

Economic well being

- ▶ Almost half of carers (47%) reported that caring had affected their finances. A third (36%) had had to reduce hours or give up paid employment. Altogether 27% (179) were affected in both of these ways; 56% (374) were affected in one of these ways.
- ▶ The financial issues of importance to the greatest proportion of carers were accessing benefits and allowances (58%) and planning for the future (48%).
- ▶ More than a fifth (22%) of carers commented on finance-related issues including: balancing caring and employment, benefits and other entitlements, funding care, breaks from care, considering future care and legal and financial arrangements.
- ▶ Working whilst caring was a struggle and some carers had reduced hours or given up work altogether to accommodate caring. There was concern how this would affect their long-term financial position. Flexible working was important for carers in employment while others wanted support to get back into employment after caring.
- ▶ Those who were caring for adult children, but also other carers, expressed concern about what would happen to the person they cared for if they were no longer able to care. Some were already making plans for the future.

A life alongside caring

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

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

Using technology

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

Shaping services and support for the future

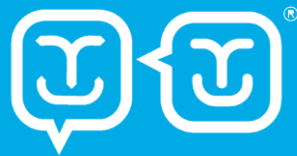
- ▶ Carers thought that VOCAL should develop more opportunities for breaks from caring (41%), services with a greater focus on both physical and emotional health (40%) and help with practical tasks (33%). More emotional support (32%) and a carers' centre in their own local area (32%) was called for by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

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

Carers' experience of VOCAL

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





HAPPY TO TRANSLATE

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



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