

Carer Survey

Midlothian summary 2015

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

Anne Birch and Christine Sheehy

April 2016



Summary

In Midlothian over 14,000 people support an older person in need of care or someone with a long-term condition or disability. The value of their care has been estimated at £171 million – providing significant savings for Midlothian Council and the NHS.

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 carers' 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 offer more support and opportunities for carers in their local areas. This survey also informed VOCAL's investment in a new Carers Centre in Midlothian and the range of services delivered from there to carers across Midlothian.

In October 2015 VOCAL launched its third and largest survey to date. 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 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 180 responses to the survey received from Midlothian carers.

- ▶ In 2015 there were 180 responses, a 44% increase on 2013 (125) (2011, 119).
- ▶ Almost a half (46%) of all respondents had been in touch with VOCAL within the previous six months (34% in 2013); 83% identified themselves as current carers and 12% as former carers.
- ▶ The majority of respondents were female (76% vs 23%) a similar finding to that in 2013 (74% vs 25%).
- ▶ 41% were under 60 years of age (47% in 2013), about a third (34%) were aged 61 to 79 years and 11% were aged over 80 years.
- ▶ Response was analysed by quintile of the Scottish Index of Multiple Deprivation (SIMD). This measure looks at deprivation arising from a lack of resources or opportunities, covering health, safety, education, employment, housing and access to services, as well as financial aspects. The first quintile is the most deprived the fifth least deprived.
- ▶ 8% of respondents (13) were from the most deprived areas of Midlothian.

- ▶ There were twice as many respondents (16%, 27) from the least deprived areas of Midlothian as there were from the most deprived.
- ▶ The largest proportion of respondents (29%, 48) was from the 3rd quintile. The majority of respondents (94%) classified themselves as white and 6% as from other ethnic minority groups.
- ▶ Over a quarter (27%) of those receiving care were aged 80 and over. More than a quarter (27%) were aged between 61 and 79 years of age and more than a third (38%) were aged under 60 years.
- ▶ 75% of carers provided care for one person, 11% for two people and 2% for 3 people.
- ▶ Carers provided care for people with physical health problems (51%), long term conditions (38%) dementia (36%) mental health problems (21%), someone with a learning disability (15%) or for a child with additional needs (11%).

Carer identification

- ▶ Over half of carers (51%) said that they realised themselves that they were a carer. Family and friends (15%) were important; as were the GP surgery (14%), social worker or occupational therapist (10%) and someone at the hospital (10%).
- ▶ Over half (57%) of carers reported that they were not directly referred to VOCAL. Almost a third said they were referred (31%, 51). Social Care Direct were most likely to refer carers to VOCAL followed by a social worker or occupational therapist.
- ▶ 27% of carers were in paid employment and/or studying. Of these 43% (22) reported that it was important that their employer or college asked them about their caring responsibilities. A third said that it was important that their employer or college has a carers' policy and 27% (14) said that it was important that there was someone they could speak to in confidence about their caring role. Other support in terms of information, links to local carer support and provision of a carer support group were important to fewer carers.

Economic well being

- ▶ Over half of the carers (51%) said that taking on a caring role had affected their finances. More than a third (36%) reported that they were not financially worse off as a result of caring.
- ▶ Expenses had increased since they started caring for 43% of carers and a quarter (24%) said that they had had to reduce or give up hours in paid employment. 11% had lost National Insurance contributions as a result of their caring. A fifth of carers (21%) had used some of their own money and savings to pay for care. Accessing benefits and allowances was an important issue to the greatest proportion of carers (59%) and reducing energy and utility bills was important to over half of carers (52%). Funding to pay for breaks from caring (45%) and planning for the future including POA (40%) were also rated as important.

Using technology

- ▶ 68% of carers had used the Internet within the last seven days. Three quarters of carers (76%) had used the Internet within the last 3 months, an increase of 7 percentage points since 2013. A smaller proportion (20%) had never used the Internet at all compared with 2013 (26%).
- ▶ Almost two thirds (62%) said they were confident using the Internet.

- ▶ Well over a third of carers used the Internet to contact friends and family online (38%) and a third to get information and support (33%).
- ▶ About one in five (21%) of those who had used the Internet within the last 7 days had saved money using the Internet.
- ▶ 83 carers had used Facebook, 37 What's app and 15 Twitter. Other social media used included Instagram (1) and Tumblr (1).

A life alongside caring

- ▶ The primary barrier mentioned by around one in five carers was lack of time due to the 'always on call' nature of caring and the particular and unpredictable nature of caring. Any free time or opportunity to go out was limited to a few hours or circumscribed by set periods of respite.
- ▶ Specific routines and caring tasks to meet the cared for person's particular needs could tie the carer to the house most of the time. Carers could find themselves committed to particular times of day, or all day every day (e.g. for feeding, drug compliance checking, to give medications at a particular time).
- ▶ Family relationships and family support was the topic most mentioned by Midlothian carers after lack of time. Some carers were caring for more than one person and sometimes across generations. This brought its own stresses and strains.
- ▶ Finding the right kind of support or respite was a concern for some carers, others did not know what respite was available. Cost was an issue and the lack of 'free respite care'. There were also concerns about care quality.
- ▶ A lack of money was a barrier to free time for some carers.
- ▶ Carers worried about what would happen to their cared for person when they were away.
- ▶ Inability to relax, lack of sleep because of the constant anxiety and being on call was experienced by some carers. They felt physically exhausted, constantly tired and lacked strength and energy as a result of the endless tasks to be done.
- ▶ Carers felt their family and social life was affected by caring. Carers could become socially isolated and lose contact with activities they used to enjoy doing. Maintaining or starting activities required determination.

Shaping services and support for the future

- ▶ Fifty per cent of respondents selected 'more opportunities for breaks from caring' as a service they would like to see developed. This was followed by services with a greater focus on health both physical and emotional (39%) and a third (33%) wanted more opportunities to meet other carers. Emotional support was selected by 32% of carers - the same proportion that wanted help with practical tasks. Just over a quarter of carers (29%) wanted a Carer Centre in their local area.
- ▶ Other suggested services and support that VOCAL could develop included; a computer learning group at centre, technology forums, VOCAL based in GP practice to provide a voice for carers, more courses/ events in the afternoon and evening and more focus on male carers.

Carers' experience of VOCAL

- ▶ Carers found out about VOCAL from a variety of sources including general practice, hospital services and community health services. Personal communication including with family and friends were also an important source. About a fifth of carers found out about VOCAL via local support/voluntary groups and a similar proportion found out via their local authority specifically via social services.
- ▶ A majority of carers (82%) rated VOCAL's overall response as '*excellent*' or '*good*', a drop of five percentage points on the last survey in 2013.
- ▶ Carers rated as '*excellent*' or '*good*' the friendliness of VOCAL's response (97%), ease of getting in touch with VOCAL (96%), getting as much information as needed (94%) and knowledge of staff and volunteers (84%).
- ▶ Help with accessing short breaks and respite was the service rated most highly (33%) by carers followed by help to plan support (31%), financial planning and benefits advice (30%) and help with Power of Attorney or legal issues (29%). Around a quarter of carers rated as useful; help with managing their caring role (27%), meeting other carers (26%), training courses and seminars (25%) and Wee Breaks (25%). A fifth of carers (21%) found information useful.
- ▶ Less than half of carers (83, 46%) had used the Midlothian Carer Centre.
- ▶ More than two thirds of carers (71%) reported that the help they received from VOCAL made a big difference to them and another 17% said it made a small difference. This was similar to the proportion of carers in the 2013 survey reporting that VOCAL's help made a difference to them (88%).
- ▶ Support and advice, reassurance, help with benefits, meeting other carers, counselling, financial help for respite, breaks and wee breaks, training courses and legal advice were all mentioned as ways that VOCAL made a difference to carers.





HAPPY TO TRANSLATE

You can get summary versions in Braille, large print, easy read and audio if you ask us - call VOCAL on 0131 663 6869.



VOCAL (Voice of Carers Across Lothian)
Midlothian Carer Centre, 30/1 Hardengreen Terrace,
Dalhousie Road, Dalkieth EH22 3NX

T: 0131 663 6869 **E:** midlothian@vocal.org.uk

www.midlothiancarers.co.uk

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