

# Edinburgh *Carer survey 2017*

Summary report March 2018





# 1. Introduction

## 1.1 Background

VOCAL - The Voice of Carers Across Lothian - commissioned Scotinform to undertake its biennial survey of carers in Edinburgh in November 2017.

A parallel survey was run at the same time with carers in Midlothian; please see separate reports for the results of the Midlothian Carers' Survey.

## 1.2 Research Objectives

The specific objectives of the research were:

- ▶ To obtain a profile of VOCAL carers;
- ▶ To assess satisfaction with services currently offered;
- ▶ To assess interest in other potential services and developments;
- ▶ To understand VOCAL's impact;
- ▶ To understand the impact of caring more broadly, in three areas:
  - ◆ – Health and wellbeing
  - ◆ – Money and work
  - ◆ – Time away from caring

The findings are to be used to inform VOCAL's strategic planning and to assist with communicating with stakeholders.

# 2. Response rate

- ▶ 7,984 surveys were distributed in Edinburgh, with 915 returns received. This represents a response rate of 12%.
- ▶ The response rate is slightly lower than in 2015 (14%), but the number of responses achieved is higher – 915 returns, compared with 728 in 2015.
- ▶ 61% of respondents replied to the paper format of the survey and 21% responded to the email.
- ▶ Increasing the use of electronic communications would improve the environmental and financial efficiency of the process, but must be carefully balanced against the characteristics of carers.

### 3. VOCAL satisfaction and impact

- ▶ VOCAL Edinburgh has a highly satisfied cohort of carers.
- ▶ Nearly half of respondents have engaged with VOCAL in the past six months, and nearly 90% have engaged within the past year.
- ▶ Carers value the provision of services at a local level, with 88% of respondents saying that it was “very important” or “important” that they had access to VOCAL services locally.
- ▶ In Edinburgh, carers particularly value the provision of information, signposting and training by VOCAL.
- ▶ Satisfaction ratings are admirable across all measures, and particularly in terms of friendliness of staff. On every measure, more than half of respondents rated VOCAL as “excellent”.
- ▶ Two thirds of carers say that the help they receive from VOCAL makes make a big difference to their ability to care.
- ▶ Respondents identify a range of positive impacts, focusing on health, the provision of information, financial assistance, time away from caring, and learning new skills.

*“I had no knowledge of anything and needed all the help I could get.”*

### 4. Impact of caring on health and wellbeing

- ▶ 59% of carers in Edinburgh reported that caring has had a negative impact on their health.
- ▶ The negative health impacts increased with the duration of care.
- ▶ Over a third of carers reported negative health impacts for each of the areas identified. The most frequent issues were concerns about contingency planning if respondents are unable to care, and insufficient sleep.
- ▶ This manifests itself in increased visits to the GP (35% of respondents) and experience of depression (49% of respondents).
- ▶ There are also social impacts as a result of caring: nearly half of carers feel isolated from family and friends.
- ▶ The sense of isolation and concern about contingency planning is underlined by the fact that only half of respondents felt that they had somebody to rely on for support.
- ▶ Carers of children and of younger adults were particularly likely to identify a negative health impact as a result of caring.
- ▶ There is some evidence (albeit with a small sample) that VOCAL can help to mitigate against some of these negative health impacts. Respondents who had not engaged with VOCAL services were more likely than the sample overall to agree that being a carer had made their health worse.
- ▶ The open-ended comments made by carers underline the significant impact on carers’ health, often exacerbated by money worries, a lack of time for self-care, and concerns about what will happen in the future.

*“I was at breaking point. I now have better coping strategies in place”*

## 5. Impact of caring on money and work

- ▶ 47% of respondents agreed that being a carer had made money and finances more difficult.
- ▶ There is tangible evidence of the financial and economic impact of caring: a third of carers are paying for care out of their own savings; a quarter have had to reduce their working hours and a further quarter have had to give up work altogether. 12% have lost out on NI or pension contributions as a result.
- ▶ Respondents highlighted the long-term impact of giving up work, both on future career prospects and on pension entitlements.
- ▶ Carers of children and young adults (who have often been caring for a long time and who have had to reduce or give up work) were more likely to report negative financial impacts.
- ▶ They were also more likely to say that they find it hard talking about these impacts. Funders and organisations working with carers must acknowledge the emotional impact of applying for financial support.
- ▶ 43% of respondents felt that they knew what financial support was available, with a third saying that they felt confident in applying for it and a similar proportion agreeing that it was sufficient. VOCAL should therefore continue to provide information to raise awareness, support carers in making applications, and lobby to ensure that the funding levels are fair. Carers of adults aged 25-64 might be a particular target here.
- ▶ Paying for care homes is a key concern for carers of adults over the age of 75, who comprise approximately half of this sample.
- ▶ There is some evidence (again with the caveat of a small sample size) that respondents who engage with VOCAL report smaller negative financial impacts than those who do not.

*“Being a carer has made money and finances more difficult.”*

## 6. Time away from caring

- ▶ Only half of carers in Edinburgh say that they have had time away from caring in the past year. A third say that they have never had time away at all.
- ▶ Time away from caring can have a positive impact on carers. 80% of those who have taken time away from caring say that it has made it easier for them to continue in their caring role.
- ▶ Barriers to effective time away include: the carer being able to relax; the preferences of the person being cared for; and the stress associated with planning and paying for a break.
- ▶ Carers of children and young adults aged 16-25 appear to experience the above barriers more frequently than carers of older people. Carers of children are more likely to want to take a break with the person they care for.
- ▶ The findings suggest that effective support for the carer and the person they care for is essential for beneficial time away.

*“Having time to myself to relax with the short break fund helped immensely.”*

## 7. Future development of services and support

- ▶ Existing users like what VOCAL is doing now, and want to see it continued.
- ▶ Interest in online services is not overwhelming. It primarily appeals to carers of working age and would need to be an enhancement of existing services, not a replacement.
- ▶ There is some evidence, however, that non-users would respond well to online support. This, with a focus on the provision of information, could be a means of engaging with new users.
- ▶ Edinburgh carers would like to see “more of the same” at the new Carers’ Hub in Leith, but with improved access and greater flexibility.

## 8. Recommendations

Based on the findings of this report, Scotinform recommends that VOCAL Edinburgh should:

- ▶ Communicate the excellent satisfaction ratings and feedback to staff, volunteers, funders and other stakeholders. VOCAL is an effective, authoritative voice.
- ▶ Recognise that long-term carers show slightly different characteristics and may require additional or different support.
- ▶ Consider the development of online services for some audiences, but as an additional service rather than to replace the current support mechanisms.
- ▶ Use the Mosaic profile (with caution, given its diversity) to inform marketing and communications strategies and to identify potential engagement targets (e.g. households on low incomes).
- ▶ Develop the Edinburgh Carers’ Hub in Leith as a flexible space with good access and opportunities for social interaction.
- ▶ Recognise the value of time away from caring whilst understanding that it is a complex and emotive issue and that the carer and the person being cared for will require support to implement it effectively.
- ▶ Consider developing additional support or guidance for carers of children, who appear to face increased barriers to securing effective time away from caring.
- ▶ Use the findings of the survey to demonstrate the financial and health impacts of caring, and to campaign for more support for carers.
- ▶ Communicate (with caution) the finding that carers who have not engaged with VOCAL appear to experience more negative benefits than carers who have done so. Consider further research with both groups to validate this initial finding.

*“It is vital to have an organisation like VOCAL that can support me so I can carry on with my caring duties – otherwise I just wouldn’t cope.”*

# Appendix

## Methodology

In order to enable comparisons with previous surveys and reflect the characteristics of the likely audience the survey took the form of a self-completion questionnaire. The design of the questionnaire was undertaken by Scotinform and was informed by:

- ▶ The design of the previous survey, allowing for comparison where possible;
- ▶ A briefing meeting with VOCAL;
- ▶ Two consultation workshops, held in Edinburgh and Midlothian with a range of stakeholders, to test out the proposed content and terminology of the questionnaire design.

The workshops enabled Scotinform to refine the questionnaire in response to the feedback provided. Different versions of the questionnaire were developed for Edinburgh and Midlothian, to reflect different service delivery and funding mechanisms. A paper-based and an electronic version of each questionnaire were produced and a prize draw incentive was offered in order to boost responses.

The questionnaire was mailed out to the VOCAL distribution database. A link to the electronic questionnaire was also shared on social media, which for the first time enabled VOCAL to capture the details of carers in Edinburgh and Midlothian who were not engaged with VOCAL.

Scotinform would like to thank VOCAL staff and volunteers for their help and support throughout the process.

## Carer characteristics

- ▶ Three-quarters of carers are female.
- ▶ There is an even split between carers of working age and older carers.
- ▶ A quarter of carers are in paid employment, despite half of the sample being of working age.
- ▶ Caring often transcends local authority boundaries – carers of Edinburgh residents lived across the Lothians, as well as in Fife and the Scottish Borders.
- ▶ The Mosaic Scotland profile of respondents is diverse, with the four main types displaying quite different characteristics. This reflects the diversity in the sample. In comparison with the population of Edinburgh, VOCAL Edinburgh appears to be engaging most effectively with audiences of average to high levels of income.
- ▶ 60% of Edinburgh carers have been caring for more than 5 years.
- ▶ Long-term carers have a slightly different profile. They are more likely to be caring for a younger person and to be caring for more than one person.
- ▶ 49% of carers are looking after someone aged over 75.
- ▶ There are varying responses to using the internet to support caring, with two-thirds of respondents saying that they are confident in doing so. The Mosaic profile is diverse and a combination of email and postal communication is required.
- ▶ The profile is broadly similar to the sample in 2015, although the figures suggest that the number of young people being cared for may have increased.



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



VOCAL (Voice of Carers Across Lothian)

60 Leith Walk, Edinburgh EH6 5AA

T: 0131 622 6666 E: [centre@vocal.org.uk](mailto:centre@vocal.org.uk)

[www.vocal.org.uk](http://www.vocal.org.uk)

VOCAL is recognised as a Scottish charity: SC020755

Private limited company (Scotland): SC183050