



Carers Survey 2024

CoEL Survey Report 2024

The CoEL survey was conducted across February and March 2024. The survey was disseminated to carers via CoEL's mailing list, social media platforms and via an East Lothian professional network to reach as many carers as possible. The survey was designed to help deepen the organisations understanding of unpaid care and ensure their services are responsive to the needs of carers. CoEL staff studied the responses for themes, gaps and areas for development. The information was compiled into a detailed report which was shared with relevant parties who can build the findings into their work, improve practice and potentially implement change for carers. These included: the CoEL Board of Trustees, the Senior Management team, CoEL's Carers Panel, the wider staff team and local commissioning officers. This summary provides an overview of the findings.

Demographics

- 199 carers completed the survey.
- There was huge diversity of caring roles experienced by those who completed the survey.
- We received feedback from carers of all age groups. The largest response groups were the 50 – 64 age group (74 responses) and the 65 – 74 age group (49 responses). The smallest response groups were 18 – 24 (1 response) and 25 – 34 (6 responses).
- 158 respondents identify as female and 33 identify as male.
- Feedback was very equally split across all geographical wards in East Lothian.
- 180 of the responses were from carers who described their ethnicity as white British or white other.

How we are responding to these themes:

- Responses from 33 male carers have been shared with our Men Who Care Worker who will analyse for themes and patterns and use this to inform his work.
- We are working closely with the Young Carers Service to strengthen our links, including how carers transition from young to adult services. We hope that this strengthens our engagement with carers aged 18-24 so that we can understand more about the kind of support that they need.
- Our next survey distribution will take a more targeted approach with carers from under-represented groups.
- We received only a small amount of feedback from carers from minority ethnic groups. CoEL are forging links with local groups (Milan, Health in Mind) to learn more about how we can hear the voices of minority ethnic groups.

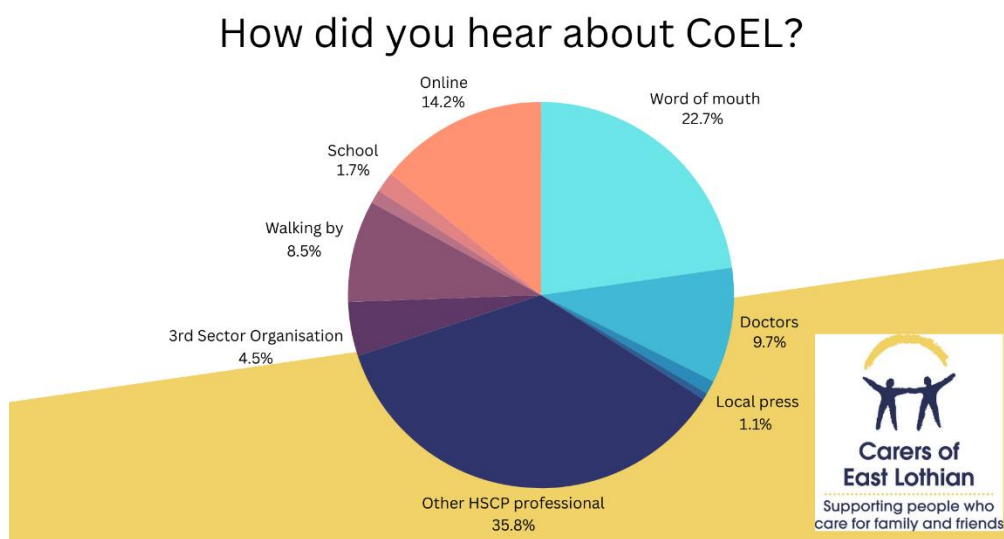
- We plan to study the number of responses received in comparison to our equal opportunities reporting data for 2023 – 2024 in order to form a plan for more targeted future engagement.

Awareness of CoEL

190 of the responses were already registered with CoEL. Of the remaining 9, 8 wished to be registered with CoEL.

Respondents had been caring for between 6 months and 40 years before they started to receive support from CoEL. The most common responses were between 1 and 3 years.

Survey respondents were asked how they heard about Carers of East Lothian. The following pie chart summarises the answers that were provided.



How we are responding to these themes:

- The Carers Panel are focusing on developing an information resource for carers that can be distributed via GP practices.
- CoEL's dedicated Communications and Engagement Coordinator can focus on press coverage more than the organisation were previously able.
- We are regularly developing carers stories with carers accessing our support. We have developed a space on our website for these to be shared to be shared and we will regularly share these via our social media channels. We worked closely with ELHSCP to ensure these stories were shared widely in Carers Week. Please follow [this link](#) to view the stories on our website.

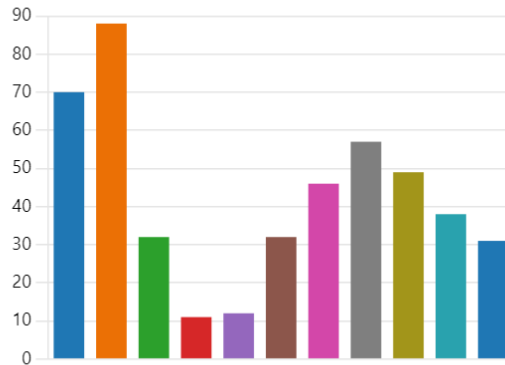
Breaks from caring

What the survey told us:

Respondents were asked several questions about their capacity to take a break from caring. These questions and responses follow:

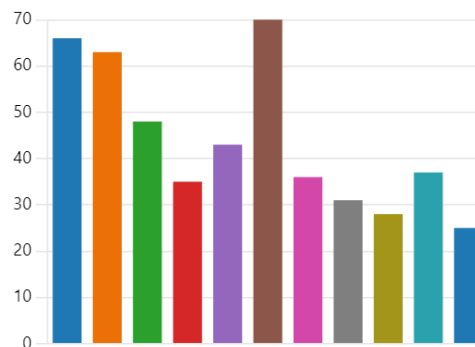
- We know from speaking to carers that many of you are not getting the opportunity to take a break from your caring role. If this is the case for you, what currently prevents you from accessing a break?

● I can't afford the cost of a break	70
● I don't have any replacement ca...	88
● The person(s) I care for will not ...	32
● I don't have the time or energy ...	11
● The budget I have been given b...	12
● I don't know who to speak to ab...	32
● I can't leave the person that I ca...	46
● No other family/ friends are willi...	57
● I don't know what kind of break...	49
● Not applicable	38
● Other	31



- What would enable you to have a break from caring?

● Another family member or friend	66
● A paid carer/ befriender/ volunteer	63
● A paid carer/ befriender/ volunteer	48
● A regular day care service or other	35
● Free or discounted access to local facilities	43
● A grant towards the cost of a break	70
● Planned respite stays in residential care	36
● Temporary live-in care for the person	31
● A budget to arrange replacement care	28
● Not applicable	37
● Other	25



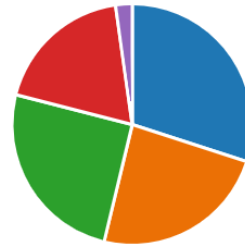
- Carers of East Lothian are exploring the idea of offering Respite breaks to carers. The aim of Respite is to provide a short break for unpaid carers in Scotland when they need it most. This is achieved by connecting carers' organisations with hospitality, tourism and leisure businesses who are willing to donate a break free of charge. Would you be interested in accessing a Respite break through Carers of East Lothian?

● Yes	136
● No	63



- Please could you tell us what sort of respite break you would be interested in?

• Overnight breaks in hotels/ B&B's	107
• Local vouchers eg. Afternoon tea	85
• Complimentary therapies	90
• Entertainment tickets eg. to a p...	67
• Other	8



How we are responding to these themes:

- We have shared responses with ELHSCP to inform their working group in relation to breaks from caring.
- A large percentage of respondents indicated that the cost of a break was a barrier. We continue to offer Time for Me grants for carers to assist in this area.
- As of June 2024, we are a registered respite delivery partner with Shared Care Scotland. We have started work on bringing local businesses on board, as well as offering respite breaks to carers.
- We are trialling a voucher scheme where we purchase vouchers from local organisations to distribute to carers who are looking for a break. We are using the data from these answers to inform the sorts of vouchers that we purchase.
- We are introducing a new grant as part of our contract with Carers Trust where carers can apply for grants of up to £300 for items or activities that will benefit them in their caring role and/or will alleviate the additional strain carers may be experiencing as a direct result of their caring role.

Adult Carer Support Plans

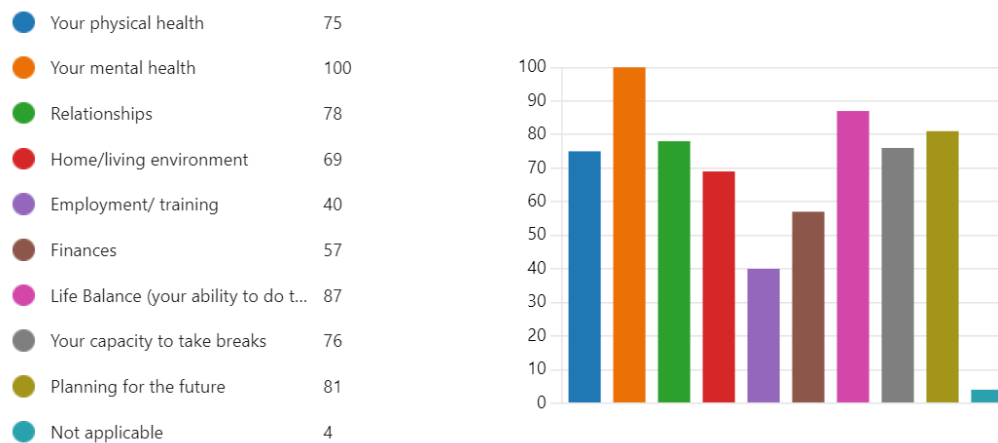
- 81 carers respondents had had an ACSP and 118 had not. The most common reasons for not having an ACSP were as follows:
 - I didn't know about it
 - I don't think I need it
 - I haven't had the time
 - In a gradually occurring caring role and didn't prioritise it at the start.

How we are responding to these themes:

- All feedback on experience of having an ACSP has been shared with members of CoEL management that oversee case work in order support staff in their work with ACSP's.
- We have worked closely with ELHSCP to develop a new and more user friendly ACSP.
- We plan to highlight ACSP on social media and Coel website.

Impact

We asked carers how they are impacted by their caring roles. We used the local eligibility criteria to categorise the areas that may be impacted. The following answers were received:



How we are responding to these themes:

- We shared the information about impact with ELHSCP when they were in the process of developing guidelines for applying the local eligibility criteria for carer support.
- We are now offering regular mindfulness training for carers.
- We sought and were awarded funding from Awards for all to enable male carers to access support for their wellbeing.
- We have continued to promote signposting to and completing joint visits with OT Carers Pathway which will help support carers to achieve balance, quality of life and self-management of their own health and wellbeing.
- We will use the survey findings to help us to plan our events and training programme over the next year.

Events, workshop and training

What the survey told us:

- Carers were asked to comment on the sorts of workshops, training and events they would be interested in attending. The most popular answers were:
 - Caring for yourself - stress management/ relaxation etc
 - Condition specific information sessions
 - Self-care workshops

How are we responding to these themes:

- This information has been passed to the lead on events at CoEL. Stress management and self – care themed sessions were built into Carers Week 2024 and we will continue to build these themes into our regular programme of events.
- CoEL are partnering with Alzheimer’s Scotland, DFEL, OT, SALT and older people’s mental health to develop a programme of Carer Education that will be trialled at Dunbar and Musselburgh DCafe’s over the next year. The method being used will try to reach carers in person and virtually by using recorded presentations and utilising the new CoEL web forum.

If this is a successful collaboration, we will consider rolling this programme out more regularly and potentially trial with other condition specific information.

Carers who were unable to attend the programme of events that we currently run shared their barriers and suggestions. The most common answers were requests for evening sessions, online sessions and sessions that offer flexibility for working carers. We ran a mindfulness course in the evening as a result of this but there was very low attendance and after the first session unfortunately the course had to be cancelled. We ran an evening craft session during Carers Week which was quite well attended. We will continue to explore this and as mentioned above, the Carer Education programme will incorporate an element of virtual support.

We asked carers where the gaps are in our current support groups offer. Most respondents reported that they felt the offer is very thorough. The following additional suggestions were made:

- Yoga group
- Information on adaptations (this has been run in the past with very little take up)
- Aftermath of death (We have recently developed a new area on our website around this theme and are signposting to a new local support group [Link here](#))
- First aid (we are on a waiting list for a volunteer through St. Andrews to deliver sessions for us)
- Computer skills
- Group for male parent carers
- Group for homeschooling families
- Rare diseases
- Sessions together with cf person
- Cooking for male carers (passed to Men Who Care Worker).

Suggestions that have not yet been actioned are all being considered by the appropriate staff at CoEL.

Volunteering and Carers Panel

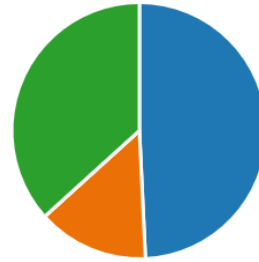
- 35 people expressed interest in the Carers Panel all of whom have subsequently been invited to join
- 27 people expressed interested in volunteering with CoEL all of whom have had their details passed to the Volunteer Coordinator
- 23 carers interested in having a befriender all of whom have had their details passed to the Volunteer Coordinator
- 6 interested in being a befriender all of whom have had their details passed to the Volunteer Coordinator

Feeling Supported and Included

Carers were asked: Throughout your caring journey, have you felt respected, supported and included by the professionals who are involved in the care of the person you care for?

The following responses were received:

● Yes	98
● No	28
● Sometimes	73



How we are responding to these themes:

This feedback has been shared with our Volunteer and Training Coordinator who will incorporate these real-life examples into our Think Carer training for health and social care professionals.

Hospital Discharge

Carers were asked whether they had experienced a hospital discharge of the person they care for. Just under 50 % of respondents had experienced this. Of that 50 % 27 said they were involved in discharge conversations and 60 said they were not.

Many of the carers who responded shared their experiences of hospital discharge of the person that they care for. Our new Hospital Link Worker has received all of this information. They plan to organise a focus group to explore this further as well as using these responses to inform their day-to-day work.

Website

Feedback on our website was shared with web developer and Communications Coordinator. There were no major action points.

Many carers shared examples of what they needed earlier in their caring journey and examples of the most beneficial support they have received to date. The full set of responses have been shared with CoEL's Senior team in order to inform CoEL's delivery plan.