

Feedback report Initial Integrated Impact Assessment East Lothian Carers strategy 2022-25

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# Initial IIA – East Lothian Carers Strategy 2022-25

**Held at Volunteer Centre East Lothian, 56 High Street, Tranent on 22 November 2022 from 10am to 12 noon.**

## Attendance

* Maria Burton, ELHSCP Carers’ Strategy Officer
* Maureen Allen, Chief Officer, Volunteer Centre East Lothian
* Yvonne Irvine, Women’s Aid East and Midlothian
* Cath Purdie, PASDA
* Marie Prior, East Lothian Council Young Carers Lead
* Jane Ogden-Smith, ELHSCP Equalities and Engagement Officer

## Invited

* CoEL – sent apologies and an endorsement of the strategy, included in this report
* Sue DfEL – no reply
* EARS – no reply
* CAPS minority ethnic worker (responded: CAPS wouldn’t ordinarily be involved in a Carers Strategy as we do not work with carers so would not contribute to what might be helpful for them. I understand that we probably do work with people who are carers but have not identified themselves as such, but I wouldn’t want to provide uninformed suggestions).
* MECOPP – no reply
* CWIC Mental Health – no reply
* Feniks – no reply
* Partners in Advocacy – no reply
* LGBT – LGBT Health could not send anyone from East Lothian but held the door open for development work to encourage involvement from LGBT people in East Lothian
* Changes – no reply
* Rural Communities – Chris Bruce, East Lammermuir Council Chair, offered the session to members of the East Lammermuir Community Council but no one came
* Carol Stobbie, North Berwick Connections – no reply
* Adult Wellbeing – no reply
* Sight Scotland – offered comments by email, included in this report
* Lived experience – the lived experience rep had intended to come but had to cancel at short notice.

## Aims of the strategy

The group chose to impact assess the seven aims of the new East Lothian Carers Strategy, which are:

1. Adult, Young Adult and Young Carers are identified and can access support
2. Carers are well informed and have access to tailored and age appropriate information and advice throughout their caring journey
3. Carers are supported to maintain their own physical, emotional and mental wellbeing
4. Breaks from caring are timely and regularly available
5. Carers can achieve a balance between caring and other aspects of their lives and are supported to have a life outside their caring role
6. Carers and young carers are respected by professionals as partners in care and are appropriately included in the planning and delivery of both the care and support for the people they care for and services locally
7. Local Communities are supported to be carer friendly

## Engagement so far

How we have gathered the opinion of East Lothian’s Carers:

* Planning for an ageing population consultation programme
* Outside the box engagement events for adults with complex needs
* Carers of East Lothian (CoEL), breakdown of Carer Support
* CoEL use of microgrants
* CoEL Carers Voice Panel
* Feedback from Adult wellbeing
* Monitoring of requests for support through Adult Carer Support Plan’s
* Young Carers Service and festival 2022
* Dementia friendly East Lothian events, QMU sept 2022, meeting centre development sessions
* East Lothian Councils Carers Group
* Carers peer support events, Foxlake, Walking with alpacas
* Outcomes sessions Oct and Nov ’22
* Integrated Impact Assessment initial session Nov ‘22
* Young Carers Survey
* Young Carers Forum

### Continuing engagement

* Scheduled PASDA engagement events to hear from carers of adults with autism
* Engagement with parent carers
* Engagement more specific to carers of people with mental health problems
* Online survey based on Strategy Outcomes

# Discussion

## Adult, Young Adult and Young Carers are identified and can access support

One of the key themes to emerge was that the group as a whole felt that carers might not want to be called carers. They were mothers or fathers; husbands, wives or partners; children, or brothers and sisters. They regarded caring as their responsibility; some might find the word stigmatising and some found it offensive. The effect of labelling people as carers was somehow disempowering. The group felt that it wasn’t about labels; it was about listening to carers and working with them to find the information, support and opportunities that met their individual needs.

PASDA also said that many carers had too much to do to have time to see themselves as carers – their days were full on, without time for introspection.

The group felt that the term/notion of being a ‘carer’ might be difficult for people in ethnic minorities and PASDA offered first-hand experience of working with a BAME family, where the son was stigmatised for being an autistic individual and he and his mother were isolated from their family as a result. However, the mother did not see herself as a carer but as a mother.

Unfortunately, we were not able to attract people representing ethnic minority/minority ethnic communities to the meeting, so we were not able to test this further.

### SpMitigation

**The Equalities and Engagement Officer will try to establish good contacts in these communities to try to ensure that their experiences and views inform development in future.**

### Stigmatisation of carers and autistic individuals

Women’s Aid East and Midlothian offered a case study where a family had been relocated to another town in East Lothian to flee domestic abuse. The mother was a carer for one child who was an autistic individual and the whole family had been shunned by their new neighbours because their family was ‘different’.

### Link workers

The group felt that Link Workers attached to all GP practices in East Lothian could play a vital role in encouraging carers to identify themselves as carers and help them to find appropriate advice and support in their local community.

## Families fleeing domestic abuse/young carers

Some families fleeing domestic abuse included young teenaged carers (aged 11 – 16), caring for mothers with mental health or substance use problems. Many could not see that they were young carers and were embarrassed by the situation they were in. They were less able to access support because they had been moved out of the area they grew up in and away from their friends there, and had to cope with attending a new school where they had no networks. It was also felt that one-to-one meetings with these young carers in a home setting were less successful than one-to-one meetings with them at school. The Young Carers Lead also stated that the term ‘young carer’ was not always helpful and that she tended to avoid the term, focusing on celebrating their achievements in supporting their family member.

## Carers are well informed and have access to tailored and age appropriate information and advice throughout their caring journey

The group shared their thoughts about the difficulties that carers faced accessing information and advice. They were supportive of the aim but noted various problems including:

* In some cases, families fractured due to the responsibilities of caring, resulting in one person having to carry the caring role on their own. If support was not available, they had no one else to turn
* Community networks were broken, so there was less likelihood of support from ‘good neighbours’ or appropriate support available in community resources. How do we build communities so that they are not only ‘carer-friendly’ but also just friendly?
* Not enough was known about carers in ethnic minority and minority ethnic communities to gauge what information was needed and what sort of advice and support would be useful
* Information and advice often linked to services and support, and the current pressures on services meant that carers may have to wait a long time for a service or just not get one
* The prevalence of online information and application/referral forms made it difficult for people who did not know how to use the internet; didn’t trust the internet, or couldn’t access the necessary hardware or broadband to use it. In a financial crisis, one member of the group observed that you would turn off your broadband before you turned off your heating.

### Mitigation

* **Establish a baseline for ethnic groups in East Lothian (from 2023 Census data), and**
* **Develop better links with minority ethnic and ethnic minority communities**
* **Put people in touch with organisations like People Know How and Connected Scotland**
* **Ensure paper versions of information are also available**
* **Ensure that people are aware of the capacity to have information in other formats, for example, translated, in Braille or rendered as BSL videos.**

## Carers are supported to maintain their own physical, emotional and mental wellbeing

The group identified a number of issues:

* Carers didn’t know where to go to get information
* Professionals didn’t put carers in touch with information
* Carers dealing with a new diagnosis/hospital stay/discharge didn’t have a single point of contact for information
* Often people looked to their GP for help with this but experienced difficulties in getting appointments/GPs having the right information
* Carers also experienced considerable problems with GPs/specialists in getting a diagnosis, for example, for dementia. This lack of diagnosis was difficult both in terms of carers’ understanding what was going on with the person they cared for and as a route to accessing appropriate support.
* Short-term funding also had an impact on carers, with services disappearing just as carers had come to rely on them
* Short-term support (for example, post-Dementia diagnosis support lasting one year only) was also an issue for carers supporting someone living with a condition that was constantly changing
* Issues with the availability of support (for example, due to care-at-home crisis, post-Covid disruption)
* Wellbeing was a very personal thing, so there was no room for a ‘one-size-fits-all’ approach – each person (and the person they care for) was different
* Some wellbeing offers, for example, discounted or free gym membership, were difficult to take up (because of time away from caring) and also not that attractive to many people
* Wellbeing often benefited if the carer was able to take up social activities away from caring.

There was also a discussion about how outcomes were monitored. The group felt that data-driven evaluation didn’t always give an accurate picture. It often reflected throughput or output rather that outcomes. Qualitative data drawn from lived experience was very important as it could show impact of actions on carers’ lives – what worked well, and what not so well.

### Barriers

* Initiatives not always being in tune with how carers have to live their lives
* Carers having to prioritise the needs of the cared-for person over their own
* Impact of the financial pressures of caring – long-term carers not having been able to have a career or even to work or study and constantly having to fret about living on a very low and very restricted income with no savings
* Carers not being physically or mentally well enough to take up social or study opportunities
* ELHSCP’s lack of information about the needs of carers in ethnic minority and minority ethnic communities.
* PASDA noted that there were still issues post-Covid across Lothian with resumption of support for autistic individuals (for example, day centres, clubs) and that this was impacting on carers’ health and wellbeing.

### Mitigation

* **Establish a baseline for ethnic groups in East Lothian (from 2023 Census data), and**
* **Develop better links with minority ethnic and ethnic minority communities**
* **Community transformation programme developing new ways of supporting people in their own communities, including outreach, and evening and weekend opening for supporting community resources**
* **Charging review.**

## Breaks from caring are timely and regularly available/Carers can achieve a balance between caring and other aspects of their lives and are supported to have a life outside their caring role

These aims were discussed together.

Some of the discussion had already taken place as part of assessing other aims. However, the group felt that it was important to understand that sometimes it was hard to get family members, friends or neighbours to look after the cared-for person so that the carer could have time just for themselves.

The group also felt that short breaks funding should be available for more than just holidays. Some members of the group pointed out that short breaks often meant taking the person you cared for with you, so although it was a change of scene it was not necessarily a break from caring. This was particularly the case if you didn’t have relatives or friends who had the appropriate skills and who were acceptable to the cared-for person to take over their care during a short break.

It was also felt that short breaks should expand their focus to include activities that would give the carer regular opportunities to take part in something that was just for them, for example, going to the hairdresser, taking part in a course, taking part in social groups.

The group was aware that Covid and the financial crisis had impacted services that could offer carers a break, such as care at home and resource centres.

One of the group also indicated that there could be problems with Self-Directed Support payments not covering actual expenditure.

## Carers and young carers are respected by professionals as partners in care and are appropriately included in the planning and delivery of both the care and support for the people they care for and services locally

The group felt that part of the work for this aim was to reconfigure the conversations that professionals had with carers. We should ‘stop trying to fix people’ and ask people about the resources (for example, family, friends, community) already around them. It was important to have ‘good conversations’ allied with good listening. There was also a need to have honest conversations about what statutory services could provide and when they could be accessed, particularly now with the situation in care at home and the financial crisis.

They also felt that it was important to challenge judgments that non-carers made about caring, and address prejudice and stigma, particularly for young carers.

The group also noted that many carers first port of call for information was their GP and that GPs often did not have a full picture of what was available. The group felt that Community Link Workers could play a key role with this.

The group also noted that time pressures for initial/assessment visits were problematic. There should be:

* A longer initial meeting to allow the carer to settle in to the meeting and talk about what was important to them before anything else happened. It was really important for carers to have the opportunity to vent about what was happening in their lives and the challenges they were dealing with
* Flexibility about the length of meetings so that if necessary initial meetings could be longer than scheduled – the group thought round about an hour was reasonable but that people often wanted to talk a little bit longer. It was worth investing extra time at the start to get a good understanding for the carer’s situation.

There was also discussion about people’s perceptions of social workers – for many people, the notion of a social worker coming to your door was associated with judgment and ‘taking your kids away’. Carers might be apprehensive about a social work visit.

## Local communities are supported to be carer friendly

The group acknowledged that it would be hard for ELHSCP to change community culture on its own, but there were things that they could do to foster greater understanding, for example:

* Encouraging workplaces in East Lothian to be Carer Positive and seek Care Positive accreditation
* Looking at the work that QMU and Edinburgh College were doing for carers, in terms of pastoral care and flexible working/studying
* There was good learning to be had from Dementia Friendly East Lothian and Meeting Centres
* Making links with minority ethnic and ethnic minority groups in East Lothian to develop a better understanding of the caring role.

Rebuilding communities was a big job and would have to be undertaken as part of wider work in partnership with East Lothian Council Connected Communities team and Volunteer Centre East Lothian.

## Comments by email

**Colin Hilditch, Head of Community Services, Sight Scotland:**

‘The strategy has potential to make a significant impact on individuals…’

‘Nothing major to add – strategy looks well rounded to me. I would add in Sensory support to “other services available to carers” (page 14) but that’s about it.’

**Jess Wade, CEO, Carers of East Lothian:**

‘…I'd be interested to see the issues raised, especially any concerns, although to me the Strategy is looking very positive.

‘I wondered about this element in the Strategy:

*“Improve identification of carers through funding of dedicated worker in community hospitals to identify carers, increase recognition of carers’ value throughout the persons stay and to support successful discharge planning”.*

‘This sounds like a fantastic idea and we'd be very keen to be involved. I know some other carers centres have gone down this route so it might also be worth seeing what we can find out about how it is working elsewhere’.