

East Lothian Health and Social Care Partnership Carers Strategy 2026- 2029 Technical Report

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Introduction

This report contains the data and information we have gathered to inform our local carers strategy

For the purpose of this report '**Relevant carers**' are carers who live and care for someone in the local authority area and carers who do not live in East Lothian but care for someone who lives in this area, if you are living in East Lothian but caring for someone in another local authority advice is to access support from the carers centre where the person lives.

Local carers strategies

Statutory guidance on the Carers Act (Scotland) 2016 gives detail on what should be included in a local carers strategy¹

A local carer strategy must cover all of the things listed at section 31 of the Act

The nine things which must be included are:

- ✓ plans for identifying relevant carers and obtaining information about the care they provide (or intend to provide) to cared-for persons in the local authority's area
- ✓ an assessment of the demand for support to relevant carers
- ✓ support available to relevant carers in the authority's area from –
 - the authority
 - the relevant health board
 - or any other organisations that the authority and health board consider appropriate,
- ✓ an assessment of the extent to which demand for support to relevant carers is currently not being met,
- ✓ plans for supporting relevant carers,
- ✓ plans for helping relevant carers put arrangements in place for the provision of care to cared-for persons in emergencies,
- ✓ an assessment of the extent to which plans for supporting relevant carers may reduce any impact of caring on relevant carers' health and wellbeing,
- ✓ the intended timescales for preparing adult carer support plans and young carer statements.
- ✓ information relating to the particular needs and circumstances of young carers.

¹ <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2021/07/carers-scotland-act-2016-statutory-guidance-updated-july-2021/documents/carers-scotland-act-2016-statutory-guidance/carers-scotland-act-2016-statutory-guidance/govscot%3Adocument/carers-scotland-act-2016-statutory-guidance.pdf>

Plans for identifying relevant carers and obtaining information about the care they provide for cared for persons in the local authority area

A number of data sources have been used to identify relevant carers and obtain information about the care they provide, these are summarised below.

National carer data

While different sources provide differing estimates of unpaid carer numbers, consensus is that the number of carers living in Scotland is around 700,000. The latest figures based on the Scottish Health Survey show an estimated total of around 696,000 carers (+/-55,000) living in Scotland, including 28,000 young carers² Census data from 2022 gives a similar figure of 627,700 people identifying as unpaid carers in Scotland, recording an increase of 27.5% (135,500) people since 2011.

Over the same census period there was a 15.7% increase in the number of people with a health problem or disability that limited their day-to-day activities a lot (up 79,600). The increase in the number of people with an activity limiting health problem or disability was driven by Scotland's ageing population however younger people also saw increases in numbers reporting a health problem or disability that limited their day-to-day activities, but for younger people these increases were relatively larger compared to 2011. We also saw a significant increase in the number of people reporting mental ill health, increasing from 4.4% in 2011 to 11.3% in 2022.

With more people reporting a health problem or disability that limits their day-to-day activities a lot, the increase in the number of unpaid carers is to be expected. The biggest increase in carer numbers was seen in the 50 to 64 age group (up 62,700). The people in this age groups are likely to have parents in the oldest age groups and we know that people in the oldest age groups are most likely to have a health problem or disability that limits their day-to-day activities.

It is hard to draw conclusions from this data as we don't have all the details of the care unpaid carers are providing, however the number of people identifying as unpaid carers has gone up faster (27.5%) than the number reporting a health problem or disability that limits their day to day activities a lot (15.7%) potentially reflecting the impact of awareness raising work across the country since the introduction of the Carers Act.

Local carer data

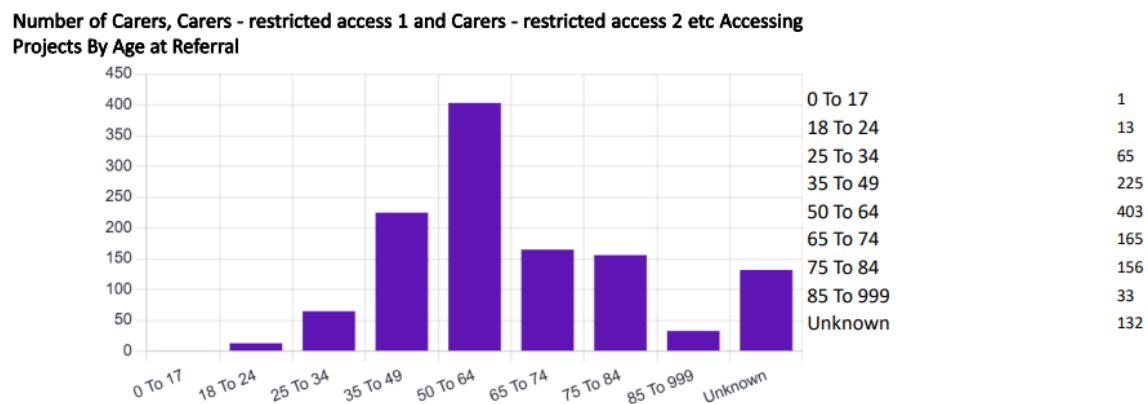
Scotland's census data puts the number of people identifying as unpaid carers in East Lothian (in 2022) at 13,147³

The number of unpaid carers increased across all age groups, with the greatest increase in the 50-64 age group, in line with Scottish trends. Data from our commissioned adult carer support service is reflective of national trends with the highest number of carers accessing support also in the 50-64 age range.

² <https://www.gov.scot/publications/scotlands-carers-update-release-march-2024/>

³ <https://www.scotlandsensus.gov.uk/2022-reports/scotland-s-census-2022-health-disability-and-unpaid-care/>

Figure 1 – Carers of East Lothian number of carers supported by age in the reporting period of October 2024- March 2025



Who are our carers caring for?

A full assessment of trends in the health and wellbeing of East Lothians population can be read in our Joint Strategic Needs assessment ⁴ which gives detailed demographic and health information. Some key points, highlighted below are focused on health conditions but help us understand who our carers are caring for.

- *The three leading grouped causes of ill-health and early death in East Lothian are; cancers, cardiovascular diseases and neurological disorders. These groups of causes account for 47% of the total burden of health loss*
- *The leading individual causes of ill health in East Lothian are low back and neck pain, depression and headache disorders. In contrast, the leading cause of early death in East Lothian are ischaemic heart disease, Alzheimer's and other dementias and lung cancer. Whilst it is encouraging that almost all leading causes of early death are lower than the Scottish average, there is still room for improvement by targeting the top 3-5 leading causes.*
- *It is estimated that one in four of the UK adult population currently have two or more long-term conditions (LTCs) and it is projected that approximately 17% of the UK population will have four or more chronic conditions by 2035, almost double the current prevalence of 9.8% (Stafford et al., 2018). The rise in the proportion of people living with multiple long-term conditions (MLTCs), also known as multimorbidity, is considered to be one of the most significant challenges facing health services, both currently and in the coming decades (Pearson-Stuttard, Ezzati and Gregg, 2019). Multi Long Term Conditions are associated with several negative outcomes including premature death, lower quality of life, reduced mobility, chronic pain, poorer mental wellbeing, higher number of hospital admissions and longer hospital stays (NIHR, 2021; Chen et al., 2020; Stafford et al., 2018; Gunn, 2012).*

⁴

https://www.eastlothian.gov.uk/downloads/file/35573/east_lothian_joint_strategic_needs_assessment_2025

The growing number of people providing unpaid care both locally and nationally reflects the increase in the older age groups and the percentage of the population with a limiting health condition or disability.

Carers can be identified by any supports or services they have contact with, East Lothian has made progress in identifying carers but there is still significant work to be done in terms of identifying and supporting carers, especially at an earlier stage.

Information about the care they provide

It is a challenge to obtain accurate information about the care each carer provides in the Local Authority area as not all carers are known to support services and data from all supports is not collated.

Scotland's census data gives an indication of the number of hours those who identified as carers are providing in East Lothian, see Figure 2. We know that the more hours spent caring the greater the impact on the carer and on their health and wellbeing. Data indicates 39% of East Lothians carers care for more than 20 hours per week and 22% for more than 50 hours each week.

Figure 2 Number if hours spent caring, East Lothian

Number of hours spent caring	Number of carers
1-19	7,985
20-34	1,167
35-49	1,127
50+	2,864
TOTAL	13,147

The Scottish Government carers census is a tool aiming to increase understanding of the needs and challenges faced by unpaid carers across Scotland, it sets out to give insight into the demographics, intensity of care and emotional wellbeing of carers and be used to inform policy, support services and provide information on how many carers are supported by local services. Any organisation completing carer support plans is required to complete a submission and locally these are completed by East Lothian Health and Social Care Partnership, Carers of East Lothian and East Lothian Councils Young Carers service. Scottish Government and Health Improvement Scotland have undertaken a review to identify the issues and opportunities to improve the data and process around this collection, however it still provides interesting demographic and equalities data showing:

- 52,000 unpaid carers supported by local services across Scotland⁵.
- Almost 3 in 5 carers (58%) were working age (18-64)
- Almost ¾ of carers (73%) were female, outweighing male carer in all age groups
- The most common impact of providing unpaid care in 2023/’24 was on the emotional well being of carers (86% of adult and 91% of young carers experienced an impact on their emotional wellbeing as a result of their caring role.

⁵ <https://www.gov.scot/publications/carers-census-scotland-2023-24/>

- Carers with more intensive roles were more likely to experience impacts, 34% of carers providing up to 19 hours of care a week experienced an impact on their health compared to 72% of those caring for 50+ hours a week

Over the last few years support services have noted an increase in the number of parent carers of children with Additional Support Needs (ASN) seeking support. Pupil Census Supplementary Statistics (March 2024)⁶ show there are 2,748 or 32.8% of primary aged children and 2,961 or 44% of children in secondary school with ASN in East Lothian. While ASN covers a wide range of needs (as shown in figure 3) the most common reasons for support are social, emotional or behavioural difficulty followed by autistic spectrum disorder. Many of these carers are supporting children with complex needs who may not meet criteria for statutory services but whose needs have a very significant impact on the lives of family carers.

Figure 3 – Reason for support in primary aged children with ASN

Reason for support	Number in primary	Number in secondary
Learning disability	105	135
Dyslexia	410	65752
Other specific learning disability	170	411
Other moderate learning disability	268	349
Visual impairment	60	52
Hearing impairment	58	73
Deafblind	0	c
Physical or motor impairment	80	129
Language or speech disorder	350	136
Autistic spectrum disorder	568	410
Social, emotional and behavioural difficulty	776	760
Physical health problem	190	221
Mental Health problem	67	291
Interrupted learning	64	111
English as an additional language	226	237
Looked after	47	89
More able pupil	50	13
Communication support needs	248	69
Young carer	210	257
Bereavement	87	97
Substance misuse	c	10
Family issues	308	309
Risk of exclusion	15	58
Other	305	302
TOTAL	2748	2958

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<https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.gov.scot%2Fbinaries%2Fcontent%2Fdocuments%2Fgovscot%2Fpublications%2Fstatistics%2F2019%2F07%2Fpupil-census-supplementary-tables%2Fdocuments%2Fpupil-census-supplementary-statistics-2024%2Fpupil-census-supplementary-statistics-2024%2Fgovscot%253Adocument%2FPupil%252Bcensus%252Bsupplementary%252Bstatistics%252B024%252B-%252BMarch.xlsx&wdOrigin=BROWSELINK>

Legal orders

Another indicator that helps us identify carers and understand the care they are providing is the number of people with legal orders in place, which when a person lacks capacity to make some or all decisions for themselves, allow someone else to do that for them.

East Lothian have been part of a national campaign running until 2025 to increase awareness of Power of Attorney (POA) and have seen a steady increase in the number of POA's registered in East Lothian since 2001, up from 77 to 1733 in 2024⁷.

There are around 200 private guardianship orders in place in East Lothian, relating to more than 300 guardians as many people have more than one guardian at the same time. Previous work has supported the Mental Health Officers team to address a backlog in both applications and reviews ensuring powers continue to be appropriate.

Where these powers are required we want to support carers to find out about what is needed and how to go about setting up and managing these orders. Having powers in place mean people have those they want making decisions on their behalf and can avoid delays in treatment or discharge from hospital.

Equalities

The principles of equality, diversity and human rights are the underpinning rights for all carers. Carers reflect the diversity of Scotland's population and should be supported to be aware of their rights, ensuring that no carer is disadvantaged due to age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity, race; religion or belief, sex or sexual orientation, in line with the Equality Act 2010. All children and young people have an established set of rights and principles based on the United Nations Convention on the Rights of the Child. These say that nobody should treat a child or young person unfairly and that when adults make a decision about a child or young person it is what's best for the child or young person that should be the most important thing to consider. The child or young person must have their say too. For Young Carers this means they must be included in discussions and decisions about the person they care for which will impact on their own life.

It is recognised that we all have a number of protected characteristics, our aim is ensuring that no carer is disadvantaged by those that make them who they are.

Ethnic minority carers

Research has shown that BME unpaid carers face worse health and financial outcomes, and this is due to additional barriers towards identification, communication and access to support services, MECOPP advocate that there is a huge amount that can be done at the local level to help support this group of marginalised carers.⁸ In a recent briefing paper⁸ their analysis of census data clearly shows the number of carers from black and minority ethnic populations is increasing in East Lothian, with a 208.3% increase from 133 to 410 identified carers between 2011 and 2022. Data

⁷ <https://www.publicguardian-scotland.gov.uk/power-of-attorney>

⁸ <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/68dbac6d07941f770ba419a4/1759226989791/MECOPP+Briefing+Sheet+19.pdf>

shows us the increases in specific populations (figure 4) which will allow us to target our outreach to specific communities.

Figure 4 Increase in unpaid carer numbers in East Lothian

Ethnic group	2011 census	2022 census	% increase
Pakistani	33	62	87.9
Indian	18	24	33.3
Bangladeshi	0	3	-
Chinese	6	9	50
Other Asian	9	19	111.1
African	6	36	500
Caribbean or Black	2	13	550
Arab	5	23	360
Other	2	40	1900
Gypsy/ traveller	1	10	900
Polish	28	76	171.4
Any mixed background	23	95	313
Total	133	410	208.3

Sex

Census analysis of number of carers by age is not given on a local basis however national data reports on age and gender, 70% of carers overall were female with female carers outweighing male carers in all age groups, however the most pronounced difference is seen in the working age carers group where 81% of carers between 18 and 64 were female.

Female carers continue to outnumber males in caring roles, in part due to family expectations and roles and this is reflected in the breakdown of those accessing carer support. Males may be less likely to come forward for support though meaning specific supports may be needed to encourage uptake

Sexual orientation

As of the 2022 Scottish Census 88.8% of the total East Lothian respondents who are aged 16 and over identify as Heterosexual Straight, slightly above the Scottish percentage of 87.8% (NRS, 2024d). Data in relation to sexual orientation of our carer population is not available.

Disability, including sensory impairment

In East Lothian 13.2% (14,864 people) identified that their day-to-day activities were limited 'a little', with a further 9.2% (10,326 people) saying they were limited 'a lot' (NRS, 2024e). This equates to a total of 22.4% (25,190 people) whose daily activity is impacted to some degree by a longer-term health issue or disability. The Census also found that 5,400 people were identified as having a learning disability, learning difficulty or developmental disorder.

Although carers are recognised in providing care for people with disabilities it can be less understood that carers can have their own health problems and disabilities too. Our local carer

support organisation have recently noted an increase in carers who themselves have barriers and trauma when it comes to receiving supports.

Supporting carers with their own needs takes extra time and resource impacting on demand for services but this should not be a barrier to support.

Poverty

According to the Scottish Index of Multiple Deprivation (PHS, 2020), East Lothian is generally less deprived than most of Scotland. In 2020, two out of East Lothian's 132 data zones fell within the '10% most deprived' areas in Scotland, and 8 data zones were in the '20% most deprived'. Though this is positive, evidence indicates a slight increase in deprivation when compared to 2016 SIMD data whereby none of the East Lothian data zones were in the 10% most deprived and only 6 were in the 20% most deprived. Although SIMD data can be helpful as an indicator of levels of poverty within a population it doesn't recognise pockets of deprivation and we know individuals and families across the locality are increasingly facing hardship.

Carers are often at an economic disadvantage due to reducing their working hours or having to give up jobs to provide care. They often receive lower incomes which can lead to more stress, poorer housing conditions, food insecurity and reduced access to leisure or healthcare.

The IJB recognise the significant financial burden faced by carers due to reduced income from work, the costs of care, and rising living expenses, which can lead to poverty and debt. We need to consider how adequate resources and funding should be prioritised for carers in financial crisis and to protect and prioritise support for breaks from caring, preventing carer breakdown.

An assessment of the demand for support to relevant carers

Demand for our carer support services has continued to increase year on year. Our carer support service for adults reported seeing an increase in both numbers of carers supported (up to 1823 in 2023/’24) and numbers of new carers (596 in 2023/’24), although the latter is a much smaller % increase over the same time period, with a roughly 50% increase in numbers of carers supported over a year since 2019, but only a 15% increase in number of new carers over that same 5 year period. Analysis from the chief executive at the time was that some of that increase may be around working with carers for longer, but some will be due to carers accessing additional supports with more on offer including more groups, clubs, activities, Time for Me, Counselling etc.

East Lothian Councils Young Carers service which was established in 2021 has seen very significant increases in the number of young people identifying as carers, starting with around 200 young carers known to other services it now has over 700 registered young carers and offers a wide range of activities to support breaks from caring for young people

Support available to relevant carers in the authority's area from

The Authority

Carer support is delegated to East Lothian Integration Joint Board and provided by East Lothian Health and Social Care Partnership (ELHSCP). ELHSCP can offer support to the carer or cared for person, following an assessment of needs. To request an assessment, carers should contact the social work team by:

Telephone: [01875 824309](tel:01875824309) or

Email: communityaccess@eastlothian.gov.uk

During this assessment the social worker will:

- Assess the level of need
- Check eligibility for support, including financial support
- Provide information and advice around available options

In order to qualify for a service from ELHSCP people must be assessed as having critical or substantial needs as defined in our eligibility criteria.

Please see our web pages for more details <https://www.eastlothian.gov.uk/info/210577/carers>

The relevant health board

NHS Lothian offers advice and information for carers
<https://services.nhslothian.scot/supportingcarers/>

East Lothian has a unique Occupational Therapy pathway for carers

https://www.eastlothian.gov.uk/info/210577/carers/12192/information_for_carers/5 which supports carers on a 1:1 basis or in a group setting. Occupational therapy focuses on 'occupations' (roles and activities meaningful to the person) and supports them to achieve balance, quality of life and self management of the carers own health and well being.

Any other organisations that the authority and health board consider appropriate

Your local carer support organisations in East Lothian are:

Carers of East Lothian <https://www.coel.org.uk/> 0131 665 0135

East Lothian Council Young Carers Service, complete the brief questionnaire on this page

<https://www.eastlothian.gov.uk/young-carers>

East Lothian Young Carers <https://www.eastlothianyoungcarers.org/>

The carers trust provide a handy postcode checker here <https://carers.org/help-for-carers/carer-services-near-you> so you can find carer support near the person you care for. (not all areas are covered by this)

Details of carer support organisations in East Lothians neighbouring local authorities are provided below

Edinburgh

VOCAL <https://www.vocal.org.uk/>

Contact centre@vocal.org.uk or call 0808 196 6666

Young carers,

Edinburgh Young Carers <https://www.youngcarers.org.uk/>

Capital Carers <https://capitalcarers.org.uk/>

Space <https://spacescot.org/young-carers/>

Midlothian

Carers 16+ VOCAL, Contact midlothian@vocal.org.uk or call 0808 196 6666

Midlothian Young Carers Project (MYCP) for under 16yrs

https://www.midlothian.gov.uk/info/1352/carers/84/support_for_young_carers

youngcarer@midlothian.gov.uk

West Lothian

All age groups - Carers of West Lothian <https://cowl.org.uk/>

Contact submit their online contact form here <https://cowl.org.uk/contact-us> Call 01506 448 000 or send a Whatsapp to 07719 064 930

Young carers <https://westspace.org.uk/services/young-carer-service-carers-of-west-lothian/>

Borders

The borders carers centre <https://www.borderscarerscentre.co.uk/>

Contact admin@borderscarers.co.uk or call 01896 752 431

Young carers, <https://www.scotborders.gov.uk/children-families/young-carers>

Action for Children for Young Carers and Children affected by substance use

<https://www.actionforchildren.org.uk/how-we-can-help/our-local-services/find-our-services-near-you/scottish-borders-chimes/>

Support from local community organisations

East Lothian HSCP invests in a number of community supports to try and meet the needs of the diverse carer population. These include local day centres for older people, development of the meeting centre model for people living with dementia, Leuchie house's Leuchie at home service for carers of people with progressive neurological conditions, Community first run by Volunteer Centre East Lothian, Alzheimers Scotland's local dementia cafes, and many smaller organisations who have received grant funding to support relevant carers.

We need better data to understand the level of unmet need. Many of the local organisations supporting carers have come about through personal experience of gaps in service, for example Dementia Friendly East Lothian, STAND and CanDo and offer a lot of support to carers but if we had a fuller understanding of the picture we could be more responsive to local need.

Support is available through the Local Authority when carers needs cannot be met by community based services, this is particularly where the impact of caring is at substantial or critical level and at risk of breaking down without further support. Our carer support organisations can still guide carers through this process and help navigate local systems if required.

Carers can find other supports near them for themselves or for the person they care for using Volunteer Centre East Lothians online locator app <https://vcellocator.org.uk/> or through the Eastspace support directory <https://eastspace.org.uk/find-a-service/>

Advocacy

Although there is no statutory duty to provide independent advocacy for unpaid carers more demand is being seen locally and more information is needed, recognising that some carers, especially the most vulnerable, benefit from independent advocacy support to help them in many different ways, including supporting them in their dealings with health and social care and other professionals.

While there are services available in East Lothian that can 'advocate' on peoples behalf in some circumstances, such as Carers of East Lothian, carers of people in East Lothian do not have access to independent advocacy. Those that advocate on their behalf are not independent of other projects/services and will also provide advice and support for specific areas.

The Care Reform (Scotland) Act 2025 significantly strengthens access to independent advocacy, including for unpaid carers who are now clearly recognised as eligible meaning they should be able to request and receive independent advocacy.

With this in mind we need better evidence to inform decisions on provision of independent advocacy for unpaid carers, including a clearer understanding of unmet need, the potential impact on carers' rights and wellbeing, and the resource implications of introducing an independent advocacy model.

Adult Carer Support Plans (ACSP) and Young Carer Statements (YCS)

The Carers Act places a statutory duty on Local Authorities (or where child is pre-school on the health board) to offer an Adult Carer Support Plan (ACSP) or Young Carers Statement (YCS). Every carer has the right to a carer support plan and this is offered to every carer that registers with East Lothians Adult or Young Carer support services. These support plans detail information on the support that carers are providing. In 2024/25 CoEL completed 177 ACSP's and East Lothian Council Young Carers Service completed 159 YCS'

ACSP's are typically completed by our local carers centre, Carers of East Lothian and Young Carers Statements by East Lothian Councils Young Carers Service, although ACSP's can also be completed with support from the adult social work department, contact details and further information are included in our leaflet

https://www.eastlothian.gov.uk/downloads/download/14083/your_right_to_an_adult_carer_support_plan

Plans should be completed in a person centred and outcome focused manner through a good conversation. They should focus on the difference support can make to a persons life and be led by what matters to the carer.

Support in work and education

As highlighted by national census and local data the greatest percentage of unpaid carers are of working age. The state of caring 2024 report shows "34% of working age carers stated they had been forced to leave their jobs at some point in their career due to the pressures of combining work with their caring roll. In addition 42% currently in paid work have reduced hours and 21% have had to take on a lower paid or more junior role to fit around their caring responsibilities"⁹

Being in paid work brings important financial security but also supports the carers health and well being and allows them to plan for the future, being out of work is recognised as the biggest driver of why carers live in poverty in Scotland.

The introduction of the Carers Leave Act and Employment relations (flexible working) Act have been positive steps towards better workplace support for unpaid carers but over half of carers couldn't afford to take Carers Leave because it is unpaid.

⁹ <https://www.carersuk.org/media/a3rg42du/state-of-caring-employment-2024-final.pdf>

National carers organisations continue to lobby for change including a revision of carer support payment by increasing the rate and making it available to more unpaid carers, delivery of a minimum income guarantee for unpaid carers and a requirement to make all organisations with public funding to be Carer Positive¹⁰

At a local level we can work with employers to encourage this recognition of carers rights and to emphasise the impact not only on household income but also the wider consequences for the local economy and workforce participation.

An assessment of the extent to which demand for support to relevant carers is currently not being met

With 13,147 self identified carers through the census and our adult and young carer organisations in touch with around 7,000 carers and providing active support to around 2,000 carers per year this leaves a significant number where we can't say with confidence if their needs are being met through other community supports or whether they have significant unmet needs.

Our carer organisations are key to providing information and advice, but it is essential that to effectively support the diverse carer population the HSCP invests in a range of local organisations and community supports that support carers where they are. While carer support organisations are the one stop shop for advice, information and support there are also a wide range of community support services in East Lothian that carers may get support from and we know that carers will usually seek support from friends and family and local groups before turning to services.

We recognise there are limitations to our data collection around carers needs and will work across the life of this strategy to improve our understanding of the carer population and the unmet need that exists in our local carer population.

Plans for supporting relevant carers

Existing support available to carers reduces impacts on health and wellbeing, we heard a lot of feedback in our carers commissioning process around the difference that support makes and how important it is that support is local and linked up with other local organisations. With the continuing increase in unpaid carer numbers we need to work with our carer support organisations to continue to increase capacity while maintaining quality.

Some of the increased demand might be addressed by offering digital solutions, offering the potential to provide advice and information and allowing in person carer support to focus on carers who require more in depth support. Carers of East Lothian Carers Panel members feedback on East Lothians strategic plan highlighted the opportunities that digital technology could offer to help carers stay well-informed and confident in their caring role. They also noted that the effective use of digital technology could reduce the need for some in-person visits, improve efficiency, and help

¹⁰ <https://carerpositive.org/>

make better use of available resources, eg. education and training, medication management, physical activity and falls prevention sessions.

Specific plans to increase support over the period of this strategy include; increasing opportunities that support breaks from caring by strengthening links with community organisations that provide support to people enabling the unpaid carer to take a break from their responsibilities, gathering evidence on the need and demand for independent advocacy for carers and reviewing mental health support available to carers as this has been highlighted as the most common reason for seeking support.

Plans for helping relevant carers put arrangements in place for the provision of care to cared-for persons in emergencies

East Lothian will support 'relevant' carers to have plans in place for the provision of care to cared for persons in emergencies. As part of our ACSP the carer will discuss emergency planning and the Carer Support Worker can introduce planning tools to support this. One of the biggest challenges is making sure any future care planning document is available to the right people at the right time. Within our dementia post diagnostic support service, staff have been piloting future care planning that can be uploaded by the medical secretaries to an individuals Key Information Summary meaning it is available to professionals in the event of a hospital admission for example. This was to be rolled out to include a carers pathway but we are currently monitoring progress on the national workstream around anticipatory care planning and our approach will be informed by this.

Locally we have developed a Carer ID card which will be available early 2026. Carers told us a carer ID card is important for three reasons including in case of emergency.

- **recognition:** carers can feel that places and services don't recognise their role and it would be helpful for them to have something to show that recognises the support they provide and encourages others to think carer
- **in case of emergency:** carers worry about what might happen to the person they care for if something was to happen to them, the carer ID card will give two emergency contact numbers that should be used in case of emergency
- **creating a carer friendly community:** our local carer support organisations already have great relationships with many local businesses and carers would like to use their cards to access discounts or special offers

An assessment of the extent to which plans for supporting relevant carers may reduce any impact of caring on relevant carers' health and wellbeing

Increasing access to supports is effective in reducing impact on carers health and wellbeing, however with increasing demands on all our services we need to work to ensure the quality of support remains high.

In many cases the growing demands placed on unpaid carers and the additional costs to their own lives are closely linked to the lack of available and high quality social care. It is clear that access to reliable, high quality support would make caring less stressful and allow carers to spend time on activities that improve their wellbeing. When social care works well it can reduce stress, prevent burn out and allow carers to look after their own health and wellbeing.

Access to care and support for the cared for person is out with the remit of this strategy but the impact on carers will continue to be emphasised. We have committed to increasing awareness of carers needs and impacts of access to support. We will continue to advocate for carer involvement at all stages of decision making around all IJB services, keeping in mind that all decisions impact on our unpaid carers.

The intended timescales for preparing adult carer support plans and young carer statements.

Because ACSP's and YCS are completed in a person centred and outcome focused manner we have not applied guidance on timelines around completion of ACSP's and YCS but expect providers to prioritise based on need. Our understanding is that waits for ACSP's and YCS can be very long in some Local Authority areas making application of timelines necessary. East Lothian carers are not experiencing these long waits but this needs to be maintained as demand potentially increases.

We comply with timelines around completion of ACSP's or YCS when caring for someone who has a terminal illness (as set out in the statutory guidance¹¹) and apply these timelines where the carer may be the one with a terminal illness

"2.1.95 The Directions require all carers of people who are terminally ill to be offered an ACSP within 2 working days of a person being identified as a relevant carer and if this is not possible, as soon as reasonably practical thereafter, as soon as an authority becomes aware that they are caring for someone with a terminal illness... Once a carer requests an ACSP or accepts an offer of an ACSP, the authority has a duty to prepare one. The Terminal Illness Regulations²⁸ set timescales within which the authority must prepare an ACSP from the point this duty arises. There are different timescales for steps in the process, to ensure that it is flexible enough to meet the needs of each carer.."

¹¹ <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2021/07/carers-scotland-act-2016-statutory-guidance-updated-july-2021/documents/carers-scotland-act-2016-statutory-guidance/carers-scotland-act-2016-statutory-guidance/govscot%3Adocument/carers-scotland-act-2016-statutory-guidance.pdf>

At this time (Dec 2025) the average wait for carer support for adults (not specific to ACSP) is around 8 weeks and every carer is offered the opportunity to complete an ACSP or YCS when they register with the adult or young carer support service.

The young carers service is meeting Key Performance Indicator of offering every Young Carer an appointment within 10 days of referral and the YCS is offered at initial contact.

Under the Care Reform Act timelines for completion of an ACSP or YCS will be brought in and East Lothian will work to comply with these.

Amendments to the Carers (Scotland) Act 2016 include a duty on Local Authorities and Integration Authorities to:

- Determine, as part of the ACSP or YCS whether a carer can take sufficient breaks from their caring role and ensure this is an identified personal outcome for every carer
- Where carers are unable to take sufficient breaks this is an identified need
- New duty on Local Authorities to provide support to enable the carer to take these sufficient breaks

The ACSP or YCS will be key to carers accessing this new right to a break, the plan will include an assessment of the carers ability to take 'sufficient breaks'. Definitions are being confirmed by the working group but the draft definition of sufficient breaks is "breaks from caring which enable a carer to have enough rest, leisure and time to:

- a) prevent negative impacts from their caring role on their health and wellbeing; relationships with others; and life balance; and
- b) help them to achieve their personal outcomes; and
- c) help foster and maintain a positive relationship with the cared-for person.

One of the concerns noted in Social Work Scotland's analysis of the National Care Service costs for carers right to breaks ¹² was that there was no acknowledgement of the additional resource required to undertake these assessments. As noted, our commissioned carer support services take the lead on ACSP's and YCS in East Lothian but this approach may have to be reviewed as we anticipate a significant increase in demand for these assessments.

Information relating to the particular needs and circumstances of young carers.

Young Carer specific information

Mental health

Summary data from Young Carers Statements completed between February and July 2025 show significant mental health impacts:

- Many young carers report persistent stress, anxiety, and low mood.

¹² <https://socialworkscotland.org/wp-content/uploads/2024/02/SWS-Summary-analysis-of-revised-NCS-FM-costs-for-carers-right-to-breaks.pdf>

- Some express feeling overwhelmed, mentally drained, or "numb" from long-term exposure to distressing home environments.
- Several describe overthinking, feeling guilt when not helping, and being affected by the emotional states of parents or siblings.

Physical Health

- Tiredness is a major theme, with some carers reporting severe sleep disruption (as little as 30 minutes per night).
- Others report loss of appetite, poor eating habits, or becoming physically unwell from stress.
- Some face physical harm, including being hurt during outbursts or meltdowns, or living in unsafe household conditions (e.g., mess, expired food, verbal abuse).

Young Carers needs are a part of everything discussed throughout East Lothians strategy and the specific needs and circumstances will be considered under each outcome. Provision of services relevant to young carers are outlined in East Lothians children's services plan¹³ "As part of the last plan, East Lothian Council established a young carers' service in 2021 and this approach has significantly increased the numbers of young people identifying as carers. They continue to receive support in school, to access short breaks and respite and help in understanding and applying for all relevant financial provisions designed to relieve some of the challenges that come with caring responsibilities. School supports include advice on the rights of young carers from professionals, peer support from people in similar situations and circumstances and regular opportunities to gather their input and experiences to influence relevant decision-making processes"

The strategy sets out how we will continue to support Young Carers to have the same opportunities as other young people.

Local carers strategy outcomes

The strategy document outlines actions grouped under five overarching outcomes:

1. Carers are identified, recognised and heard
2. All carers have the same opportunities to access support to meet their needs
3. Carers are meaningfully involved in the support of the person they care for
4. Carers are supported to look after their own health and well being and lessen negative impacts caring has on other parts of their lives
5. Carers can take breaks from caring when they need them

¹³

https://www.eastlothian.gov.uk/downloads/file/31411/children_and_young_people_services_plan_2023-2026

However when the IJB are making decisions about health and social care in East Lothian, it must be recognised that unpaid carers are key partners in care and that carers are fundamental to the success of health and social care in East Lothian and across Scotland.

IJB structure and decision making

East Lothian Health & Social Care Partnership (ELHSCP) has established Programme Boards to support the work of the Partnership to carry out the strategic plans, objectives and directions as agreed by the Integration Joint Board (IJB) The Carers programme boards remit includes:

- Legislative requirements and responsibilities in line with the Carers Act (Scotland) 2016, including publication of a local Carers Strategy, publication of a Short Breaks Services Statement and development of local Carers eligibility criteria.
- Increasing uptake and meaningful support as a result of completing an Adult Carer Support Plan.
- Development of opportunities to support breaks from caring, to support carers and in preparation for the introduction of the 'right to a break'.
- SG funding allocation, reporting on budget allocation to support delivery of local carers strategy and expansion of carer support at a local level.*
- Commissioning and reporting on progress of development of newly commissioned services and where gaps and areas of concern are highlighted by Carers and services.

Strategic planning of carer specific projects are planned and monitored by the Carers Programme board however when the IJB are making decisions about health and social care in East Lothian, it must be recognised that unpaid carers are key partners in care and that carers are fundamental to the success of health and social care in East Lothian and across Scotland.

Carer representatives on IJBs play a vital role and can act as a key link to carer centres. COCiS' series of reports, including the most recent *Equal, Valued and Sustained*¹⁴, provides a toolkit for carer representation on IJBs, which COSLA and Health and Social Care Scotland have shared with their networks. This provides practical support to address well known issues for carer representation such as recruitment, retention and succession planning. The report highlights a range of carer representation across Scotland with an overall improving picture and continuing discussion around voting rights. In East Lothian we have had consistent representation from a very active carers representative but must now start succession planning for this important role.

The IJB's five year financial plan has been updated to reflect the most recent planning assumptions and financial projections. It is projecting a financial pressure of £4.2m for 2025/26 reflecting increased demand for services. As part of the budget setting paper approved by the IJB at its March 2024 meeting, a range of efficiency plans have been agreed which bring the 2025/26 position back into balance.

https://www.eastlothian.gov.uk/downloads/file/35507/east_lothian_integration_joint_board_-_annual_performance_report_2024_to_2025

¹⁴ <https://www.carersnet.org/wp-content/uploads/2025/07/Equal-Valued-and-Sustained.pdf>

Carers are included in the impact assessment process for proposed changes and we will further embed carers voices into this process and explore the addition of carers as an additional protected characteristic in the standard impact assessment process in East Lothian.

It is challenging to identify the total resource invested in supporting carers, as carers can be supported indirectly by support to the cared for person. East Lothian is proud of our open and transparent approach to allocation of carers act funding.

Use of carers act funding to deliver and expand support to carers at a local level is reported quarterly to all board members.

East Lothian also has a very significant budget for 'replacement care' which is care delivered to the cared for person where the primary purpose of putting support in place is to give the carer a break from their caring routine and responsibilities.

Important legislation, policy and local documents

Carers Act (Scotland) 2016 <https://www.legislation.gov.uk/asp/2016/9/contents>

Is the most significant piece of legislation around carers rights. It came into force in April 2018 and provides rights in a number of areas; right to an ACSP/YCS, right to advice and information, right to support for carers where they meet local eligibility criteria, right to be involved in hospital discharge planning

Care Reform (Scotland) Act 2025 <https://www.legislation.gov.uk/asp/2025/9/contents>

Will introduce some key changes to how social care and support is delivered for unpaid carers, brings amendments to the carers act to include the right to a break from caring for all unpaid carers based on an assessment of whether the carer can access "sufficient breaks"

The Carer's Leave Act 2023 <https://www.legislation.gov.uk/ukpga/2023/18>

This means that, as an employee you can apply for unpaid carer's leave for up to five working days if you are arranging or providing care for someone with a long-term need. This applies within a 12 month period. See carersuk.org/help-and-advice/work-and-career/the-carers-leave-act-2023 for more information.

Getting It Right For Everyone (GIRFE)

<https://www.gov.scot/publications/getting-it-right-for-everyone-girfe/>

Is Scotland's approach to designing and delivering public services that focus on peoples needs. It focuses on the individual, ensuring all professionals involved in their care work together to create a package of support that meets all of their life needs.

Human Rights Act (1998) <https://www.legislation.gov.uk/ukpga/1998/42/contents>

Incorporates the rights set out in the European Convention on Human Rights (ECHR) into UK law. It allows individuals in the UK to bring cases against public authorities that violate their rights as defined by the ECHR

United Nations Convention on the Rights of the Child

<https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

Is a legally binding agreement signed by 196 countries (as of July 2022) which outlines the fundamental rights of every child, regardless of race, religion or abilities

Children and Young People (Scotland) Act 2014

<https://www.legislation.gov.uk/asp/2014/8/contents>

Includes systems to support children and young people and to help identify any problems at an early stage. The Act allows the Commissioner for Children and Young People to investigate cases affecting individual children and young people. The Commissioner can decide whether an individual's rights have not been respected and will be able to make recommendations about what should be done to make things better.

Getting It Right For Every Child (GIRFEC) <https://www.gov.scot/policies/girfec/>

Is Scotland's commitment to provide all children, young people and their families with the right support at the right time, so that every child and young person can reach their full potential. It encourages a proactive approach, focusing on early intervention to tackle challenges before they grow into bigger problems.

Education (Additional Support for Learning) (Scotland) Act 2004 (amended in 2009)

<https://www.legislation.gov.uk/asp/2004/4/contents>

This introduced the concept of 'additional support needs' in Scotland, which is a wider definition than special educational needs. It also gives local authorities new duties to support children with additional needs and gives the right for parents to request an assessment of needs at any time and to appeal against decisions.

Public Bodies (Joint Working) (Scotland) Act 2014

<https://www.legislation.gov.uk/asp/2014/8/contents>

This Act requires Integration Joint Boards and partnerships to have representation from carers and carers' organisations. In addition, guidance on the commissioning of services has a requirement to involve carers in the design and delivery of future integrated services.

Social Care (Self-Directed Support) (Scotland) Act 2013

<https://www.legislation.gov.uk/asp/2013/1/contents>

Self-Directed Support (SDS) enables service users to have more choice over the care they receive and can enable control over their own care budget. The Self-Directed Support Act gives a duty to local authorities to offer SDS to carers as well as to the person with the illness or disability. The Act reinforces the full involvement of carers in the assessment of needs for support and the provision of support for themselves.

Scotland's national carers strategy 2022

<https://www.gov.scot/publications/national-carers-strategy/documents/>

Recognises the diverse experiences of carers and sets out a range of actions to ensure they are supported fully in a joined up and cohesive way

State of caring 2025

<https://www.carersuk.org/reports/state-of-caring-the-cost-of-caring-in-scotland-2025/>

Shows a challenging picture for Scotland carers, with significant costs to financial security, health, employment and opportunities

Population Health Framework and Health and Social Care renewal framework 2025-‘35

Well known challenges including shifting demographics, growing demand, the impacts of a changing climate on peoples health and increasing financial pressures are recognised and the framework sets out how Scottish and Local government can work together to ensure people of all ages live well, with the right support, to lead healthier and more fulfilling lives and how we shift the balance to enable a community oriented approach to health and social care.

<https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2025/06/health-social-care-service-renewal-framework/documents/health-social-care-service-renewal-framework/health-social-care-service-renewal-framework/govscot%3Adocument/health-social-care-service-renewal-framework.pdf>

East Lothian Joint Strategic Needs Assessment

https://www.eastlothian.gov.uk/downloads/file/35573/east_lothian_joint_strategic_needs_assessment_2025

This is a key document for the East Lothian Integration Joint Board (JB), it looks at the current and future health and care needs of our local population to inform the IJB's role in the strategic planning and commissioning of health and social care services for the local area.

East Lothian IJB Strategic Plan

LOIP

East Lothian Partnership Poverty plan 2024-28

https://www.eastlothian.gov.uk/info/210705/elp_poverty_plan

Highlights that poverty is never a choice but forced upon people through complex circumstances and has a significant negative impact on peoples wellbeing, confidence and sense of worth. It recognises that households with caring responsibilities may be at greater risk of poverty

East Lothian Children's Strategic Partnership, Children and Young Peoples Services Plan 2023-26

https://www.eastlothian.gov.uk/info/210691/how_we_work/12518/east_lothian_childrens_strategic_partnership

Outlines a shared vision to improve the lives of children, young, people and their families by delivering services that respond to their needs, it emphasises early intervention, partnership working and a commitment to reducing adversity.

East Lothians local Dementia strategy 2023-28

https://www.eastlothian.gov.uk/info/210577/carers/12802/dementia_support/5

With rates of dementia among our ageing population expected to increase significantly over the next 25 years ELHSCPs dedicated dementia strategy sets out the needs and intended actions to help support people living with dementia and their families, covering information provision, diagnosis and post diagnostic support, dedicated support for carers, expanding community connection, maintaining independence, transport, housing, staying safe and understood as well as care services and end of life care.

East Lothians Care at home strategy 2025-2030

Focuses on improving delivery of care services to meet the needs of residents in their own homes, key areas are; collaboration, systematic change, community support, personal outcomes and engagement

East Lothian Communication and Engagement Strategy 2026-30

Explains how East Lothian Health and Social Care Partnership (ELHSCP) aims to:

- Connect and communicate
- Ensure information is provided in an accessible format that is easy for everyone to access and understand
- Invite, enable and empower people to have conversations that offer their perspectives, enable them to share experiences and insights to help provide health and social care services that best balance peoples needs and human rights.
- Actively listen to suggestions, explain how we will respond, or why we are unable to deliver on these.

Engagement data

We engage with our local carer population on an ongoing basis and have a lot of information about carers experiences, the things that matter and will make a difference to them. East Lothian HSCPs communication and engagement strategy will guide our engagement approach going forward and responds to feedback that people are often asked but don't always hear what happens as a result of their engagement. It aims to bring all engagement activity together so that people are not asked the same things at different times and by different parts of the organisation. We are very supportive of this aim and will share our carer data to support this.

Brief summary of what we already know

- Many carers don't identify as such because they don't recognise what they are doing is more than being a mum, partner, brother, friend, caring is less recognised in their community or they don't like the term.
- The number of carers is increasing as is the intensity of the support they provide.
- From carers who recognise this role and engage with support, we know what makes a difference to them.
- We know that those who access support find it very valuable and that this has supported them to continue caring while recognising the need to promote their own health and wellbeing.
- National research has explored many topics relating to carers experiences including general research into the impact of caring and more specific projects including older carers, cost of living, working carers and access to breaks.
- We have local carer specific data from service reporting, gathered from carers organisations, Carers of East Lothian and the Young Carers Service, but additionally carer information is included in all service reporting.
- We have good links with many organisations supporting carers in different local areas and from different groups, for example carers of people living with dementia, carers from south Asian communities.

Engagement to inform our strategy outcomes

As discussed above we want to achieve a balance between not repeatedly asking carers what we already know and keeping an open mind that there will always be impacts and needs that we may not have heard previously or understood. Therefore, to inform our carers strategy outcomes we asked 3 very broad questions through a survey.

Questions asked were:

1. **What is the most serious issue for you as a carer?**
2. **What would make the biggest difference to you as a carer?**
3. **What improvements to overall support for carers do you think could be made in East Lothian**

These questions were finalised with input from Carers of East Lothians carers panel who amended wording to ensure carers understood what we were asking

Summary of responses:

- 15 responses were received online
- Questions included in carers of East Lothians organisational survey bringing 90 responses
- Session with young carers advisory group, gathered feedback from 8 young carers
- Staff at MILAN supporting carers from the south Asian community, feedback from 4 carers
- 117 responses gave more unique pieces of feedback, Q1 161, Q2 136 and Q3 143

Themes

We asked - What is the most serious issue for you as a carer

15 themes were identified – carer health and well being (44), support for cared for person (21), breaks from caring (16), cared for health and well being (11), caring role (10), Young carers (10), finances (8), carer recognition (5), employment (5), condition of cared for person (3), future planning (3), education (3), appointments (2), health services (2), assessment of need (1), cared for health and wellbeing, carer recognition (1) support for carer (1)

We asked - what would make the biggest difference to you as a carer

16 themes were identified: Breaks from caring (23), carer support (19), support for cared for person (17), young carers (10), carers voice (7), carer health and wellbeing (6), caring role (5), assessment (4) cared for health and wellbeing (2), early intervention (2), employment (2), finance (2), information sharing (2), education (1), future planning (1), health services (1)

We asked – What improvements to overall support for carers do you think could be made in East Lothian

10 themes were identified from Carer support (34), Support for cared for person (19), Young carers (11), Breaks (10), accessing services (6), finance (4), social work (3), education (2), information (2), staff training (1)

The strategy document outlines actions grouped under five overarching outcomes that cover these themes:

1. Carers are identified, recognised and heard
4. All carers have the same opportunities to access support to meet their needs
5. Carers are meaningfully involved in the support of the person they care for
6. Carers are supported to look after their own health and well being and lessen negative impacts caring has on other parts of their lives
7. Carers can take breaks from caring when they need them

Holidays or isolation (a local perspective)

As we have noted the increase in demand for support from parent carers of children with additional support needs, we also did a specific engagement project working in partnership with Shared Care Scotland and children's services around parent carers of children with Additional Support Needs

experience of holidays periods. This gave a local perspective on Shared Care Scotland's national research titled Holidays or Isolation¹⁵

Feedback from local carers and organisations supporting carers has been telling us that families are finding it difficult to do the things other families might take for granted like going to the park, having a day out together at a local attraction or to find childcare/activities that are suitable for young people with additional support needs during the holidays. This work aimed to explore that with young people, carers and providers of activities and then think about what might be done to improve these families' experiences.

The overall feeling from carers was of a very difficult time with limited choices of places to go and things to do that suited them and their children with additional needs.

Carers described feeling restrained, restricted and stuck with many feeling universal activities were not possible for them but that there was a lack of more specialist supports and competition for places in what specialist provision is available.

Families really felt the inequality of caring for a child with additional needs compared to a child without additional needs. They told us how other families can drop their children off places while they have to stay because the staff may not be able to support their young person's needs. They told us how holiday clubs and childcare settings cannot meet their child's needs and therefore they can't use them to get a break or to work at this time.

Families also described the impact of getting the right support and how this can transform the experience of this time for the whole family

The feedback has been important in informing East Lothians children with disabilities service review and actions from this work include

- Improving information to parents and young people with additional support needs about what is available and what they can access
- Pilot of support to primary aged children during Easter and Summer periods 2026
- Formation of a playpark advisory group to ensure all local improvement truly meet the needs of children with additional support needs and their families.
- Improvement to changing place at the George Johnston Centre (Tranent) to meet the needs of families who need these facilities.

Carers highlighted the importance of professionals in recognising what they do and in meaningfully including them in assessment and support planning, with this in mind we engaged with a number of HSCP staff to understand current practice, challenges around including and supporting carers and potential changes that could improve carers experiences of working with services.

Staff engagement included online engagement sessions with different teams

- 2 sessions with East Lothians Rehabilitation Service staff, 13 and 5 attendees
- 1 in person session with internal care at home organisers, 7 attendees

¹⁵ <https://www.sharedcarescotland.org.uk/resources/research-library/>

1 in person session with Care Home Assessment and Review Team, 6 attendees

Online session with members of learning disabilities social work team, 6 attendees

Online session with members of the adult social work team, range of roles, 5 attendees

Follow up conversations offered and in depth discussion with Community Care Worker (carers)

Themes from staff conversations:

Sessions highlighted to staff just how regularly they are in contact with unpaid carers, no matter their role, staff recognised that they speak with carers every day and sometimes have more contact with them than the supported person. Staff recognised how important it is to include carers but noted challenges around time, conflicting opinions and information sharing. Staff tended to feel their involvement was focused around the cared for person and though they often recognised carer stress and the need for support they didn't feel it was their role or that they had time to give that support to the carer. Staff had good awareness of carer supports in the local community and often shared details but weren't often proactive in making referrals for support and didn't know if that carer followed up.

Many identified improvements around communication and information sharing, especially when it comes to care arrangements. A lot of the upset and tension they experienced with carers was because the individual and carer expected one thing and this was not delivered, for example the person may have been discharged out of hospital with what they thought was a 4 times a day care package but this assessment had been changed to twice a day without this being clearly communicated.

Many staff felt they were left in the difficult position of being the ones who had to meet with supported people and families and explain to them when they already felt let down and sometimes angry.

Social work staff highlighted how lack of resource meant they were often reducing the support in place to people and carers and that where resource panels had not agreed support they were still the ones who had to deliver this message to families.

Strategic plan engagement

Data with specific reference to carer support was shared including full responses from Carers of East Lothian, MECOPP and Scottish Disability Sport