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

This strategy sets out our shared vision, aspirations and ambitions for unpaid carers of people in East Lothian, it assesses where we are now, where we want to get to and the actions we will take to make this progress.

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Our vision

Carers of all ages across East Lothian are able to access the help and support they need, when they need it and to maintain their quality of life and health and wellbeing, however they define it. They will be able to live their own life alongside caring, maintain relationships, physical, psychological and social health and continue caring while it is their choice to do so. Carers are recognised by all in society for their fundamental role in supporting people and sustaining our communities, are aware of their rights and no carer is disadvantaged due to any protected characteristic, in line with the Equality Act 2010.

In setting out **Our Vision** we commit to continuing to work to achieve these goals but we listen to and are hearing carers voices that tell us they are still having the same conversations, feel that progress is too slow and do not see significant change in their personal circumstances. Scotland has some of the strongest policy and legislation when it comes to recognising carers and agreeing their fundamental human rights (see technical report, under Important legislation, policy and local documents) however by listening to carers locally and in national forums it comes across that their experience and reality often does not match up to what is written on paper. This strategy will focus on local actions, strengthening what we do and aspiring to meet what is written.

It is relevant to carers who live and care for someone in the East Lothian 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. Details of support available in other local authorities in technical report, under support available to relevant carers in the authority's area.

Why are carers important?

The support that both adult and young unpaid carers provide is invaluable to Scotland as a whole and to our local communities, however the costs of caring; financial, health and opportunity can be too high for individuals. Caring comes from existing relationships, it is not always something people choose but is born out of these relationships to family and friends who are closest to us. 3 in 5 of us will become a carer at some point in our lives so caring must be valued, recognised and seen in supporting our health and social care system and communities. Taking action to make things better for carers will make things better for all of us.

What do we know about the impacts of caring?

2025's State of caring survey[1] focuses on the costs of caring: financial, health, opportunity and longer-term costs for unpaid carers.

Unpaid carers often face additional costs like providing specialist food, contributions to cost of care, and higher energy costs. Household costs for those supporting someone with a disability are often overall much higher due to these costs. With the increase in the cost of living, and what is often seen as insufficient support from the social security system, many carers are finding it increasingly difficult to make ends meet, cutting back on essentials and in some cases building up debt to meet living costs.

Caring can also mean missing out on wider opportunities, to be in education or employment or take opportunities to do things that increase quality of life. Young carers can have difficulty with attendance at school or even where they do attend can find it difficult to concentrate due to being overtired or worrying about the person they care for. Carers can miss out on opportunities around paid employment, opportunities for personal development such as training or career progression and more often actually have to reduce working hours, change roles or give up work completely to care.

Caring has a very significant and long lasting impact on the carers own health and wellbeing, carers report serious impacts on both physical and mental health as well as impacts on opportunities around leisure and relationships, with carers having limited time or energy to give to the things that bring a quality of life for the rest of us.

Caring doesn't just impact people in the moment, it can shape their lives for years to come, meaning planning for the future often becomes incredibly challenging. Missing out on opportunities for work and training can lead to long-term financial strain. It often means pausing pension contributions or facing gaps in employment, making it harder to build enough for retirement. These difficulties don't just disappear once caring responsibilities end and can impact a carer for the rest of their life. On top of that, many carers have no clear plan for what would happen if they could no longer provide care, whether because of illness or other circumstances. This uncertainty creates real anxiety and adds another layer of stress to an already demanding role.

"The support that unpaid carers provide is invaluable to Scotland and to our society, but State of Caring 2025 provides clear evidence that the cost of caring is simply too high."

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[1] https://www.carersuk.org/media/yqzk0fjv/state-of-caring-the-cost-of-caring-in-scotland-2025-web-version.pdf

What progress have we made?

The Scottish Government allocates funding to support the implementation of the Carers Act (Scotland) 2016, which comes via the Integration Joint Board's (IJB) budget offer from East Lothian Council. Funding increased over a 5 year period following the implementation of the Carers Act, reaching £1.549 million in 2023/'24, it has since remained at this figure. Although not strictly ringfenced ministers have repeated pleas that this funding be used to increase support to unpaid carers at a local level.

This is East Lothian's third local strategy and over the lifetime of these support available to carers in the local area has increased. Each strategy has helped provide a framework for the improved recognition and support to carers.

Since 2019 Funding to our carer support organisations has increased more than three fold (CoEL funding 2019 £154,355 to 2025 £492,000, Young Carers 2019 £70,674 to 2025 £234,717) and they are supporting more and more carers (CoEL supported 1202 carers in 2019/20, of which 516 were new to the org, and 1595 in 2024/'25, of which 571 were new to the org. When East Lothian Council's Young Care Service was established 176 names of known YC were passed to the service, this resulted in 39 formally registered in March 2022 which has increased to 754 in March 2025)

We have increased awareness and support available through the Local Authority and Health Board and have also invested in and increased links with many community organisations to increase support for carers.

While it is important to recognise and reflect on the progress that has been made locally and nationally, we must ensure we are listening to and acting on the experiences of unpaid carers who don't feel that their lives have improved and keep working to address the things that carers tell us are most important to them and will make the biggest difference. The outcomes of this strategy have been directly informed by carers voices, key actions are noted under each outcome which will be fully developed in the associated action plan.

What are we aiming to do next?

We know that our population is changing, East Lothian has the second most rapidly growing population of all of Scotland's Local Authority areas, while this has potential to bring economic benefits it also means increasing pressure and challenges to already stretched services (see technical report and East Lothian Joint Strategic Needs assessment[2] for fuller context). As the balance of care continues to shift from hospital to community settings more people are staying at home for longer and with more complex care needs. As a result more people are pushed into caring and into more intensive roles, ultimately impacting more on the carers life at that time and on their opportunities for their future. More carers will therefore require support and further investment and expansion will be needed to meet the demand. This presents a significant

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

challenge at a time when budgets are not increasing in line with demand and means more than ever we must make best use of the resources we have.

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 overall success of health and social care in East Lothian.

The strategy 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 wellbeing and lessen negative impacts caring has on other parts of their lives
5. Carers can take breaks from caring when they need them

The data and feedback used to inform our local strategy outcomes and actions can be found in our technical report.

Who did we listen to in bringing together this strategy?

East Lothian's local carers strategy has been developed by listening to local carers and those involved in supporting them (a summary of this can be seen in the technical report, engagement data section) and sets out how we will work together to ensure all of the different people who work with unpaid carers across East Lothian will do so in a joined up way to ensure there is no wrong door and reducing the need for carers to repeat their story. Progress to expand and improve carer support at a local level depends on strong relationships and recognises we all have a role to play in supporting our unpaid carers. The strategy's implementation and progress will be monitored and evaluated by East Lothian Health and Social Care Partnership's Carers Programme Board. Updates will be provided to the Strategic Planning Group, Carers of East Lothians Carers panel and East Lothian Councils Young Carers Advisory Group.

Carers Strategy Outcomes

1. Carers are identified, recognised and heard

We all have a role to play in identifying unpaid carers. Many of those who care do so without recognition. By recognising what a carer does for someone they care for we can help carers feel more valued and supported by our communities and by society.

The increase in carer numbers is most likely due to a combination of the increase in the actual number of people providing unpaid care as well as increased awareness and identification as a result of local and national awareness raising. We understand that not everyone identifies with the term 'carer' and our goal in promoting identification and recognition is not to label people, but to help them see that the support they provide goes beyond what is typical for a parent, child, relative, or friend. Recognising this can open the door to the help and resources available to carers in their own right.

East Lothian has a diverse population, and while we are successful in reaching some groups of carers, others remain underrepresented. Many of the carers we are engaging less come from minority communities or include individuals with a number of protected characteristics, often with overlapping needs. We must do more to actively reach and support these communities. We know from Scotland's census that there has been a huge increase in the number of Black and Minority Ethnic (BME) carers in East Lothian, (carers within the Black and Minority ethnic community increased by 208% between 2011 and 2022[3]) even with very likely under reporting of unpaid caring in BME communities. MECOPP research[4] shows that Black and Minority Ethnic "carers face worse health and financial outcomes due to additional barriers towards identification, communication and access to support services" The first step in addressing these poorer outcomes has to be identification and we will work to increase our reach into communities and identify carers by increasing cultural competency in our overall workforce as well as proactively reaching out to specific communities and increasing services and opportunities for breaks from caring that are culturally and linguistically appropriate.

Professionals across health, social care, housing, education, and other sectors play a vital role in identifying and supporting carers. This responsibility is twofold. First, professionals have a duty to involve carers in both individual support planning and the design of local services but on a more human basis when unpaid carers are genuinely included as equal partners in care, outcomes improve, not only for the person receiving support but for the carer themselves.

Second, recognition must extend to supporting carers in their own right. Many carers are unaware of the help available, where to find it, or how to access it. Professionals can make a significant difference by helping carers understand their role, identify carer stress, and connect with support early, before challenges become crises.

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[3] https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/68dbac6d07941f770ba419a4/1759226989791/MECOPP+Briefing+Sheet+19.pdf

[4] https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/68dbac6d07941f770ba419a4/1759226989791/MECOPP+Briefing+Sheet+19.pdf

Caring has a huge impact on opportunities around education, employment and training across the lifespan. Schools, educational establishments and workplaces have a really important role in identifying those individuals with caring responsibilities and in becoming more aware and responsive to the extra pressures that carers face on their time and capacity for learning or work. If these key establishments can identify and support carers fewer may feel forced into giving up work, education or training. We will work with the Local Employability Partnership to ensure carers issues are recognised and promote opportunities to increase support to carers

Carers, including young carers, also have a legal right to be included in the hospital discharge process when someone they care for is in hospital. East Lothian is committed to the "Home First" ethos, recognising that a person's own home is the best place for them to recover and that in some cases more time in hospital can actually cause harm. This makes it even more important that carers are included in discharge planning as early as possible, carers are key to a person's successful discharge, their involvement can determine how well the patient recovers and whether they avoid readmission. Therefore, we need to work to ensure the carer is involved from the point of admission through to discharge and is central to planning for discharge.

Carers' voices need to be heard and valued and to achieve this we must embed their perspectives into all systems and processes. This means ensuring carers are supported to inform and shape services, respond to local issues affecting them and the people they care for and influence national policies and plans. East Lothian is starting from a strong position, but we can do more to give carers the voice they deserve and enable them to truly effect change. To do this carers need to be informed, confident, interactive and able to advocate for themselves. We will commit to strengthening carers' voices within individual assessments and plans, as well as across all IJB decision-making and more broadly.

Key actions

Improve the information available to carers so they are more able to access support

Outreach/ targeted awareness raising into minority communities

Research models of carers voice and self advocacy in other areas that will inform us around what works and might be replicated in East Lothian

Increase awareness around supporting carers in employers and educational settings

Embed carers voice into our equality impact assessment processes and consider making caring an additional protected characteristic

2. All carers have the same opportunities to access support to meet their needs

The principles of equality, diversity and human rights are the underpinning rights for all carers, who represent the wide mix of people in our communities. We want to make progress towards ensuring no one 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.

Caring is a recognised social determinant of health inequalities. 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.

Women are more likely to take on caring roles reinforcing gender gaps in income, pensions and career progression.

Carers own health and wellbeing may suffer due to the physical and emotional strain and carers may delay or skip their own medical appointments which can lead to further health problems. Their social connections, friendships, community connections and self-care are often impacted by caring.

The 2022 census showed that the number of Young Carers (aged 3-15) in Scotland had increased by 36% since 2011. In East Lothian identification of Young Carers has increased by over 400% since 2022 yet many remain hidden either through choice (fear of stigma) or lack of recognition (adults believing that only other adults are carers). Young carers should have the same chances and opportunities as their friends and peers. Through “Getting it Right for Every Child”[5] schools and other children’s services across East Lothian have a robust process for ensuring that Young Carers obtain the right support, at the right time from the right people. Young carers talked about school and support from school staff more than anything else, 72% of those completing Young Carer Statements state that they have an adult in school that they can speak to and 70% state that their school understands their caring role. However, it remains the case that some Young Carers feel that they are not recognised as such, especially where there is an adult carer in the household or that the impact or complexity of their caring role is not fully understood and this results in them not getting the support they need. The Young Carers Advisory Group therefore continues to call for further work to be done on increasing understanding of Young Carers. We will continue to work with schools to raise awareness of young carers and how understanding and support can allow them to have the same chances as their peers without caring responsibilities.

Accessing support should never carry stigma. We are committed to ensuring that no carer feels seeking help is a sign that they cannot cope or are failing in any way. Instead, accessing support should be seen as an acknowledgment of their vital role and give recognition and value to what they do. Getting support should help carers speak up for themselves, understand their rights and make choices about their education, employment, health, and their future. It should help them build confidence, feel less alone and allow new opportunities. Ultimately, support should enable carers to thrive, not just cope, ensuring they can go after what they want in life without being disadvantaged by their caring role.

Supporting carers in navigating and accessing services is an important part of what our carer support organisations do, they can advocate on carers behalf and often attend meetings to support carers in relation to adult protection, hospital discharge or education. Self advocacy is

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[5] https://sites.google.com/edubuzz.org/girfecineastlothian/home

important but the need for independent advocacy for carers requires greater understanding to improve access in line with the Care Reform Act[6].

Many local areas are exploring the potential for increasing support to carers through digital technology. Remaining aware of digital exclusion, we will explore how digital support could increase accessibility for carers, allowing them another means of accessing the information and advice they need at the time they need it.

Key actions

Improve our understanding of the carer population and the unmet need that exists in our carer population.

Gain better evidence to inform decisions on independent advocacy, 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.

Promote use of the digital tools linking people with available community supports

Explore models of digital support balanced with traditional service models

3. Carers are meaningfully involved in the support of the person they care for

Carers often tell us that they have to manage absolutely everything for the person they care for and for their household, managing everything involved in keeping a home, co-ordinating appointments plus navigating complex health and social care systems that don't always talk to each other and share information, carers are often overwhelmed. They tend to feel they are in a constant fight for every bit of support for the person they care for and for themselves.

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.

The reality for carers is that supports for the person they care for are reducing as resources become tighter and that this increases the amount of support carers are providing. We must ensure carers are meaningfully involved in assessment and support planning and that the impact on carers of any changes is recognised and considered as part of that process.

We want to know that if a carer has concerns about the person they care for these will be taken seriously and fully considered as part of any diagnostic process or treatment planning. This is particularly important where the individual may lack mental capacity, confidence or insight to make informed decisions, for example where there is a significant mental health problem, dementia, learning disability or young person with additional support needs. We must ensure consent is appropriately respected but that we start from a position of including those closest to the individual in any way we can. Where this requires legal powers to be in place we will

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[6] https://www.legislation.gov.uk/asp/2025/9/contents

support carers in knowing what is required, how to go about organising these and managing them once in place. While the numbers of Young Carers acting as the sole carer for someone are small (1.7% of registered Young Carers in East Lothian) it is crucial that their knowledge and experience is recognised, and their views sought.

Staff working in health and social care get training to deliver care and this should also be available to unpaid carers. Improving information on the persons condition and in managing anything that comes about as a result, for example advice on managing medications or behaviours that can be challenging could make a huge difference to a carers confidence in giving support and should be more available to them.

Carers should also be meaningfully included in educational settings**.** This applies both to young carers and to adult carers of young people with additional support needs. Carers of children with additional support needs can feel their child’s needs are not being met, they frequently work closely with schools or other educational establishments to identify what support is required and ensure it is put in place. This process can be challenging because schools have limited resources to meet the needs of a growing number of young people with additional support needs. However, these young people have a right to appropriate support and most often, it is the carer who fights to make sure this right is upheld.

We have made progress in East Lothian including carers in the hospital discharge process, developing a model of carer support in hospital that is embedded into the multidisciplinary team with the aim of increasing carer awareness in all staff. Carers are central to ensuring that the right support is in place at home for the person to be treated or continue their recovery out with the hospital environment. We will continue to work to increase involvement of carers in supporting a successful discharge and in enabling people to remain at home in their local communities.

Carers are also supporting more people in palliative and end of life with many people expressing their wish to die at home. This comes with a huge practical and emotional impact and we want to ensure carers are supported to look after someone nearing end of life and know what to do and where to go if they need help in doing this.

Key actions

Review how information sharing between key organisations could be improved carers experiences of assessment and support planning

Consider and improve carers involvement in the diagnostic process, potential focus on dementia and neurodevelopmental conditions

Review support planning and assessment processes with our commissioned partners to ensure they ‘think carer’

Review training available to unpaid carers and work to address identified gaps

Include carers experience in service reviews

Scoping of services for family and carers under the workplan for the palliative and end of life delivery group

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

East Lothian has made significant investment in carer support services, offering advice, information and support to carers that are open to all, in line with our strategic priority of early intervention and preventing crisis. We are one of few HSCP's that devotes full allocation of Carers Act monies, given by East Lothian Council, to funding carer support activities. As discussed above, Carers Act implementation funding is at a fixed value and therefore management of this budget is increasingly pressured. While we strongly support increased funding for carer support organisations, without additional resources for the IJB, any increase in one area would inevitably mean a reduction in another. This is particularly critical where direct services, such as short breaks, a priority outcome under this strategy, could be affected. Therefore, future funding decisions will require careful assessment and consideration.

We know providing care can have serious and long lasting impacts on a carers own health and wellbeing. Carers are put under physical strain with caring often involving physical assistance, disturbed sleep and hyper vigilance. Carers are likely to be at risk of musculoskeletal problems, fatigue and illness. Health issues can worsen with the intensity and duration of care, with carers too busy to seek help or treatment for their own health problems.

Caring can be exhausting and isolating as carers have less time and energy to put into other things in their lives. Some carers live with high levels of anxiety or fear around what might happen to the person they support or to themselves and overall carers are more likely to experience anxiety, depression and loneliness.

The combined impact on all aspects of their lives ultimately affects their mental health and their overall ability to cope and continue caring.
Mental health support and counselling are available to carers through Carers of East Lothian (for adults) and The Mental health and Wellbeing Team (for young carers). More widely adult carers can access mental health support through East Lothians Mental Health Single Point of Contact[7]. Carers do have access to help and support but it often feels it comes too late, when the carer is in a state of crisis, and we should consider how dedicated support might be delivered earlier to avoid this.

It can also be very hard when a caring role changes, the person being cared for may require more support than the carer can offer and move into long term care, they may be admitted to hospital or they may die. Big changes are really difficult for carers, especially those who have had to give up everything else to care and adjustment can be very hard. This is why carer support shouldn't stop when things change and carers might in fact need more support to adjust to change or in coping with a bereavement.

Staying connected is important to all of us, not only does it increase wellbeing but it is protective against loneliness, isolation, depression and other mental health problems including dementia. Some carers want to talk while others want to escape and do something fun together. Peer support offers the chance for carers to connect with others who understand what their life might be like, they might be able to offer each other practical tips, knowledge or just a listening

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[7] https://www.eastlothian.gov.uk/info/210662/health_services/12677/east_lothian_mental_health_services

ear but carers have told us just how important that can be. Carers can connect in person or online and should have the opportunities to find the right time and group to suit them.

Carers may benefit from support with practical tasks to help reduce negative impacts. For example, if someone needs to wash sheets every day, the most meaningful support might be having someone else take on that responsibility. Support planning should look at the whole situation and support the carer to decide what would make the biggest difference to them.

All carers have the legal right to complete an Adult Carer Support Plan (ACSPs) or Young Carers Statement (YCS). This should be the record of a conversation about the caring role, how it affects the carers life and what support might make things easier. Having one helps the carer get the right support in place. Creating the plan can take as long as is needed so it can focus on achieving the right outcomes, there are no timelines in place for completing a carers plan but this can be prioritised if the carer has urgent needs. Under the Care Reform Act timelines for completion of these plans will be brought into place and we will work to comply with these.

Existing timelines around completion of ACSPs or YCS for a carer of someone with a terminal illness will still apply. Although statutory guidance[8] does not say it is required, in East Lothian we also apply these timelines in the case of the carer being the one with a terminal illness.

The ACSP or YCS will be key to the introduction of the carers 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 drafts indicate this will include sufficient time for rest and leisure and to meet the carers personal outcomes. This has potential to increase demand for ACSP’s and YCS and we will need to plan for how we meet that demand and ultimately get the right supports in place to meet carers personal outcomes and make things better for them.

Key actions

Review dedicated mental health support for carers and ensure carers are considered in development of East Lothians Community Mental Health Strategy

Increase opportunities for connection and peer support

Ensure the ACSP and YCS gives a full assessment of the carers ability to take ‘sufficient breaks’

Implement guidelines around timelines for completion of ACSPs and YCS’

Monitor unmet need to inform planning and commissioning

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[8] 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

5. Carers can take breaks from caring when they need them

Shared Care Scotland recently published research into carers experiences of accessing breaks which highlighted the gap between need and access with **60 % of carers often or always feeling the need for a break from their caring responsibilities but only 7.5% regularly or frequently receiving a break from caring**[9]

Being able to take breaks is key to maintaining carers health and wellbeing. With breaks being so fundamental to wellbeing, the approaching introduction of a legal right to a break under the Care Reform Act[10] and in recognising the gap between the need for, against actual access to breaks, this is a priority outcome for everyone involved in supporting carers.

Some people use the term short break, some use different words such as respite, breaks from caring or even time for me. What is important is for us is to develop a shared understanding of breaks that is broad and includes **any form of assistance** which enables a carer time away from their regular caring routines or responsibilities. Breaks should be flexible, be short or long, during the day or overnight, at home or somewhere else and with or without the person they care for.

East Lothian HSCP have over the last few years increased opportunities for breaks from caring by; investing in community supports including older peoples day services and Leuchie House, through a targeted small grants programme which we hope will be expanded in future supporting local capacity building around breaks, increasing funding to individual carers through Carers of East Lothians Time for Me fund and reviewing access to individual budgets through adult social work as part of East Lothian HSCP's Self Directed Support Improvement plan. Registered Young Carers have access to free Enjoy Leisure membership, Active schools activities and school holiday programmes. Carers of East Lothian became a Respitality[11] partner in 2024 giving carers of all ages another opportunity to access donated breaks from the hospitality sector.

We have made good progress in increasing opportunities for breaks from caring however, we recognise that at this point in time many carers cannot take the breaks they need and as they offer more support to people their own need for a break is only increasing.

Although the Care Reform Act, including the right to a break, has been passed much of the detail on implementation will be left to secondary legislation and decided by Scotland's incoming government of 2026. The current government indicates this will be a gradual process building capacity over years to come and on a local basis it will certainly take time to build capacity in our workforce and local organisations supporting carer breaks.

This new right for carers, which could be transformative for so many, has the potential to really change lives but can only do so with access to clear information, services with the variety and capacity to meet carers needs and with adequate, suitable and sustainable funding to meet the needs of this diverse group.

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[9] https://www.sharedcarescotland.org.uk/media/fbldl2wc/scs-short-breaks-and-respite-care-survey-2024-report-web-singles.pdf

[10] https://www.legislation.gov.uk/asp/2025/9/contents

[11] https://www.respitality.org.uk/

Work is ongoing to prepare for the right to a break coming into place, with the acknowledgement that there is still a lot of unknowns around implementation.

We do know that the Scottish Government has stated it will maintain and increase investment in the national voluntary sector short breaks fund which exists to provide easy-access breaks. If this is honoured more carers should be able to access breaks through ‘easy access’ routes, and without assessment.

Given that breaks are defined as any form of support that allows carers to take time away from their caring role, and recognising the importance of staying connected to people and communities, our first priority when exploring opportunities for breaks is to look at what exists within local communities and how these resources can meet carers’ needs. Access to information is crucial with recent feedback from parents of children with additional support needs highlighted that while there are many places and spaces carers can enjoy, some simply aren’t aware of what is available or what they can and cannot access.

If the needs of the person being cared for are more complex these universal supports become less able to meet individuals’ needs and more specialist supports can be needed. Often these can only be accessed by referral or by assessment and access to a budget for support. This is especially true where the carer needs “replacement care” to enable them to take a break, this means they are unable to take a break without someone else replacing the care they would usually provide, this can be the case where someone could be at risk if left alone.

Local Authorities already have a duty to support carers identified needs where they meet local eligibility criteria at substantial or critical. The biggest change under the right to a break is that instead of being based on eligibility criteria, access to funded supports for breaks from caring will be dependent on assessment of whether the carer can take “sufficient breaks”. 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”

We know that many carers already struggle to access the breaks they need. It is therefore reasonable to expect an increase in demand for support with the introduction of this legal right, although the scale of that increase remains difficult to predict.

Scottish Governments intention is to also increase funding for breaks through Local Authorities so that where a carer is unable to take sufficient breaks the support required to meet that need is recorded in the ACSP or YCS and the Local Authority will have a duty to provide the support necessary to meet this need.

Recognising that it will take time to build capacity in terms of community supports and services to support breaks we should also think creatively around other ways of reducing the impact of caring, by using telecare for example or putting in practical supports that reduce the impact of caring in other ways. As a whole system, but particularly in statutory services, we need to think differently about breaks, moving away from and substantial and critical criteria to focusing on carers personal outcomes and trusting carers as experts in their own situation, knowing what will make the biggest difference to them.

Most importantly we will not wait for the right to a break to be enacted but will continue prioritising opportunities for breaks for all carers.

Key actions

Increase opportunities for breaks from caring across carer groups

Increase joint working with children's services and organisations supporting young people to provide opportunities for breaks from caring for parents/carers of children with Additional Support needs

Improving practice around breaks from caring and specifically Replacement care in line with Self Directed Support principles of practice

Develop relationships with and increase support to organisations that already offer or could support opportunities for breaks from caring

Monitor unmet need for breaks through completed ACSP's and YCS to guide future investment

Conclusion

The strategy we have set out will take local actions to try and reduce the costs to carers while supporting carers to have their voices heard locally and campaigning for change at a national level.

Glossary of terms

Adult Carer Support Plan (ACSP) or Young Carers Statement (YCS) – the record of a conversation about your caring role, how it affects your life, and what support could make things easier.

Mental Capacity – a person's ability to make specific decisions for themselves, the ability to understand, retain and weigh information and to communicate that decision.

Digital technology

Disability – a condition or impairment that significantly affects a person's ability to perform normal day to day activities

Diversity – a variety of differences between individuals

East Lothian Health and Social Care Partnership – a collaboration between NHS Lothian and East Lothian council aimed at providing the best health and social care services for the community, its primary goal is to integrate health and social care services to improve overall wellbeing of residents

End of life care - the support and medical assistance provided to individuals with advanced, progressive, incurable illnesses in their final days, weeks or months of life. The primary goal is to control pain and other symptoms, ensuring the patent experiences dignity and comfort in their final moments.

Equality – fair treatment and equal opportunities for all individuals, ensuring that everyone has access to the same resources and opportunities regardless of their background or characteristics

Home first – a Scottish Government approach emphasising that the best place for someone to recover once medical treatment is complete is at home

Human rights – fundamental rights and freedoms that belong to every person regardless of background or characteristics

Integration Joint Board – brings together services from council and NHS to deliver health and social care in a Local Authority area

Local Employability Partnership – a strategic group aiming to assist East Lothian residents in securing fair and sustainable jobs

Palliative care - an approach that improves that quality of life of patients and their families' facing problems associated with a life limiting illness, it should prevent and relieve suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychological or spiritual.

Protected characteristics - specific aspects of a person's identity that are legally protected from discrimination

Strategic Planning Group - a representative group that includes representation from the public, people who use services, their families and Carers and organisations that deliver, or have an interest in, adult health and social care.