



# CONTENTS

## 1 Foreword

## 2 Introduction

- 3 1.1 What is caring?
- 4 1.2 Impact of Caring on Adult Carers
- 5 1.3 Impact of Caring on Young Carers
- 5 1.4 When do carers look for support
- 6 1.5 Continuing recovery from COVID-19
- 7 1.6 Cost of living crisis

## 8 Carers Outcomes

- 9 2.1 Adult, Young Adult and Young Carers are identified and can access support
- 10 2.2 Carers are well informed and have access to tailored and age appropriate information and advice throughout their caring role
- 12 2.3 Carers are supported to maintain their own physical, emotional and mental wellbeing
- 14 2.4 Breaks from caring are timely and regularly available
- 15 2.5 Carers are supported to have a life outside of their caring role and can achieve a balance between caring and other aspects of their lives
- 20 2.6 Carers and young carers are respected as Equal Partners, involved in planning and delivering care and support for those they care for, and their voices are heard and supported
- 22 2.7 Local Communities are supported to be carer friendly

|    |  |
|----|--|
| 23 | <b>Delivering our vision – Monitoring and Evaluation</b> |
| 24 | <b>Appendix 1 –Carer Consultation and feedback</b>       |
| 25 | <b>What our Carers Told us: Emerging Themes</b>          |
| 31 | <b>Appendix 2 – Local and National resources</b>         |
| 35 | <b>Appendix 3 – Policy context and data</b>              |
| 39 | <b>East Lothian's Carers – Who are they?</b>             |
| 43 | <b>Conclusion</b>  |

# FOREWORD

East Lothian Integration Joint Board (IJB) welcomed the Carers Act (Scotland) 2016[1] and fully supports its aims of making sure that young carers, young adult carers and adult carers are supported to manage their caring responsibilities with confidence and in good health, and that they are able to have a life of their own.

The East Lothian Carers' Strategy 2023 is our second local strategy and sets out how we want to continue to build on work done towards our aims. We hope the strategy will be accessible to more people and belongs to everyone involved. It is the result of consultation and engagement with carers, carers' representatives, partner organisations and communities, that will continue over the lifespan of this strategy to inform decision making and future directions.

The strategy focuses on seven outcomes but throughout these we will be recognising the backdrop of; continued recovery from the COVID-19 pandemic, the considerable cost of living crisis and the effect this is having on individuals and households, limited budgets and resources to meet growing demand. We will work together across partnerships and do things differently, with the goal of achieving what we have set out to do. It will be a community effort, as it should be.

Finally, we would like to thank everyone who has worked on this strategy – Carer's, carers' representatives, and partner organisations in the independent, third and statutory sectors for their wisdom, insight, care and commitment to improving the lives of carers of all ages in East Lothian.

**Maria Burton**

*Carers Strategy Officer, East Lothian  
Health and Social Care Partnership*



[1] Carers Act (Scotland) 2016

# INTRODUCTION

This strategy describes our intention for development of support services for carers across East Lothian. It sets out the way in which services will be developed over the lifetime of the strategy and how we intend to deliver the outcomes that carers say are important to them. We recognise that without the continued support of carers we cannot deliver our key priorities of:

- Delivering more care closer to home
- Developing stronger, more resilient, supportive and inclusive communities with a focus on prevention
- Supporting people to live healthier, more active and independent lives.

East Lothian Health and Social Care Partnership is acutely aware that the majority of care is provided not by doctors, nurses or care workers, but by family, friends and neighbours and that caring roles come from the family, social and community relationships that are important to us. Our goal of moving care away from institutional settings back into the community cannot be achieved without the incredible contribution of carers.

The strategy underlines our commitment to work collaboratively to ensure that the support carers receive is provided to a high standard. We will seek to build on existing resources and ensure that these services reach more of our carers through improvements in carer identification.

## Values Statement

We want to ensure carers are recognised by all in society for their fundamental role in supporting people and sustaining our communities. Our aim is for Carers of all ages across East Lothian to be 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.



We also aim to improve systems to better signpost carers to information and advice services earlier, ensure that preventative support is prioritised, provide a range of options for carers to access short breaks and integrate carer support into assessment processes to allow carers to access individual budgets in their own right. We will continue to progress the agenda of enhancing the community support available to carers, making it clearer and easier for carers to access these services and work to facilitate relationships between our partners in the Third Sector. We will enhance the ability of carers to articulate their views and engage with planners and decision makers meaningfully.

The principles of equality, diversity and human rights are the underpinning rights for all carers. Carers reflect the diversity of Scotland's population. We will ensure that Carers are aware of their rights under this legislation and that no carer is disadvantaged due to age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity, race; religion or belief; or sex or sexual orientation, in line with the Equality Act 2010.

The strategy aims to empower and ensure a Human Rights based approach where the rights of people using Health and Social Care services are protected, promoted and supported in practice and embedded in the culture of all services. We want to empower Carers to know and claim these rights.

## 1.1 What is caring?

A carer is anyone who provides care, unpaid, for a friend or family member, who due to illness, disability, or a mental health problem cannot cope without their support. Their role ensures that cared for people can continue to remain as independent as possible, and as such, carers are often the most important person in the lives of the people who are given support. Carers are therefore often family members, friends and neighbours first and caring emerges and evolves as part of this existing relationship.

Carers are unique people of all ages, in employment, education, unemployed, retired or care full time. They may provide considerable levels of care, or may provide care a few times a week depending on what is needed and around other more formal support in place. Each carer will have their own specific set of circumstances.

While caring may involve providing a range of tasks including personal care, supporting a person their daily life and providing emotional support and reassurance, these tasks are often integrated into daily family life and many carers adapt and manage with their changing circumstances in providing this support and often don't realise that they are a carer.

## Did you know?

Estimates vary but there are at least 690,000 people in Scotland caring for a friend, relative or neighbour. Some estimates suggest this could have risen to over 1 million during the pandemic. There are an estimated 30,000 Young carers in Scotland.

132,000 carers care for 50 hours a week or more

8 in 10 carers say their health is worse because of caring

## 1.2 Impact of Caring on Adult Carers

Carers report that undertaking this role can have many positive rewards including strengthening the relationship between the carer and the cared for person and a sense of satisfaction in contributing to the life of the person they care for however it must be recognised that caring, especially when the role is more intensive, can have a huge impact on the life of the carer, their general health and well-being, their finances, their relationships and caring can increase social isolation.

Carers UK 'State of caring' (Scotland) survey 2021 [2], found that among adult carers:

- 33% of carers are struggling to make ends meet
- 32% said the biggest barrier to accessing support was that care and support services in their area did not meet their needs
- 72% said their mental health had deteriorated as a result of caring in the pandemic
- 72% said their physical health had deteriorated as a result of caring during the pandemic
- 30% described their physical health as bad or very bad
- 30% described their mental health as bad or very bad
- 38% stated they were often or always lonely

[2] State of Caring survey 2021

## 1.3 Impact of Caring on Young Carers

Young carers are children and young people first and foremost. Many have pride in the responsibilities that caring can bring. However, some young carers may experience more difficulty in accessing social, recreational and educational opportunities, may face barriers to performing well in their education and experience increased levels of stress, depression and anxiety. They may also be more likely to experience bullying than their peers and have greater levels of reported self-harm.

Anything that causes disruption to a child or young person's life at this early stage is likely to significantly impact their options in the future.

A Carers Trust Scotland<sup>[3]</sup> survey undertaken during the pandemic found that 59% of young carers and 67% of young adult carers who participated were taking on more caring hours every week. One in ten young and young adult carers surveyed have seen their caring role increase by 30 hours a week or more and 24% of young carers and 34% of young adult carers were caring for more people than they did before the pandemic. Additionally, 38% of young carers and 44% of young adult carers that participated felt less able to cope.

### Did you know?

Young adult carers aged between 16 and 18 years are twice as likely to be not in education, employment, or training.

## 1.4 When do carers look for support?

We know that adult carers initially use the resources they have around them, including family, wider community networks and support services to assist them to cope with their role and many carers only approach Health and Social Care services for assistance once they are feeling stretched. Young carers, however, are often not in a position to initially use the resources around them and need support early on to help them to access the networks of support available to them.

When carers seek support from services it is crucial that these build on and fit into existing arrangements that carers have already put in place.

Quality services are vital in relieving the stress of caring. Badly designed, or ill-fitting support creates rather than relieves stress, and carers do not benefit from additional support if they do not have confidence in the service they are receiving. Services must also consider the cultural needs of groups across the county and ensure that they meet the requirements of ethnic minority groups.

By helping carers to benefit from social support and to access resources in the community we can positively relieve the impact caring can have and help carers to maintain the vital relationships in their life. There is a great deal of community interest in supporting carers. Connection to the community helps to combat loneliness, isolation and the emotional stress of caring. There is much that we can do to help to capitalise on these existing resources and make these easier for carers to access and to know what is available to them in their local area.

[3] COVID-19 In Scotland: The impact on Unpaid Carers and Carer Service Support



The challenge to Health and Social Care services is to focus more resources on preventative work at an earlier stage to improve access to these community resources, strengthen relationships important to carers and thereby prevent crises and reduce stress. However, we must recognise that not all carers will wish to identify themselves for a variety of reasons.

As the impact of a caring role increases we must work to provide carers with timely support, help them to plan ahead to consider future needs, and put contingency plans in place to anticipate changes in their caring circumstances. As carers begin to use more formal services, we must be mindful to ensure that these services enhance and protect their relationships and reduce the potential for isolation from the things that matter to them.

This means the support we provide should be holistic, working with a wide range of services such as housing, transport, libraries, community resources, day centres, churches as well as the more traditional health, social work and third sector services to provide a range of resources that carers can use to support them.

## 1.5 Continuing recovery from COVID-19

As a result of COVID-19, many carers have taken on longer and more intense caring roles and there is strong evidence to suggest that the pandemic has, and continues to have, a disproportionate impact on unpaid carers.

Information from the Carers Trust survey on the impact of COVID on Young Carers and Young Adult Carers highlights:

- 40% of Young carers and 59% of Young Adult Carers reported their mental health was worse since Coronavirus
- 66% of Young Carers and 74% of Young adult carers reported feeling more stressed
- 11% of Young Carers and 19.7% of Young adult carers reported an increase of 30hrs or more in the amount of time they spend caring every week
- 58% of Young Carers, 63.6% of those caring for longer since Coronavirus spending on average 10 hours a week more on caring responsibilities.

The Scottish Government have recognised in their COVID recovery strategy[4] “It is clear that the impact of the pandemic has not been felt evenly. It has both highlighted the inequalities in our society and made them worse. Those who were already the most disadvantaged have suffered disproportionately. They have been more likely to get seriously ill, more likely to be hospitalised, and sadly more likely to die from COVID. They have also been the hardest hit socially, educationally and economically, by the restrictions that were brought in to control the spread of the virus”. Their strategy sets out measures that will be taken at a National level to address inequalities.

As we move into the new phase of living with COVID-19, some carers need support to rebuild confidence and feel safe to re-engage with wider communities and services. Communication with carers is a key element of that but there are also practical measures to consider in supporting our carers.

We must acknowledge that although the COVID pandemic had a huge and ongoing impact, for many the cost of living crisis will be felt even more harshly and has become the biggest issue for many carers.

## 1.6 Cost of living crisis

We are living through an unprecedented time, with increasing inflation and the cost of energy, food, fuel, and basic commodities all rising at the same time. Unpaid carers have been among the groups hardest hit by the cost of living crisis in Scotland. Many carers already faced higher essential costs because of their caring role. This includes, but is not limited to:

- higher energy costs so that their home is warm enough to ensure the person they care for stays well
- essential equipment that requires power such as hoists, oxygen and wheelchairs
- additional laundry costs as a consequence of incontinence
- extra transport costs to support a person to and from health appointments
- special diets to support the nutritional needs of the person they care for.

These issues are often exacerbated by carers having to give up paid work or reduce their working hours to provide care.

Lobbying groups have been calling for carers to be included in any extension of the Warm Home Discount scheme, additional support for carers with energy bills and action to help carers on Carer’s Allowance whose incomes are falling behind inflation. Carers can access social security benefits to help with the financial impact of caring, but the interaction between caring responsibilities, a person’s income and their ability to maintain connections and interests in addition to being a carer is complex. At a local level we need to ensure carers are supported to access all the help they are entitled to and support carers voices to be heard more widely in lobbying for change.

[4] Covid Recovery Strategy: for a fairer future

# CARERS OUTCOMES

Over the last few years we have continued to engage with Carers with a variety of experiences and have gathered this feedback here so the voice of Carers and their representatives are heard first in putting together this updated strategy and Action plan. See Appendix 1: Carer Consultation and feedback

The strategy focuses on seven outcomes that have been developed in consultation with carers but throughout these we will be recognising the backdrop of; continued recovery from the COVID-19 pandemic, the considerable cost of living crisis and the effect this is having on individuals and households. We also acknowledge the chronic lack of workforce available to meet the needs of individuals in our local community that will have an impact on our ability to deliver on all our aims.

- 1) Carers are identified and can access support.
- 2) Carers are well informed and have access to tailored and age appropriate information and advice throughout their caring journey
- 3) Carers are supported to maintain their own physical, emotional and mental wellbeing
- 4) Breaks from caring are timely and regularly available
- 5) Carers can achieve a balance between caring and other aspects of their lives and are supported to have a life outside their caring role
- 6) Carers and young carers are respected as Equal Partners, involved in planning and delivering care and support for those they care for, and their voices are heard and supported
- 7) Local Communities are supported to be carer friendly



## 2.1 Carers are identified and can access support

Carers often don't identify as such, seeing themselves as a partner, daughter/son, parent, friend or neighbour first. Some can take years to recognise their additional caring role, missing out on the financial, emotional and practical support during that time. Assisting carers to identify with their caring role unlocks access to vital information, advice and support. Other carers do not want to be identified as such and we have a responsibility to help them access the same advice and support through good conversations.

Many people who support family members with mental health problems, such as anxiety and depression, or drug or alcohol issues do not identify themselves as carers and there is still a lack of understanding from others surrounding this caring role. In addition, the person with care needs may deny that they need or are getting support from a family member or partner. This makes it difficult for people to self-identify as carers and for others to see them as such.

There are further challenges in identifying Young Carers as some fear the shame of appearing unable to cope, whilst others are wary of the intrusion in their lives/families lives if they highlight the difficulties they are facing. It is therefore likely that the figures reported nationally for young carers are an underestimate of the actual levels of children and young people providing care.

There is work to be done to showcase the positive role of social work in supporting carers, to gain the trust of those who are wary of engaging with services.

There is an awareness that many voices are not heard or are under-represented, 'hidden carers', might include people who live in deprivation or those with protected characteristics and thought needs to be given on how to engage meaningfully with these individuals.

There is a continuing conversation around the language used in relation to Carers. Just in our engagement we picked up on so many issues in relation to language. Some people find the term 'Carer' confusing as it makes them think of care workers, some find the term unpaid carers derogatory and would prefer to be known as family carers. We are sticking with the term 'carers' as this is what the Scottish government use and therefore how funding has been allocated but we fully recognise this issue and our responsibility to help carers access the same advice and support through good conversations, regardless of how they identify.

We all have a role in identifying carers and whether carers come into contact with NHS, council or third sector services we recognise that all these services need to do more in terms of identifying carers and increasing awareness of their role and rights to support.

## 2.2 Carers are well informed and have access to tailored, age appropriate information and advice throughout their roles

Carers often tell us they find it difficult to access the information they need at the time they need it, we appreciate people need a mixture of local and national resources but we need to improve navigation for Carer support as all too often Carers don't know where to go for information and advice.

Access to good quality and age appropriate information is crucial in enabling carers to benefit from the practical and emotional support available to them locally, helping them to maintain their role and allowing them to make the decisions that best fit their own personal circumstances.

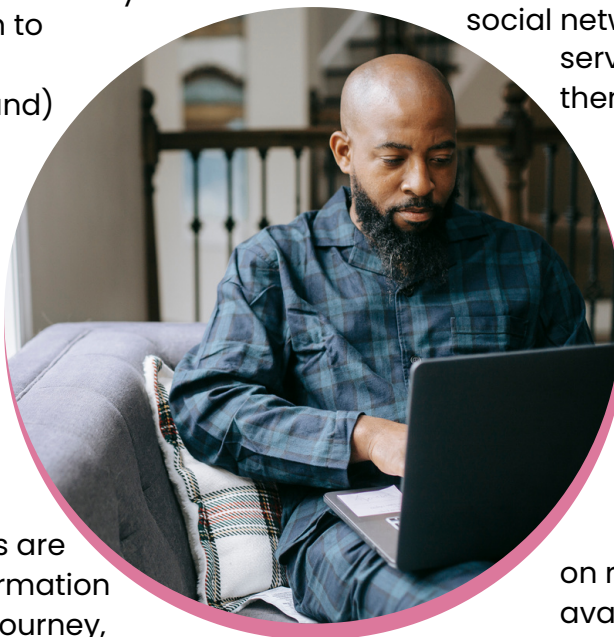
Timely, accurate and good quality information and advice is needed throughout all the stages of the caring role including:

- When someone is new to caring
- When an initial diagnosis is made
- When considering formal support or accessing other services
- When crisis situations occur
- At times when support needs increase or change
- Planning for future need
- When a carer or the cared for person experiences a change of service
- When someone is discharged from hospital
- When supporting someone at the end of life
- When someone dies
- When moving in/out of East Lothian
- When a carer decides they can't or don't want to continue caring

Carers often need information about both their own circumstances as a carer and about the health condition of the person they care for. This can mean that carers face a range of advice services which can be difficult and time consuming to navigate. Feedback from carers is that effective support most often begins with a quality conversation between them and a carer support worker to identify issues and concerns the carer has and allow them to access tailored information based on their requirements. In line with the Carers (Scotland) Act, East Lothian commissions services to specifically provide advice and information for carers locally.

However the State of Caring Survey (2022) [5] results show almost a third of carers don't know what is available in their area and this is even more prevalent in those struggling to make ends meet (47%).

Further work is needed to ensure that carers are provided and signposted with the right information and advice at each point along the caring journey, with information required from a range of sources including the NHS, welfare rights organisations, education services, housing and through online resources.



Raising awareness of carers needs across these organisations will ensure that these services support carers earlier to plan in advance, for example, for future housing needs, finances, how best to manage hospital admissions and support the cared for person in self-management of their illness for as long as possible. We must also bear in mind that Young carers may not have the experience or social networks in place to access the information services above and that additional guidance for them may be required.

Carers with protected characteristics and from minority ethnic backgrounds experience additional difficulty in accessing carer services with many reporting that they are unaware of the social work services available to them, or of their entitlement to assessments, much of which

can be attributed to language barriers in accessing this. All of East Lothian's written information is available in other languages

on request and translation services are also available.

Consideration needs to be given of how to ensure information and support is available to others with barriers to access, for example to those who do not have the skills, resources or choose not to access information online or for people with hearing or sight impairment which can make accessing information and services more difficult.

[5] State of Caring in Scotland 2022

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

We know that caring can be incredibly physically and emotionally demanding, and that as carers age themselves they are more likely to experience health concerns of their own.

Scotland's National Health and Wellbeing Outcomes 6 [6], states "people who provide unpaid care are supported to look after their own health and wellbeing including to reduce any negative impact of their caring role on their own health and wellbeing". While this is a great aim many carers tell us that they care at the expense of their own health and wellbeing.

The recent Care Inspectorate report into Adult Carers experience of social work and social care services[7] found that "caring can have a negative impact on carers' physical and mental health and wellbeing, as a result of caring without all the support they needed."

Results of Scotland's 2022 Census are due to be published in 2023 but these figures from the 2011 Census[8] shows we have some way to go in achieving the goal of supporting Carers to maintain their own health and wellbeing:

- 40% of carers of all ages report experiencing one or more health conditions compared to 29% of non- carers
- One of the most commonly reported conditions cited by carers is the impact of caring on their mental health and that this affects those between the ages of 25 and 49 the most
- Older carers in our area are less likely to be able to rate their health as either good/very good
- Ill health affects those carers between the ages of 50 and 64 the most
- A greater number of carers who provide the largest number of hours of care rate their health as poor/very poor compared to those providing fewer hours (12% compared to 3%).

[6] Scotland National Health and Wellbeing Outcomes

[7] Inquiry into adult carers' experiences of social work and social care services (Dec 2022)

[8] National Records of Scotland – Census 2011

Caring at a young age can also have significant and long lasting impact upon a young person's mental and physical health. Much of the support we can offer includes supporting Young Carers in school.

More recognition is now given to 'sandwich' carers who may be caring for an older person and a child with additional needs. We also know that many of our older carers provide the greatest number of hours of care and are more likely to experience health concerns of their own and that our carers generally experience greater ill-health than our non-carers.

Caring for a friend or family member at the end of life can be very physically and emotionally demanding. When someone has a terminal illness and is living at home their GP has overall responsibility for their medical care. They will co-ordinate the involvement of other professionals and are the first point of contact if you have questions and need support or assistance.

Access to counselling and emotional support is valued by carers and essential in supporting them to maintain their own health and wellbeing, Carers report that knowing they are not alone assists them greatly in continuing to care.

Supporting carers to overcome barriers to breaks from caring and providing short-term, timely support from quality services to allow people time away from caring has a huge impact on Carers' ability to maintain their own health and wellbeing. Putting in place contingency plans for alternative or family support to enable carers to access health appointments will help those to manage health conditions of their own.

It is estimated that 270,000 or 1 in 7 adults in the workforce carers are juggling the demands of their employment with their caring responsibilities and may be experiencing a greater degree of stress and mental ill-health. Improving awareness among employers in the area and encouraging them to become 'Carer Positive' can help adult carers better balance their careers with caring. Support from HR and paid leave at critical times allow carers much needed flexibility as their caring situations change, or crises occur. Carers also identified a lack of childcare and wrap around services for children with additional needs that would enable parents who want to work. Increasing awareness of unpaid carers in employability services could help Carers maintain or return to work at different points of their caring journey.

Supporting carers to develop self-management strategies through Adult Carer Support Plans (ACSP) and Young Carer Statements (YCS) can increase support for carers without reliance on formal support services.





## 2.4 Breaks from caring are timely and regularly available

The term 'Breaks from Caring' can cover any form of support that enables a carer to have time away from their caring responsibilities. With a recognised shortage of formal care and support services, Carers and those who support them, have had to come up with more creative ways of accessing breaks.

Carers have told us that these breaks from caring are essential in allowing them to continue to care for longer and in better health, and a successful short break can provide a meaningful experience for both the carer and the person they are looking after, however responses to the State of caring survey 2022 show that 39% of carers have had no break at all in the last 12 months and when asked about the top needs of carers nearly half (46%) identified more breaks or time off from their caring role.

"Money is useless if there's nothing to spend it on. The same as hours, you can legislate entitlements, but entitlements are useless without actual service provision." Quote from the National Carer Organisations response to the Scottish Government's consultation on a National Care Service.[9]

Breaks can take place in a number of ways and for differing lengths of time. They can be done jointly with the cared-for person, or without them, depending on people's preferences. We recognise that time taken away together can do much to preserve the relationship between the carer and their loved one. Young carers particularly benefit from a break taken with their family. However, regardless of age, carers should be enabled to take their break in a way that fits the carer and their situation. Carers should be able to access breaks from their caring role by care being provided for the person they care for in a number of ways including:

- By another family member or friend
- Creative 'breaks from caring' such as leisure or relaxation opportunities, equipment or help with domestic tasks that add to the impact of the caring role.
- At the home of the cared for person by Community or Outreach services, care, or "sitter" services
- By the cared for person attending a day centre or a local interest or activity group
- Flexibly by using a personal budget through Self Directed Support
- In the home of another person through the Share the Care or Shared Lives Schemes
- In a care home or other residential respite service

[9] NCO response to consultation on a National Care Service

Where support is required to enable a break, Carers of people in East Lothian can access this via Carers of East Lothian who can provide flexible small grants and support in thinking about what kind of break will meet the carers needs. They have a dedicated short breaks and 'Building better breaks' service aimed at helping carers overcome some of the barriers to accessing breaks. The Health and Social Care Partnership is committed to continuing to ensure that such support remains available, especially at a time when what formal support services are able to offer in terms of respite is limited. The service is already receiving feedback that people really value the help in arranging breaks instead of just being given another form.

Short breaks are also available through East Lothian's Young Carers Service, who can support young carers to access a wide range of activities and groups that allow young carers time away from caring and the opportunity to be a 'child first'.

As the impact of caring increases support may be given through social work (following an assessment process) as part of a more formal support package.

Carers have told us there are a number of additional barriers to taking a break which can include; anxiety about the impact on their relationships with the cared for person, feelings of guilt at leaving the person they care for and concerns that the care won't be of a high quality to ensure the person is comfortable and safe. Responses to this strategy highlighted a lack of support for parents of children with additional needs with long waiting lists existing and breaks being difficult to manage depending on the needs of the person being cared for.

Information on local resources to support breaks from caring can be found in our Short Breaks services statements here: [Short Breaks Statements | East Lothian Council](#)

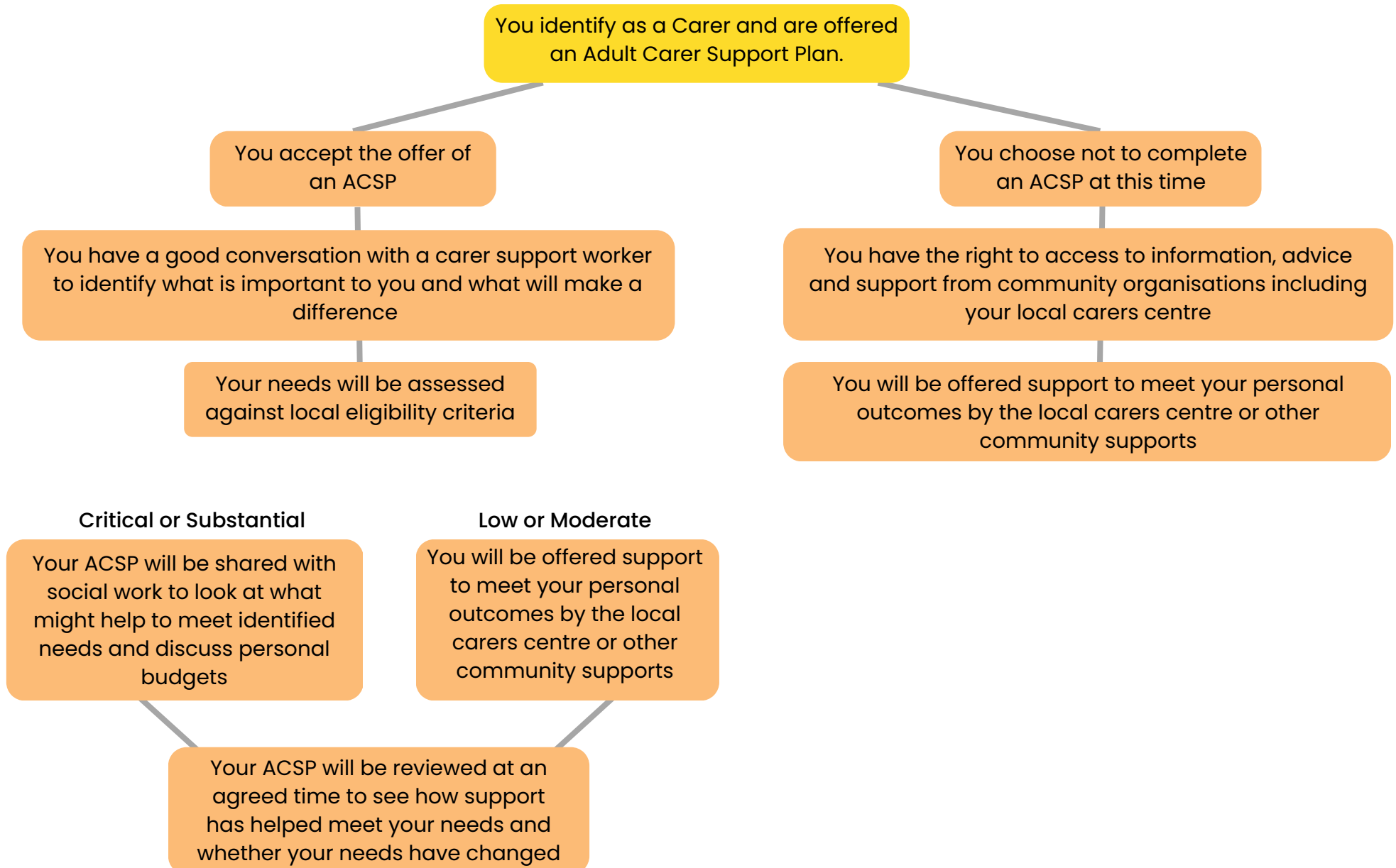


## 2.5 carers are supported to have a life outside of their caring role and can achieve a balance between caring and other aspects of their lives

From our consultation carers highlighted that in reality this balance is very hard to achieve as responsibilities can clash and with the lack of resources and adequate training to staff. Others said being able to achieve a balance can be very dependent on how the person is at that point in time.

Under the Carers (Scotland) Act 2016, carers have the right to their own Adult Carer Support Plan (ACSP), or Young Carer's Statement (YCS) which promotes their right to access advice, information and support. Below you can see a typical 'Carer pathway' for support.

# Carer Support Pathway



Support plans and statements help the individual to think about their situation and what support may make the caring role easier, they have been designed to allow carers to consider how caring is affecting each of the following areas of their life:

- Health and Wellbeing
- Relationships
- Life Balance
- Breaks from caring
- Living environment
- Employment and Training
- Finance
- Future planning

Helping carers to define what is important to them, and what will make a difference in their lives, will allow us to better signpost carers to the right information, advice and support to assist them. This may include supporting carers with the broader issues such as planning in advance for future needs, putting in place plans for when/if the cared for person's health needs may change and signposting carers to information about managing finances.

Carers will be able to access support to complete their plan through either their carer support centre, or with their social worker. These plans can be completed by carers themselves but feedback is that what really helps is the 'good conversation' that can support them to identify what will make a difference to them.

## **Assessing Eligibility for Additional Support**

While all carers will be able to access advice and information from Carer support organisations, some carers will be assessed as having additional "eligible needs" and the Local Authority have a duty to help meet those needs. Information held in the carer support plans and statements will be used to assess against Eligibility Criteria to help decide whether carers have eligible needs which the local authority has a duty to meet. In general support is moving away from looking at eligible need and instead considering impact on the individual more generally and personal outcomes. Significantly with the creation of the National Care Service, where there is an identified need for a break from caring the Local Authority will have a duty to meet that need whether they meet local eligibility criteria or not.

During the course of the consultation, our Carers told us that it was important for them to ensure that help was given earlier, before their situation became critical and that information provided at the right time does much to alleviate the stressors of the caring role. We have listened to the feedback and designed our criteria in such a way that recognises the importance of appropriate signposting at the lower levels of the criteria.

Carers needs and outcomes will be assessed against the following criteria:

- Low – no immediate impact from caring
- Moderate – some impact on your life from caring
- High/Substantial – a significant impact on your life from caring
- Critical – the caring role is seriously affecting many/all areas of your life

East Lothian's eligibility criteria for carer support can be viewed here [Carers Eligibility Criteria | East Lothian Council](#)

### **Choice and Control through Self Directed Support (SDS)**

Carers have told us that it is critical that any support that they receive is suited to their individual situation in order for it to be effective in reducing the negative impact that caring can have. Care that is ill-suited or does not fit around the carers daily life increases stress and can contribute to ill-health. With this in mind, those carers eligible for services will be able to design support that will best suit their own circumstances using the Self Directed Support options<sup>[10]</sup>.

Carers should be able to:

- Receive money to directly buy goods or services that will help them to meet their outcomes
- Direct the local authority to manage the funding available to them and choose how this is spent
- Have the local authority manage and purchase the support they require
- A mix of the above

It has been acknowledged that local authorities are at different points in implementing the principles of SDS and SDS guidance has been updated, making it clearer that SDS is for everyone in Scotland, including unpaid carers.

In East Lothian we have some carers accessing personal budgets through SDS, although the number of carers is currently low.

Some of the most common ways that carers choose to use their support includes:

- Support to attend college
- Support to access employment
- Leisure pursuits
- Short breaks
- Equipment

As more people are becoming familiar with SDS, we are finding that they are using the funding available to them in a variety of innovative ways. Under the new strategy we aim to increase the number of carers accessing personal budgets to support them to achieve a greater balance in their lives including accessing short breaks, peer support, replacement care or to maintain social relationships.

[10] A guide to the Self-directed Support (Scotland) Act 2013

## Timelines for completion of Adult Carer Support Plans/ Young Carer Statements

Many of our Adult Carer Support Plans are completed by Carers of East Lothian. With our updated form it will be clearly identified who will be responsible for meeting each outcome and when the carer would like the plan reviewed.

There may be different timescales for completion of individual ACSP's depending on which organisation is doing the plan and taking into account the urgency of needs for support and any fluctuation in those needs. We will focus on achieving the right outcomes for the carer rather than sticking rigidly to set timescales, we will keep carers informed throughout the assessment process.

Young Carers Statements are completed with support from East Lothian Councils Young Carers service.

As part of the Terminal Illness Regulations (2021), for carers of those diagnosed with a terminal illness there are specified timelines that workers must adhere to as follows:

- Carers should be offered an ACSP within 2 working days of a person being identified as a relevant carer
- Once the carer requests/accepts the offer of an ACSP the Local Authority must prepare one
- There are different timescales for steps in the process, to ensure that it is flexible enough to meet the needs of each carer.
- Step 1 – is a substantive conversation with the carer about urgent outcomes and needs for support. Authorities must offer this conversation with the carer within five working days of the carer accepting an offer or requesting an ACSP
- Step 2 – Completion of a light touch ACSP, based on the substantive conversation. If that conversation takes place within the five working days mentioned above then the authority must complete the ACSP within ten working days of the date when the carer originally requested or accepted the offer of an ACSP.

In East Lothian we also recognise that the carer can be diagnosed with a terminal illness and will apply the same timescales as above in this situation

## 2.6 Carers are respected as Equal Partners in care, included in planning and delivery of care, support and services locally. They are supported to have their voices and views heard

Feedback from our carer consultation highlighted the importance of carers feeling respected and recognised for their role, and that professionals listen to their views when planning services for the supported person, unfortunately this was not everyone's personal experience when coming into contact with services and individuals said that staff are still often not seeing the strain carers are under.

Feedback from Young Carers is that they can feel ignored at health appointments and that they can have difficulty picking up prescriptions for the person they care for. The United Nations Convention on the rights of the child<sup>[11]</sup> reported Young Carers often felt forgotten in decision making processes and were reluctant to engage with social work due to fear of child protection interventions and due to stigma and shame of being a Young Carer.

Although the Carers Act clearly states "Each health board must ensure that, before a cared-for person is discharged from hospital, it involves any carer of that person in the discharge." (section 28), The State of Caring survey 2022 responses showed 62% of carers were not involved in decisions about hospital discharge.

Ensuring all staff who come into contact with adult and young carers are trained to be more aware of carers, their needs, and to effectively support plan with them will lead to carers having the opportunity to consider the outcomes they want to achieve, protect important relationships in their lives and access more of the community supports available to them. It will also improve early identification of carers and allow support to be provided earlier. Cultural Competency training is also offered to Partnership staff to ensure that workers take into account the cultural needs of ethnic minority groups when completing assessments and planning care.

The Equal Partners in Care (EpiC) framework will be used to offer learning to the workforce that is consistent with their role and function. It also allow us to align our training with other skills and career development frameworks currently in use.

[11] UN convention on the rights of a child

NHS Education Scotland (NES) have developed a new website landing page and Turas Learn page for Caring for Unpaid Carers, facilitating easier identification and access to information, resources and learning can be found by following these links:

[Caring for unpaid carers | Turas | Learn \(nhs.scot\)](#)

[Caring for unpaid carers | NHS Education for Scotland](#)

All partnership staff will have access to this training but more work is needed to actively promote this to staff and increase awareness of carers throughout the workforce.

Carers of East Lothian provide 'Think Carer' sessions to teams within the Health and Social Care Partnership and third sector partners. This programme targets awareness raising to teams likely to come into regular contact with carers.

Training and information workshops for carers, on specific topics, will be available through Carers of East Lothian, for example; understanding dementia, power of attorney and Time for me. Access to training can also be supported through the support planning process.

### **Carers' voice**

Although we actively seek the views of carers, these are often heard through carers organisations or professionals and more consideration is required with regards to hearing and acting upon the lived experience of carers themselves. A programme for carers to make their voices and views stronger and clearer should be significantly enhanced. Carers should be empowered and confident to speak and engage at different levels with support and training provided to increase carers ability to articulate their views and engage with planners and decision makers in a meaningful way.



## **Equal Partners in Care**

Working together to achieve better  
outcomes for carers and young carers



## 2.7 Local Communities are supported to be carer friendly

We know the value of social relationships, and the strength and support that people derive from being connected to family and community. Without these connections carers can feel very isolated.

Groups such as day centres, church groups, libraries and third sector organisations are often a first port of call for people, including carers, when they realise they need additional help. By working to enhance community support, encouraging community contact and ensuring carers remain connected to local services via community groups we will positively impact the experience of carers, do much to increase their resilience and reduce feelings of social isolation.

Better signposting from community groups to support services will help improve carer identification and make it easier for carers to access support before they reach crisis point. Community organisations are a key resource in helping to provide the preventative support required during the early stages of caring. They are also vital in helping to achieve many of the other outcomes outlined above.

Increasing awareness within the local community will take time to embed but we will aim to support the work these organisations do by facilitating relationships between groups, highlighting their roles, providing information about their services and working to raise awareness of carers across communities.



# DELIVERING OUR VISION MONITORING AND EVALUATION

It is important that we can demonstrate that the strategy makes a positive difference for carers. The strategy is ambitious and sets out the support we want to see in place for carers of people in East Lothian. We hope that through the strategy we have set an optimistic tone in the face of real challenges and that while we cannot expect to fully deliver on all our aims within the term of this strategy we do aim to demonstrate progress towards them.

Work on the strategy is taken forward and reported on by the Carers Change Board and the Carers Change Board Reference Group which comprises a wide range of stakeholders, partners and agencies including Carers, their representatives, carers' organisations and representation among staff members in Adult Community Care, Acute Care, Children's services and the NHS.

Underpinning the strategy will be an annual Action Plan which will outline in more detail what actions will take place and by when. This will be taken forward across the Health and Social Care Partnership and in partnership with our Third Sector partners and community organisations.

The action plan will be monitored over the lifetime of the strategy to ensure we are accountable for doing what we have committed to do and what carers told us they wanted us to put in place. Progress on the Action Plan will be reported annually to the Strategic Planning Group and the Carers Voice panel. We will continue to seek feedback from carers and carer organisations through the Carers Strategic Group and through continued engagement.

The strategy will be reviewed within 3 years of the date of publication.



# APPENDIX 1

## CARER CONSULTATION AND FEEDBACK

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

- Planning for an ageing population summer consultation programme 2022
- Outside the box engagement events for adults with complex needs and their carers
- Carers of East Lothian (CoEL), breakdown of Carer Support
- CoEL use of microgrants
- CoEL Carers Voice Panel, ongoing feedback and dedicated strategy session (Nov '22)
- Feedback from Adult wellbeing.
- Monitoring of requests for support through Adult Carer Support Plan's
- Dementia friendly East Lothian events, QMU Sept 2022, meeting centre development sessions
- East Lothian Councils Carers Group
- Carers peer support events, Foxlake, Walking with alpacas
- Outcomes sessions Oct and Nov '22
- Integrated Impact Assessment initial session Nov '22
- Young Carers Service feedback and survey
- Young Carers Forum
- Young Carers festival 2022
- Outside the Box engagement on experience of those with dementia and their carers
- Care Inspectorate report into adult carers experience of social work and social care (Dec 2022)
- Further engagement required:
  - PASDA are holding engagement events to hear from Carers or adults with Autism
  - Engagement with parent carers
  - Engagement more specific to Carers of people with Mental health problems

The draft strategy was put on our consultation hub between 16thth Jan 2023 and 26th Feb 2023 and we consulted on it in libraries and other public spaces with 64 responses being made.

We asked:

- Do you agree with our aims?
- What is most important to you as a carer?
- Is there anything we have missed?

The feedback was collated and used in producing the final version of the strategy.

# WHAT OUR CARERS TOLD US: EMERGING THEMES

Although our focus is on the Carers needs, the reason they need support is because of the caring role and people continue to tell us that not being able to get the right support for the person they are caring for increases the impact on them.

## What Carers told us about support for the cared for person

- Carers struggle to get appropriate support for the Cared for Person which increases the impact on them
- A modern resource centre/community hub where everyone went initially....this would ensure that people had more opportunities to be with their friends, have a routine and structure. Most of the carers agreed that this would help the people they are caring for, be more active and engaged.
- Good, consistent service from paid carers
- improve and invest in care work, starting with pay and conditions, training and support, job satisfaction, and pay for additional hours worked.
- Good carers were not rewarded and that the conversation should be changed to shift the focus away from negative stories about carers and focus on good news stories about them. She said that bad publicity deters people from accepting care.
- Those living with families couldn't access social care and some had been on the waiting list for assessment/care packages for over a year, placing real strain on families
- People felt that paid carers were not given enough time to do the job and said there was a chronic lack of carers. Even with four visits a day, people weren't getting the social interaction they needed which was where the new befriending service would come in. Befrienders could provide that interaction and also give unpaid carers a break.
- I'm not sure what we will do if 4 visits become not enough. 15 minutes can sometimes make Mum more anxious/upset.
- I've heard it might be very difficult to get a social work assessment and feel like we will just be waiting to get funding for her to go into care because nothing else is available.

## What carers told us about Advice, information and support

- Carers want a 'one stop shop' for access to information and advice, this needs huge and continuing promotion
- Much more focus needed on identifying carers by services they come into contact with
- Information should be much more visible, for example on navigating services, benefits, SDS, employing carers etc
- A carers handbook would be great, with example scenarios and where to go for help, information about navigating services/ informing carers of their rights/ information about Adult Carer Support Plan.
- List of support organisations given at point of diagnosis
- More information earlier could prevent carer breakdown
- Being able to talk to other carers helps people feel they are not alone
- Carers would like to see an Advisory group for carers to help them plan for the future and learn from/be mentored by carers who have already been there and done it
- Emotional support
- Emotional and practical support/training on different issues, .e.g. how to avoid or de-escalate violent behaviour, cope with refusal to eat or take medication, wandering - especially at night.
- Provide more accessible information about what's available – support, activities, events etc
- More information on social media, radio, schools, places of worship, hospitals and local supermarkets.

## What carers told us about the impact of caring

- Carers felt forgotten during COVID when any normal community supports were closed and they were left 'to fend for themselves'
- Early intervention, More information and focus needed on prevention & early intervention rather than at crisis point
- He said one of the things he struggled with was his wife's incontinence – he said incontinence was rarely talked about even though it affected many people. It was very difficult to keep her dry for any length of time, which led to wet carpets, furniture and beds on a regular basis and was incredibly wearing.
- Carers need support in managing incontinence as soon as it happens as this has such a big impact
- Many people's finances were dealt with by their families but carers were worried about the rising cost of living. The need to install new fire alarms earlier in the year was an additional pressure on tight budgets.
- I started coming through to give respite to my sister who was in tears on the phone. I'm able to come more since I stopped working
- Young carers are worried about their mental health
- Young carers don't feel they get enough time to themselves
- Young carers education is negatively impacted

## What Carers told us about Breaks from caring

- Being able to get a break from caring
- CoEL – “We have more carers than ever seeking support to access social care and respite, in particular looking for support to set up sitter services and other replacement care as people struggle to access this locally.”
- Carers who are able to shout the loudest and who are more informed about systems are more likely to be able to access respite and that a more fair, transparent and equal approach needs to be implemented to ensure that carers who are quietly struggling are supported.
- Who is furthest from the table/ conversation and how are their needs for respite being identified?
- Getting respite at the right time and avoiding crises
- AFFORDABLE, REGULAR RESPITE.
- AFFORDABLE SITTING SERVICE. Respite is often dependent on a sitting service or access to a day centre. A sitting service pool of staff/volunteers is available who are trained and can also help with toileting and if required change incontinence pads.
- To ensure that Doctors, Social Workers, HR depts. can be a part of this too. A break is the last thing you think about as a carer.
- Planned respite would help, for example if I could say to my sister that every 3 months that Mum had agreed to go in to somewhere so she could have a break.
- We need to know services are quality so not worrying about the person the whole time you're away or what situation you might have to deal with when you get back
- Lack of services available to accommodate breaks from caring
- Need more flexible and specific services to allow carers of those with mental health problems to get a break
- Better out of hours services, opportunities to do things at evenings and weekends (for cared for person and carer)
- Budgets are very good but not meaningful if there aren't the services to spend them on
- I thought maybe Marie Curie did an overnight service which I would be really interested in
- I would like us to have a holiday or just a change of scene
- It would be good if the care hotel made provision for carers, so they could have a holiday too, while their loved one was being looked after by care staff.

## What Carers told us about Communication

- Better Communication – don't know what is happening in the area, having a more joined up approach would help
- Creating better links with professionals
- A named person to contact – can carers have a named professional within Health Services and within Social Care who understands their role as a carer and the details of their situation
- Improved information sharing so I don't have to tell my story over and over to different organisations
- Unpaid carers are frequently not respected or acknowledged by health and social care professionals. One member described feeling as though they were lied to
- The following personal account was shared: As soon as health services were aware that there was an unpaid carer in the family, the case was no longer treated as a crisis and the book was passed to the unpaid carer rather than their identification encouraging collaboration
- More openness with carers when there is a lack of resources (eg. Current respite limitations). Carers do not want to be patronised or treated as though they are stupid.

## What Carers told us about Community

- More Carer awareness is needed – for carers themselves, professionals and the wider community
- Being involved in normal community activities is just as important as 'Carers' services, more integration into the local community.
- People with dementia & unpaid carers/supporters don't want to feel confined to 'dementia only spaces'
- Safe spaces for people to use as a base or starting point as they access community based services
- More access to affordable leisure opportunities for Carers
- Unpaid carers in East Lothian want to be part of the process of developing more community-based activities and supports for people with complex needs
- Young carers would like schools and other local services to be aware of their needs
- Discussion around free access to leisure and exercise facilities for carers
- Access to therapy/ yoga/ mindfulness.
- Carer friendly venues/ badges in windows to show carer friendly spaces.
- More carer positive work places.



## What Carers told us: Young Carers

- To be able to spend quality time with their family
- Have regular breaks from caring, particularly during school holidays
- Have regular opportunities to meet up with friends and other young carers both locally and authority wide
- Have someone in school who can offer information and advise
- To have emotional support when needed
- For school staff, other professionals and their peers to have a better understanding of their needs.

## What Carers told us: Older Young Carers

- Help to make important decisions when moving on from school
- Help to transition from being a young carer to an adult carer
- Support with independent living and wellbeing
- Accessing and trusting help from agencies.

## What Carers told us about Planning for the future

- Planning for the future – every carer who attended the sessions (with Outside the box) expressed a worry for the future, More information/planning/advice for when the carers are no longer able or well enough to provide the care – needs to be in place long before crisis point
- Many unpaid carers are struggling with uncertainty about their future service and what it may look like and mean for the family.

## East Lothian Carer Support services

### Adult Carers: Carers of East Lothian

- Information, advice and emotional support
- Advice and support around welfare and benefits
- Specialist support and small grants to support breaks from caring
- Workshops, events and monthly support groups
- Surgeries on Power of Attorney, dementia, financial planning etc
- Counselling service
- Carers Voice Panel, strengthening carers' collective voice

### East Lothian Councils Young Carers Service

- Information for carers
- Support and time out from caring
- Provision of short respite breaks
- Young carers forum
- Support with practical, emotional and financial elements of caring
- Family Support



Information and advice for carers can also be accessed from a variety of other sources including:

- GP and NHS Services: Often a first port of call for many carers. Access to condition specific information and advice. Signposting to carer and other support services.
- Specialist health services: Access to specialist condition specific information and advice that can help carers understand and deal with difficult or challenging symptoms. Sign posting to carer and other support services
- Post Diagnostic Support Services: Provides condition specific information, advice and support for carers usually for a time limited period following diagnosis. Currently in place for Dementia and Autism. Sign posting to carer and other support services
- Social Work and Social Care Services: Can help carers identify the rights, entitlements and support available to them locally and can work with carers to review support arrangements as needed
- Social Security Scotland
- SDS Scotland
- Carer specific information on East Lothian Health and Social Care Partnership website
- National Condition Specific Organisations: Often able to provide condition specific information, advice and support for carers usually via web information and phone helplines. Limited knowledge or signposting to local services.
- Care Information Scotland:  
[Home | Care Information Scotland \(careinfoscotland.scot\)](https://www.careinfoscotland.scot)
- Web and helpline based national information about care services
- National Carer Support Services (eg Carers Scotland and Carers UK): Often able to provide carer specific information, advice and support usually via web information and phone helplines. Limited knowledge or signposting to local services.
- ALISS a national digital programme enabling people and professionals to find and share information on resources, services, groups, and support in their local communities and online:  
<https://www.aliss.org>
- VCEL East Lothian's Third Sector Interface offer support, learning and development opportunities for individuals and organisations. They also maintain a local directory of services found here:  
[Community Directory – Volunteer Centre East Lothian \(volunteereastlothian.org.uk\)](https://www.volunteereastlothian.org.uk)

## Other services for carers available in East Lothian

**East Lothian Access to a Better Life:** Online information and tools to manage your health and well-being and a resource if you care for others

**CWIC, East Lothian Mental Health Support:** CWIC Mental Health is a primary care service for people in East Lothian aged over 17 years and 9 months. We work closely with GP practices, Adult Mental Health services and local third sector services to help you get the right support for your needs

**Changes:** Provides support with mental health issues and anxiety, including counselling, stress control techniques, information on mindfulness, and other courses

**Dementia Friendly East Lothian (DfEL):** Providing information, advice and support to those with dementia and their families. DfEL are developing East Lothian's first Meeting Centre in Musselburgh, a social club for those with mild to moderate dementia and their Carers

**PASDA:** Supporting families of Autistic Adults

**Citizens Advice Bureau:** Provides support with employment rights, money and debt advice and support with housing issues. Access to information on welfare benefits for carers in conjunction with Carers or East Lothian

**Tenancy Support:** Workers provide advice around maintaining tenancies, practical support with housing applications

**Day Centres and adult resource centres:** Local day centres can offer support to the Cared for person and respite to Carers

### **Advocacy Services – EARS, CAPS, Partners in Advocacy:**

In East Lothian EARS provide advocacy for Older People, Physical Disabilities, Acquired Brain Injury and Stroke. CAPS cover substance use and mental health (adults), PIA cover Learning Disabilities and Autism.

Independent advocacy is not offered to carers at present

CoEL Carer Support Workers can help advocate on your behalf, support you to explore your options and rights in certain circumstances, to attend meetings and to have your thoughts and concerns heard. However, they are not a specialist independent advocacy service. For more information on independent advocacy see: <http://www.siaa.org.uk/>

**MELDAP:** Signposts carers supporting people with substance and alcohol misuse to advice and support

**East Lothian Young Carers Charity** – a local charity established in 2002 to provide support to Young carers aged 0 to 24 living in East Lothian, they provide information, support and breaks from caring to Young Carers and their families

**Lothian Centre for Inclusive Living (LCIL)** – Independent advice and support to understand your SDS options, information and one-to-one support to manage your own self-directed package

**Sight Scotland** – offer support to people in Edinburgh and the Lothians to learn or re-gain essential living skills following a diagnosis of sight loss

**Deaf Action** – A deaf led charity, offer a range of services in East Lothian designed to make life easier and more fulfilling for deaf and hard or hearing people

**Marie Curie** – help people living with any terminal illness, and their families, make the most of the time they have left

### National Policy Context

There have been a number of key strategies and acts that support Carers right and have increased the focus on carers, putting them front and centre in the drive to move support for the cared for person back into the community rather than in institutional care.

The **Independent Review of Adult Social Care** or **Feeley Review** was published in February 2021, one of the key recommendations was implementation of a new **National Care Service** that would allow Scottish Ministers to transfer Social Care responsibility from Local Authorities to a new national service. The National Care Service Bill was submitted to parliament in Jun 2022. Among the stated aims are to:

- Support people in their own homes or among family, friends and community wherever possible, with seamless transitions between services;
- Introduce rights to breaks for unpaid carers
- Focus on prevention and early intervention before people's needs escalate.

Feedback from Carers organisations highlighted many participants found it difficult to engage with the NCS consultation questions, as they felt that the proposals lacked detail. They also found it challenging to relate to how structural changes can deliver real progress, ultimately improving their lives and the lives of the people they care for. Many unpaid carers struggled to imagine what tangible difference setting up a National Care Service would make to their lives and preferred to focus on changes that need to happen at a local level in relation to direct service provision.

The Scottish Government strongly encourage Local Authorities to act now in terms of the 'right to a break' rather than waiting for the legal statute to come into place.



## Key Policy Drivers

Independent review of Adult Social Care (2021)

The National Care Service Bill (2022)

Carers (Scotland) Act 2016

The National Carers Strategy – Caring Together

Human Rights Act (1998)

The Equalities Act (2010)

United Nations Convention on the Rights of the Child

Getting it Right for Every Child (GIRFEC)

Additional Support for Learning (Scotland) Act 2016 - Keeling Schedule (2017)

Children and Young People (Scotland) Act 2014

Public Bodies (Joint Working) Act 2014

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

The introduction of the Carers (Scotland) Act 2016 is the most comprehensive piece of legislation in relation to carers yet. The update of the national Strategy was published in December 2022 and takes into account the continuing effect of the COVID-19 pandemic, the significant cost of living crisis, as well as the implications of the proposed National Care Service with its specific rights for carers. This strategy sets out the National approach to building a wider understanding and recognition of caring so that it is visible, understood and valued across society. Those who provide care to loved ones must be supported to do so in the most effective way and in a way that allows them to lead a balanced and varied life. The potential wellbeing, economic and social risks of caring need to be recognised and mitigated by formal and informal support in systems beyond health and social care. This will require systemic change over an extended period, as well as immediate action.

Building on Scotland's Reshaping Care for Older People: A Programme for Change 2011 – 2021, consultation closed in Jun 2022 on Scotland's Health and Social Care strategy for older people, acknowledging that health and social care needs to adapt now to the increasing ageing population and complex care needs that older people can have. It recognised that all involved have a role to play in providing support to older people, the government identified the need to shift resources to unpaid carers to allow older people to remain at home longer.

The Public Bodies (Joint Working) Act set out the framework for integrating Health and Social care services to ensure that provision of services remains consistent and sustainable in order to meet increasing demand.

Through Self-Directed Support (SDS) people now have more choice and control over how their services are delivered and the level at which they wish to be involved in managing their support. Under SDS, carers were, for the first time, able to access support for themselves in their own right. The Framework of Standards was published in March 2021 and aims to strengthen implementation of SDS and improve prevention and early intervention.

## Young carers

The agenda for children and young carers has likewise evolved and encourages a co-operative approach between all services involved in a child's care to create one plan through **Getting it Right for Every Child (GIRFEC)**, it has been used and tested across Scotland since 2006.

The **Additional Support for Learning (Scotland) Act** puts a duty on schools to identify, provide and review the ASN of their pupils, which can arise in the short or long term, as a result of the learning environment, family circumstances, health, wellbeing needs or a disability. We will help young carers secure the use of their own rights under additional support for learning legislation via the service My Rights, My Say.

In November 2017, the Scottish Government published updated anti-bullying guidance:

['Respect for All: The National Approach to Anti-bullying for Scotland's Children and Young People'](#)

Young carers are more likely to be bullied because of their caring role. The Bullying and Equalities Module on SEEMiS, the schools management information system, was updated to reflect the new approach. SEEMiS now allows schools to select 'young carer' as a perceived reason for bullying.

Education Maintenance Allowance (EMA) is available in Scotland to eligible people aged 16 to 19 who have reached school leaving age. Scottish Funding Council guidance [\[49\]](#) encourages local authorities and colleges to promote the uptake of EMA to young carers. The guidance also highlights that a degree of flexibility around attendance patterns should be afforded to young carers when administering EMA. To enable this to happen, young carers should highlight their caring responsibility on the EMA application form. A conversation to agree on a suitable flexible attendance pattern should take place with the school or college, and then written into the student's learning agreement.





## Equality diversity and Human Rights

The principles of Equality, Diversity and Human Rights are the basic rights for all carers. Carers and others should be aware of their rights under this legislation and no carer should be disadvantaged due to age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity, race; religion or belief; or sex or sexual orientation, in line with the Equality Act 2010

### Local Policy Context

In implementing the Carers (Scotland) Act 2016, East Lothian Health and Social Care Partnership have been tasked by the East Lothian Integration Joint Board to ensure that our partners work together to assess unpaid carers needs, deliver a range of support services to reduce the impact of the caring role and ensure that all unpaid carers receive an assessment of their needs, if they so wish.

As part of our ongoing work, a range of other strategies are under development within East Lothian and will incorporate planning for Dementia, Mental Health, Physical Disabilities, Palliative Care, Housing and more. There will be common themes among many of these and interlinking goals. Although the Carers Strategy has been produced to outline the overall support available and the outcomes we wish to achieve for carers, it is anticipated that each strategy will consider the needs of carers within their own right and outline any specialist support to carers required.

### Who are carers and why do they need support?

Carers play a vital role in the provision of care. Carers UK estimate the value of unpaid care in Scotland at 10.8 billion per year. The people they care for can be affected by disability, physical and mental ill health, frailty, substance misuse and other conditions or a combination of the above.

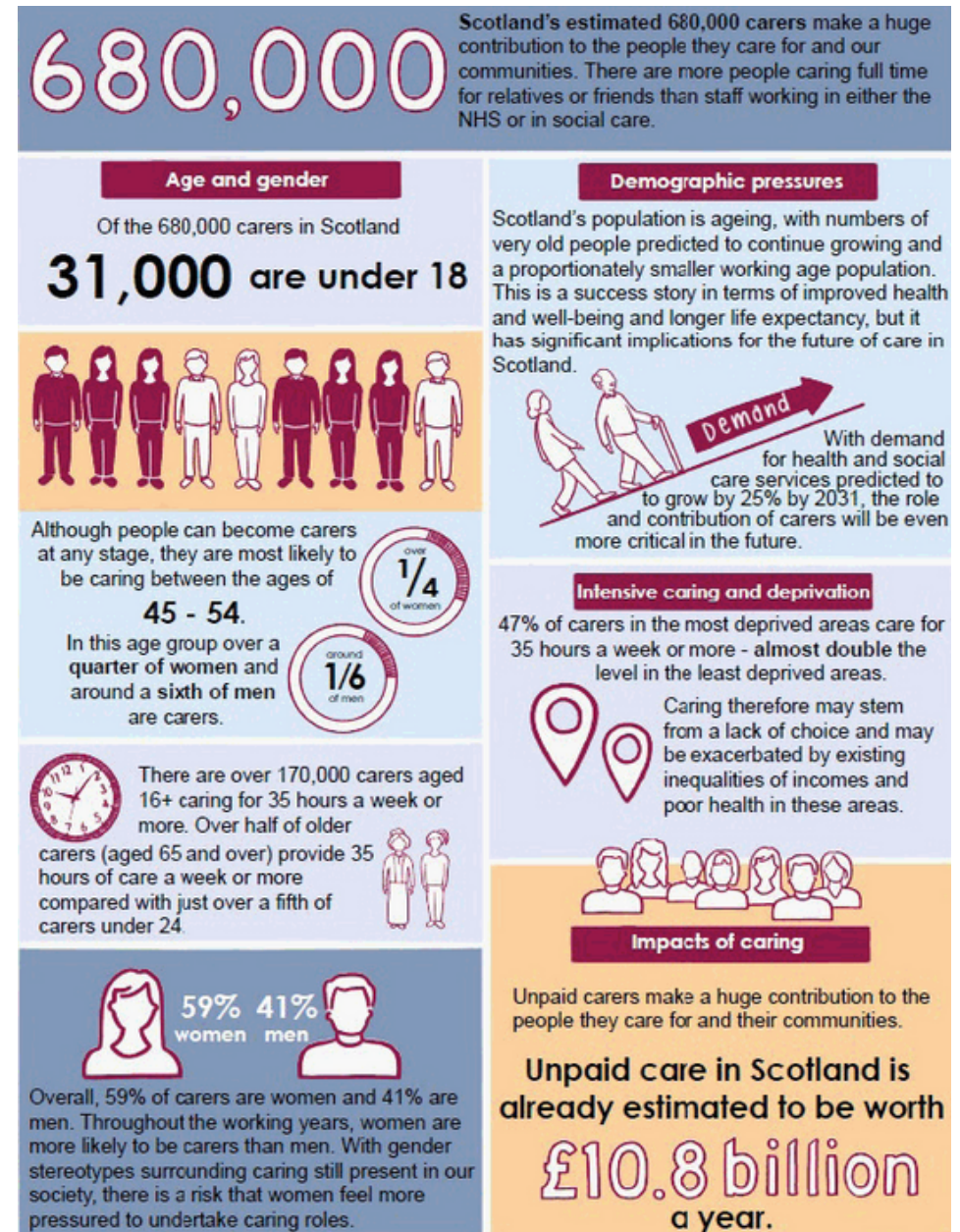


Diagram from: <https://www.gov.scot/publications/carers-strategic-policy-statement-draft-consultation/>



# EAST LOTHIAN'S CARERS WHO ARE THEY?

Estimates of the carer population across Scotland vary with the latest estimate from Scottish government lower than previous estimates at 680,000. We estimate there are around 20,000 carers in East Lothian (based in the 1 in 5 general population estimate).

East Lothian by numbers indicates that the % of population within East Lothian, providing regular help for any sick, disabled or frail person has remained consistent, but by sex, has decreased in males from 9-7% and increased in females from 18-22% (over 2012-'15 to 2016-'19)

Local Census data from the 2021 census will be published from 2023 onwards but figures from the 2011 Census tell us

- That the greatest number of carers are aged between 50 and 64
- In East Lothian it is people over the age of 65 who provide the greatest number of hours of care
- Those providing more than 35 hours of care per week were 20% less likely to be in employment than non-carers.

Across Scotland, the most common effect of caring on an adult carer's employment was to either to reduce their hours or to leave work altogether in order for them to cope with the demands of caring.

While we would not expect to identify all of the carers within East Lothian, we would aim to ensure that those carers who feel they would benefit from information, advice and support were known to either ourselves or our Local Carer Organisations.

The table below shows Carers of East Lothian's statistics around who is accessing support. We know there are many more Carers in East Lothian who are not accessing support, or are supported through other networks, but these figures give us an indication of the potential population of who our carers are locally.

| <b>Carers of East Lothian analysis of support 2022</b> | <b>Q1 (%)</b> | <b>Q2(%)</b> |
|--|---------------|--------------|
| <b>By reason of accessing support</b>                  |               |              |
| Carer wellbeing  | 41            | 48           |
| Finance/benefits                                       | 27            | 26           |
| Social Care  | 13            | 11           |
| <b>By gender</b>                                       |               |              |
| Female   | 79            | 78           |
| Male   | 21            | 22           |
| <b>By age</b>  |               |              |
| 24 and under   | 1             | 1            |
| 25 - 34  | 6             | 7            |
| 35 - 49  | 22            | 23           |
| 50 - 64  | 36            | 37           |
| 65 - 75  | 16            | 16           |
| 75 - 84  | 16            | 14           |
| 85+  | 3             | 3            |
| <b>By service user group</b>                           |               |              |
| Dementia   | 28            | 27           |
| Physical disabilities/neuro                            | 33            | 32           |
| Mental Health  | 11            | 11           |
| Child (under 16)                                       | 14            | 14           |
| Frail/Older  | 6             | 6            |

East Lothian's population Demographics (from East Lothian by numbers, 2016)

- East Lothian's population has increased 20% in the 20 years from 2020 and this trend is predicted to continue, increasing by a further 12.8% between 2018 and 2043, therefore reaching 121,743 by 2043
- East Lothian life expectancy is estimated (2018-20) at 82.9 for females and 79.3 for males and expected to increase by 2.4% for males and 1.8% for females in the period until 2042/43. Significantly the estimates of healthy life expectation are 65.3 years for females and 63.7 for males meaning people may need more support in these later years
- Compared to the rest of Scotland East Lothian has a larger percentage of youth (10-15 years) and older adult to elderly (41-90+)
- Between 2016 and 2020 the percentage of people within East Lothian living in the most deprived 20% has increased from 3.7 to 5.2% and in the most deprived 20-40% from 26.1 to 29.8%
- Estimates on ethnic minorities residing in the county are difficult to establish, data from the 2021 census is due in 2023 but we estimate the Asian population to be the largest ethnic minority group (1%) in our area. The Polish community has also increased substantially in the area in recent years. Consideration must be given to the individual needs of these communities when delivering carer services.

## Young Carers in East Lothian

The National Carers Strategy estimates there are 28,000 young carers in Scotland, under the age of 18.

In East Lothian, the 2021/22 SEE Survey which is completed annually by pupils in P6, S2 and S4, 26% of pupils stated that they “regularly help to take care of someone...who is physically or mentally ill or has problems with drugs and/or alcohol. The table below illustrates the potential number of young carers attending East Lothian schools based on the various estimates. However, we must be mindful that we also have children and young people attending private schools and young carers under 18yrs who no longer attend school.

|                              | East Lothian 2022 | East Lothian 2025<br>(based on current annual increase of 3%)* |
|------------------------------|-------------------|--|
| <b>ELC School pupil roll</b> | <b>15092</b>      | <b>16,491</b>  |
| 4%                           | 604               | 660  |
| 10%                          | 1,509             | 1,649  |
| 26%                          | 3,923             | 4,287  |

As of October 2022 ELC has formally registered 173 Young Carers. We also are aware of and correspond with 76 young carers (based on information provided by the charity East Lothian Young Carers when their contract ended in June 2021). Therefore, a total of 249 Young Carers are known to us.

The following table shows the number of Young Carers living in each of the 6 local areas compared with figures from previous strategy document.

| Local Area    | Known YC 2017 | Known YC 2022 | Registered YC 2022 |
|---------------|---------------|---------------|--------------------|
| Musselburgh   | 28            | 71            | 50                 |
| Tranent       | 28            | 52            | 32                 |
| Prestonpans   | 27            | 32            | 19                 |
| Haddington    | 12            | 25            | 16                 |
| North Berwick | 12            | 27            | 16                 |
| Dunbar        | 11            | 42            | 40                 |
| <b>Total</b>  | <b>118</b>    | <b>249</b>    | <b>173</b>         |

The majority of young carers known to services continue to reside in areas the west of the county. The significant increase in registration in the Dunbar Area is likely due to the fact that the local schools were among the first to accept offers of awareness raising sessions from the Young Carers Service.

The Young Carers Service reports a more even spread of young carers across all age groups rather than the previous reported concentration of 5-11year olds (from ELYC) and 15/16 year olds (from Bridges Project). There continue to be a higher proportion female young carers 57% to male 40% with 3% now identifying as non-binary. It is worth also noting that:

*47% report caring for a parent, 44% care for a sibling and 7% care for a grandparent, 27% are the main carer within the household.*

### **Assessment of unmet demand**

We have estimated the number of adult carers in East Lothian at around 20,000 and Young Carers at 600 (based on 4% figure above)

Considering Carers of East Lothian are in contact with around 5,000 and our Young Carers service around 200 that leaves a very significant number of Carers where we are not aware if their needs are being met through other community supports or whether they have significant unmet need.

We know that there are many excellent community support services in East Lothian and that Carers will usually seek support from friends and family before turning to services.

We would presume that the answer is a mixture of both but this highlights significant work still to be done in terms of identifying and supporting carers, especially at an earlier stage.

We know that we are not meeting carers needs in all areas, for example we still have a significant problem in accessing residential respite for older people within East Lothian, people can access budgets but services are simply not available meaning considerable unmet need in this area.

We will continue to identify where needs are not being met and use this information along with carers input to inform our planning.

# CONCLUSION

This strategy aims to build on the foundations we already have in place and it places more emphasis on building relationships with groups who have currently have less representation. This will help us to better address inconsistencies and help deliver our services to those who need it. It will also enable us to better understand the needs of a much wider constituency and produce robust evidence for future strategies, policies and services. It is very much focused on providing frameworks for working with people and developing partnerships that will work with us to improve health and wellbeing in East Lothian.



East Lothian Integration Board  
&  
East Lothian Health and Social  
Care Partnership

John Muir House  
Brewery Park  
Haddington, EH41 3HA  
01875 824 309  
[elhscp@eastlothian.gov.uk](mailto:elhscp@eastlothian.gov.uk)  
[www.eastlothian.gov.uk/elhscp](http://www.eastlothian.gov.uk/elhscp)