Midlothian Unpaid Carer Strategy 2025-28 Consultation Activity

Introduction

As we developed our Unpaid Carer Strategy, we listened to local unpaid carers about the roles they undertake and their experience as carers. This helped us to understand what they can contribute, the impact of caring on them, the support they need to continue, and how we can help support them to have a life of their own alongside their caring role.

We also listened to staff in services delivered by the Health and Social Care Partnership and our commissioned partners.

We researched and listened to a range of carer experiences, including being identified as a carer, accessing support and feeling supported, the impact on finances and employment, carer wellbeing and having a break from caring, and being involved in decisions about their own care and plans for the person they care for.

Who we asked

Carers Action Midlothian meeting

In person (Oct 2025)

5 Carers and **2** members of staff from VOCAL

Public Survey

Online (Nov/Dec 2025)

34 people commented on our draft strategic priorities

Staff workshop

In person (May 2025)

26 members of staff from

- Third sector (Alzheimer Scotland, British Red Cross, Midlothian Community Action, VOCAL)
- Midlothian Council (Children's Services and Communities and Lifelong Learning)
- Midlothian Health and Social Care Partnership

Existing data

Service reporting, inspections and **Health and Care Experience Surveys**, **Midlothian Carers Survey 2023.**

Main findings

Rights & Identification

✓ What is working well

- Carers and services sharing information

✕ What isn't working

- Carers not identified early
- No central information point
- Low awareness of rights
- Barriers like guilt or shame

Economic Wellbeing

✓ What is working well

- Support to maximise income
- Grants
- Supportive employers

✕ What isn't working

- Accessing benefits advice
- Lack of day/holiday support
- Low awareness of rights
- Support to plan for the future.

Planning Care

✓ What is working well

- Peer support

✕ What isn't working

- Having to be an advocate or care coordinator is hard
- Carers are signposted without support
- Service criteria can be hard to understand

Advice & Support

✓ What is working well

- Support at the right time
- Adult Carer Support Plans

✕ What isn't working

- Limited services to support the person they care for
- Lack of clear information
- Unclear how to get support

Health & Wellbeing

✓ What is working well

- Emotional and wellbeing support
- Flexible planned breaks

✕ What isn't working

- Lack of respite
- Carers too stressed to navigate supports
- Limited carer-specific resources

1. Carers' rights and identification

What works:

- ✓ Organisations working together.
- ✓ Sharing information by peers and professionals.

What doesn't work:

- x Identification and support aren't offered early enough – aften carers are signposted to support, not referred, which can result in it not happening as carers don't have time or may struggle to prioritise their own needs.
- x Lack of central point of information and limited methods of sharing information; carers need information in more formats.
- x Lack of awareness of carers rights.
- x Carers can experience barriers to identifying as a carer: shame, guilt.

What good looks like:

- Caring widely recognised.
- Information is easy to find and is accessible.
- Early identification is part of GP, school and hospital processes.

"It was quite scary and difficult at first. My work were not helpful. It was quite stressful too trying to work and bring up my daughter and then care for my mum too."

"A vaccination nurse used the term (carer). I was surprised! It was quite a revelation."

"I think that it made me more compassionate towards myself, before that I just thought I was a rubbish parent struggling."

2. Information, Advice & Support

What works:

- ✓ Having access to the right support at the right time – from both peers and specialists.
- ✓ Production of good quality Adult Carer Support Plans – can alert services to the needs of carers.

What doesn't work:

- x Lack of availability of services for cared-for person impacts on carers.
- x Lack of specialist support e.g. transition to adult services; employing a Personal Assistant.
- x Lack of accessible information people can explore themselves, e.g. having information in a range of formats.
- x Carers are expected to be proactive in finding information, advice and support.
- x Hard to find a point of contact to access support.
- x Lack of understanding of support plans and what they are used for.

What good looks like:

- An accessible, central "one-stop shop" for information and support.
- Respite and replacement care for the cared for person.

"Accessing support in my local village has made it possible for me to receive support . . . being able to talk to a carer support worker has been life changing."

"I honestly don't know much about support or services available to me."

"I often feel alone as a carer don't know if I'm right about anything I am doing."

3. Carer Economic Wellbeing

What works:

- ✓ Having access to a network of community services supporting income maximisation and advance planning, e.g. Power of Attorney (POA); care planning; guardianship.
- ✓ Access to funds and grants to support hardship to cost of caring, and to access breaks from caring.
- ✓ Work and training with employers to highlight carer rights, and to keep carers in work.

What doesn't work:

- x Difficulties accessing benefits and financial planning advice.
- x Lack of replacement care including specialist support/care during the day and holidays to enable work.
- x Lack of awareness of employment rights and support from employers.
- x Lack of information about support available.
- x Lack of support for planning for future – e.g. changing caring role, long-term care fees, reducing work, reduced pensions.

What good looks like:

- Carers can easily connect to supports and access up to date, individualised information on benefits and funds.
- Funded support enables carers to work out of school hours and during school holidays.

"I feel like I am living from month to month, and I feel as long as my daughter is okay then I will make do."

"I feel financially vulnerable and worry daily about how to pay bills. I rely on social security benefits as I cannot take a job, have no income or savings."

"It is just so hard, and I feel very alone…I worry about my own future financially and emotionally."

4. Supporting Health & Wellbeing (incl. Breaks)

What works:

- ✓ Carers having access to different types of support – enhanced opportunities for emotional support and wellbeing.
- ✓ Carers having access to flexible, planned breaks from caring.

What doesn't work:

- X Lack of or limited support for cared-for person, including access to regular and flexible respite care.
- X Carers can feel too stressed to find out about taking a break or take on advice.

What good looks like:

- Carers having opportunities to connect to peers and professionals.
- Meaningful breaks available to carers.
- Carers accessing support to maintain their own health.

"My caring role has impacted my health significantly to where it affects me every day."

"Even when you're doing your 'own thing' your caring role is always in your mind."

"I feel too guilty to take a break away without the person I care for."

5. Carer Involvement in Care Planning

What works:

- ✓ Listening to what carers want through surveys, focus groups, planning meetings and groups.
- ✓ Including carers when creating plans.

What doesn't:

- x Carers can feel overloaded when taking on the role as advocate for the people they care for.
- x Carers need more direct referral and support to access services instead of signposting to services.
- x Lack of information about criteria and services to help prepare for the assessment process and guidance to help manage expectations.
- x Carers having a care coordinating role which is challenging when services are taken away and the carer has become the care manager, on top of their caring role. Carers can be passed from service to service in trying to access support for the person they care for, which is hard.

What good looks like:

- Carers are involved in discussions, share information and participate in decision making. Carers are listened to and treated as experts in their own life.
- Carers are proactively offered outcomes focussed plans which are not crisis driven.
- Carers are represented within governance and strategic planning arenas.
- Carers are involved in discussions and decisions around all significant transition points.

"Worry about what will happen to person I care for when I die or am no longer able to care for them causes anxiety."

"Uncertainty for the future (what future support will the person I care for have?) causes huge anxiety and stress."

"I seem to be constantly worried about the unknown future."

How we used the consultation to shape the strategy

Across all engagement, carers and staff expressed strong support for the draft priorities **and a clear desire for change in how services connect, communicate, and respond**.
The most urgent needs are:

1. **A single point of contact and better navigation support**

   – Aligning with the mission of the Midlothian IJB Strategic Plan, the Unpaid Carers Strategy highlights and supports that carers will be able to access the right support, at the right time, in the right place for them.

2. **Early and proactive identification**

   – A priority identified for the Carers Strategy is 'Carer Rights and Identification', with an aim of supporting 'Carers are identified early in their caring role' and targeting outcomes of Carers reporting feeling more informed, experiencing improved health and wellbeing, and feeling more confident in their caring role.

3. **Accessible, consistent information**

   – A priority identified for the Carers Strategy is 'Providing information, advice and support', including actions to ensure that the information and advice service is provided in a flexible, person-centred way through a variety of methods, locations and formats.

4. **Financial support and employment flexibility**

   – A priority identified for the Carers Strategy is 'Providing Carer economic wellbeing' maximising employability opportunities to support carers to return to work, and work with Midlothian employers and partner agencies to identify and support carers in the workplace.

5. **Replacement care to make breaks possible**

- A priority identified for the Carers Strategy is 'Supporting health and wellbeing (including breaks from caring)'. Actions supporting this priority include developing a range of services to facilitate breaks from caring including: formal, personalised respite support; easy access breaks through short break funds; and community-based supports for carers.

6. **Meaningful involvement at all transition points**

– A priority identified for the Carers Strategy is 'Supporting Carer involvement in care planning', aiming to ensure positive involvement of carers in support and care planning, and at transitions points or events.