

Unpaid Carers

Strategic Plan Engagement 2021

The Midlothian Health and Social Care Partnership is responsible for services that help people live well and get support when they need it. This includes all community health and social care services for adults in Midlothian and some acute hospital-based services.

To help us in developing our new strategic plan we spoke with stakeholders, volunteers and people with lived experiences about their views on the services we deliver and what could be improved.

We would like to thank the **152 people** (including 62 staff) who took we spoke with, and the community organisations and service providers we met with including: Carers Action Midlothian; VOCAL Midlothian; and, Alzheimer Scotland. VOCAL Midlothian also carried out a survey with local carers in Sept – Oct 2021. 392 responses were received. Due to the shared themes, we've included some feedback.

We spoke to people for 6 weeks from August - September 2020.

93 Questionnaires completed

- Carers
- People who are cared for
- Staff - Third Sector, MHSCP NHS, MHSCP Council staff

12 Focus groups completed (42 people)

- Carers
- Staff - Third Sector, MHSCP NHS, MHSCP Council staff

17 x 1:1 Interviews

- Carers
- Staff - Third Sector, MHSCP NHS, MHSCP Council staff

Prevention

Carer Identification

Early identification and connection to support, information and advice is of significant value to carers managing and being able to continue in their caring role for as long as they wish to do so.

Key Points

Active referrals and signposting which involve people make a difference

Carers spoke of trusting word of mouth referrals. A significant number of carers described word of mouth as having motivated them to make contact with services. Carers and staff thought carers were more likely to connect with services if there was a 'warm' hand over.



There was a worry from staff that if help is not offered proactively carers can go unsupported until a crisis.

'We need to reach out not expect people to reach in'

'Carers often come along for support at a critical stage [...] If at a calm time, time can be taken, plans made, at a crisis then this is different.'

Once you're in, you're in

A lot of people mentioned that once people are involved with services (third sector & public sector) they were likely to identify themselves as carers and be linked in to other support.



'Once you start with one support, this starts a snowball'

'It is not always easy to find out where to go for support; however, once contact is made with the support/s these are very effective'

A central starting point helps

People felt that a centralised point of initial information and support was helpful. People also spoke of good cross-referring happening between local statutory and third sector agencies.

'All organisations and what they can help with in one leaflet, found this useful'

'[name of organisation] as a centralised point of support is really useful'



VOCAL

77% of respondents who have engaged with VOCAL say that this has made a difference to their experience as a carer.

'Before speaking with VOCAL I didn't even know I was a carer even though I had been for a few years.'

'I know what is out there to support me if I want to access it.'

'They provided me with information I didn't know was available.'

Key Points

Access to help is not visible enough

A strong recurrent theme was missed opportunities to 'identify' carers and tell them about possible support when the person cared for is in hospital and through GP surgeries.



People spoke of the need to increase staff training. Workload and time pressures were barriers. More visible, consistent and positive public awareness raising was also cited multiple times.

'I attended an appointment where I broke down [...] the person asked if I was ok, I wasn't but nothing was explored.

'The majority of carers are out there on their own, they don't necessarily have a clue who to go to or to get in contact with'

It's not always easy to recognise when you become a carer



Many people felt that there is a high number of carers who don't recognise they are carers.

'It's hard to know *when* you become a carer.'

'It's difficult to adjust to being considered something other than just a husband or wife'

Stigma, guilt and value

In the focus groups stigma was discussed most strongly by parent carers and carers of someone with a substance misuse issue. Many people felt that more needs to be done to convey that identifying as a carer is a positive thing and can help.



People mentioned: having Carer ID as being positive, wanting better financial recognition/support and a need for consistent positive public awareness raising campaigns.

'That would make a difference in my opinion, to be valued for the contributions and sacrifices we make in our own lives to enable us to care.'

Future plans – see crisis section.

Support & Treatment

Improve access to Support, Information & Advice

Key Points

1:1 emotional support is essential

When speaking about feeling valued and listened to, most carers referred to third sector organisations. They spoke about 1:1 carer support and the difference it makes knowing they can pick up the phone or email, not feel judged and be guided through support. Carers felt that third sector organisations had the time to do this and were trusted to do this. Consistency of support was spoken about positively. Some carers referenced working with the same person from the beginning or for a long time.

Counselling support was also mentioned by many as an important 1:1 resource



'I know there is always someone on the end of the phone that can I can talk to'
'Professionals don't always make me feel good, for this I call [name of organisation]'
'It's nice to get away, but the guilt of going on a break, talking made a difference'
'It meant we were talking about me'.

VOCAL

'If I didn't have VOCAL to get help I would feel totally lost in my caring role.'

'Helped with acknowledging my feelings.'

'Knowing there is an organisation there to help with practical issues and emotional support who know how you feel was very important. I didn't feel so alone.'

Peer support is valuable

A lot of carers spoke about the power of having connections with people in similar situations – in peer Support groups and peer support which also offers support for the cared for person. Ways to build on peer support mentioned include: making it easier for staff to introduce carers to each other, opportunities for peer groups to help resolve wider issues e.g. replacement care, more co-located peer support (for the carer and cared for) and opportunities to mix and meet.



'Speaking to other carers and hearing how they manage makes you feel less alone and more able to keep going.'

'Being with people who know what you're going through without you having to explain'

Key Points

Access to third sector support is good

People spoke positively about timely access to support from third sector organisations. Carers and staff liked the fact that carers can self-refer to these services and that once you had contacted them the process was 'easy'.



'[name of organisation] and [name of organisation] were both easy to contact and responded quickly.'

VOCAL

53 respondents cited that the impact arose through VOCAL's information or Advice (service). 'The dementia classes were so useful in helping me understand.'

Consistent and informed health and social care support

A lot of carers said having consistent Health and Social Care workers would make a big difference. There was a contrast between the described rapport and trust with third sector organisation where people often mentioned having a consistent worker and time to be listened to, and that with public sector services where allocations were often described as short-term and multiple.

Carers described the value of someone knowing their situation, not having to repeat their story and knowing you can contact someone who will listen/proactively check in with you; alongside the importance of being treated as an equal.



The need for good information sharing systems between agencies or a centralised system was mentioned as part of this as was ensuring all staff are trained in good conversations.

'Hardest thing is starting a new relationship with a professional, it initiates all the emotion again'

'Unpaid carers are made to repeat their story multiple times.'

'You need to speak to someone who knows your circumstances and who will then call you every couple of months, someone who just knows your story and knows your situation.'

'Professionals need to work around barriers such as data protection, use common sense and do what makes a difference'.

Health and wellbeing support is not always at the right time or place

Several carers spoke about timing being a barrier to making use of health and wellbeing supports (training and wellbeing events or sessions).



It was felt that things should be local, with options both in the East and West of Midlothian. Penicuik was mentioned as an area where it is believed there is comparatively less support.

There was mixed feedback about digital versus physical support.

'A lot of things are during the day and I can't make this with work'

'Locality support would help [...] support in a community setting is important'

'Online support has been amazing but online can't replace face to face'

Improve Carer Health & Wellbeing

Key Points

Being able to take a break from caring is essential

A break from caring was one of the most talked about ways to help carers continue caring - both overnight breaks and smaller regular breaks as well as breaks and companionship provided by befriender services. Carers described different ways of coping, e.g. emotional support including 1:1 carer support and counselling to overcome barriers such as guilt.

Breaks which involved the cared for person were mentioned by a few people as positive.

‘being able to be out socialising with others and being ‘me’ not just a carer’



‘I don’t want [the person I care for] to go into a home for a week, I just want a day to myself once in a while.’

‘I don’t always like it, I don’t think my wife always likes it, but I appreciate the break and know it’s part of keeping her living at home with me.’

VOCAL

25 respondents identified benefits accrued through time away from caring (either by going away or by using Wee Breaks funding more flexibly during Covid when this was not possible).

‘Being able to access short breaks to help me recharge.’

‘The support I received to achieve the break was positive and made a big difference to the person I cared for.’

Key Points

Replacement care is not accessible

Replacement care was a barrier to having a break from caring. Sitter services and residential respite were mentioned multiple times as services which make a big difference but which can be very hard to get, even in a crisis.

Carers spoke about the precariousness of support and several carers described lived experience of feeling pushed to breaking point.

Day to day support for the cared for person was described as lacking and/or with long waiting times. There were a few good examples of collaborative working mentioned e.g. third sector agencies working with statutory agencies to provide minor equipment and Adult Carer Support Plans.



‘While breaks are good and can make a big difference, they don’t fix problems in daily life. It is crucial that we help people get the basics right at home.’

‘Being able to do my running, walking, mindfulness and arranging days out, in order to do that you need support.’

‘I have not been able to use the breaks as in order for me to go anywhere or do anything, as I need someone to take care of my Mother’

‘I need to make a big jigsaw of things [care]. It only takes one part of that to tumble down and I cannot do anything’

‘What would make a difference? Volunteers who could help in giving me free time even if only 2hrs per week’.

Self-directed support was often described as not working; the money was there but the resources needed to achieve the outcomes were not (most mentioned: packages of care, sitter services, respite).



‘We’re giving them the money which they can’t spend. There are no resources even with all the flexibility of SDS’

Improve financial support & economic wellbeing

Key Points

People need more help to get money they are entitled to.

The impact of financial stress on a carer’s health and wellbeing was mentioned multiple times. Financial hardship was also cited as a barrier to being able to plan ahead.



A need for more support with finances was highlighted, including help to apply for benefits and maximise income and finance ‘checks’.

‘Carers save the economy a fortune but financially are often left with very little.’

‘I didn’t know about Attendance Allowance or how to apply’

Key Points

Workplace support should to be better

There were positive examples e.g. being supported to approach an employer to address issues but most comments focused on the need for work to be done with local businesses.

'It adds such a burden when you're not sure if your employer understands your situation or supports you.'



VOCAL

37 respondents identified positive financial impacts, including securing Power of Attorney and help with applying for support.

'I was not even aware we were entitled to the benefits that VOCAL helped me apply for.'

'I am unaware of the benefits system and they explained it to me.'

Support in a Crisis

Planning ahead

Emergency and future planning can be areas of concern from carers, and we know that carers benefit from the opportunity to explore these issues and make plans – even if they are never used.

Key Points



Legal support makes a difference

‘Having POA in place provides a small piece of mind’

‘Carers ... feel better once legal powers and processes are explained ... Knowledge is power.’

Emergency planning helps

Carers and staff who had completed an emergency plan viewed them as positive. It was said to give peace of mind and has helped some people have conversations they may not have otherwise had with their family.



There was a significant number of people who had not heard of emergency plans.

‘Planning for emergencies terrified me, keeps me up at night time [...] but it’s important’

‘These [emergency plans] should be offered to carers as a matter of course.’

VOCAL

‘Without them I would not have a care plan in place for my mother.’

A plan and access to resource should be offered from day one

A number of those consulted want to see space and time given at the beginning of someone’s caring journey to plan better. They want to know there is someone they can come back to and they want to have a consistent person to follow them in their caring journey. Anticipatory Care Planning could be a part of this.



There was mixed feedback about Adult Carer Support Plans. A significant number of people consulted had, had one. One of the worries raised was that this was not reviewed and did not necessarily lead to any action or change.

Several carers mentioned wanting to have more access to condition specific training.

‘It’s a confusing and chaotic journey’ someone needs to sit down with you at the beginning [...] explain things to you, tell you what help is available. They then need to check in with you as time goes by to see where things are at and guide you.’

‘I feel the Carer Support Plan, while good in concept, in practice is a useless exercise. It is created but nothing is acted upon as a result.’

‘Information can be overwhelming at first maybe it could be done in stages’