

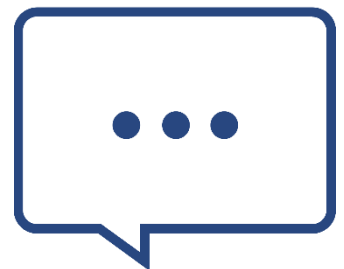


**Midlothian**  
**Health & Social Care**  
**Partnership**

# Carers Consultation

August – Sept 2020

Report author Becky Hilton, data analysis Caroline King



The Midlothian Health and Social Care Partnership (MHSCP) 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.

We recommissioned community services for unpaid carers and in 2020 consulted with staff, volunteers and people with lived experiences about their views on the services we deliver and their thoughts about what could be improved.

We would like to thank the 152 people (including 62 staff) who took part and the community organisations and service providers who helped us reach people.

The questionnaires were available, and mostly completed, online. Hard copies were sent out with support from third sector agencies. Virtual focus groups and 1:1 interviews (virtual and telephone) were set up across Midlothian. Due to Covid-19 risks we did not hold face to face engagement. The consultation lasted for a total of 6 weeks from Aug – Sep 2020.

## **93 Questionnaires completed** - online via Survey Monkey & paper questionnaires

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

## **12 Focus Groups** (42 people)

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

## **17 x1:1 Interviews**

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

# Carer Identification

## **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.

**'Neighbours, friends, colleagues, when people share information informally it's powerful.'**

**'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 generally felt that having a centralised point of initial information and support was helpful, it made things simpler. 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'**

---

## **Access to help is not visible enough**

A significant number of people did not think there was enough information available/visible.

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 and for everyone to feel it is their responsibility. Workload and time pressures were barriers mentioned by staff. 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'**

**'I arranged Power of Attorney after seeing a television advert'**

---

### **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. Several carers with a progressive caring role/ for someone they are in a close relationship with noted particular difficulties in identifying as a carer. These concerns were shared by staff.



**'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'**

**'It takes time to accept that identity'**

---

### **Stigma, guilt and value**

Stigma was mentioned several times as was feeling guilty either for asking for help or for not being able to manage. 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.

**'so what if I have the label of a carer. What does this mean?'**

**'Acknowledging 'I am a carer' is hard.'**

**'I only need recognition, maybe from the GP or health professionals if that leads to help'**

**'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.'**

---

# Support to continue caring

## **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. Carers valued both overnight breaks and smaller regular breaks as well as breaks and companionship provided by befriender services. Carers and staff think current supports make a difference but that there needs to be more support for breaks (see also replacement care below).



Breaks which involved the cared for person were mentioned by a few people as positive. It was stated that this prevents the stress of sourcing replacement care (see replacement care below)

**'I didn't realise how much I needed that [a break]'**

**'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.'**

---

## **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. There was a familiarity with other staff members and a rapport and confidence inferred.



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 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.'**

---

## **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'**

**'Coming to the carers coffee morning is like getting therapy.'**

---

## **Replacement care is not accessible**

Replacement care was the most often talked about barrier to having a break from caring by staff and carers. Sitter services and residential respite were specifically 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.



**'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'.**

---

## **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 just knowing your situation, not having to repeat your story and the benefit that comes from knowing you can contact someone who will listen/ having someone 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'.**

---

## **Workplace support should to be better**

The need for better work place support was highlighted by several carers and staff members. There were positive examples e.g. being supported to approach an employer to address issues but most comments focused on the need for improvement and 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.'**

---

# Carer's own health & wellbeing



## **Being able to take a break from caring is essential**

*(See above)*

---



## **It's important to spend time with other people and do things you enjoy**

Carers described different ways of coping, connecting and having time out and the importance of this. Common supports were:

- (1) emotional support including 1:1 carer support and counselling to overcome barriers such as guilt and
  - (2) replacement care, to know the person you care for is safe and well cared for.
- 



## **Access to third sector support is good**

In general people spoke positively about timely access to support from third sector organisations. One or two carers mentioned having to wait but most spoke of receiving a quick response. Carers felt this was very important. 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.'**

---



## **The right care for the person I care for is not easy to get**

A strong recurrent theme was that the ability for a carer to consider their own needs and or take a break depends on the right home or respite environment. Day to day support for the cared for person was largely 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.

Self-directed support was mentioned quite a lot, it was spoken about in positive terms with regards to the flexibility and the potential it offered and some people really valued parts of what it had enabled them to do. However it 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). This was highlighted by both staff and carers.

**'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.'**

**'If the person I care for is looked after and well then my health will be better.'**

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

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

---

---

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

Several carers spoke about timing being a barrier to making use of health and wellbeing supports. This was mainly in reference to training and wellbeing events or sessions. Carers said these were good things to be offered and several described benefitting from them but work, family and caring commitments got in the way.

It was felt that things should be local, with options both in the East and West of Midlothian. Local co-ordinators, use of volunteers, peers were suggested. Penicuik was specifically mentioned several times as an area where it is believed there is comparatively less support.

There was mixed feedback about digital versus physical connectivity. Some people felt that the move to digital fast-tracked by Covid-19 had made things more accessible. Others missed the face to face contact and worried not everyone would be able to access online 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’**

---

### **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 by carers and staff. 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, annual or biannual finance ‘checks’ and support for in-work carers. Others also suggested discounts e.g. gym membership or incentive schemes to provide indirect financial help to unpaid carers.

**‘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’**

---



# Planning ahead

## Legal support makes a difference



Legal advice was mentioned multiple times as being beneficial. This included the benefit of support to apply for legal powers and plan ahead e.g. Power of Attorney and Guardianship and for helping carers become more informed. A few carers said that this then helped them feel more empowered during conversations with professionals as they understood the language and helped them to be better prepared for the caring journey. Some people would like to see clinics offered to carers earlier on in their caring journey.

**'The Power of Attorney has made life easier as my parents dementia has progressed.'**

**'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 and that it's an important thing to get help with. 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.

**I would love a plan in place that I could calmly look at and action with confidence'**

**'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.'**

---

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

A significant theme was the belief that there is a lack of support/information and signposting at the beginning of the caring journey.

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. It was mentioned several times that 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'**