

Respite

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 staff, 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 people who took we spoke with, and the community organisations and service providers we met with.

We spoke to people throughout 2021.

Prevention

Key points

Some people mentioned that COVID-19 had left a gap in residential respite.



"When he's well my sleep's okay but when he's not it's awful. Sometimes I'm up ten times in the night with him. Twice I've got lost when out due to lack of sleep."

"We've been unable to offer people residential respite because we don't have Highbank and care homes can't take people because of Covid 19. Felt bad because my client's carer really needs a break."

Some people mentioned there needs to be better equality of access to respite across Midlothian - that carers turn down respite because of the distance to the facility.



"Planned local respite can be very successful. Familiar face helps a lot."

"Majority would say they don't use it because of location."

"Resilient communities rather than Day Care. More flexible. Longer day care hours".

"People can have small geographical mindset - would travel within Penicuik, but not go to Dalkeith".

"Travelling long distances is inappropriate for frail elderly people."

"Deprivation is a huge issue for accessing respite – how are you going to get there?"

Some people said respite wasn't always in the right place, by the right service / person. Respite must be a positive experience.



"I would like respite to be suitable for my cared for person, and not just a 'holding area' that they can be put into until I come back to collect them."

"Lack of local provision forces other alternatives, which are not always ideal."

"Do we have the right to place people in respite when they don't want to go, but the carer needs a break?"

"I would like to have a menu of service providers that I could access in different circumstances".

Support & Treatment

Key Points

Some people mentioned the need for a clearer definition of what respite is.

When asked about respite, almost invariably people spoke about residential respite. Carers, and those supporting them, need to be aware of the availability of other respite services such as day opportunities and befriending, which should be clearly marketed as respite.

“What is respite and what is a break? It feels like it has been switched round by the NHS. Doing the shopping or going for a cup of tea is just living, it is not respite.”



“I would like the carer to be considered as the beneficiary of respite care and assessed on that basis, rather than the assessment being done based on the needs of the cared for person.”

Some carers prefer the term short break as they associate the word respite with relief from a burden, and they refuse to regard the person(s) for whom they are caring as a burden. In emergency care situations where the carers is unable to care for health or personal reasons, rather than because they are choosing to have a break, a different terms such as ‘replacement care’ may be clearer.

Some people said there needed to be better information on respite and how to access it.



There is very little information and guidance on what carers can expect in terms of accessing respite care. Carers are saying they often feel they have to “fight for it’.

“I do not want to be a Social Worker. I want the professionals who are paid to provide services or manage them for us to act proactively so that i can get on with the job I do – being a carer.”

“Such a complicated system with so many people involved. Which one to contact?!”

Support in a Crisis

Key Points

Some people said that resources are not available to provide the core respite carers need which can lead to crisis and caring situations breaking down.

“My heart goes out to people we are not able to fully support in the way that we should be able to. It’s awful going out to people and seeing situation they are living in. Don’t want to raise hopes.



“I know of two or three caring situations that have broken down. It happens to carers especially when they can’t sleep or they have mental health problems. Acute infections act as a trigger for carers – they can’t cope.”

“Difficult for Social Workers. Assess situation and see need, but don’t have armoury to deal with this.”

“Respite now happens at crisis point, was different 5 years ago. People often don’t want to go home after respite – both the carer and the cared-for person find this. Now more advanced care needs, more challenging. Families caring for people at home for longer.”

Some people mentioned difficulties in accessing emergency respite



“Not a ‘hope in hell’ of getting regular respite. In the past it was a responsive service which was able to help.”

“Trying to get respite in an emergency is impossible. It just isn’t there.”
