**Carers Panel 12.9.24**

Maria Burton - Strategic Planning and Commissioning Officer (Carers), East Lothian Health and Social Care Partnership visited the Carers Panel to consult on the service specification for the local Carer Services for Adult Carers.

Maria introduced the session informing members of the duty under the carers act to provide an information, advice and support service for carers. The service will be recommissioned in June 2025 with a tendering process early next year. Currently services are delivered by CoEL. At this stage, the service specification is being developed and they are looking for input from carers to ensure they are recognising important elements and acknowledging gaps. Maria also explained that the spec will be more outcome focused, so they are keen to hear directly from carers about the difference that good support makes.

The meeting was framed using the following three prompt questions for members:

* What are the most important aspects of the service?
* Where are the gaps?
* What difference does good support make?

Members gave the following feedback.

**Most important aspects of the service**

**Carer A**

**Summary –**local knowledge, understanding the detail of local provision, sense of community, familiarity. Groups are a strength, creative offerings a tonic.

It is local so there is a local knowledge of the area and the demographics as well as a familiarity and community built up around a team which comes to know the clients.

This makes it easier to communicate on informal and more formal levels. It covers a wide range of carers, which I see as a strength as more particular needs or groups can get more specific help and guidance about their particular caring circumstances and can be signposted to these by the service, who know the detail of local provision. I have to say that the local area groups offer a very welcoming and, for many, a responsive and supportive atmosphere, though I am aware that this is dependent on the composition of the group. The art, craft and singing groups have been a real tonic for many.

I think that the communications have been improved immensely - with the newsletter, leaflets and website.

My contact with CoEL helped with managing my expectations but made me realise too what a huge shortfall in resources there is. It is important that a carer support agency is independent of the professional services so that they maintain integrity in the carer’s eyes. However, a good working relationship with all other relevant organisations is paramount. I see that working in EL because of the personal relationships and the mutual trust which has been established. That is always going to be easier, or potentially more difficult, in a smaller local authority.

**Carer B**

**Summary – high quality and timely information. Person centred support that is empathetic and practical.**

I think the most important aspects relate to the responsiveness of the service. You provide high quality and timely-offered information to carers. You are an advice service that starts from where the individual is and offers a side-by-side, empathetic and very practical support system.

**Carer C**

One stop shop for information for carers. Vital wide-reaching promotion of that service for carers to ensure they know what they can access.

**Carer D**

**Summary -** **advice, form filling, planning and emotional support**.

I would consider the most important aspects of COEL to be support and information.

Around 7 years ago, I was caring for my 95-year-old mother who was displaying signs of early onset dementia and although not officially diagnosed, my doctor recommended I met with Margaret Elliot, who held a surgery at our local health centre in North Berwick.

I met with Margaret from time to time where she checked on my wellbeing. Unfortunately, 4 years ago, my husband was diagnosed with semantic dementia at which point I formally registered with COEL and Margaret has been a tremendous support to me personally, and has given us help with advice, form filling, planning and emotional support. Margaret always strikes a perfect balance between professionalism and friendly helpful advice. She knew exactly what support I needed at all times. She has profoundly helped me through some very difficult times – just to know I had someone I could speak to who understood was invaluable.

The amount of information available online is also very helpful but personal contact seems to be very important.

I belong to a dementia group that meets once a month where we have an opportunity to meet with other carers. As a group there are several members who are registered with COEL. Our feedback is very positive and we encourage others to make contact.

**Carer E**

The support to recognise when you are classed at an unpaid carer and the advice you can receive about any aid you may be entitled to assistance to perform a role as a carer.

the person-centred nature of the support offered everyone’s individual story and circumstance is listened to and advice given matches the need if the individual.

**Carer F (not present at meeting)**

The all-important aspect is maintaining good mental health for all carers so that they can perform their vital role.

**Carer G (not present at meeting)**

Advice, practical help with paperwork etc and support.

**Carer H**

Core work of helping carers access support and advice - financial and welfare rights - and as first point of call if they are stressed about caring - and to support them and advise them how to do this and potentially still get breaks from caring when it is getting too much. Each carers need will be different. Signposting and counselling is important. Promotion of the service and roles through communication and engagement - no point in having a great service if no one knows about it.

Hospital Link post (understand this is a pilot piece of work).

Peer- peer learning - how others have managed - group is a good thing as well as being supportive for those struggling.

**Carer I**

I feel the most important aspect is to be able to get good, informative, empathetic 1:1 support for acute issues straight away. Carers stress about all the issues involving their role, however small or large, and need help on the spot. Whether this is just an empathetic listening ear, signposting, referring to other support services for the cared for person, referring on for financial support/ benefits, or for help with their own mental health, it is all of utmost importance and an absolute lifeline at the time, which may be they have reached crisis point. In my circumstances, I feel that COEL has achieved this very well.

After this initial call of 1:1 support, which may be continued for several sessions, and when the carer feels up to it -  then continued support groups and being able to meet other people in a similar situation, which helps the carer to understand that they are not alone, is of utmost help. This has helped me to meet other carers, share issues and find out what support others may have or how they dealt with issues. Networking among carers, making friends, supporting each other plays a very positive part in maintaining positive mental health and being able to continue.

Then there are other more positive and light-hearted, perhaps, but still of utmost importance, sessions to attend which have come under different funding but are also of vital importance to try and help keep and maintain that positive aspect on life, which as a carer, and in my own experience, can sometimes be nigh on impossible. These include the singing group, carers week activities, mindfulness, craft and art sessions and many more.

Another aspect which has been an immense benefit to my own family situation is partnership working and "networking" with another agency in partnership with COEL. This has really improved our family situation in helping our cared for young adult to gain volunteering work experience and excellent support and career advice in order to be able to progress and improve health and wellbeing and getting outdoors again.

**Carer J**

Having a regular check in call with a CSW where I can vent to someone who understands. As a younger carer of someone who has dementia, I don’t have many peers, so having someone who really listens is really beneficial. She seems to understand the juggle of being a parent as well as a carer.

I don’t know all of the available support or strategies that might help. CSW brings my attention to appropriate benefits I can apply for/ blue badge applications, or things I can do in my relationship to make a difference.

I also think the grants offering carers a break are really important. Although I haven’t yet convinced myself that I’m entitled to this. So, the organisation have a key role in helping carers to differentiate between their family relationships and their caring role. It’s not ‘just a daughter’, it’s more than that.

Group discussion around the importance of a mesh between local specialism (dedicated CSW’s in specific areas of EL) and overall knowledge of the whole of East Lothian and how all of the local services interconnect and can work together. Effective signposting to the most relevant support for the carers situation that is time economical for staff so that they can support as many carers as possible, well.

**2. Gaps-**

**Carer A**

Support outside office hours, particularly over weekends, but I realise that this would be costly in terms of resources and there are crisis helplines available but people may not think about phoning these for any number of reasons.

Gaps are going to appear as the carer group gets larger, as demand for activities offered either regularly or as one-offs gets more pressing.

A few people have voiced their disappointment at not getting on things. Trying to ration these in any transparent fair way would be a logistical nightmare.

Unfortunately, the biggest and most concerning gap is that of the main services of Social Work and the lack of carers. Nobody wants to be hanging on to the phone desperate to get a resource, repeating the same information to different people but that seems to be the norm now, a battle.

My contact with CoEL helped with managing my expectations but made me realise too what a huge shortfall in resources there is. It is important that a carer support agency is independent of the professional services so that they maintain integrity in the carer’s eyes. However, a good working relationship with all other relevant organisations is paramount. I see that working in EL because of the personal relationships and the mutual trust which has been established. That is always going to be easier, or potentially more difficult, in a smaller local authority.

**Carer B**

I’m not sure there are gaps. I might have said that perhaps there could have been more documented support for the carer’s changing role – particularly when the cared-for person moves into a full-time care setting (or dies) but I know that has been addressed in the material that is soon to be published.

In the previous response, I spoke about timely-offered information. All of this assumes early identification of the carer’s role – both by the carer him/her self and by all relevant outside agencies. Helping the carer to see themselves in that way and be able to declare that for themselves and more importantly, finding a way that they can be freed up from their care role to make best use of the service early on can be extremely difficult to set up. I don’t have answers here – just a lingering uncertainty about the extent/capacity of the outreach to capture – at the most meaningful times - those whose need is greatest. But I’m an optimist so I believe this is an area for steady and sustained progress.

**Carer C**

Important/ gaps

* Breaks from caring according to need from a few hours a week up to a full week.
* Sitting service to allow carers to attend appointments or social activities.
* Quick response to cared for person developing incontinence problems.
* One stop shop for information although COEl fulfils a lot of this so it's important to know COEL exists.
* Good professional carers with at least a basic level of dementia training and same few carers attending to ensure continuity.

*These carers should have enough time allocated to ensure the cared for person actually eats their meals and takes medication if they live alone.*

**Carer E - carer was reassured that this is in development**

A peer-to-peer support forum with possible sub-groups for young carers, parent carers, and spousal/kinship carers. There is much positive impact had when carers can get together and share experiences, however given the round the clock nature and unpredictability of the care some days and times of physical meetups may not always be manageable for some. An "as and when" parent forum may be an idea.

An online forum\_ whatsapp group where carers can connect directly but at a time that suits them. Ask advice, share experiences.

**Carer F (not present at meeting)**

The gaps are very obviously in support for carers suffering with mental ill health.

**Carer G (not present at meeting)**

Not enough time given to carers to discuss their concerns regarding day to day caring role with like minded people.  Also very beneficial to share experiences and realise you are not alone.  Accept money and availability of staff are an issue here.

**Carer H**

CoEL cover everything well - as per your mission statement and contract. The biggest gap I see is:

* the lack of availability of substantial  breaks - even though they have reached amber and red on the carers assessment tool. This is not prevention/intervening early. As there are no spaces in Nursing Homes to take patients in for a week, or relief live-in carers that can go to person’s house for a week to allow a break, there is a high risk of crisis care or visits to A&E or withdrawal from caring for their own health. It isn’t a gap in CoEL - but is a gap in ELH&SC - that affects CoEL - so I would be expecting more and more crisis care engagement work.
* Maybe that limit of £300 needs to be increased to £500? TFM grants (clarified exceptional circumstances are acknowledged)
* ELH&SC need more people to step into the gap for "live in care" - and I this is being done, but private companies rather than "not for profit” sadly.
* “Crisis live in care supplier for 24-48hrs" in some situations - as you know the carers - and get reimbursed by H&SC? Big step I know - but valuable. Maybe have an East Lothian summit on the crisis of carers breaks between funders and potential suppliers in EL to look for solutions. (invite the Day Centres - its a fairly small step from providing “reach out” for a number of hours to providing an overnight service for the same people they see and know rather than a stranger, but this will take training time and money.
* Carer H also raised a gap in CSW being GP surgery based (1 afternoon a week), to work with carers who may not already be known to the service.

**Carer I**

In my experience and in my personal family situation of caring for 2 adult children with Neurodivergent diagnosis, I feel there is a gap in knowledge and experience in the staff team in the area of Neurodivergent diagnosis and support for cared for adults with ADHD/ ASD.  I used the mental health support service as one of my cared for adult children experienced a very serious ADHD/ mental health psychotic crisis last year and the COEL MH support worker was of invaluable support to my husband and I.

However, as there is more and more Neurodivergent diagnosis in the general population, this is becoming an area where more expertise and a greater understanding is rapidly and urgently needed.  Not least because many of the parents/ partners or other carers may also have the diagnosis as it is well known now that this is a familial condition. I felt that the support of other team members was a little lacking in knowledge and understating in regard to adult Autism, and services for the high functioning ASD adult.

**Carer J**

Education around the specific condition because this helps carers to empathise and understand what is happening with the person who is cared for. I would be looking for this in a physical group. (this carer is referring specifically to fronto-temporal dementia, but recognises the importance of this for carers in all caring situations).

ID card and support to encourage carers to self-identify and seek support.

**Carer K**

Gap in terms of support for young adults. Impact of caring on mental health. Transitions between childhood and adulthood.

**3. The difference that good support makes-**

**Carer A**

I know that good support can be transformational on so many levels. From recognising yourself as a carer who is giving significant support to, not just a loved one, but society. That you as a carer have needs that should be recognised. Reducing the stigma that has been around having needs, physical and mental, both of the cared for and carer. Ensuring that carer legal and financial rights are made clear to carers and that these are being supported by local and national structures. It provides a supportive world of friends, enjoying activities together and supporting each other without needing explanation. I am so lucky to have such positive ongoing relationships with CoEL staff and volunteers.

I know that my world before meeting the CoEL team was lonely, isolated, stressful and angry. I was not a particularly nice person to be around and certainly not to be cared by. My husband realises that CoEL is important for his welfare as well as mine.

**Carer B**

Good support removes the sense of isolation that a carer often has. Once onboard with CoEL, the sense of relief that comes from knowing that there is a support system that understands and can help you negotiate the physical, mental, emotional and financial strains/traumas of caring – without feeling guilty that you’ve expressed these things out loud – is beyond price. Family and friends can be an immense help – but they’re not always near and sometimes you feel the need to shield them from the worst of it all. You do so because you want to preserve (for them) the memories they may have of the cared-for person. And sometimes they just wouldn’t “get it” anyway! But CoEL does. Good support – as provided by CoEL is a lifeline for the carer.

Carer raised metaphor for lifeboat they took from seasons for growth. Explained that CoEL has really helped them to prioritise relationships that help them to look after their mental health.

**Carer C**

Good support lowers stress levels for carer and cared for person.

**Carer D**

A perfect balance between professionalism and friendly helpful advice. She knew exactly what support I needed at all times. She has profoundly helped me through some very difficult times – just to know I had someone I could speak to who understood was invaluable.

**Carer E**

For me the validation that I am in fact an unpaid carer was a lightbulb moment for me. I am a parent carer working in a full-time role in the third sector myself. Part of my day job is supporting others in a caring role but I just couldn’t connect the dots until I thought about being involved with carers of East Lothian. Coel helped me reframe my own thinking which has been the catalyst to me seeking my own support. The individual approach and having someone listen to my story and offer me advice and support has been invaluable!

**Carer F (not present at meeting)**

When I am mentally at my best, all parts of my life function better.

I know first-hand how I've functioned well with good input from a mental health expert. Likewise, I know how bad I've felt when unable to access services and how detrimental it has been to my caring role and other parts of my life. It is vital to functioning optimally as carers who are isolated, unpaid and in an extremely stressful situation.

**Carer G (not present at meeting)**

An unbelievable difference when support is given.  Carers are totally on their own from day one of diagnosis, finding out what and where is available is an uphill struggle whilst in the throws of caring for their loved one.

A confidential space where you can say anything that you want to and open your heart is exceptionally helpful. To be able to talk in a room of people who know what you are going through is so reassuring. At diagnosis point, you are dealing with your relationship being turned completely upside down and you walk around in a cloud for 6 months, realising that you are the main person in the relationship now. And you feel like you don’t know anything and there’s so much that you need to know. Support stops you from feeling like you are on your own. Michael and Margaret have been an absolute god send to me. Knowledgeable, considerate and patient professionals make so much difference.

**Carer H**

Good support and advice gives peace of mind that you are doing the right thing and are getting all the benefits you are entitled to. This is what CoEL has done for me. That is two pressures off your mind when you are juggling work and home life.

**Carer I**

A very positive difference. Knowing what to do, how to go about helping the cared for person, what to say, etc, has been hugely beneficial for the whole family situation. Attending the MH groups, which include information sessions, have been immensely helpful.

The right help & support in mental health situations is a matter of life and death, when one is caring for a person with suicidal possibilties, and the mental health of the carer.

**Carer J**

It means the world to be listened to. A sigh of relief. A weight off. Don’t need to fight anymore.

Carer H ended the meeting sharing that they felt strongly that CoEL is a preventative service and without it, it would be disastrous for the HSCP.

Several members said that they don't know where they would be without CoEL and that the support has been an utter lifeline getting them through incredibly difficult times.