**Carers Panel meeting 17.11.22 – Pefferburn Room**

*Hybrid meeting Pefferburn Room ELCH and Zoom*

***Attendees:***

*H. Wedgwood (via zoom)*

*L. Sandie (via zoom)*

*M. Scrimgeour (in person)*

*P. Gordon (in person)*

*D. Binnie (in person)*

*J. Aston (in person)*

*CoEL staff member: Gemma Twells-Davison, Volunteer and Training Coordinator*

*Guests:*

*Maria Burton, Strategy Officer, Carers ELHSCP*

*Claire Spiden, Deputy Chief Executive, CoEL*

**Meeting Agenda**

Panel met to input their views into ELHSCP’s draft carers strategy 23 -26, following a planning meeting on 26.10.22. Prior to meeting on 26.10.22, panel members were provided with the following context for the session from M. Burton to enable their planning:

*The existing strategy is available online here  [East Lothian Carers Strategy | East Lothian Council](https://www.eastlothian.gov.uk/downloads/download/12974/east_lothian_carers_strategy%22%20%5Ct%20%22_blank) if anyone wants to access it in full, it is out of date, covering 2018-21 but I came into post in May so trying to catch up and then it will be reviewed every 3 years to show our plans for each period, it will be supported by action plans.*

*The Outcomes have been reviewed and are now as follows:*

*1)     Adult, Young Adult and Young Carers are identified and can access support.*

*2)     Carers are well informed and have access to tailored and age appropriate information and advice throughout their caring journey*

*3)     Carers are supported to maintain their own physical, emotional and mental wellbeing*

*4)     Breaks from caring are timely and regularly available*

*5)     Carers can achieve a balance between caring and other aspects of their lives and are supported to have a life outside their caring role*

*6)     Carers and young carers are respected by professionals as partners in care and are appropriately included in the planning and delivery of both the care and support for the people they care for and services locally*

*7)     Local Communities are supported to be carer friendly*

*These should be considered against the general back drop of continuing to recover from the COVID pandemic and the cost of living crisis.*

*What I am looking for is suggested actions under these headings that will form part of the strategy in terms of what we will do, and some consideration of priorities would be really helpful.*

Discussion on 17.11.22 focused on individual strategy outcomes. GTD introduced each outcome by sharing with Maria what the panel had discussed in their planning session. Additional points that were raised in meeting on 17.11 are included in the notes in red.

Adult, Young Adult and Young Carers are identified and can access support.

*Panel members feel strongly that this is a high priority area*

* Much more focus needs to be put on identifying carers by services they are likely to come into contact with (health services inc hospitals and GP’s, social care, schools, youth groups, housing).
* Above mentioned services should all be routinely signposting carers to the help and support that they may need in their caring journey.
* Information that can help carers in their caring roles should be much more visible to carers at the beginning of their caring journey that can prevent them from reaching crisis point (for example, navigating services, benefits systems, information about SDS, manual handling, employing carers etc).
* More information and advice at the start of their caring journey could prevent carer break down.

**Actions suggested:**

* A carers handbook carers with example scenarios and where to go for help, information about navigating services/ informing carers of their rights/ information about Adult Carer Support Plan.
* At point of diagnosis carer and person cared for are both given at least two paper copies and sent an email with relevant support organisations on it. There is follow up contact made by a professional not later than one month after diagnosis.
* Panel members have regularly discussed the introduction of a Carers identification scheme in East Lothian. This was raised again at today’s meeting. Benefits of a carers ID scheme are felt to be:

* + Increasing self-identification
	+ Encouraging access to support, services and associated schemes
	+ Contributing to carer friendly communities
	+ Increasing dialogue about caring between professionals and carers that promotes identification and access to information and advice
* GP’s have a system where the word CARER is immediately visible to them, to other practice staff and to reception staff , every time the surgery is contacted either in person or by phone by a carer.
* Schools, work places, HR dept, Doctors, Social Workers, MP’s, Housing should be supported to identify carers.

*A discussion opened around how a ‘handbook’ might be managed to ensure information remained live, relevant and useful for carers. Suggestions included:*

* *Staff responsible for upkeep of the resource*
* *Keeping information simple and resource lists concise and basic, but ensuring carers were signposted to CoEL to get more detailed information*

*National concession card raised as a potential vehicle for ID scheme.*

*A panel member asked MB to share where she felt successes had been so far in terms of identification. MB shared that focus had been on making improvements in processes within Health and Social care, such as Social Work, Hospital, Primary Care processes and paperwork. Gaps in identification within primary care were discussed by panel members.*

*Panel were briefed that MB’s post was a newly created post to respond to the needs of the implementation of Carers Strategy. This piece of work was previously encompassed within the role of Ashley Hardy (Strategy Officer, Adult Wellbeing), but it was felt that a more specific role was required to cover the extent of strategy for carers.*

*Parent carer panel member fed back that her children had been more formally identified as carers since the new YC council based service has been established and that support has been forthcoming via school. Discussion around the difference between historic YC service and newly implemented service. Panel member defined the difference as historic service offering activity based support and new service being more paperwork based. Suggestions were made that this dual approach/ mixed economy is effective and that it may be useful to consider how this could be more replicated for adult carers.*

Carers are well informed and have access to tailored and age appropriate information and advice throughout their caring journey

* Information that can help carers in their caring roles should be much more visible to carers at the beginning of their caring journey that can prevent them from reaching crisis point (for example, navigating services, benefits systems, information about SDS, manual handling, respite schemes, employing carers etc).
* More information and advice at the start of their caring journey could prevent carer break down.

**Actions suggested:**

* A carers handbook carers with example scenarios and where to go for help, information about navigating services/ informing carers of their rights/ information about Adult Carer Support Plan.
* An East Lothian Carers Register is established and kept up to date with relevant safeguards re confidentiality and access. As soon as a professional gains permission from the carer, the professional to contact register holder with name etc of carer to be added or withdrawn from the register.
* ONE STOP SHOP for carers to access information /signposting / dwp benefits/grants - Carers find it extremely difficult to find the right person/ department and become very stressed trying to do so. HUGE and regular publicity and awareness raising re the One Stop Shop.
* GP’s have a system where the word CARER is immediately visible to them, to other practice staff and to reception staff , every time the surgery is contacted either in person or by phone by a carer.
* All dementia carers are made AWARE OF POST DIAGNOSTIC SUPPORT. This support may not be needed immediately after diagnosis, so carers and people living with dementia should be able to choose when to access it. At the end of the one year post diagnostic support, carers should be told who is still available to support them. Some say they feel abandoned once they are signed off.
* Cheap or free access to local groups and places providing all types of classes /company / training /chat
* SUPPORT WITH INCONTINENCE. At the first instance of incontinence, the carer receives support and incontinence pads within 48 hrs.
* BLUE BADGE APPLICATIONS. ELC system should be easier with advice given to the applicant re best wording.
* Emotional and practical support/training re HOW TO AVOID OR DE ESCALATE VIOLENT BEHAVIOUR, cope with refusal to eat or take medication, wandering - especially at night.
* More information on social media, radio, schools, places of worship, hospitals and local supermarkets.

*Discussion around post diagnostic dementia support. Panel member raised that post diagnostic support was limited and came at the point where things were not critical. It was suggested that at the point where things become more challenging for carers, post diagnostic support has ceased. It was raised that the support came at a point where the carer might not know the questions to ask, or the issues they might face in the future.*

*MB shared that during COVID, capacity for link work lessened and demand increased.*

*In response to One Stop Shop suggestion, there was a discussion about whether this already exists in EL in CoEL. Discussion around CoEL business delivery plan. C. Spiden clarified for panel that as a commissioned service, CoEL’s plan is in line with Carers Strategy and contributes towards the implementation of the strategy. Panel have viewed the BDP in the past, but GTD to resend as new members have joined the panel.*

*Discussion around the importance of accessing national information/ resources as well as local, in case of a lack of resources in a particular area locally.*

*Individual panel member raised a lack of information/ resources for post 16 autism support in EL.*

*Panel member alerted to CoEL Day Services Carer Forum.*

*Question raised around how specialist services (eg. Specialist nurse for terminal cancer/ specialist nurse for terminal cancer) blend with other carers’ services to promote a positive journey for the carer? And how is this encompassed within the Carers’ Strategy?*

*Panel member asked about how ideas are implemented for carers in EL. MB gave brief explanation of the function of the IJB/ Change Boards/ Reference groups. Follow link for further clarification of functions:*

[*https://www.edubuzz.org/elhscp/east-lothian-integration-joint-board/change-boards-and-reference-groups/*](https://www.edubuzz.org/elhscp/east-lothian-integration-joint-board/change-boards-and-reference-groups/)

Carers are supported to maintain their own physical, emotional and mental wellbeing

Panel members raised the following points:

* Much better promotion of Adult Carer Support Plan is needed. Why is uptake low?
* Can ACSP be routinely integrated into the assessment of the person with care needs, so that an acknowledgement of the carer whenever there is someone with support needs.
* Panel were informed that there is a group established to review the ACSP form. Members were in agreement that the document should be carer focused.
* Eligibility criteria for carers to access support should be more visible and transparent for carers.

**Actions suggested:**

* Improved promotion of ACSP
* Combined assessments routinely offered.
* REGULAR REVIEWS OF CARER SUPPORT PLAN. Carer should not have to request this. Professionals carrying out reviews to be trained to recognise when carers are becoming exhausted and in danger of becoming ill themselves.
* Carers should not have to reach crisis point. Good/ relevant information and advice should be accessible early in a caring journey.
* More gym offers to be affordable, crèche if needed. Offers of spaces for sports therapy, massages/ physiotherapy etc.

Breaks from caring are timely and regularly available

Panel members raised the following points:

* Carers who are able to shout the loudest and who are more informed about systems are more likely to be able to access respite and that a more fair, transparent and equal approach needs to be implemented to ensure that carers who are quietly struggling are supported.
* Who is furthest from the table/ conversation and how are their needs for respite being identified?

**Actions suggested:**

* AFFORDABLE, REGULAR RESPITE. A minimum of 3 hrs once a week up to one full week.
* AFFORDABLE SITTING SERVICE. Respite is often dependent on a sitting service or access to a day centre. A sitting service pool of staff/volunteers is available who are trained and can also help with toileting and if required change incontinence pads.
* To ensure that Doctors, Social Workers, HR depts. Can be a part of this too. A break is the last thing you think about as a carer.

*Discussion around the difference between replacement care and respite care. MB to follow up with panel member that raised this question.*

*Individual panel member asked if anything is happening in East Lothian re sitter service? Could a sitter service be developed with volunteers to enable carers to have a break/ find balance between caring and the other aspects of their lives? MB shared information about Leuchie at home service in development, as well as sitter service development through day centres.*

Carers can achieve a balance between caring and other aspects of their lives and are supported to have a life outside their caring role

* Shared jobs/ flexible hours.

Not discussed at length due to time constraints of meeting.

*Short discussion reiterating information re sitter services.*

Carers and young carers are respected by professionals as partners in care and are appropriately included in the planning and delivery of both the care and support for the people they care for and services locally

*This has been a very prevalent theme in historical panel conversations and panel members felt that this is a priority area.*

Panel members raised the following points:

* Unpaid carers are frequently not respected or acknowledged by health and social care professionals. One member described feeling as though they were lied to.
* The following personal account was shared: As soon as health services were aware that there was an unpaid carer in the family, the case was no longer treated as a crisis and the book was passed to the unpaid carer rather than their identification encouraging collaboration.
* More openness with carers when there is a lack of resources (eg. Current respite limitations). Carers do not want to be patronised or treated as though they are stupid.

**Actions suggested:**

* ONE STOP SHOP for carers to access information /signposting / dwp benefits/grants - Carers find it extremely difficult to find the right person/ department and become very stressed trying to do so. HUGE and regular publicity and awareness raising re the One Stop Shop.
* Continuity of care – Can carers have a named professional with Health Services and within Social Care who understands their role as a carer and the details of their situation.
* Work places to be more carer positive.

Gemma shared with the panel that CoEL are contracted to deliver 10 ‘Think Carer’ training sessions each year to ELHSCP and asked for the panel’s input about where the training should be targeted. Panel felt that they don’t know enough about this to comment. It was agreed that this would be revisited in a future panel meeting.

*Discussion around high quality mandatory training for Health and Social care professionals to help them to understand the needs of carers/ impact of caring/ carers rights.*

Local Communities are supported to be carer friendly

**Actions suggested:**

* Introduction of ID card scheme as mentioned above.
* Cheap or free access to local groups and places providing all types of classes /company / training /chat.
* To ensure teachers at school identify and support. Lessons on carers and attitudes to support and care on curriculum.

*Discussion around free access to leisure and exercise facilities for carers.*

*Access to therapy/ yoga/ mindfulness.*

*Carer friendly venues/ badges in windows to show carer friendly spaces.*

*More carer positive work places.*

*Question raised: What is being done to ensure men are included in accessibility to services? Are there barriers to engagement with support for men who care? What could be done differently? It was raised that the Carers’ Panel is predominantly female. GTD to liaise with Men Who Care facilitator to ask those he supports if they would like to contribute to the strategy conversation.*