**Meeting Note – Carers’ Panel**

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| **Title** | Carers’ Panel |
| **Venue** | Zoom |
| **Date** | 06/05/2021 |
| **Attendees** | Agnes Stevenson, Anne Bisset, Helen Wedgwood, Jacki Aston, Kirsteen Powell (CoEL) |
| **Apologies** | Yvonne Macaulay |

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| **Agenda** |
| * Review of previous meeting note * Feedback on Carers Hustings – Comments? Learning? Next Steps? * Carers Week (7th to 13th June) – Ideas? * Carer engagement opportunities/ hot topics * Any other business |
| **Summary of discussions** |
| **Review of previous meeting note**  No comments or changes were made – notes approved.  **Feedback on Carers Hustings**  Panel members felt that candidates were generally supportive of carers but the key would be holding whoever was elected to account. Anne was interested in Paul McLennan’s suggestion that the starting place for improving services for carers had to be a proper needs analysis of what care was required in East Lothian. There was also a discussion of Martin Whitfiled’s written response on ring-fencing Carers Act funding. Councillor Shamin Akhtar had assured Martin Whitfield that Carers Act funding received by East Lothian Council from Scottish Government was used for its intended purpose to support carers. Panel members wanted to know how much money was in this pot, and how it was being spent, pointing out that many carers were currently struggling to access the respite so funds did not seem to be sufficient.  **Making Change Happen**  There was a discussion of how to improve services when the challenge seemed insurmountable and the pace of change was slow. Kirsteen asked if it was worth thinking exploring previous local success stories. Anne reported that there were now dementia support services in East Lothian where 15 years ago there had been nothing – changes largely secured through individual campaigners, community initiatives such as Dementia Friendly East Lothian (DFEL) and a drip-drip effect of raising political and public awareness.  **Carers Week**  Panel members discussed ideas to raise awareness during Carers Week. Anne explained she was holding a stall in her local village. Jacki noted that having a carer-friendly employer enabled her to continue working, and that work for her offered a break from her caring role. Jacki will explore with her manager the possibility of writing an article to be shared on COEL website/ in local press as appropriate. Helen suggested a statement such as “Are you a carer too?” could be used to raise awareness amongst people who might not identify as carers. It was suggested a stall at central venue e.g. Haddington Farmers market may be a way of reaching out to people one-to-one and face-to-face, which was the preference of the panel members present. No market scheduled for Carers Week but Kirsteen will explore possibility of having a stall at a later date in the summer.  **Respite**  Brief discussion of carers’ need for respite and that respite options need to be personalised – day centres are great for some but they don’t meet the needs of everyone.  **Telephone access to services**  Anne stated that accessing the appropriate professionals e.g. in social work on the telephone was a real struggle for some carers at present. Carers have been given incorrect information by call handers as they desperately try to find the right person to speak to in situations approaching a crisis.  **Inconsistencies in services/ professionals’ approaches**  Agnes shared her experiences of unhelpful and undermining interventions by professionals in relation to caring for her husband. There was general agreement that there was great variability in the quality of services, people’s experiences and professionals’ approaches. Jacki felt there was a role for unpaid carers in educating final year health care students on their real life experiences. |

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| **Next steps/ Key decisions** |
| * David Binnie, carer rep on IJB to be invited to speak to Carers Panel online if face-to-face meeting not possible in next three months. |

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| **Actions** | | |
| **Who** | **What** | **By when** |
| Kirsteen | Contact Councillor Shamin Akhtar, or other HSCP rep as appropriate, to ask about Carers Act funding on behalf of panel – how much is it and how is it spent, is carer respite included in this budget? | 31/05/2021 |
| Kirsteen | Contact Haddington Farmers Market to explore possibility of Panel members having an awareness raising stall one month in the summer | 31/05/2021 |
| Jacki | Explore with manager the possibility of writing an article about the difference having a carer-friendly employer has made to her to publish on CoEL website/ local media as appropriate | 31/05/2021 |

Appendix 1 – Carer Engagement Opportunities & Hot Topics

**Carer engagement opportunities – May 2021**

**Immediate (next 6 weeks)**

**#1 Carers Week - 7th to 13th June**

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK. Theme for 2021 is “Make Caring Visible and Valued”. More information here: <https://www.carersweek.org/>

CoEL is currently pulling together a programme of online and outdoor events to mark Carers Week to be published mid-May. ELHSCP are offering a free day out for carers on Friday 11th June at Foxlake near Dunbar. Full details of this event and how to register here: <https://coel.org.uk/elhscp-carers-big-day-out-at-foxlake-friday-11th-june/>

Would the Panel like to do any awareness raising activities?

Possible ideas include:

* Interviews with local radio stations (East Coast FM, Radio Saltire etc.)
* “As a carer, I feel valued when…” series of statements on social media/ other channels (could later be used in health and social care staff training/ sent to councillors & MSP etc.)
* Other thoughts?

**Medium term (next 3 months)**

**#1 East Lothian Health & Social Care Partnership (ELHSCP) Structures**

I have invited (through CEO Jess Wade) the Carers Representative on the Integrated Joint Board (IJB) of East Lothian Health & Social Care Partnership (ELHSCP) to attend a Panel meeting to explain the ELHSCP’s structures and how carers can hold the ELHSCP to account on the delivery of the East Lothian Carers’ Strategy. The Carers Representative David Binnie, who is a former chair of CoEL, has said he would prefer to meet face-to-face with the Panel. If this is not going to be possible for a long time (plus of three months), I will revisit the possibility of organising a meeting online with David.

[East Lothian Carers Strategy and East Lothian Carers Action Plan](https://www.eastlothian.gov.uk/downloads/download/12974/east_lothian_carers_strategy)

[Change Boards and Reference Group Structure](https://www.edubuzz.org/almac/change-boards-and-reference-groups/)

In the meantime, I am trying to pull together an up-to-date map of the working groups within the ELHSCP where there is, or should be, a carer representative.

**#2 Re-opening of day centres**

Day centres for adults and older adults are currently running at significantly reduced capacity or providing outreach services only. We have no clear timeline yet as to when and how they will reopen or return to full service. The transformation group, which is overseeing the redesign of day supports for adults and older adults, was due to meet at the end of April but no date for the meeting has been set yet. Services are limited by social distancing guidelines and, of course, resources!

Panel may wish to discuss and/or hold an event about what more could be done and/or what could be done differently in extending support to those who have not been able to access day centres since the start of the pandemic to present to decision makers within ELHSCP.

**#3 COEL 5 year strategy**

CoEL has just appointed a new chair, Jim Conway, who is also a carer. This means work on developing CoEL’s new five-year strategy can now move forward. Both Jess and a representative of the Board would be keen to attend a Panel meeting to listen to your views about CoEL and support for carers in general.

**Longer term (next 6 months or timeline still to be confirmed)**

**#1 Training opportunities for carers**

There may be funding for training for panel members e.g. assertiveness training

**#2 ThinkCarer! Training/ Student Education**

There may be opportunities for carers to become involved in delivering ThinkCarer! training to health and social care staff or in developing the curriculum for health and social care students.

**Ongoing engagement opportunities**

**Care Opinion**

Opportunity to share publicly your experiences of UK health and care services, good and bad. (NB. All comments are pre-moderated to avoid any libel issues. Care Opinion sends published comments to service provider, relevant registering body and local political representatives). It has the potential to increase transparency although East Lothian Council does not currently subscribe to or promote the service. <https://www.careopinion.org.uk/>

**Improving the Cancer Journey (ICJ) – open call to people affected by cancer**

Improving the Cancer Journey (ICJ) is a Macmillan funded programme to address the non-clinical needs of people affected by cancer living in the Lothians. If you are interested in sharing your experiences as a patient or a carer to help shape the new service, please contact [loth.icj@nhslothian.scot.nhs.uk](mailto:loth.icj@nhslothian.scot.nhs.uk) or call 07977 307 286.

**Hot Topics in April 2021**

Topics raised and discussed during COEL staff team meeting 28/04/2021

**#1 Carer Invisibility**

Carers are not being seen/ recognised/ identified as very few services are offering home visits and very few carers can access face to face appointments (so no opportunity to see poster or read leaflet about carer support in a GP’s waiting room etc.)

Jess gave example of joint working in East Renfrewshire where multiple services across the statutory and voluntary sectors share the same referral form. Members of the public can access information and support on a wide range of issues through multi-agency staffed “talking points” in community locations (unclear if/how this is operating during the pandemic) East Renfrewshire also has a Carers Collective that are involved in the development and design of services.

**Action**: Kirsteen to contact Mark Mulhern for further information about the East Renfrewshire Service Model/ Carers Collective.

**#2 Difficulties communicating with ward staff in East Lothian Community Hospital (ELCH)**

Carers are having difficulty communicating with ward staff when the person they are caring for is an inpatient (especially in ward 3). Staff are not visible in the wards or are not available on the phone. Inconsistent messages are given by staff about who can visit and when.

**Action:**Jenny to establish current hospital visiting policy with nursing officer/ appropriate hospital senior and how carers can expect to keep in touch with, and receive updates about, the person they care for when they are in ELCH.

**#3 Adult Carer Support Plans (ACSP)**

Plans are being completed by staff with carers creating an expectation that support will follow. However, only cases that are considered to be “critical” are being actioned by Social Work at present and there is often no response or follow up when a Plan is submitted. This makes staff and carers feel that the Plans are a waste of time.

**Action**: Jess will update team on addressing issue with ELHSCP next month in light of new target that 100% of carers are offered an ACSP.

**#4 Carers ID Card**

Even before the pandemic carers were asking about a carers ID card (in particular the Musselburgh Carers Group). Feedback on the carers ID letter suggests that many carers have found it useful and/or reassuring. The Coalition of Carers in Scotland (CoCiS) are exploring the feasibility of a national carers ID card. If this proposal is not taken forward, there is a possibility of developing a scheme at a local level as has been done in other parts of Scotland.