**Meeting Note – Carers’ Panel**

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| **Title** | Carers’ Panel |
| **Venue** | Zoom |
| **Date** | 03/03/2021 |
| **Attendees** | Agnes Stevenson, Anne Bisset, Helen Wedgwood, Jacki Aston, Kirsteen Powell (CoEL), Terry Cooper, Yvonne Macaulay |
| **Apologies** | Michael Turnbull |

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| **Summary of discussions** |
| **Review of previous meeting note**  Anne highlighted the need for nuance – some professionals sometimes didn’t listen or look beyond a carer becoming upset or angry but this was certainly not always the case.  Agnes felt very strongly that the 24/7 nature of some caring roles was not recognised. This led to a discussion of how difficult it is to comprehend or communicate what it is like to be a round-the-clock carer. The consensus view was that one had to experience it to understand it. Kirsteen posed the question of what might help build a better understanding even if the gap could never be fully bridged.  It was felt that social work and service providers too often assumed carers would and could cover gaps in the system e.g. when home care staff were not available or were sent to an individual’s home without knowing his or her support needs (highlighting the importance of support plans being in place and being used effectively – Yvonne’s point).  **Carer engagement opportunities**  There was a discussion of some of the carer engagement opportunities highlighted by Kirsteen (see Appendix 1 for list circulated in advance of the meeting). Panel members felt document was a useful reference point for what was happening nationally and locally.  **Independent Review of Adult Social Care**  The language of the Review was felt to be positive and forward thinking but there was some uncertainty about what the next steps were – if and how the recommendations would be implemented and funded and what a “national care service” would actually mean in practice at a local level.  Anne and Jackie volunteered to attend CoCiS members meeting on 10th March 2021 where the Review will be discussed with the Minister for Health and Wellbeing. Time will be set aside to discuss this further at the next meeting.  **Other issues raised**  Panel members agreed a hustings with local election candidates for carers would be a good way to raise awareness of carers’ issues and press political representatives for their personal and party’s view on implementing the Review’s recommendations. Helen also felt Carers Week presented an opportunity to raise awareness locally.  Anne asked for a future meeting to discuss East Lothian Health & Social Care Partnership (ELHSCP) Carers’ strategy and Action Plan and opportunities for carers to hold ELHSCP to account within the statutory structures (IJB, change boards, reference groups)  There was a discussion on the importance of day centres in providing meaningful activities for people with a range of needs, carer respite and serving as a hub to mobilise community support and attract volunteers. Anne shared that she had heard at an online event organised by Together In Dementia Everyday (TIDE) that a day care centre in the west of Scotland had re-opened.  Jackie asked for a future session to discuss challenges faced by working carers and Carer’s Allowance. |

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| **Next steps/ Key decisions** |
| * It was agreed to make future meetings 90 minutes long to allow time for discussion * Next meeting to focus on hustings with local election candidates for carers / events for Carers Week * Subsequent meetings to focus on:   + Carers’ Strategy and Action Plan and opportunities to hold ELHSCP to account on their delivery   + Challenges facing working carers and Carer’s Allowance   + Day centres and respite opportunities |

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| **Actions** | | |
| **Who** | **What** | **By when** |
| Kirsteen | Organise next Carers’ Panel Meeting (consult all on choice of date and time again) | 05/03/2021 |
| Anne & Jackie | Attend CoCiS meeting on 10th March on behalf of panel members | 10/03/2021 |
| Kirsteen | Ask local election candidates if they would be willing to participate in an online hustings for carers | 12/03/2021 |
| Kirsteen | Update carer engagement opportunities doc and circulate to panel members in advance of next meeting | 26/03/2021 |

Appendix 1:

**Carer engagement opportunities – March 2021**

**Immediate (next 4 weeks)**

**#1 Coalition of Carers in Scotland (CoCiS) – Members Meeting 10th March 2021, 10:30 to 12:30**

“If not now, then when? The future of social care for unpaid carers” online event offers carers an opportunity to hear from the Minister for Health and Wellbeing, Marie Gougeon, and find out more about the Independent Review of Adult Social Care. [If not now, then when? Online Event Booking](https://www.eventbrite.co.uk/e/if-not-now-when-the-future-of-social-care-for-unpaid-carers-tickets-140782224423)

CoCiS is one of seven national carers organisations in Scotland with links to the Carers Policy Unit (the team of civil servants who are tasked with working out the implications of Scottish Government policy decisions for unpaid carers). You can sign up to CoCiS e-bulletin via their website: <https://www.carersnet.org/campaigns/>

**#2 Health and Social Care Alliance Scotland – What Matters to You Campaign**

Opportunity for carers across the country to write opinion piece or contribute to short film on what is important to them in their caring experience. By highlighting “what matters” the Alliance hopes to promote person-centred approaches and narrow the gap between policy and implementation. More information about how to get involved is here: [What Matters to You](https://www.alliance-scotland.org.uk/blog/opinion/what-matters-to-you-as-an-unpaid-carer-living-in-scotland/%22%20/l%20%22expanded)

NB. What Matters to You Day is on Wednesday 9th June 2021.

**#3 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/>

**Medium term (next 3 months)**

**#1 Scottish Parliamentary Elections – Thursday 6th May 2021**

According to CoCiS, carers represent 16% of the voting population in Scotland – an important section of the electorate. In nearly every constituency, the numbers of carers are bigger than the sitting MSPs majority. CoCiS are involved in producing a Carers Manifesto, probably in conjunction with the six other National Carers Organisations in Scotland.

Recommendations from [Independent Review of Adult Social Care](https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2021/02/independent-review-adult-social-care-scotland/documents/independent-review-adult-care-scotland/independent-review-adult-care-scotland/govscot%3Adocument/independent-review-adult-care-scotland.pdf) are likely to feature in manifestos of different political parties including the possible creation of a “national care service” (NB. this is different from the nationalisation of all social care providers).

If there was interest, there may be the opportunity to organise an online hustings with local candidates for unpaid carers to question candidates about how they will take forward recommendations of Independent Review of Adult Social Care.

**#2 Improving the Cancer Journey (ICJ) – Opportunity to form part of service user group**

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. The programme team are interested in hearing from people affected by cancer in East Lothian (patients and carers) who would be interested in helping shape the service locally.

**#3 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”. Opportunity for Carers’ Panel to shape the activities and publicity locally for this week.

**#4 Adults with Complex Needs Transformation Programme – Carer engagement plan being developed**

There is a strong feeling amongst some carers of adults with complex needs that they have not been kept informed of what is happening since an engagement meeting that caused general alarm several years ago. A key concern is the potential loss of building-based services as the programme team explores the development of alternative community-based supports to meet individuals’ outcomes. The programme team have committed to working with COEL and carers’ representatives on developing an engagement plan.

**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 curriculum for health and social care students.

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

As I understand it, ELHSCP has a Carers Change Board and Carers Reference Group to oversee the implementation of the East Lothian Carers Strategy and Action Plan. Theoretically, there should be opportunities for carers to be or have representatives on these groups. David Binnie, former chair of COEL, sits on the Carers Change Board. I believe the Carers Reference Group is currently being reformulated due to low levels of engagement in the past. There may be an opportunity for panel members to help with this and attend statutory sector meetings as carer representatives.

[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/)

**#4 COEL 5 year strategy**

COEL is due to develop a new five year strategy, which will require carer input. I am not yet clear on the timelines for this. Several factors may delay the start of this process including the recruitment of a new chair of the board of COEL.