**Meeting Note – Carers’ Panel**

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| **Title** | Carers’ Panel – Introductory Meeting |
| **Venue** | Zoom |
| **Date** | 29/01/2021 |
| **Attendees** | Agnes Stevenson, Anne Bisset, Fiona Cooper, Helen Wedgwood, Jacki Aston, Kirsteen Powell (CoEL), Michael Turnbull, Selena Kennedy, Terry Cooper |

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| **Summary of discussions** |
| **Purpose of Panel**Kirsteen stated that driving force of setting up the group was to amplify carers’ voices so that their views could influence the design and delivery of services, within CoEL, locally and nationally, to improve outcomes for carers and the people they care for.This sparked a conversation about carers not being listened to, understood or valued at different levels – by professionals, services, government and society in general.**Issues Raised****Complaints*** It can be difficult to make a complaint – knowing who to contact and how and in what format etc.
* It’s exhausting to make a complaint and carers already lack time and energy
* Carers can feel powerless when services appear to put up barriers and professionals close rank
* Carers can worry that complaining will have a negative impact on the service the person they care for receives – they can be nervous about “rocking the boat”
* It’s not always easy or obvious how to access decision makers in the complaints process
* Important to set anger aside when making a complaint/ attack the problem or system rather than the person (Michael’s point)

**Listening to, and understanding, carers*** Professionals do not really understand what it is like to be a carer looking after another person some or all of the time – the relentless 24/7 nature of the role (Agnes feels very strongly that the non-stop 24/7 nature of the role is not recognised)
* As a result, professionals can take carers’ words out of context (Agnes’ experience) jumping to the wrong conclusions, leading to a breakdown in trust
* Professionals do not routinely recognise carers’ expertise – carers often know the cared for person, and their state of health and wellbeing, better than anyone does.
* Carers are often not recognised as equal partners in care when services plan interventions
* Some professionals sometimes do not look beyond a carer becoming angry or upset to consider the truth of what a carer is trying to communicate (Anne’s point although not everyone can be tarred with the same brush – Anne has experienced wide range of responses from professionals some of whom have been very sympathetic)

**Valuing carers*** Carers are not valued on many levels – in the financial support they receive when they give up work to care, in media coverage of caring through the pandemic, in wider society.
* Carers are not being given the same priority as paid staff in the vaccine roll out

**Lack of access to respite*** Carers are struggling to access respite, particularly during the pandemic when so many specialist and universal services are suspended
* Traditional respite services cannot always accommodate people with higher levels of need (e.g. day care services being unable to support people who need assistance with personal care)
* Alternative respite options are not offered or there are long delays in accessing support (e.g. waiting for PVG checks)

**Lack of access to community-based services*** Carers are seeing the health and wellbeing of the people they care for deteriorate in the absence of leisure centres, physiotherapy, speech and language therapy etc.

**Loss of trust*** Carers lose trust after negative experiences with services and avoid asking for help from or engaging with services in the future e.g. social work

**Gap between policy and practice*** There have been improvements in some areas but there is often a gap between policy and practice (Anne’s example of the development of some support services for people living with dementia and their carers in East Lothian over the last 20 years)

During the discussion, some ideas for improving the situation were suggested:* Simple information sheet on who to complain to and how when things go wrong
* Assertiveness training for carers
* Advocacy – informing carers of their rights and how to access them?
* Increasing public awareness (how?) – case studies of carers’ experiences?
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| **Next steps/ Key decisions** |
| We briefly discussed next steps:* Agree common issues/ priorities that the group wants to work on
* Map out opportunities to influence policy and practice at different levels locally and nationally
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| **Actions** |
| **Who** | **What** | **By when** |
| Kirsteen | Organise next Carers’ Panel Meeting (consult all on choice of date and time again) | 05/02/2021 |
| Kirsteen | Circulate summary of key opportunities to influence policy locally and nationally at present  | 05/02/2021 |
| Kirsteen | Draft map of how Carers’ Panel can feed into/influence other policy development and advocacy groups | 19/02/2021 |