

15<sup>th</sup> January 2023

Dear Gillian,

Follow up to attendance at HSCS Committee, 13<sup>th</sup> December 2022

Firstly, thank you for allowing Care Home Relatives Scotland to have two members present at the session in December.

Please see below for our responses to the follow up questions.

**General hopes and fears**

How would we like organisations such as ours to be represented on care boards?

We think it would be useful for care boards to engage with care home residents and relatives and we believe that Integrated Joint Boards or Care Boards ought to have the capability to contact people in care homes and their relatives - for example to issue updates on guidance etc. and to carry out surveys on standards of service. We have constantly been told throughout the pandemic that nobody is able to contact Powers of Attorney/Guardians/next of kin yet the State is paying at a minimum, the personal care allowances for residents. They should have contact details. Care Home Relatives Scotland is a Facebook group and is not formally constituted and we have no current plans to constitute. We are not aware of any Scottish organisations such as Residents and Relatives Association England. We do not have the capacity to send representatives to care boards and fear that relatives would not sustain that commitment e.g., when their loved one dies. However, if a care home residents/relatives advocacy role were developed, for example through the care home collaborative, they could represent care home relatives on and residents on boards.

What challenges have you experienced working with IJBs?

Throughout the pandemic, we did not find the IJBs or HSPCs very willing to engage with us when we were desperately trying to enable contact with our loved ones. As guidance on family contact improved, we wanted to ensure that this information was given to all care home relatives in a timely way so they were aware of the current guidance but were always told this was not possible. As we have stated above, we would hope that the ability to email or text main contacts for every care home resident, and indeed residents themselves if they have capacity, is important to ensure everyone is aware for example of changes to guidance, allowances etc. and to seek the views of relatives and residents on proposed changes. Relatives and residents also need someone to turn to for advice and help through the process of going in to care or where difficulties arise from their placement not covered by the Care Inspectorate (e.g., when you can no longer afford the fees).

What do we understand to be the purpose and objectives of creating a national care service and to what extent are the principles in the Bill an accurate reflection of that purpose and those objectives?

We know for example that Ministers were frustrated that even when they introduced improved guidance on visiting, there were occasions when care homes and public health simply refused to implement it. We feel one of the main drivers for an NCS is to ensure that Ministers who often feel they carry the can when things go wrong, have meaningful powers not only to provide policy direction but to ensure it is implemented across the whole country. A national

service could make it clearer what standards people can expect, allow people to move between council areas etc. However, given how difficult things currently are in the sector, with staffing shortages and lack of resources, it's hard to see how simply changing the structure will result in any improvement. Will anyone get an extra hour of support because of the NCS and all that will be spent setting it up? We hope so but we are not sure.

We are also extremely disappointed that while the Bill gives a clear commitment to free personal care at home, even for millionaires, there are no plans to explore a fairer way to fund residential and nursing home care. Our relatives who need 24/7 care in a nursing home or residential home are still required to sell their homes, draw down their savings and spend everything they have on their care. The current set up is brutally unfair. 'Self-funding' residents are not only paying their own way but in the opinion of many, including care home providers, are forced to subsidise underpayment by local authorities through the care home contract - often paying double the council rate for the same care home place. Surely the Scottish Government cannot in all conscience be party to the financial exploitation of vulnerable adults in this way. As part of the preparations for an NCS, we ask you to explore fairer ways of funding that do not impact so heavily on people with low incomes but who saved throughout their lives and bought their homes. They should be allowed to retain at least a percentage of their assets or have fees capped and if they choose to do so, they should be able to purchase care home places at the same rate as the local authority.

We would also prefer to see a commitment to a mixed economy of care with much more encouragement for the not-for-profit sector. We do not believe that the whole scale privatisation of elderly care has benefited either our relatives or those who work in the sector.

### **Anne's Law**

We are unhappy with the way Anne's Law is described in the bill. Section 38 refers to Rights to breaks for Carers. We believe Section 40 should state Rights of Care Home Residents to visits in or out of the care home which would reflect the First Ministers commitment 'to allow families and friends the same access rights to care home residents as staff' (September 2021). We appreciate that the framework depends on the underlying visiting directions and we have been working closely with the Anne's Law policy team on the directions. We were happy with the last draft directions we were shown but are extremely aware these directions can be changed at any time. Our loved ones cannot survive without human contact - it is not too much to ask that some of that contact is with their own husbands, wives, son, daughter, mother or father or another essential visitor. We completely agree with Henry Simmons who spoke at the same committee that public health ignored the harms of isolation and loss of family contact. The legislation needs to make it clear that some family contact must always be enabled.

### **Unpaid carers and breaks for carers**

We welcome the improvements and commitment to breaks for carers. A huge amount of work has already been done in this area and what is needed now is implementation of the Dementia Strategy, the National Carers Strategy etc will build on this. However, please note that when a loved one goes in to care, they still have extremely close links with the carer(s) who has been looking after them for many years and the rights of family carers, those with Powers of Attorney and Guardianship need to be respected. This did not happen throughout the pandemic.

**Evaluation and sequencing**

The Feeley Review was only looking at adult care and was clear that to be a success, the NCS would need to be broadly supported across civic society - as part of a Social Covenant. At present, many key players are expressing concerns, from Cosla to the Trade Unions and other bodies. It is difficult to see right now how a timetable for implementation could be drawn up without taking some time to work through these concerns. This creates a problem for us on Care Home Relatives Scotland as we are clearly keen for Anne's Law to go ahead. However, we have never believed it was necessary to tie Anne's Law to the NCS. We would hope that if there is to be any delay, Anne's Law would progress on a standalone basis as a matter of urgency.

Yours sincerely,

Alison Leitch and Cathie Russell