

Parliamentary Clerks
Health, Social Care and Sport Committee

31st August 2022

Re National Care Service Bill consultation
Care Home Relatives Scotland (CHRS) response

Please find attached our CHRS submission in response to the NCS Bill consultation.

This submission summarises the views and experiences of our group members, focusing on Anne’s Law and the importance of family contact. We remain concerned that the right for a person in care to see their husband, wife or other essential caregiver, in the same way they have contact with paid carers, is not stated as a “right” - but simply that the Minister has the right to direct.

We reiterate that our loved ones were locked up for many months, and we were prevented from spending time with them, in some cases for up to a year, on the direction of Ministers.

Our attached submission outlines and illustrates our concerns in more detail as well as referencing the improvements that have been made, and which are much appreciated.

In addition to this, we would like to express our concern that the financial issues faced by those who require residential / nursing care are not being addressed within the Bill. We would value the opportunity to discuss both Anne’s Law and the financial issues around residential and nursing care as you consider the NCS Bill.

Our CHRS core group would be pleased to have the opportunity to meet with the HSCS committee.

We look forward to hearing from you.

CHRS Core Group

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31st August 2022

National Care Service Bill
Statement from Care Home Relatives Scotland (CHRS) Re Anne's Law

CHRS Introduction

Thank you for the opportunity to submit our comments

Care Home Relatives Scotland was established In August 2020 to support the growing number of friends and relatives who for the previous six months had been totally denied any opportunity for meaningful contact with their loved one in residential care. The outpouring of anxiety, guilt, grief, sadness, anger, despair and heartbreak has been immense. The voices of the residents in care sadly remained silent and unheard.

- Daughters were forced to watch from a distance as carers held a dying mother's hand
- Elderly husbands peered through windows to see their distressed wife reaching out for a familiar touch.
- Children and young adults were left distraught and with no comprehension as to why they were "abandoned" by their family.
- The use of prison style screens and intercom communication were cold, unfeeling and gave no comfort.
- I-pads and online communication was impossible for the many residents with no understanding of zoom calls or facetime.

Compared to the general population, residents within care home environments were considered at greater risk from the harms that any infection could present. This should not have legitimised the need for enforced restrictions or bans on freedoms, such as access to loved ones. Infection prevention and control measures, applied in the right way at the right times will keep people safe from the harms of all infections whilst protecting their human rights through compassionate care.

A person receiving care must always have some form of human contact - there should be no discrimination between care given by a paid member of staff or a family carer. Until the onset of the COVID pandemic our care homes adopted an open access policy with family and friends free to visit at all times. The need for enforcement of Anne's Law should therefore only be required in extreme circumstances e.g. during an infection outbreak or pandemic.

Our Experiences

The following quotes from our CHRS group will perhaps help to illustrate our concerns and the importance of implementing Anne's Law –

- *The only way I can get family news to my mum is to speak with the handyman / gardener over the fence – he is then able to go into my mum's room and chat with her, but I am forbidden.*
- *The girls who give my mum her care and have contact with her every day, then go home to families and husbands. I live alone but I am not even allowed to pop in to see her for 5 minutes. I'm her most important carer and would follow all the same PPE rules as the staff.*
- *In late summer 2020 when restrictions were eased for the general public, nothing changed for my Mum who has advancing dementia and is non verbal. I still had to sit 2 metres away and watch my Mum be restrained from walking towards me. A carer was able to sit next to my mum, hold her hand and attempt to calm her agitation. As a daughter first and foremost, and as power of attorney, I should have been able to do this for my Mum. The discrimination against residents was disproportionate and extremely damaging.*
- *Imprisoning my [PD] in her care home for 14 months was cruel. Having to console my distraught [PD] via facetime up to four times a day for many of those months was soul destroying. Watching her sobbing on Christmas day, while a carer who was considered less of a risk to her health than me was trying to console her, was nothing short of inhumane.*
- *I got in to see my mum for first time a few weeks ago. As you can imagine the half hour went like 5 mins. I've hardly slept a wink since. I'll never forget the look on her face when they came to take her away. She broke down in tears and begged them to let her give me a cuddle. Two of them one on each arm basically dragged her away in tears like prison wardens.*
- *Having to fight for this pitiful excuse for a one time internal 15 minute Christmas day visit, just inside the front door area of the nursing home, is absolutely 100% against human rights and needs to end now!! Staff member on duty at all times and clock watching to ensure I'm there not a minute past my 15 minutes.*

Positive progress

We are aware that within the recently updated Health and Social Care Standards (31st March '22) a commitment was made to ensure a nominated relative / friend would always have contact with a care home resident when routine visiting is restricted because of infection.

- Health and Social Care Standards –5.16 *I am an adult living in a care home and restrictions to routine visiting are needed to prevent infection, I can nominate relatives/friends (and substitutes) to visit me.*

The current care home guidance states that if a home is experiencing infection outbreak conditions, “Providers” should implement their policy of facilitating one designated visitor per day. We agree that this should indeed be the default position.

We also understand that Anne’s Law will give Ministers the power to set “Directions” which will determine in more detail how providers are to facilitate visiting and enable residents to maintain contact with the people who matter to them. This is a welcome addition, as experience following the recent pandemic demonstrated reluctance from some care homes and Public Health teams to implement updated guidance on a consistent basis.

Our Concerns

Human and Equality Rights

Residents’ human and equality rights must be respected at all times by recognising the section 5.16 within the Care Standards. This simple message must not become lost within the plethora of revised guidance documentation or possible changes made to any ministerial directions.

Option to Suspend Designated Visitors

The ability by a “Competent Person” to suspend Designated Named Visitors in certain circumstances, and the emphasis on requiring individual risk assessments, is concerning. Our experience during the recent pandemic made us very aware that there was little time or capacity to assess individual residents, and inconsistent guidance was applied by the various “competent bodies” expected to provide support and advice to the care homes.

Adults with Incapacity

Adults with Incapacity (Scotland) Act 2000 safeguards the welfare of adults over the age of 16 who lack the capacity to make their own healthcare decisions. Many care home residents will fall into this category i.e. mental health needs, frailty, or with Adults with Incapacity (AWI) section 47 treatment orders in place.

For these vulnerable residents, it is absolutely essential they have regular contact with family, their Power of Attorney or Independent Advocacy to ensure fair decision making and good care. Restrictions imposed during the COVID pandemic resulted in harmful isolation policies, with family carers prevented from carrying out their vital advocacy roles. This underlines the importance of having Anne's Law in place and the need to consider Infection Prevention Control (IPC) measures as the enabler for meaningful contact, rather than the barrier.

The Carer's Scotland Act 2016 (revised 2018) recognises that unpaid family Carers have a right to receive assistance in their role. This support should continue even if their loved one requires 24 hr care, but again this was not recognised during the care home restrictions.

Summary

Whilst we welcome the ability of Directions giving powers of enforcement to Ministers, we continue to have grave concerns that within the Ministerial Directions for Anne's Law, the commitment to ensure care home residents will never again endure enforced separation and isolation could become diminished within the numerous caveats and possible changes to Directions.

As we have stated on numerous occasions, being a care home resident necessitates regular and close human contact for personal care requirements. That essential contact must also continue between husbands, wives, mothers, fathers, family members or close friends.

For clarity, we would request that the default position should be the resident's right to contact with their nominated relative / friend at all times, and if necessary, by following any recommended PPE precautions as per care staff. We must be recognised as a vital part of our loved one's care team.

On 7th September 2021 the First Minister stated in Parliament –
"We will introduce Anne's Law giving nominated relatives or friends the same access rights to care homes as staff".

This right cannot be diluted in any form. Residents must never again be cut off from those most important to them.

Sent on behalf of Care Home Relatives Scotland

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