

The National Care Service Charter of Rights and Responsibilities

Established in 2019, About Dementia is Age Scotland's Policy and Practice Forum for People Living With Dementia and Unpaid Carers. As a project which has been heavily invested in the creation of the National Care Service, we welcome the opportunity to respond to the National Care Service Charter of Rights and Responsibilities. About Dementia takes a Human Rights based approach to working, and this submission is informed by discussions at our Human Rights of People Living With Dementia and Human Rights of Unpaid Carers working groups who meet on a monthly basis.

In recent years, our core activity has focused on both of our lived experience Human Rights groups, creating a safe space for people living with dementia and unpaid carers respectively. Members work together to highlight the impacts to their human rights by sections of society. Both groups have been actively engaged with influencing our response to National Care Service and our submission for the new National Dementia Strategy. We have also explored particular policy areas through a number of thematic 'sub-groups'. The groups gathered evidence and proposed policy improvements around the following: Housing, Transport & Mobility, Human rights of Unpaid Carers, Prevention & Living Well, Technology, and Befriending & Peer Support. Our response is founded on the evidence gathered and stories shared by voices of lived experience.

We are encouraged by the progress and development of the Charter thus far and acknowledge the commitment to co-design, however, we are concerned that such a charter may not be enforceable if it is not included in primary legislation. We would urge that considerations be made to ensure The National Care Service Charter of Rights and Responsibilities does not simply become guidance, but binding statute which will produce genuine recourse should those rights be breached.

What other rights would you expect to have when you are accessing or using NCS services?

We commend the existing list of rights put forward. We believe that a National Care Service built on the ability of citizens to uphold their rights must be at the heart of this charter.

About Dementia would propose the inclusion of the following additional rights:

The Right to dignified treatment and care.

At the core of the National Care Service must be an individual, person-centred approach to the requirements of the people it serves. The right to dignified treatment and care must be a thread running through all rights within the Charter. Throughout our engagement, we have been reminded that high-quality and person-centred care can and should be delivered in every element of social care. This approach should be practised in every task, from consulting and ensuring the cared for person receives a cup of tea according to their preferences, all the way to delivering personal care which upholds the privacy and respect of individuals. We believe that access to appropriate person-centred and personalised social

care is an important solution to enabling people living with dementia to access their rights and live with dignity. In the words of one carer, *'it's not about any care, it's about the right care'*.

The Right to available and relevant information.

At an engagement session we delivered in Stirling, when speaking with professionals and people with lived experience of dementia, one unpaid carer stated that the biggest barrier they faced when trying to obtain support and care was the lack of access to relevant information. This has been a common theme throughout our engagement with unpaid carers and people living with dementia, who are often unaware of how to initiate the process of care assessments. Many experience delays in allocation of a social worker, delays with the assessment process itself, and limitations in support between assessment and a package of care commencing.

Those who have been able to access information often find the details and signposts are outdated, not inclusive, or difficult to utilise without assistance or technology. We believe that accessible information is a vital prerequisite to a citizen's ability to access services they are entitled to.

The Right to complain without fear of reduced support.

During our engagement around the new National Dementia Strategy, we ran several workshops on hospital treatment and complaints procedures. Many spoke of heavily weighing up the risk of *'being labelled a complainer'*, and worried that it may reduce the level of care they were receiving. The expression of a fear of services being disrupted or delivered to a lesser extent was felt by both People Living With Dementia, and Unpaid Carers. Whilst their concerns may never come to fruition, any Charter should take steps to actively mitigate such concerns. We ask that the Charter protects the right to complain, and that steps are taken to ensure the fear element of complaining is removed from the equation.

The Right to access preventative social care at the earliest possible point.

At the heart of Feeley's recommendations was the desire to view social care interventions as preventative, however current eligibility criteria act against this. We regularly hear from people living with dementia who share that they are unable to access social care in their area as their needs are not yet high enough. We have spoken to several unpaid carers, who told of being unable to receive care packages for their loved one at home, only achieving access to social care as a result of care home admission. A crisis-driven approach to social care is not only costly to the public purse, but also leads to poorer outcomes for people who have cause to draw on support. A preventable move into more intensive forms of social care such as care home admission can result in a significant loss of independence for individual and lead to harmful and premature separations of families, as well as having a significant financial impact. We also call for the introduction of a fairer model of funding of long-term care.

The Right to access to personalised, high-quality care in order to meet identified needs.

As with preventative care, personalisation was an important theme in Feeley's recommendations. Throughout our work About Dementia have highlighted Self-Directed Support (SDS) as a mechanism to achieve person-centred and timely care. However, we have been repeatedly told of the barriers people face in accessing SDS due to assumptions around capacity, and restrictive local eligibility criteria. The confusion around SDS, from both the people who try to access it and the people who hold such access, contributes to an implementation gap in delivery. If people living with dementia and unpaid carers had access to SDS earlier and with full choice, we are of the belief that many crisis points could be avoided. Truly personalised care may be the key to improving quality of life and maintaining connection, we believe that personalisation must not simply be an aspiration but should be the minimum that all those who have need to draw on support can expect. As we have noted, the legislation to achieve this already exists, but there has been a significant gap in implementation. The NCS must work to address this.

The Right to be involved in the design of services and strategic decision making as a full voting member.

We welcome the commitment to co-design in the approach being taken to the NCS. However, we believe that this is too important a principle to leave to chance. We are designing an NCS not just for today, but for the future. Co-design will be important therefore at every stage in the running of the NCS, and the right of citizens to be involved in this must be enshrined in such a way that this cannot be subject to change in government administration. We also advocate for co-design to be a continuous process including the involvement of people with lived experience in designing and carrying out any evaluation work around the NCS.

The Right to Privacy and Home Life

As we have detailed, the right of people to be involved in the design of services is key, however we propose that involvement in delivery is just as important. Many unpaid carers we engage with speak of a lack of privacy when social care package starts, this can lead to feelings of being 'pushed out' or losing the feeling of home life altogether. Unpaid carers have expressed having little time to adjust to the influx of paid care staff and equipment, with one informal caregiver relaying this initial period felt like a '*tsunami*'. Adjusting to sharing care with paid carers can be an unsettling time for informal caregivers, with some communicating they felt there had been a lack of consideration shown towards them and their prior family relationships. Many unpaid carers spoke of having to fight to be seen as an equal partner in care and battling for their insight to be recognised. Whilst there is no doubt that the social care workforce are under immense strain, respect for privacy and home life should not be sacrificed in the aim of saving time or delivering standardised care. To give truly person-centred care under the NCS, the pace in which social care is currently delivered should be reviewed. Insufficient time frames of care can result in subpar experiences for people living with dementia, too often settling for care visits at inappropriate times, such as very early morning for breakfast visits or too early in the evening for bedtime support.

During recent engagement around the new National Dementia Strategy, we were given a shocking example of a person living with dementia being asked to eat their breakfast on the toilet, to allow for personal care to be given within the same short care window. Disruption to home life can add to carer stress, leading one unpaid carer to remark that 15 minute care windows can be the equivalent to *'sticking a pin in a balloon'* with unpaid carers spending hours to deescalate the aftermath.

In these circumstances, small windows of time for care visits are not time and cost efficient but instead offer a false economy, as they may contribute to the distress of a person living with dementia by upsetting or rushing their home routine, potentially escalating the likelihood of care home admission. The examples shared illustrate how significantly the privacy and expected home routine of both unpaid carers and people living with dementia can be impacted in favour of time-saving measures. We would urge that any Charter of Rights under the NCS gives emphasis to ensuring respect is given to the privacy and family life of the people it serves.

The Right to a Social Model of Social Care

About Dementia adopts a Social Model approach to dementia. The social model is drawn from an understanding that the challenges faced by people living with dementia are often caused by the organisation and structure of support, rather than from the disease itself. Our engagement throughout the course of our project has revealed concerns that taking a strictly medical approach to dementia can be de-personalising and lead to the individual being overshadowed by their disease. This is not to say that we do not accept the need for medical intervention, particularly in the later stages of dementia. However, when designing a Charter of Rights for the NCS, we offer a reminder of Feeley's recommendation, that we should not be aiming to formalise or medicalise social care (Feeley, 2021). All people living with dementia are entitled to excellent care and treatment, with as much choice and involvement as possible. As such, the overarching view is that taking a social model approach enables one to see a person with dementia as an individual and reframes opportunities to engage in therapeutic and social activities. An NCS which envisions the ability for people living with dementia to live well will only be realised if underlined by a Right to a Social Model of Social Care, with interventions through social prescribing such as Playlist For Life or Peer Support initiatives. Such interventions can help to enable people to live active, connected lives following a diagnosis, which can help them to remain well for longer. Such an approach also creates room for individuality within the workforce, with paid carers being able to draw from their own holistic skill sets to deliver truly person-centred care. This approach may also enhance the visibility of dementia and reduce the stigma that continues to be associated with it.

What would a Charter need to tell you to support you when you're trying to access or using NCS services?

Throughout the lifespan of our project, request for information around rights and services has broadly fell into two categories: information on what you are entitled to, and information on what to do if things go wrong. No dementia journey comes with a road map, and as such, many people learn by trial and error, often only discovering rights and entitlements long after the opportunity has passed. Having accessible, jargon-free information on entitlement, that can be accessed at any point, is vital. Equally, when things do not go to plan, there must be clear guidance and signposts of who to turn to for independent advice. We put emphasis on the independent nature of this advice, as many unpaid carers and people living with dementia speak of avoiding complaints due to fearing recourse or subpar care as a result of raising issues directly with care providers.

In our view, there is only so much supplementary advice and guidance that can be effectively given to successfully aid access to NCS services. It is less of a question of what a Charter can say, more a question of how information can be relayed in a manageable way and at a digestible time. In recent engagement, this sentiment was expressed succinctly by one unpaid carer, who noted 'information is only useful if it's relevant'. On a related point, both unpaid carers and people living with dementia have spoken of being inundated or overwhelmed with information in initial stages post-diagnosis. To aid access to appropriate NCS services, we would recommend that people are supported through this process by independent advocacy, preferably with advocates who specialise in dementia. Being supported by an advocate may mitigate some of the stress, confusion and misplaced guilt that can be felt during this time. Additionally, with the guidance of an advocate, people may be signposted to services that are more suitable for their longer-term support. We have observed the painful abandonment that can occur when services pull back or are stopped due to increased care requirements of the individual. Sensitively delivered and independent advocacy, that can be accessed at the start of a social care journey and irrespective of the options chosen, may support transitions through care and better prepare people for an uncertain future.

What would the Charter need to contain or be like to help support people living with Dementia in particular?

As we have detailed above, all people who draw on social care and unpaid carers should be given access to independent advocacy and advice under the National Care Service. We ask that the charter provides its citizens with access to independent advocacy to ensure that every right under the charter can be upheld and enforced, as well as assistance should there be a breach. This very mechanism was recommended by an unpaid carer during our National Dementia Strategy engagement, recommending that advocacy started as an automatic right by default when seeking social care. It may also be worthwhile to better publicise the Charter and rights a citizen holds under the Charter, perhaps providing a printed copy when citizens first come into contact with the NCS.

Advocating on behalf of someone living with dementia requires additional skills and competencies that generalist advocacy services may not have access to. At present there is a stark lack of specialist independent advocacy for people living with dementia. As a result, advocating on behalf of people living with dementia often falls to carers. This places a lot of pressure on family members who may not be fully aware of their own rights and entitlements.

As part of our response to the National Care Service consultation and the Feeley Review, we have called for the provision of dementia specialist independent advocacy to be available at all points during the dementia journey to empower individuals to express their wishes and preferences. We reiterate that call here.

An easily digestible Charter which has a clear pathway to enforcement will also be crucial to ensuring advocacy and proper implementation. Awareness and education on the charter is important for everyone in Scotland. We would also like to see that staff are given adequate training and awareness around these rights, and that they are also given a clear route to report a breach of the charter.

What other responsibilities would you expect to have when you are accessing or using NCS services?

Taking a human rights based approach to social care necessarily frames social care as an enabler of citizenship, in a similar way for example to social security. While we acknowledge the need for citizens to hold responsibilities or duties under citizenship, we would like to shine light on the significant power differentials in place between a person in need of care, and a service able to provide care. Whilst there is a need for those drawing on social care to meet certain eligibility, the weight of responsibility to ensure dignified, well rounded and person centred care should fall more heavily on those delivering the services. We believe the charter of rights must therefore emphasise the rights of people who have cause to draw on social care support, and the responsibilities of those charged with providing this and enabling those rights. Social care must be seen as a mechanism to enable people to achieve full citizenship, to enable their rights. As it was well expressed by activist Kiana Kalantar during the National Care Service Forum in Perth earlier this year, the conversation must change:

“We shouldn’t be asking, what is the bare minimum people need to survive? Rather ... what support do people need to thrive and enable their best lives? On paper, I have Human Rights. In reality, I can’t access those rights. We need change”.

Duties or responsibilities must therefore not be expected as a pre-requisite to enjoyment of rights, though they may be applied after full citizenship has been attained.

We believe that under the current system this balance is not working in the citizen’s favour. Our response to the Independent Review on Adult Social Care in 2020 highlighted the problematic nature of shifting responsibility onto citizens. Many unpaid carers and service users shared challenges of managing the reporting requirements of their care, in ways that were often disproportionate to the service being received. Unpaid carers managing SDS

Option 1 packages described being expected to meet reporting requirements that were more akin to procurement processes for large public sector contracts, than small enablers of daily life. The same informal caregivers shared examples of being penalised for making mistakes when reporting due to lack of awareness and support, fearing certain options would be removed from them and the person they support. Shifting responsibility onto the citizen, which often falls on an unpaid carer if there is a diagnosis of dementia, places another unnecessary task on their roster.

Where possible, responsibility to enforce rights and services should fall on those providing services, rather than on users, or unpaid carers. Many of whom may not yet be fully aware of their rights, or the benefits they are entitled. This knowledge imbalance cannot be taken advantage of by services, and thus the responsibility on the user should be considerably lower than that on the services.

As we began our response, we were encouraged by the approach taken of the co-design team by ensuring the National Care Service is underpinned by a Charter of Rights. However, we still share some reservations as to how much power such a Charter can wield in reality. All people living in Scotland already hold human rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Convention on Human Rights (ECHR). Existing legislation which should already protect, amongst others; the right to private life and family, right to freedom from inhuman and degrading treatment, and the right to live independently and be included in the community. Although, as we have seen from recent proposals by the UK Government to replace our Human Rights Act with, as our members felt, a much reduced UK Bill of Rights, hard fought rights are still under threat. In such a climate, coupled with an ever-growing implementation gap, the introduction and realisation of additional rights by way of an NCS Charter may seem unachievable for some.

Yet perhaps for rights to be met, we should recalibrate how we want rights to be exercised and utilised. As we have noted, the responsibility of rights realisation often falls to the people drawing on social care support, often feeling as though they have no choice but to use rights as a tool of accountability. Throughout our extensive engagement, we have found a strong awareness of the challenges facing the social care workforce. A key realisation of our human rights group has been their belief that rights are often impacted through lack of awareness, rather than intent. If we were to instead consider realisation of rights as a joint venture to work towards between all involved, including people who draw on care, unpaid carers, and paid carers, we may reframe rights as a growing goal we should always be looking to move closer to. Using this framework, a Charter of Rights under the NCS moves from a negative tool of punishment to a collaborative plan between equal partners. When adopting such a lens, the NCS Charter could offer an effective mechanism to ensure regular conversations around rights and outcomes are built in to care plans, promoting a linear approach to rights realisation.