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Health, Social Care and Sport Committee
The Scottish Parliament
Edinburgh
EH99 1SP

Via e-mail only

16 January 2023

Dear Convenor,

Please accept my sincere thanks for the opportunity to provide evidence to the Health, Social Care and Sport Committee on Tuesday 13 December as part of the Committee's Stage 1 scrutiny of the National Care Service (Scotland) Bill. It was a welcome opportunity to highlight the impact of the proposals for the National Care Service on people with dementia and their carers.

Further to the evidence presented in person, please find attached a copy of Alzheimer Scotland's report on the delivery of the 'Time For You' fund. This report highlights the successful provision of carer funding directly to carers and the creative and innovative approaches used by carers to meet their individual needs.

Additionally, please find below responses to the supplementary questions posed by the Committee in regard to the proposals put forward in the National Care Service (Scotland) Bill:

General hopes and fears

- **How would you like organisations such as yours to be represented on care boards? What experiences have you experienced in working with IJBs? What lessons would you draw from these experiences for the creation of a national care service?**

Representation is vital in the delivery of care boards that are designed to plan and respond to the needs of individuals and communities. Alzheimer Scotland believes that care boards must ensure that key stakeholders are represented to provide appropriate direction and influence in how the care boards identify and meet the needs of their local populations. As the National Care Service moves forward, lessons must be learned from previous attempts to integrate health and social care at a local level, and the experience of Integration Joint Boards (IJBs).

Third sector organisations are currently represented on IJBs but do not hold voting powers which makes their contribution to the work of the boards less impactful on the decision-making process, particularly around the commissioning and evaluation of services. Alzheimer Scotland asserts that the third sector brings high-quality, specialist knowledge and understanding of the issues affecting individuals and brings many solutions to challenges within the health and social care sector. Local care boards, as well as

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national special care boards, must enable third sector providers to inform their processes for decision-making and enable third sector providers to participate in care boards and special care boards as full and equal partners. Alzheimer Scotland is committed to enabling the voice of lived experience to be at the heart of everything we do as we strive to improve the lives of people with dementia. With the support of over 9,000 members and ongoing support for the work of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), Alzheimer Scotland believes that we can represent the collective interests of people with dementia and their carers on care boards and special care boards across Scotland, promoting the principles-based approach needed to meet their specific needs. A collaborative approach to local planning and delivery of social care services will ensure that the most robust and transparent process is adopted in respect of decision-making.

The legislation, as it is set out in Part 1, Chapter 1, section 4 and in Schedule 1, Part 5, does not make specific provision for the inclusion of third sector organisations or for people with lived experience to form part of the membership of the proposed care boards. Alzheimer Scotland has previously highlighted that this would present a missed opportunity for the legislation to establish a clear acknowledgement of the value of third sector organisations and the need for the voice of lived experience to be represented on care boards and special care boards.

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

Alzheimer Scotland welcomed the recommendations set out in the *Independent Review of Adult Social Care* when it was published in 2021, including the proposals for a national care service, and the commitment to implement those recommendations in full. We recognised the challenges of delivering effective social care designed to meet the needs of individuals and specific communities at that time and believe that the Review presents a compelling and transformative vision for adult social care in Scotland.

The principles of the National Care Service set out in the draft legislation reflect the values of Alzheimer Scotland. We support a person-centred, human rights-based approach to the delivery of adult social care services that meets the needs of individuals. We encourage the promotion of equality and human rights across all parts of the social care sector and acknowledge the need for a paradigm shift in how we view and value social care support.

We maintain the position that the National Care Service should be regarded as a social investment designed to promote positive outcomes for people and communities. We believe that it is important that the National Care Service is adequately resourced and funded to be able to deliver on its aims and achieve positive outcomes for individuals across the whole of Scotland guided by sound principles and that its measure of success is based on wellbeing and quality of life rather than monetary terms of reference.

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- **Are the principles in the Bill suitably aligned with the principles in other legislation and policy such as that relating to Self-directed Support and health and social care integration?**

Scotland is internationally recognised as having some of the most progressive national dementia policy across health and social care. Alzheimer Scotland agrees that the principles underpinning current health and social care legislation are consistent to the degree that they seek to achieve an improvement in the experiences of people accessing those services through a human rights-based, person-centred approach.

However, progress in the implementation of key national policies has been inconsistent, or, in some cases, simply not delivered. While the COVID-19 pandemic highlighted the shortcomings in the delivery of policy objectives, the gaps in implementation and outcomes existed before the COVID-19 pandemic. Failure to deliver policy aims and objectives results in negative outcomes for individuals and communities which undermines the principles of respect, equality and dignity regardless of the intention behind the policy. More must be done to effectively enact and implement policy to ensure that the underlying principles form part of individual experience and outcomes.

The introduction of the National Care Service (Scotland) Bill coincides with a period of significant change across various parts of legislation and policy that will have an impact on how the National Care Service will be delivered. Alzheimer Scotland believes that all of the legislation and policy approaches must work cohesively alongside each other. This will enable the development of a consistent and supportive network of policy and legislation that governs the delivery of services across the health and social care sector.

Anne's Law

- **What is your understanding of why the Anne's Law provisions of the Bill as introduced might not afford a named family member or friend the same access to a loved one as a staff member?**

Alzheimer Scotland supports the introduction of Anne's Law as a way to embed a legal right for family and friends who care for, and about, those closest to them to be considered as equal and full partners in care. Alzheimer Scotland has supported calls to establish a legal right for care home residents and a named person to continue to have the opportunity to have meaningful contact during a crisis, such as the COVID-19 pandemic. We have supported dialogue with the Scottish Government and key stakeholders to recognise the harm that people living in care homes and their families experience when they are not able to be in with, and engage with, the most important people in their lives. Key family members are not "just visitors" but a crucial part of an individual's care team and vital to wellbeing for both the resident and their family.

Lessons must be learned from the experiences of care home residents and their families who were kept apart during the pandemic. We call for assurances that, even in times of a public health emergency,

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there is a greater balance between protecting people from illness and the harms caused by the restrictions such as those seen in care homes across Scotland during the pandemic. Denying care home residents the right to contact with their loved ones contradicts the principles of a human rights approach which underpins the principles of the Bill.

The Scottish Government has indicated that the key principle of Anne's Law may be superseded by Public Health Scotland in the event of a public health emergency. The right of Scottish Government Ministers to issue directions that can override the rights of a named family member or friend to access their loved one in a care home in the event of a further pandemic means that individuals may experience the same trauma that this legislation seeks to eradicate. This dilutes the purpose of this legislation and safeguards need to be established to ensure that care home residents and their families are assured of essential contact, even under the most difficult circumstances. People with dementia do not have time to lose and every contact is valuable and irreplaceable.

While we accept that it is difficult to fully anticipate the implications of future pandemics, steps must be taken to plan for all eventualities and to consider all opportunities to address the challenges that might arise under pandemic conditions. This includes considering the viability and sustainability of the existing landscape of long-term care. We believe that now is the time for a rigorous debate and discussion about the future model of long-term care when we now know the added risks of group living when pandemics emerge.

Unpaid carers and breaks for carers

- **To what extent are you satisfied that these proposed amendments to the Carers (Scotland) Act 2016 alone will be sufficient to support people in their caring roles? Are other amendments required to the Bill to strengthen support for carers, considering the invaluable contribution they make?**

Alzheimer Scotland recognises that family and friends who care for people with dementia make a substantial contribution to meeting their needs yet are rarely, if ever, acknowledged as equal partners in care. We believe that they should be recognised and valued for the role that they play in supporting people with dementia. We also recognise that fulfilling that role is not without its challenges, and there needs to be a wider recognition that carers deserve to have their own needs met.

Alzheimer Scotland fully supports the Bill's inclusion of a right to breaks from caring. Furthermore, we support the rights of carers to have choice about how their needs are met, and to exercise power and control over how they use the opportunity to have a break from caring. Supporting carers must reflect the varied needs of carers and how they will best experience the offer of support. A 'one size fits all' approach to providing respite does not provide the flexibility that carers need when addressing their need for a break from caring and a more creative and innovative approach to carer support is required, as highlighted through the evaluation of the 'Time For You' fund. Carers must be fully engaged in determining how support will best meet their needs.

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Additionally, the financial impact of breaks from caring must be considered and adequate funding must be provided to support carers to access respite or other means of assistance.

Alzheimer Scotland supports the wider recommendations of the *Independent Review of Adult Social Care* relating to the rights of unpaid carers, and believes that issues raised in the Review including the provision of support to access employment, education and social connections while providing care; appropriately addressing the financial implications of caring; and, the provision of support to return to employment or education at the end of caring must be addressed. The impact of caring is felt across all parts of carers' lives and support for carers must involve a more holistic approach than a single-faceted approach to the provision of respite.

Evaluation and sequencing

- **What would be a realistic timescale for the key provisions of the National Care Service Bill to be implemented and what should be the order of priority in implementing those provisions?**

The key provisions of the National Care Service must be implemented as quickly as possible to address the existing challenges currently being experienced across the health and social care sector. Steps must be taken to ensure that individuals accessing health and social care services experience high-quality care and support and that they are able to exercise choice around the services they access. Issues affecting the effective delivery of current health and social care services must be addressed concurrently, including issues around workforce development, effective commissioning and the availability of funding and resources.

The delivery of much of the National Care Service through secondary legislation and with the participation of key stakeholders, including individuals with lived experience, in the development and design of that legislation means that timescales must reflect the time necessary for meaningful engagement. The delivery of timely secondary legislation can, and must, be supported by a strong, clear and detailed framework of primary legislation that sets clear structures for the delivery of the National Care Service. This will enable design and development processes to be robust and streamlined and will allow a more seamless transition to the delivery of National Care Service functions following the completion of the drafting of the secondary legislation.

Nonetheless, people living with dementia, and those caring for someone with dementia, do not have time to wait for improvements that the legislation seeks to deliver. People living with dementia and their carers need an immediate response to alleviate the pressures and challenges that they are experiencing now. With the implementation of the National Care Service still far away, it is important that these issues are addressed ahead of the implementation of the National Care Service.

Progress in the local implementation of key national commitments outlined in the national dementia strategy and other health and social care legislation remains inconsistent despite promises to deliver existing policy aims, objectives and outcomes. We call on the Scottish Government to adopt the agreed

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principles to implement existing legislation and policy to enable the delivery of services and resources that best meets the needs of individuals, and to bridge the gap between policy and practice.

I hope that this additional information is helpful to the Committee as it continues its scrutiny of the National Care Service (Scotland) Bill. If you require any further information, then please do not hesitate to contact me.

Yours sincerely,

A handwritten signature in black ink that reads "Henry Simmons".

Henry Simmons
Chief Executive