

Alzheimer Scotland

Scottish Government – Carers Charter

Introduction

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

Alzheimer Scotland supports the National Dementia Carers Action Network, a group established in 2011 a national campaigning and awareness raising group whose members all have experience of caring for someone with dementia. Alzheimer Scotland also supports local networks of carers across Scotland, to help influence and inform decisions which will affect them.

Alzheimer Scotland welcomes the opportunity to contribute to this consultation response on the Carers Charter, as part of the Carers (Scotland) Act 2016. Our response has been informed and written around the experiences and views of carers of people with dementia.

General Comments

Alzheimer Scotland broadly welcomes the creation of the Carers Charter as part of the Carers (Scotland) Act 2016. We recognise the value of such Charters in acting as instruments of change to improve the experience of people being supported by health and social care services.

Since its publication in 2009, Alzheimer Scotland has encouraged the use of the Charter of Rights for People with Dementia and their Carers, advocating for its use as the basis of policy and practice for people with dementia, their families and carers. The Charter is an articulation of existing rights of people as enshrined by both domestic and international legal framework, aiming to:

- Empower people with dementia and their carers to assert their rights in every part of their daily lives and wherever they are.
- Ensure that those who provide health, social care and other services understand and respect the rights of people with dementia and their carers.
- Ensure the highest quality of service provision to people with dementia and their carers.

This document is the foundation of much of Alzheimer Scotland's campaigning work, therefore we recognise the importance of an accessible summary of a person's rights. It also contains reference to the PANEL principles (Participation, Accountability, Non-discrimination, Empowerment and Legality), which can help explain how a rights-based approach should be applied in practice. It would be useful for the Carers Charter to use the PANEL principles.

We believe that within the Charter, there should be clear links and reference to carers' entitlement to support and the relevant legislation or policy, including the Carers (Scotland) Act 2016, Social Care (Self-Directed Support) (Scotland) Act 2013, Scotland's National Dementia Strategy (2017-2020) etc. This does not require a detailed account of the relevant policy, however, it should allow carers to more easily understand and articulate their right to support.

Alzheimer Scotland's response to this consultation is broken down into the themes which were raised by the carers we worked with, broadly in line with the sections of the Charter. Whilst some of the issues raised within this response may be outwith the scope of the consultation on the Charter, if these issues are not resolved, the purpose and usefulness of the Charter will be impeded and will not improve the outcomes for carers.

Adult Carer Support Plans (ACSPs)

Carers welcomed the broadening of the definition of a person who could be recognised as a carer. It was felt this would be particularly helpful where more than one person has a caring responsibility, for example, where family members may be sharing caregiving responsibilities. Additionally, carers shared with us that they welcome the inclusion of a need to recognise and consider the extent to which a carer is able/willing to give support.

Alzheimer Scotland understands that there is an increasing expectation that unpaid carers will continue to provide unpaid care on an ongoing basis, particularly when the needs of cared-for persons are being reviewed. Not only is it unfair for professionals to make this assumption, it fundamentally fails to take into consideration the ever-increasing workload and associated affect this inevitably has on the health and wellbeing of the carer. This is especially true for carers of working age who may have to manage working and family, in addition to their caregiving role.

A notable omission from the Charter is the lack of reference to review of the ACSPs. Whilst we understand that the regulations in relation to this point have been subject to recent consultation, the right to a review of the ACSP and the carer's circumstances is a point which has been made strongly by carers. Additionally, carers shared that their 'personal outcomes' change over the course of their role, particularly as the person with dementia's condition progresses and their caregiving role changes. It is therefore imperative for references to the review of ACSPs be included in the final Charter. As part of this, the 'personal outcomes' definition should be altered to reflect that they are subject to change over the person's time as a carer and should be reviewed as part of the ACSPs.

Another point of concern Alzheimer Scotland identified during its engagement with carers is the number of carers who were uncertain as to whether they had received a carers assessment. We believe that as part of implementation of the Carers (Scotland) Act 2016, professionals should be clearer in their communication with carers about the process of assessment (both for the cared-for person and the carer themselves) and what has been done. Accordingly, we would welcome this being included within the Charter itself.

Support as a Carer

Carers expressed a number of areas of concerns with this section of the Charter, expressing frustration at the gap between policy and practice in Scotland which means that people often do not get the support to which they are entitled.

There is a particular concern with local eligibility criteria as carers often experience minimal support, with anxiety that they will be left in situations where they are vulnerable, as thresholds for support may be set above the point that individuals feel they are able to cope with their caregiving role. Whilst we understand that the scope of the Charter cannot influence local eligibility criteria and that the primary legislation has a limited specification of what local authorities must provide, this section should be revised to provide a greater focus on what support must be provided universally (e.g.

information centres), in addition to reference to what may be provided subject to meeting local eligibility criteria.

A common theme expressed by carers is that their 'choice and control' is limited by local eligibility criteria; carers who had received carers assessments felt that their needs had not been fully met and that they were offered what was available rather than given a real choice. This is also often true in places where services are being reduced and/or where recruitment issues exist, with care and support provided on the basis of what is available as opposed to what best suits individual need. A specific example of this is in relation to short breaks, the cost and availability of which are often variable and sometimes prohibitive.

The reference to short breaks in the section is welcome, with carers sharing that the formality of a break from caring isn't always what carers were looking for; a break may be a break from a routine, not necessarily from the person that they care for. Carers welcomed the acknowledgement of other agencies/organisations being able to offer breaks – particularly if they were able to deliver a higher quality, more quickly than social work services. In relation to bookable places for respite, carers felt that this was an important but that having the right did not help if the practical application would negate its benefit. For example, it does not necessarily benefit the carer to know they can book a holiday in advance if they do not know where the cared-for person will be placed, as this will add to the stress of the carer.

Self-Directed Support (SDS)

Related to the above points on support for a carer, we believe the Charter as a whole is limited in its articulation of how carers may go about exercising choice and control over the supports and services they receive. Whilst it is welcome that SDS is mentioned, the extent to which it can radically change the way in which carers can exercise choice and control over the support they receive is not emphasised; as this document is about informing carers of their rights, we believe this is a missed opportunity to help ensure carers are aware of this kind of support.

Specifically, Section 2 (Adult Carer Support Plans) does not talk about SDS, with no suggestion that a carer could get a budget in lieu of traditional social care services and that this could be identified and discussed as part of the process of assessment. Similarly, Section 4 (Support as a Carer) only mentions SDS as a footnote, with no detail about how the process works, the different options and the way in which carers could utilise this. Additionally, there is reference to short breaks being an option, with no description of how people may exercise flexibility and control over this. Whilst we appreciate the full detail cannot be included in the Charter, the implementation across Scotland has been particularly variable, with many people still not aware of their options. We therefore believe the Charter could helpfully raise awareness and empower carers to ask for this kind of support.

As the charter is an affirmation of the rights of carers, and given the SDS legislation is grounded in a human rights-based in approach, we believe there must be more explicit reference to the ways in which carers can exercise choice and control, with SDS being a key mechanism to achieve this.

Carer Involvement in Services

Alzheimer Scotland fully supports the inclusion of this section and believe this fits in with the wider policy agenda in Scotland to enable people who use services and their carers to be involved in the decisions which affect them. However, we are aware that there is significant variation in the quality of involvement and engagement by local authorities, health boards and Integrated Joint Boards

(IJBs), both strategically and individually. This was highlighted as part of the Scottish Parliament's Health and Sport Committee inquiry into how well IJBs were fulfilling their obligations to involve people with lived experience and stakeholders in decision-making processes.

Although appreciating that it is referencing the primary legislation, it is unhelpful for imprecise language such as 'take such steps as they [local authority] consider appropriate' in relation to the involvement of carers in planning and evaluation of services. It would be useful for the document to set out how these different bodies may be held to account if it is felt that they have not sufficiently involved carers in the decision-making process. Additionally, reference to a rights-based approach (possibly the PANEL approach), as well as obligations for consultation in the Public Bodies (Joint Working) Act 2014 and the Community Empowerment Principles, would empower carers to better understand and articulate their right to be involved.

In this section, we believe the wording of section C (related to the assessment of the cared-for person) should be amended. As with sections 2 and 3 of the Charter, the local authority has a responsibility to consider the ability of carers to provide care, in addition to their willingness and intention to provide care. This is crucially important, both to avoid carers having their health and wellbeing irreparably harmed and to avoid the subsequent crisis situation which could arise as a result of the carer's sudden inability to care for a person.

Hospital Discharge

Alzheimer Scotland welcomes the inclusion of the section on hospital discharge as this is one of the key changes being introduced as part of the legislation and is a key area in the care and support for a person with dementia; this care transition often exposes disconnects and gaps between health and social care services. Carers have told us that inclusion in the discharge process is crucial to ensure that decisions are made with the person's interests and wider circumstances considered, with proper and appropriate supports in place in the community; doing so is likely to reduce emergency readmissions from people who were inappropriately discharged.

Some carers felt that the Charter did not go far enough in relation to involving carers and in particular, the fact that hospitals were only required to involve the carer where they were likely to require further support from the carer. This reflects the phrasing within primary legislation, however, we believe the Charter should highlight that, where consented to by the cared-for person or where proxy powers are held, carers should be involved with decisions about the person they care for, especially in discharge planning, as they are likely to know relevant and helpful information about the cared-for person.

Similarly, carers expressed concern about the use of the phrase 'reasonable and practical' in the section in relation to the discharge planning for a cared for person. Again, whilst we appreciate that this reflects the wording of the primary legislation, we still consider this to be vague and is unhelpful in helping carers to understand how they should be involved in the discharge planning process.

Conclusion

Alzheimer Scotland broadly supports the draft Carers Charter, believing that it is relatively concise and covers most of the key elements of the Carers (Scotland) Act 2016. However, there must be a revision of a number of aspects. Carers have highlighted a number of issues, including over emphasis on reflecting the wording of the primary legislation and a lack of reference to other legislation and policy drivers which underpin the rights of carers. Furthermore, key information for carers such as

the right to a review of their plan, better communication of the assessment and decision-making processes and limited reference to mechanisms of choice and control (including SDS) must be addressed before the final revision of the Charter is published.

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