

CONSULTATION QUESTIONS

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 the provision of specialist and personalised services. We also offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

We welcome the opportunity to contribute to the consultation on proposed legislation on support for carers in Scotland. Alzheimer Scotland support the National Dementia Carers Action Network (NDCAN) and our response is informed by that group, as well as by the experience and knowledge of our services delivered across Scotland, and of our membership.

Any legislation resulting from this consultation must recognise and accommodate the diversity of the population of carers, the ways in which they carry out their caring role, and the different relationships that carers have with the person or people for whom they care. It is worth noting that with the increase in the retirement age, increasing numbers of carers are in future going to be balancing employment with a caring role; any legislation, guidance or eligibility criteria developed will need to take account of this.

The Carer's Assessment: Carer's Support Plan

We agree with the aims of the proposals set out regarding the Carers Support Plan , but we have some suggestions to improve the approach taken to this that do not fit with the specific questions the consultation asks.

It must be remembered that carers do not exist in isolation and that, while their support must be tailored to their own needs, those needs often depend on the needs of, and the support given to, the people they care for.

Alzheimer Scotland has developed integrated models of support for people with dementia that not only join up the various aspects of health and care support, including housing and community connections, but also include recognition of the role of the carer and provision for support that they might need, including planning for the future. In particular, Alzheimer Scotland's '8 Pillars' model of community support for people with dementia¹ includes support for carers as an integral part of the model.

The 8 pillars model recognises that the caring experience is subjective and unique not only to each carer but also the person with dementia they care for. It also

¹ http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support

recognises that the carer's needs will change over time as their circumstances change and as the condition of the person they care for changes.

Pursuing an integrated model of support will better support both the cared for person and the carer. The 8 Pillars model uses a Dementia Practice Coordinator to provide a consistent, personalised approach to support for a person with dementia, and tailored carer support is a key element of the model.

Alzheimer Scotland therefore recommends that carers' support needs are not considered in isolation, but that a holistic approach is taken that recognises the impact of the support the cared for person will receive on the support needs of the carer. A partnership between formal and informal carers supports both carers and the person they care for to achieve a better quality of life. This holistic approach can be taken even when the cared for person is not at a particular time using any services.

We also recommend, consistent with the 8 Pillars model of support, that support for carers should include both:

1. Training and support in caring interventions to both reduce the time spent on caring activities and to improve the quality of care that the carer is able to provide, and
2. Support such as respite to enable the carer to maintain their own social networks, opportunities for peer support and assistance to maintain community connections.

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

Yes

No

Comments:

While the name change provides a welcome shift in emphasis from appraisal to support, it must be accompanied by strengthened guidance that is co-produced with carers. In addition, the Scottish Government must support awareness raising among the relevant authorities of their obligations and among carers about their entitlements regarding a Carer's Support Plan if this proposed name change is to lead to better outcomes for carers.

An alternative suggestion from within Alzheimer Scotland's Carer's Action Network is to change the name to 'Carer's Action Plan', thus avoiding both the connotations of deficit associated with the word 'support' and the connotations of testing associated with the word 'assessment', while implying a positive journey for the carer.

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

Yes

No

Comments:

Alzheimer Scotland welcomes the intention to remove the 'substantial and regular' test; however, we also recommend that carers are entitled to regular review of their support needs.

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?

Yes

No

Comments:

Alzheimer Scotland supports this recommendation, as it is necessary to ensure that support is personalised to the needs of the carer. Many people with dementia have significant care needs but do not receive formal care because they are deemed not to meet the eligibility criteria thresholds. In such cases informal carers are the mainstay of support, often putting in long hours, while balancing other responsibilities such as work and other family commitments over long periods of time with little or no support. Over time this can have an impact on the physical and mental wellbeing of carers. As a result many carers are in crisis before they or those they care for receive formal support. It is Alzheimer Scotland's view that proposed eligibility criteria must in our place a greater emphasis on prevention. Smaller less costly carers support at the right time may be a better use of resources which may prevent many of the expensive crisis interventions that often arise because of the pressure that carers are often under.

Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?

Yes

No

Comments:

Alzheimer Scotland supports this proposal, but also recommends that third and private sector organisations who are engaged with the carer or the individual can also, with the carer's consent, refer the carer for a Carer's Support Plan.

Carer's needs should be routinely assessed alongside any assessment of the support needs of the person they care for, but carers should also be able to access support if the person they care for is not in receipt of any services.

Alongside the duty proposed below to require provision of information and services, the legislation should also include a duty to provide information to carers about their right to have an assessment/support plan.

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

Yes

No

Comments:

Alzheimer Scotland warmly welcomes this proposal; support for carers and those they care for should be provided to respond to the individual needs of each person in the caring relationship. A holistic approach should be taken that recognises the impact of the support the individual will receive on the support needs of the carer. Carers and the people they support have the right not to be defined by a caring role or their need for support. They have the right to be a son, daughter, husband, wife, partner, sister, friend etc., and to have those relationships taken into account in the support they receive. Focusing on supporting the positive contribution of carers rather than the deficits can enable people to continue to have a relationship which goes beyond that of a carer or and person needing care.

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

Yes

No

Comments:

Alzheimer Scotland supports this proposal; the principles of personalisation and co-production require carers to be treated as equal partners in planning for their support, including entitlement to reasonable timescales that respond to their needs and full information about the support process.

Question 7: How significant an issue is portability of assessment for service users and carers?

Comments:

This is a significant issue; the stress of moving will compound other stresses upon carers and service users. Guidance on the Carer's Support Plan should make it clear what the elements should be common to plans across Scotland in order to ensure portability. In addition, core eligibility criteria must be agreed across Scotland for the same reason.

Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?

Yes

No

Comments:

Guidance on the Carer's Support Plan should make it clear what the elements should be common to plans across Scotland in order to ensure portability. In addition, core eligibility criteria must be agreed across Scotland for the same reason. This will also support cost recovery and other interactions between local authorities necessary in cases where the carer lives in a different local authority to the person he/she supports, as discussed below under questions 25 to 27.

Carers groups such as the National Dementia Carers Action Network, as well as non-statutory sector organisations that provide support to carers should be included as partners in the development of the proposed improvements.

Information and Advice

Question 9: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

Yes

No

Comments:

There should be a duty to ensure that such a service exists and that it is accessible to all who may need it. For this duty to be implemented as part of a comprehensive carers strategy, it would sit better with Health and Social Care Partnerships (HSCPs) than with local authorities.

Carrying out this duty need not be done by HSCPs or local authorities themselves; existing carers support services should be used where appropriate. Moreover, carers must have a decisive role in determining how information and advice services are provided.

Question 10: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

Yes

No

Comments:

As this duty currently resides with health boards, it is appropriate to repeal it in light of the shift to the proposed duty on local authorities to support carers, and also the creation of Health and Social Care Partnerships under the Public Bodies (Joint Working) (Scotland) Act. However, this obligation must be replaced by one requiring HSCPs to develop a strategy, in partnership with carers and organisations that provide support to carers, about how they will implement their

duties and otherwise support carers.

Support to Carers (other than information and advice)

Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

Yes

No

Comments:

Alzheimer Scotland supports this proposal as the best option for ensuring that carers are entitled to receive support. However, the eligibility framework must:

1. Have a focus on prevention.
2. Be produced in conjunction with carers,
3. Be specific to the needs of carers,
4. Take into account the needs of and support being received by the cared for person insofar as that affects the needs of the carer
5. Take into account other factors such as the carer's own health needs, other family commitments and responsibilities, employment, education, and other aspects of life beyond their caring role.
6. Include core common elements and standards that enable portability of Carer's Support Plans between local authorities on an equitable basis.

Question 12: Alternatively, should we retain the existing discretionary power to support carers and young carers?

Yes

No

Comments:

Alzheimer Scotland does not support this alternative option, as we consider carers to be entitled to receive support.

Question 13: Should we introduce a duty to provide short breaks?

Yes

No

Comments:

While Alzheimer Scotland supports the principle behind the creation of this duty,

we recommend that it is framed differently in order to provide for the flexibility in support required to personalise it to the needs and wishes of each carer. For example, it could be that the carer and cared for person wish to take a holiday together, and require support to do that, rather than traditional respite care.

Stages and Transitions

Question 14: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

Yes

No

Comments:

Alzheimer Scotland welcomes this proposal; our experience of working with carers of people with dementia has shown us that transitions between stages of caring can be some of the toughest periods in the carer's journey. The Carer's Support Plan should include anticipatory support planning encompassing both known future changes and contingencies for crises or emergencies.

Question 15: Should new carers' legislation provide for young carers to have a Carer's Support Plan if they seem likely to become an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.

Yes

No

Comments:

This proposal would enable the relevant support providers to plan appropriate provision.

Carer Involvement

Question 16: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

Yes

No

Comments:

The principles of personalisation and co-production should apply in all areas of

service planning and delivery, not only those under the remit of Health and Social Care Partnerships.

Question 17: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

Yes

No

Comments:

Carers' organisations may well have as much to contribute in areas outwith the scope of integration as they do within it. Health boards and local authorities should be seeking input from carers' organisations in all areas that provide services to carers, not just those within the remit of Health and Social Care Partnerships.

Question 18: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

Yes

No

Comments:

The principle of carers' involvement in their own support planning should be established in any new legislation resulting from this consultation. Involvement is crucial to supporting the implementation of Human Rights legislation, in particular the PANEL² approach requiring active participation in decisions that affect people's human rights. This human rights based approach should be explicit in the primary legislation, aligning with and strengthening other Scottish legislation around health and care including the Self Directed Support Act and the Public Bodies (Joint Working) Act. Involvement must be meaningful, so health and social care professionals require appropriate training to make sure that they are able to work in this way.

In addition to this requirement to implement a human rights based approach to care and support planning and delivery, involvement of carers in planning both their own support and in care planning for service users makes good policy sense in terms of increasing the likelihood of achieving positive outcomes; the support that carers are able to provide has a huge impact on the further support that may be required from other organisations, including the local authority or the NHS.

Question 19: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?

² See <http://www.scottishhumanrights.com/careaboutrights/whatisahumanrightsbasedapproach>

Comments:

A human rights based approach to planning and delivering care requires the involvement of carers – and service users - of any age as far as possible in the planning, shaping and delivery of services. However, staff working with young carers require appropriate training to be able to undertake this in an appropriate and meaningful way.

Planning and Delivery

Question 20: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

Yes

No

Comments:

1. Developing a carers' strategy will ensure that the relevant authorities are confident and transparent about how they will meet their obligations in respect of providing support to carers.
2. The development of carers strategies should be the responsibility of Health and Social Care Partnerships to ensure that health and social care supports are integrated, person centred and holistic.

Question 21: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

Yes

No

Comments:

This should be the responsibility of Health and Social Care Partnerships, who must work in partnership with the third and – where appropriate – private sectors in order to ensure that a sufficient range of services is available to enable them to implement their carers strategies and to meet the current and anticipated cumulative support needs of carers in their area as identified in Carer's Support Plans; this is why anticipatory planning is a crucial part of individual Carer's Support Plans.

Identification

Question 22: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

Yes

No

Comments:

Alzheimer Scotland support maintaining a carer's register insofar as that will enable improved more personalised support to be provided for carers. However, any register must have a clear purpose and be clearly linked to the delivery of a Health and Social Care Partnership's Carers Strategy. Any register must also link a carer with the person they care for, so that any changes in the circumstances of either person in the caring relationship can be assessed for the impact they might have on the other.

While GPs will have an important role in maintaining and updating this register, the onus also falls on other health and social care partners to contribute to its upkeep; Health and Social Care Partnerships are therefore best placed to be responsible for the register both in order to ensure alignment with the Carer's Strategy and to ensure coordination between relevant partners, including, where appropriate, third and private sector partners.

Question 23: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

Yes

No

Comments:

GPs will often be in a position of being best placed to initially identify carers, therefore they should be supported to be able to use any register of carers proactively to signpost or refer carers to appropriate local carers support organisations. Ensuring this happens should be a carefully managed process between the Scottish Government, Health and Social Care Partnerships and GPs.

Question 24: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

Yes

No

Comments:

If GPs are to have duties towards carers as a result of this legislation, then compliance with these duties will need to be included in the GP contract.

Carer and Cared-for Person(s) in Different Local Authority Areas

Question 25: What are the views of respondents on the lead local authority for undertaking the Carer's Support Plan and agreeing support to the carer where the carer lives in a different local authority area to the cared-for person(s)?

Comments:

It is our view, informed by members of our National Dementia Carers Action Network, that the lead local authority in these circumstances should probably be the one where the cared for person lives; the support the carer receives will have, as discussed above, a direct impact on the amount and type of support that is required by the cared-for person.

Question 26: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances?

Comments:

Based on the reasoning above, the local authority where the person being cared for lives should cover the costs of support to the carer.

Question 27: Should the Scottish Government with COSLA produce guidance for local authorities?

Yes

No

Comments:

Guidance will be necessary in order to avoid difficult negotiations that would add to carers' stress. This guidance must be agreed by all local authorities in order to work, and should include:

1. Cost recovery where a local authority other than the lead authority is providing an element or elements of the support identified as necessary in the Carer's Support Plan.
2. A process for agreeing which local authority should provide each element of the support identified in the Carer's Support Plan.
3. Provision for carers who are caring for more than one person, including people who live in different local authorities to each other. It must be possible to respond to the cumulative impact of more than one set of caring responsibilities.