

CONSULTATION QUESTIONS

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) welcomes any potential change to the help and support carers receive as we understand the reality of how complex life as a carer can be and the stresses and strains that it can bring. In our case, caring for someone with dementia is where our experience and knowledge come from and we feel the new proposals can bring some positive change to the situation.

Being treated as TRUE equals and respected as such when discussing, forming, developing and implementing any decisions, policies or methods of working in the lives of our loved ones with dementia is of paramount importance to NDCAN.

We feel inclusion is more productive than exclusion and that in adhering to the human rights of both the person with dementia and their carers we should be consulted and involved as the norm.

NDCAN has always promoted the culture of co-production and believe it is the only way forward in achieving good dementia care.

No-one knows the person with dementia better than their families or the ones taking care of them. That level of experience and knowledge cannot be measured financially nor can it be 'bought or taught' by any professional. This knowledge and experience is a hugely untapped resource that should be used to help train and inform professionals in the truest sense of co-production so that the carers are fully involved, respected and given equal status in the delivery of dementia care and practice.

Below are our responses to the proposed changes to carers' legislation:

The Carer's Assessment: Carer's Support Plan

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

Yes

No

Comments:

NDCAN members felt that the wording 'support' is better than 'assessment'. However there was some concern that the word 'support' implies a deficit, as not all carers require support all of the time. There were also concerns that the inclusion of the word 'support' would raise expectations as to what support might be provided, where in some areas there is little or no appropriate support available.

Some members of the group suggested calling it a 'Carers Action Plan'.

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:

NDCAN members felt strongly that all Carers should have access to a support plan.

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:

It is essential that all carers receive appropriate support, regardless of whether their loved one qualifies for local authority support or not. Sometimes the cared for person may not require (or be eligible for) local authority support at that time, but a little extra support to the carer would be invaluable.

It is some carer's experience that they have had to give up work in order to care for their loved one when no appropriate local authority support is available. In these cases support for the carer is essential in order to maintain the caring relationship.

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:

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

Yes

No

Comments:

NDCAN members felt strongly that the Carers Support Plans should not comment on the carer's ability to care, but instead focus on the support needs of the carer. If the Carer's Support Plan was commenting on their ability to care, some carer's would be less willing to complete them.

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:

Having a set timescale is very important, as then carers know what to expect.

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

Comments:

NDCAN members felt that carers should receive universal care and support, not be subject to a postcode lottery. Moving can be a stressful time and it is therefore essential that any potential stress is limited by the transition of support for both service user and carer be seamless.

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:

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:

Carers are essential for supporting individuals to remain independent and well for as long as possible. It is therefore essential that adequate information and advice services are provided to support all carers in their caring roles.

NDCAN members felt it was important to recognise that young carers have different needs to adult carers and appropriate support should be offered according to their needs.

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:

NDCAN members felt there needs to be some kind of checking mechanism or audit trail.

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:

NDCAN would like to see more details of the proposed eligibility framework. Will this be consulted on?

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

Yes

No

Comments:

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

Yes

No

Comments:

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:

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:

A Carer's Support Plan should be offered to all carers in a timely manner to allow for the adjustment and transition.

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:

NDCAN feels strongly that carers should be involved as equal partners in care for their loved ones. Health and social care professionals need support and training to learn how to do this in a meaningful way.

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:

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:

Co-production is key, there shouldn't even be the question should they be involved, it should be automatic. NDCAN feels strongly that carers should be involved as equal partners in care for their loved ones. Health and social care professionals need support and training to learn how to do this in a meaningful way.

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?

Comments:

Carers are carers whether young or older and they usually have a strong understanding of what the person being cared for requires. NDCAN feels strongly that carers should be involved as equal partners in care for their loved ones, regardless of age. Health and social care professionals need support and training to learn how to do this in a meaningful way and in particular to support young carers so they can be actively involved.

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:

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:

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:

The wording of this question is unclear – to clarify, NDCAN feel that GPs and local authorities **should** maintain a Carers register to support the identification of carers.

NDCAN members felt that GPs have a vital role in identifying carers as they are often the first point of contact for people when they look for help. Involving GPs in this way will help to better identify ‘hidden’ carers, particularly people who don’t identify themselves as carers and/or ask for help. Having this heightened awareness may also help GPs better pinpoint people at risk of becoming unwell

due to their caring responsibilities.

Regarding a list of carers, NDCAN members feel it is important that there are clear guidelines for what this list can be used for; it should have a clear purpose and not just a tick box exercise.

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:

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

Yes

No

Comments:

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:

The lead local authority should be where the person being cared for lives.

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:

The lead local authority for covering costs should be where the person being cared for lives.

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

Yes

No

Comments: