

# Consultation on Carers Legislation



## RESPONDENT INFORMATION FORM

**Please Note** this form **must** be returned with your response to ensure that we handle your response appropriately

### 1. Name/Organisation

#### Organisation Name

MS Society

#### About the MS Society

The MS Society is the UK's largest charity for people living with MS, with over 38,000 members and more than 300 branches across the UK. In Scotland the MS Society has around 4,000 members to date and there are currently 32 local branches. There are approximately 100,000 people living with a confirmed diagnosis of MS in the UK and over 10,000 in Scotland.

The MS Society is the UK's largest charitable funder of research into MS. We are committed to bringing high quality standards of health and social care within reach of everyone affected by MS. Our comprehensive range of services cover all aspects of improving the lives of people affected by MS, from information and support to improving standards of treatment and care through research, education, campaigning and raising awareness.

## CONSULTATION QUESTIONS

### 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: Support Plan has more positive connotations than the term assessment, and renaming it reflects the intended outcome (support) rather than the process itself.

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: 'Substantial and regular' is interpreted differently within different local

authority boundaries, resulting in inconsistent and inequitable access to support. It has also presented a barrier for some carers of people with MS. MS is unpredictable and episodic; relapses and changes in condition can present carers with changing and irregular support requirements. Carers tell us that sometimes even a subtle change can be the difference between coping and not being able to sustain increased caring responsibilities. Removing the 'substantial and regular' test would make support more accessible to those caring for people with MS and other fluctuating conditions. It also enables, as proposed in the consultation, different types of personalised support plans to be developed, including lighter touch where appropriate.

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: Even if the person they care for is not receiving community care services, carers can still be under considerable pressure to balance life and work responsibilities alongside providing care and support. Our evidence suggests that carers of people who do not themselves have formal care packages with the local authority are much less likely to expect any support themselves.

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: Yes. This should be introduced in legislation. As part of that offer, the local authority must explain what it is and why it might be beneficial. The legislation and / or statutory guidance should also ensure that should an individual decline a Carer's Support Plan they should be able to request or be re-offered one at a later date. We would also like to see it stipulated that local authorities must keep records of the CSPs they offer and undertake. Currently there is no way to robustly assess the number of people being offered or undertaking Carer's Assessments in Scotland and whether policy and practice developments are making any improvement. This legislation and statutory guidance is an opportunity to address this.

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

Yes

No

Comments: The term 'ability to care' can be interpreted to imply a negative view of the carer's competence or skills. We agree with the principles for an outcomes-based approach for setting out a range of issues (with examples) within the Statutory Guidance. The Statutory Guidance should be used to ensure the new

CSP enables greater consistency and quality, as well as create personalised support planning. These outcomes should also include employment and personal development goals, social and leisure activities, respite and financial wellbeing.

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: Yes, and data should be collected from each authority about local timeframes and how they are meeting this obligation. We also believe it is preferable for the Scottish Government to set out a standard for reasonable timeframes within the statutory guidance. Local authorities can be held to account to their own timescales but they should fall within the nationally recommended framework.

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

Comments: In principle services provided in one local authority should be able to be replicated in another. While in practice there will always be some service level / resource variances, we believe care plans should be portable. Currently carers tell us that this is a challenge.

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: The MS Society has observed wide variation in the availability and consistency of information about carers' entitlements. Having a standard of service that is replicated across each local authority would improve consistency of information as well as likely uptake of carers support plans.

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: However, we would like to see provisions in the new Carers legislation to cover the reporting and review of carer information strategies.

### **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: We are aware that not all carers who have their needs identified are able to access the support to meet those needs, and this is a major concern. We believe that this duty should be introduced in order to improve consistency in and access to services, and are keen for carers organisations to be involved in developing this eligibility framework.

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: Yes. As recognised in the consultation, short breaks are often a highly valued intervention to support carers and the people they care for, but demand far exceeds supply and this is unlikely to change in the short term without investment in and development of the market. Any processes to determine eligibility would need to ensure that the most vulnerable and in need are given fair access to this intervention.

### **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: It is fundamental for people caring for someone with MS that there is consideration given to how their caring role and own support needs may change in response to the fluctuating nature of the condition. Including provisions on managing stages – or changes – in caring within the statutory guidance should better enable local authorities to respond in a timely manner to a sudden change in circumstance.

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: It can be particularly challenging for individuals when they transition from being a young carer to adult services. Support plans need to look ahead and pre-empt potential crises or breakdown of the support and / or the caring relationship.

## 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:

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: Carers and young carers should have significant input at policy and service development levels and be involved as equal partners in the individual level.

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:

### 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: This is critical for identifying local needs, reviewing progress and enabling transparency and monitoring outcomes against the strategy.

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: Yes, this legislation offers an important opportunity for local authorities and Health Boards to develop and enhance their service provision for carers.

### 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 vast majority of carers will visit their GP in any given year, therefore GPs are key gatekeepers for carers to access appropriate support. The MS Society considers that guidance will not be sufficient to incentivise all GPs to identify carers and signpost to support and that it would not address the current inconsistency. There should be statutory incentives to establish the registers and for each practice to evidence the number of carers they support.

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: Please see answer to question 22.

### **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: This sounds sensible. Without a lead authority arrangement there is a danger that carers in these circumstances could slip through the net. It needs to be supported by clear guidance (if not a statutory provision) about responsibilities in order to ensure that this does not happen.

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:

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

Yes

No

Comments: