

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: Parkinson's UK supports this change. However, we know that many carers of people with Parkinson's find it difficult to identify as such, and that this could provide a barrier to people asking for either an assessment or a support plan.

Similarly, we know that some carers – including those who provide very significant amounts of care - are very reluctant to acknowledge that they have support needs that are separate from the needs of the person with Parkinson's. Undergoing an assessment can help the carer to identify needs and possibilities for support that they had not previously considered. While we believe that it is likely to be helpful to link the process of assessment to a carer's right to support, it will be important to monitor the effect of the name change does not have the unintended consequence of prompting these carers to reject a support plan because of a perception that they "don't need" support. There are also very high rates of unmet need - in a recent survey, three quarters of people caring for someone with Parkinson's in Scotland had not had a carer's assessment.

In the light of this, there is a risk that many people who could benefit from support could "self select themselves out of the process".

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: Parkinson's UK welcomes this proposal. Some carers fail to meet the "substantial and regular" test because Parkinson's is a fluctuating condition, and the severity of people's symptoms can vary from day to day – and even hour to hour. Some people with Parkinson's have very intense support needs at certain times, but need less care the rest of the time.

We are also aware that some people with Parkinson's provide care to others at the same time as they receive care. Removing this test could better enable couples who provide care to each other to be identified and to get the support to which they are entitled.

However, we are concerned about the resource implications of broadening the qualifying criteria for eligibility, and the risk that this could slow the system down

and make it harder for everyone to get access to the support that they need, even in the event that there is a graduated system of support as suggested.

It is estimated that informal carers provide up to 80% of the costs of care provided to people living with Parkinson's. Those who care for people with more advanced Parkinson's typically have extremely high needs for support because the person can have very significant care requirements arising from their Parkinson's, including help with medication, severe mobility problems, disturbed sleep, pain, communication difficulties, continence issues, mental health symptoms and dementia. In a recent survey, nearly two third of carers of people with Parkinson's in Scotland were providing care for more than 50 hours a week. In the Carers Week 2012 survey, 79% of those caring for someone with Parkinson's said that their caring role had affected negatively their own physical health and 85% their mental and emotional well-being.

Delays in providing support, or responding to changing needs, can have a disastrous impact on carers, and there needs to be a system in place to make sure that those with the greatest need are able to access support as quickly as possible.

It is hard to see how the new system is going to work without local authorities having significant additional funding to provide support for carers. We are already hearing that the services needed to support carers simply are not there in many parts of Scotland and the consultation document does not indicate that there are plans for additional resources to be provided.

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: Parkinson's UK strongly supports this change, it is consistent with the integration of health and social care, and recognises that people with long term health conditions like Parkinson's may not receive their care via local authorities.

People with Parkinson's often live with the condition for some time before they access local authority services because they receive their care and support through specialist multi-disciplinary teams (usually based in NHS secondary care). Carers are typically closely involved throughout someone's journey with Parkinson's and can provide very high levels of unpaid care before local authority care is provided.

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: We believe that it is essential that both routes are offered, as our work with people with Parkinson's and carers suggests that many carers of people with Parkinson's are unaware that they can apply for a carers' assessment, and that the existing duty for local authorities to offer a carers' assessment is not being adhered to.

We believe that the legislation should create a statutory duty on HSCPs and/ or local authorities to offer a Carers' Support Plan to an individual carer if there is identifiable need for the carer to receive support. This provision needs to be monitored to make sure that it is happening in practice.

We note that the Scottish Government intends to indicate the areas that might be included in a Carer's Support Plan in guidance. We would support a stronger measure that establishes a basic offer of support. We have some concerns that without this, there could be considerable local variation in the nature of the support offered to carers.

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

Yes

No

Comments: Parkinson's UK welcomes this change. People with Parkinson's, carers with other long term conditions or disabled people are sometimes assumed not to be able to provide care for others because of their own care needs. We believe that this change will enable those who provide care for someone else as well as receiving care to be recognised and receive support.

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: Parkinson's UK is disappointed that the Scottish Government does not propose to introduce a time limit for local authorities to develop a Carers' Support Plan. People's access to support is currently subject to unacceptable variation by local area, and we would like to see stronger measures put in place to make sure that people receive the support they need as quickly as possible.

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

Comments: Portability of assessment can be a very significant issue for people with Parkinson's and carers. It is particularly common for older people with Parkinson's to move home to be nearer to relatives who will take on a greater caring role as the condition progresses, or to move to accommodation that is easier to manage in the light of their symptoms.

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: We support this joint working, but would like to see something on the face of the Bill to guarantee greater portability, rather than just a commitment to further discussion.

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: This is essential to address the fact that people who care for people with Parkinson's do not receive the information they need to get the support to which they are entitled.

People affected by Parkinson's consistently tell us that the current system is confusing, both in terms of identifying support available and in working out what you have to pay. The system needs to be easy to understand with clarity about where to turn to for support, types of support available and the cost of services.

The information needs to include access to support provided within the voluntary sector – for example, there are more than 40 Parkinson's UK local groups across Scotland. Many of these provide specific support for carers, including carers' courses to find out more about caring for someone with Parkinson's, respite projects, and peer support including specific support groups for carers.

The statutory guidance needs to specify that information needs to be provided in non-online formats. Many carers do not have direct access to online sources of information. More than a quarter of UK Households does not have broadband, and in Scotland about 39% are not online. In our biggest city, Glasgow, nearly half of homes do not have broadband. In addition, OFCOM data suggests that even where people are using the internet, they are not using it to access information from councils or Government – in Scotland, only 13% of people access these type

of sites.

People living with Parkinson's need to be empowered to make appropriate choices and therefore we believe that the Bill needs to include duties to make advocacy available for carers.

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: Parkinson's UK has some concerns that without central monitoring of the provision of carers' information, it will be impossible to tell whether the provisions are being enacted.

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: Parkinson's UK welcomes this proposal, which should help local authorities to allocate resources in line with need.

We believe that the law needs to explicitly state that where a person's needs are found to meet the eligibility criteria, the local authority / HSCP is responsible for ensuring that these needs are met.

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

Yes

No

Comments: See above.

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

Yes

No

Comments: Parkinson's UK believes that such a duty is important as it will ensure that local authorities / HSCPs prioritise the provision of appropriate respite facilities and staffing. This requires urgent and ongoing action.

We know that access to short breaks is a considerable problem in many parts of Scotland, where independently or self-funded respite arrangements are unable to go ahead because of a shortage of suitably qualified care workers locally. In addition, there is a shortage of appropriate placements for people with complex neurological symptoms like Parkinson's, which can prevent carers from getting the breaks from caring that they need. Carers will often refuse short breaks if the facility offered is not appropriate (eg a working age person with Parkinson's may be offered a respite bed in a care home with residents who are decades older than them). There may also be problems if the person with Parkinson's or carer does not like the placement on offer, or if the person or their carer does not trust the care provider to meet the person's needs.

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: Parkinson's UK would welcome this guidance. However, we would like to make sure that the specific issues around different stages in providing care for a person with a long term, degenerative condition are considered alongside other trajectories of caring. People with conditions like Parkinson's may require very high levels of care over many years.

We interpret the reference to "end of caring" as being to the death or institutionalisation of the person being cared for. We think it would be helpful to be explicit about what is meant here. We believe that access to support around grief and bereavement is essential for carers before as well as after the person they care for dies.

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: -

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: Carers of people with Parkinson's can sometimes feel shut out of the process of planning care for the person that they care for. It is still common for decisions to be taken without including the person with Parkinson's or their carer in decisions.

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: We welcome this measure. However, we would like to see the role of other types of organisation recognised too. We have a lot of contact with carers who are not in touch with their local carer organisation.

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: Although we support this measure, Parkinson's UK is a little concerned that the integration of health and social care is being driven via locality planning with no option to feed in their views at a national level. We are a UK wide charity with limited staff resource and there are around 10,000 people with the condition in Scotland, around half of whom are in the more advanced stages of the condition – both they and their carer would typically struggle to attend locality meetings.

We believe that it will be extremely challenging to provide local level support throughout Scotland, and are concerned that the voices of people who care for those with conditions like Parkinson's may be lost from the process, despite the very high care needs of this group of people.

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: We would strongly welcome this obligation. We hope that Scottish Government will also consider at this stage how to involve people who might lack time to attend meetings because of their caring responsibilities. We would also like the legislation to specify that this strategy should be publicly accessible (eg published on website, distributed to public libraries.)

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: On balance, Parkinson's UK understands the reasoning behind the Scottish Government's rejection of this idea, although we tend to be supportive of the idea of a national carer's register and of consistency in terms of the information that's collected across different GP practices.

(Please note: This question is awkwardly framed ! In speech, you would agree with the statement by saying "no there shouldn't be ...")

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: Carer registers will only be effective if they are consistent and easy for GPs to complete. We are aware that it may be challenging to persuade GPs to maintain a register.

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: This is a complex area, but is key to addressing the issue of portability, and getting it right will be important.

It is important to consider issues relating to cross-border caring in this section too.

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: We believe that different families may have different views about what will work best for them in these circumstances.

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

Yes

No

Comments: -