

Consultation Questionnaire

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 2 : Values and Principles

**Question 1a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 1b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 1c: Do you have any further comments on this section of the guidance?

Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Parkinson's UK believes that it is important to acknowledge that the Person's Pathway through assessment is not always linear in this section, although similar points are raised later in the document, eg in Section 4. In common with people with other degenerative neurological conditions, people with Parkinson's are very likely to require re-assessments as their condition progresses and their support needs become more complex. In addition, they may require reassessment of the mechanisms that they use to direct their support.

Parkinson's is a fluctuating condition, and a person's support needs can change significantly from day to day, and even hour to hour. The assessment process needs to take account of the range of needs a person is likely to have over time.

About half of all people with Parkinson's are in the more advanced stages of the condition, when medication offers limited symptom control. A high proportion of people are assessed for care packages at a time of crisis – such as during a hospital admission. It would be helpful to embed the idea of ongoing reassessment here, to make it clear that people can revisit their assessment when they are more settled.

ISD has identified that about one in every ten people with Parkinson's is at very high risk (more than 50%) of a hospital admission in the next year.¹

Although many people with Parkinson's and their unpaid carers are as able to manage a direct payment as people without the condition, some people with Parkinson's are at particularly high risk of budgeting problems, or may become so as their condition progresses. This is because mental health, cognitive and behavioural issues are common in Parkinson's. Issues can be caused by the condition itself and/or the medication used to treat it. All of these can have a very significant negative impact on people's ability to plan and budget. Individuals may be able to manage direct payments at some times, but require additional support at others, and may not have insight into when additional support may be needed. Professionals will require very strong skills to balance risk against self-determination for people in this category.

At any given time up to 40% of people with Parkinson's will have depression. Up to 40% of people with Parkinson's will experience anxiety and up to 50% will experience mild psychotic symptoms. Despite the high rates of mental health need, many people go without treatment. As few as 20% of depressed people with Parkinson's receive treatment.

Impulsive and compulsive disorders are also common. An estimated 17% of people who take dopamine agonists to treat their Parkinson's, and 7% of those using other Parkinson's medication, develop compulsive shopping, gambling, hypersexuality or overeating. People who experience these behaviours face particular challenges in managing direct payments where they hold the budget, and a third party budget holder may be a better option if people with ICDs wish to use direct payments.

One in three people living with Parkinson's have some form of dementia and up to 80% of people with Parkinson's may develop dementia. Parkinson's dementia is a specific type of dementia, and people's executive planning functions (which are needed to budget and think ahead) are significantly affected from the start, often long before cognitive issues are diagnosed.

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Consultation Questions

Section 3: Values and Principles

Question 2a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
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¹ ISD (2011) SPARRA database: Number of patients in Scotland at risk of emergency admission/readmission in the period 1 July 2011–30 June 2012 by risk probability group, and those with an admission history of Parkinson's disease. Unpublished data. Reference: /conf/sparralive/Ad Hoc/Parkinson's UK

<input type="checkbox"/>	<input checked="" type="checkbox"/>
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**Question 2b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 2c: Do you have any further comments on this section of the guidance?

Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

This section was confusing to read, because it identified 4 statutory principles, as outlined in Section 1 of the SDS Act, and then listed them again, along with non statutory principles (and creates a 5th statutory principle by splitting Participation from dignity when they are bracketed together in para 11). The principles were also listed in a different order (alphabetical). The combination of repeated and new information in the table made it very hard to follow.

Would it be possible to describe in the text preamble the purpose of the statutory and general principles, and then put all the information relating to all the principles in the table? If there is a hierarchy of principles, perhaps group the statutory ones and the general ones separately?

It might be easier to use checkbox columns (and format over a double page?) to highlight principles that are key aspects of independent living, if it is important to include this information.

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Consultation Questions

Section 4: Eligibility and Assessment

Question 3a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 3b: How useful did you find this section of the guidance? (please tick)

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 3c: Do you have any further comments on this section of the guidance?

Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Parkinson's UK notes that the draft guidance is unable to resolve the tension

between the application of eligibility criteria, and the need to invest in low level preventative services. While the need for authority's to invest in these services is acknowledged, in a time of reduced public expenditure and growing demand for services, it is easy to see how local authorities will be unable to meet a commitment to funding preventative services.

This is an important issue in preventing crisis in people living with Parkinson's. Many people with Parkinson's do not meet substantial or critical eligibility criteria, because their condition is long-term and fluctuating. The eligibility criteria typically do not take account of the long-term impact of a condition, and can limit service provision to crisis interventions. People with Parkinson's report that in some areas of Scotland preventative services and early interventions that would enable them to receive care at home are not being funded. In some parts of Scotland, this is combined with long waiting lists once the criteria have been met. We are aware of a number of cases where people affected by Parkinson's have waited for many months to receive an assessment of their support needs.

Parkinson's UK has concerns about the assessment process as outlined, because there is no explicit role for the person's specialist healthcare team. This is dealt with far later in the document under Section 8, which refers to the contribution that healthcare professionals can make to a single shared assessment, but we believe that it is important to note this potential contribution far earlier in the guidance, particularly for people with long term conditions.

People with Parkinson's tell us that it is essential that health and care professionals who deal with them understand their condition and how it affects them. Parkinson's is very complex, with a wide range of symptoms that can affect every aspect of people's lives. The NHS HIS Clinical Standards for Neurological Health Services state that everyone with Parkinson's should have access to a specialist multi-disciplinary team to help them to manage their condition.

Parkinson's affects each individual very differently. However, in addition to mobility problems, the symptoms of advanced Parkinson's often include problems with swallowing, weight loss, frailty, continence falls, immobility, mental health issues and dementia. Parkinson's is often not well understood by social work professionals, serious symptoms may not be visible, and the person may be reluctant to disclose them during an assessment. We would like to see a formal mechanism to involve members of the person's MDT in the assessment process where the person wishes this to take place.

Parkinson's UK strongly supports the paragraphs outlining a good assessment, and in particular the need to anticipate changes and avoid "fixing" crisis interventions in the long term. People and families can benefit from knowing exactly how to revisit their assessment, with details of how and when it can be helpful to do this. Accordingly, we believe that it may also be helpful to add a fourth product from the assessment process outlined in para 39 – the process by which a re-assessment will take place (eg review at fixed period, in response to changing needs reported by individual / carer / professional.)

In addition we welcome the acknowledgement that providing assistance for the

supported person to make – and communicate – an informed choice is very important. People with Parkinson’s commonly have communication problems, mental health issues and cognitive symptoms, and would need speech therapy, assistive technology and / or advocacy to be able to participate. We are therefore a little disappointed that the following section, on Support Planning provides details on advocacy services, but no further mention of addressing communication support needs, such as interpretation services, SALT involvement or assistive technology. We note that the guidance does briefly mention this, at section 9.2, but believe It should also be mentioned here.

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Consultation Questions

Section 5 : Support Planning

This section of the guidance covered:

- general guidance on support planning
- risk
- resources
- the choices that must be made available to the supported person and
- information and support

**Question 4a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 4b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 4c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

As noted above, Parkinson's UK believes that more detail about the need to provide communication support should be included under the "support" section in this section, to ensure that this remains part of the assessment process.

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Consultation Questions

Section 6 : Monitoring and Review

**Question 5a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 5b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 5c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

In light of current concerns about capacity within the assessment system, Parkinson's UK is concerned that it may not be possible to meet the recommendation that all social care recipients receive an annual review of their

needs. We are concerned that this may mean that people do not receive the support they need to be meaningful partners in their care, or that people who require initial assessments may not be able to receive them in good time.

We would also question whether all users of social care and support can have their needs met if there is only one review a year. This may be sufficient for people whose condition is stable and whose life circumstances are also consistent. However, for people with rapidly changing needs, including some people with Parkinson's, more frequent reviews will be needed. It is essential that this is acknowledged within the guidance, and that local authorities plan to accommodate these needs.

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Consultation Questions

Section 7 : Facilitating genuine choice for individuals

**Question 6a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 6b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 6c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Parkinson's UK has no further comments to make.

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Consultation Questions

Section 8 : The role of the NHS professional

**Question 7a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 7b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 7c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

that are more appropriate for statutory guidance rather than Regulations?

Parkinson's UK welcomes this section, although as previously noted, we feel that the role of the NHS professional should be raised sooner within the guidance. This section appears to focus on the financial aspects of joint working, rather than emphasising the complementary roles of NHS and social care professionals in working with individuals to plan care packages. Parkinson's UK would like to highlight the need to involve professionals who understand the impact that Parkinson's has on an individual's life, which may be difficult for someone without specialist knowledge of the condition to appreciate.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.1 : Children and Families

Question 8a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

Question 8b: How useful did you find this section of the guidance? (please tick)

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 8c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

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Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.2 : Supported decision-making and circles of support

**Question 9a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 9b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 9c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Parkinson's UK welcomes the identification of communication support as an important issue, but believes that it should be raised earlier in the guidance.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.3: Carers

**Question 10a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Question 10b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 10c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Parkinson's UK believes that this section of the guidance assumes that the unpaid carer only has needs associated with their caring role. We are aware of many cases where someone caring for an individual with Parkinson's also has significant health issues or impairments of their own. We wonder whether it would be helpful to include additional guidance and principles to address situations where the carer may also have their own support needs, and / or be cared for in some capacity by the supported person.

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Consultation Questions

Section 9.4: Direct payments

Question 11a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 11b: How useful did you find this section of the guidance? (please tick)

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 11c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Parkinson's UK notes that this section contains information on monitoring, but very little on **support** for people who are using direct payments. We would like to see a greater emphasis on ongoing support to ensure that people who need support receive it.

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Section 9.5: Wider legal duties and strategic responsibilities

Question 12a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 12b: How useful did you find this section of the guidance? (please

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 12c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

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Draft Statutory Guidance on Care and Support

Consultation Questions – General Questions

The Guidance document as a whole

Question 13: Do you have any further general comments on the guidance?

For example, are there any gaps in terms of the topics covered by the guidance? Are there any major changes that you would recommend? Do you have any comments on the style and layout of the guidance, or the language used in the guidance?

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The costs and benefits arising from this guidance

Question 14: Do you have any comments on the financial costs or benefits of the requirements set out in the guidance?

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the guidance. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

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The equality and human rights impacts of the guidance

Question 15 (a): Do you have any views on the impact of the guidance on any or all of the following equality categories:

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

Some advice to help you to answer this question - By “equality impacts” we mean whether or not the guidance will affect certain groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/9876>

We plan to update the Equality Impact Assessment in light of the comments and information from this consultation.

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Question 15 (b): Do you have any views on the impact of the guidance on human rights?

For more information about human rights please see the Scottish Human Rights Commission's website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

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Consultation Questionnaire

Draft Regulations

Consultation Questions

Question 1: What are your views on Part 2 of the draft Regulations (calculation, payment and termination of direct payments)?

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Question 2: What are your views on Part 3 of the draft Regulations (appropriate/inappropriate circumstances for the employment of close relatives)?

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Question 3: What are your views on Regulation 11 which deems individuals who are placed under a variety of criminal justice orders to be ineligible to receive direct payments?

For example, is it appropriate to impose the exclusions listed in Regulation 11? Are there any persons not listed in regulation 11 to whom it would be inappropriate to offer the option of a direct payment?

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Question 4: What are your views on restricting access to direct payments for those who are homeless, those who are fleeing domestic abuse or those who require support in relation to drug or alcohol addiction?

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Question 5: What are your views on restricting access to direct payments in relation to the provision of long-term residential care?

This question was raised during the initial consultations on a draft SDS Bill. The Scottish Government would like to invite detailed views before making a final decision prior to the laying of the Regulations before the Scottish Parliament. Should the restriction be removed from the final regulations, thereby allowing direct payments for residential care? Or should it be retained? Please provide reasons as to your support or opposition to requiring authorities to provide direct payments for residential care.

Question 6: The draft Regulations do not specify circumstances where the direct payment option should be unavailable for care and support to children/families. *Should* there be specific restrictions on choice of support in relation to children/families support (i.e. support provided under Section 22 of the Children (Scotland) Act 1995) and should these restrictions apply to the direct payment only, or to other options as well?

Question 7: Do you have any further comments on the draft Regulations?

For example, are there any gaps in terms of the topics covered by the Regulations? Are there any major changes that you would recommend? Are there any topics that are more appropriate for statutory guidance rather than Regulations?

Draft Regulations

Consultation Questions – General Questions

The costs and benefits arising from these regulations

Question 8 : Do you have any comments on the financial costs or benefits of the Regulations?

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the Regulations. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

The equality and human rights impacts of the regulations

Question 9 (a): Do you have any views on the impact of the Regulations on any or all of the following equality categories:

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

By “equality impacts” we mean whether or not, and in what ways, the Regulations will affect certain groups, and whether they will impact on those groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act 2013, available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/9876>

We plan to update the Equality Impact Assessment in light of this consultation.

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Question 9 (b): Do you have any views on the impact of the Regulations on human rights?

For more information about human rights please see the Scottish Human Rights Commission’s website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

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