

Consultation Questions

Question 1(a): Is paragraph 9 clear and easy to understand? (please tick)

Yes	No
Generally yes	

Question 1(b): Do you agree with the waiving of charging circumstances as set out in paragraph 9? (please tick)

Yes	No
Generally yes	

Question 1(c): If you do not agree with the waiving of charging circumstances as set out in paragraph 9, please state your reasons below:

With regard to short breaks, the primary concern is to ensure that carers, and the people they support can have 'time-out' from their caring routines and responsibilities, on a regular and flexible basis. The frequency, length and form of break will be established through an assessment of need and will take into account both the wishes of the carer and the person being cared for. If the carer(s) require some form of replacement care in order to have a break without the person they care for, then there should be no charge applied to arrange or provide this replacement care service. As 'equal partners in care', carers deserve to be given similar rights to those providing care on a paid basis, and this includes holidays and rest breaks. We will elaborate further on these points in the responses that follow.

To inform our response to the consultation we have undertaken an online survey, together with our National Carer Organisation colleagues. The full survey is attached but some headline analysis has been included in our responses below. We received 248 responses. 67% of these responses are from carers. We would not wish to give the impression this survey has been carried out with any academic rigour but nevertheless the level of response is significant, and the comments contributed are we think particularly helpful and insightful.

Question 2(a): Are you content with the examples of support to carers and young carers, as set out in paragraph 10, where charges will be waived? (please tick)

Generally yes

Question 2(b): If you are not content, please state your reasons below:

We are generally in agreement with the examples of support listed however we are concerned that local authorities can apply a charge - or expect others to offset their expenditure by applying a charge - for any services or supports provided to carers who do not meet the 'regular and substantial' threshold and therefore not eligible

for a carer's assessment. Many people with caring responsibilities will benefit greatly from information, advice, advocacy and signposting services, the help of a translator, or indeed training, even though their caring responsibilities may seem less demanding. These supports, when offered and taken up early on, can prevent the caring role from escalating to a point where more intensive services may be required.

We suggest this could be overcome by local authorities establishing a minimum level of support - or a minimum local offer - where certain core services would be available to all carers at no charge. Those needing more than the minimum offer of support would then be asked to complete an assessment.

Question 2(c): Are there further examples that you would like to add? (please tick)

Yes	No
	Not at this stage but we note that the list is not intended to be definitive and therefore local authorities will need remain flexible.

Question 2(d): If there are further examples that you would like to include in the list, please state these below and also set out your reasons for suggesting their inclusion.

Comments

Question 3(a): Do you agree with the exceptional circumstances set out in paragraphs 12 (with examples) and 13 about support to carers to help pay for driving lessons and taxi fares? (please tick)

Yes	No
	No

Question 3(b): If you do not agree, please state your reasons below:

The term ‘exceptional’ is difficult to define. It implies the circumstances when charges will be waived will not be the ‘norm’ – but determining what is ‘normal’ is very much a subjective judgement. In remote areas it might be argued, for example, that a majority of families face problems with access to public transport and therefore this is the ‘norm’. We would prefer an approach along the following lines: *‘The Scottish Government would expect local authorities to provide financial or other support to minimise any transport related difficulties faced by carers in carrying out their caring role, as identified through a carer’s assessment.’* The examples provided are useful to illustrate different ways that carers, and people receiving care, can benefit from this support, but again this is not a definitive list and local authorities should always be prepared to consider other appropriate ways transport difficulties may be overcome.

It is not entirely clear if this section on transport also includes the waiving of any charges that may be incurred in transporting the person with support needs to a short break service – where this is providing the replacement care to enable the carer to have a break. Sections 17&18 make clear that the ‘whole of the charge’ for replacement care will be waived and so we assume this to be the case but it would be helpful to have this clarified.

Question 4(a): Do you agree with the waiving of charges as set out in paragraphs 14 and 15 with regard to short breaks? (please tick)

Yes	No
Generally yes but with a different approach	

Question 4(b): If you do not agree, please set out your reasons below:

This is difficult to respond to. Ordinarily, we would welcome the prospect of carers’ receiving funding to have a break of their own, whether this is a one-off holiday or something more regular – where this has been assessed as the best form of support to achieve an identified outcome. Many studies tell us that caring has a profound impact on household income and so there is a strong argument to support carers in this way. **71%** of respondents to our online survey agreed.

However without additional funding in local authority budgets we are concerned this may result in funding being severely rationed or diverted from elsewhere, at the expense of preventative work which may benefit those carers currently under the threshold of ‘substantial and regular’.

We therefore propose a different approach. We would suggest that local authorities create a local support fund to which carers can apply for some assistance with the costs of their own break. This fund could be established in partnership with local third sector organisations. The Short Breaks Fund 'Time to Live' model is perhaps a good example of this type of support, with carers themselves being involved in determining the decision-making criteria, and the process for applying for support. A different approach should be developed for young carers where local young carers groups could be funded to provide group activities, holidays and other forms of more individualised breaks.

We would like to reiterate that this proposed approach does not wholly reflect the views of the respondents to the online survey who were strongly of the opinion that all carers assessed as needing a break of their own should be supported financially.

Question 5(a): Do you agree with the position set out in paragraph 16 that when the carer and cared-for person take a break together, then as well as waiving the cost of the break for the carer, the additional costs of the break to enable the break to take place will also be met by the local authority? (please tick)

Yes	No
Yes	

Question 5(b): If you do not agree, please state your reasons below:

Many people in caring relationships would prefer to have a break together, as a family or as a couple for example, but are prevented from doing so by the fact they can't replicate the care support they receive at home. As a consequence people can feel imprisoned in their own homes, and isolated from their communities, friends and family. We therefore strongly agree with the proposal to support breaks together, where this is the choice of the carer(s) and the person being cared for. **82%** of respondents to the online survey strongly agreed/agreed with this approach.

We agree this can be facilitated by local authorities meeting any additional costs necessary to ensure the person being cared for receives the level of care they need, and consequently supporting the carer to benefit from the break too. Our comments in relation to Q4(b) apply here too although, as the carer will still be involved to some extent in the caring, we do believe it is reasonable that the carer's holiday costs should be waived in these circumstances.

Question 6(a): Do you agree with the position set out in paragraphs 17 and 18 that local authorities will waive the cost of replacement care when they provide or commission replacement care in circumstances when others cannot provide replacement care free of charge? (please tick)

Yes	No
Yes	

Question 6(b): If you do not agree with the position, please set out your reasons below:

We agree strongly that carers and those receiving care should not be charged for replacement care that enables the carer(s) to have a break from their caring role. 87% of respondents to our survey agreed with this too. We also agree that no charge for this replacement care should be passed on to the person receiving care. The choice, frequency and length of the replacement care must be determined through a proper assessment which is outcome-focused and based on the needs of both the carer(s) and person receiving care to ensure maximum benefit is gained.

However, we do not agree that 'social isolation' is an appropriate measure for local authorities to use when determining if they should step in. Social isolation is not defined particularly clearly in the guidance and therefore is likely to be interpreted differently, and perhaps not always with the best interests of the carer(s) in mind.

Our survey provides many examples of occasions when it would be impractical or inappropriate to involve family, friends, neighbours or volunteers as replacement carers. It could also be argued that breaks should be concerned with preventing the carer (and the person being cared for) experiencing social isolation, which then leads to poor health and wellbeing, increased risk of depression and so on. By restricting replacement care to only those that have become socially isolated local authorities are missing the opportunity for more preventative interventions.

We would propose therefore that 'social isolation' is removed from this section. We suggest instead that the availability and *appropriateness* of replacement care provided by family, friends, etc. should be discussed as part of an assessment. Where this support is not available or appropriate then the assessment would determine the level and type of replacement care the local authority should arrange or provide.

Question 7: Do you have any additional comments? If so, please use the space below to provide these further comments. Local authorities may wish to comment on any financial consequences arising from the Regulations. If so, please set out estimates of anticipated support to be provided to carers and cost estimates.

We refer to the introductory paragraphs in the consultation paper. We wish to highlight the fact that the lack any legal obligation on local authorities to provide support or services to carers in response to the outcome of a carer's assessment remains a major concern. It also raises fundamental questions about the extent to which these regulations will have any impact on carers at all when local authorities are free to exercise their 'right' not to provide support. We appreciate local authorities do what they can for carers but in the face of funding pressures we know they face tough choices and are likely to prioritise funding to their statutory obligations, which are generally concerned with responding to people at point of crisis, or at imminent risk. This is the 'elephant in the room' in our opinion and we would strongly urge government to monitor this closely. There is little to be gained for carers through these regulations if local authorities comply simply by exercising their option not to provide services to carers – or do so selectively based on cost minimisation.

With regard to the wider consultation on the statutory guidance, the self-directed support 'Statement of Intent' powerfully sets out the vision that all organisations in the public, voluntary and independent sectors must now work towards, collaboratively, and in equal partnership with those who require care and their carers.

We anticipate many hurdles along the way as all concerned adapt to this new environment. We believe careful monitoring and review will be required at both local and national levels to ensure the strategic vision, and the underpinning aims of empowerment, choice and control, feed through to action on the ground. Where the pace is too slow, or there is a clear drift from the vision, we would wish to see corrective action taken, and any unintended consequences quickly addressed.

We are not clear how this monitoring will be undertaken, what will be expected of local authorities in terms of their data collection and success criteria, and what scope there is for aggregating local data to inform the overall national picture. The shift to outcomes-focused delivery does not replace the need for robust indicators and milestones against which we can measure progress and ensure equity and fairness.

Finally, despite these concerns, we would like to congratulate the Scottish Government and the many individuals and organisations that have been involved in carefully steering the Act and Regulations to this point. This is a very complex piece of work with multiple stakeholders and different perspectives and we certainly don't underestimate the level of effort that has been expended. We very much look forward to playing our part in supporting the implementation of the Act in 2014 and beyond.

Question 8: Do you have any comments on the draft Regulations as set out in this Annex A? If so, please use the space below to set out these comments:

Comments

Thank you for completing this consultation. Please return your completed 'Respondent Information Form' and this 'Consultation Response Form' to alun.ellis@scotland.gsi.gov.uk by **Wednesday 10th July 2013**.