

## Consultation Questions

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

Yes	No
	X

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

Yes	No
Mostly	

**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:**

We agree with the general circumstances regarding waiving of charging to carers for support and breaks provided to them. Carers are equal partners in care and deserve to be given similar rights to those providing care on a paid basis, and this includes regular holidays and rest breaks. If carers are assessed as needing a short break from caring, the cost of this and for any replacement care required should not be charged for.

We have significant concerns about **Line 5** of the draft regulations, which stipulate that in relation to replacement care to facilitate a short break for the carer, carers should arrange for friends, family, neighbours or other volunteers to provide replacement care and only where this is not possible will the local authority step in to arrange the care. In partnership with the National Carer Organisations, we have consulted widely with carers and stakeholders regarding the draft charging regulations and have included some headline figures and comments in this response. Our concerns are set out in further detail in the response to Q6 a) and b).

Regarding clarity, anecdotal evidence from a number of carers and carers' centres states that many people found the regulations difficult to interpret. We recognise that this is not a simple area of legislation, and that the primary audience of these Regulations is service providers, but it may be worth considering whether clearer and more illustrative language could be used. Specific examples within paragraph 9 that illustrate the six individual situations may be helpful.

Line 2 of the guidance refers to support provided to young carers. Whilst we welcome the waiving of charges for young carers, we are concerned that the power to provide services free of charge to young carers is contingent upon having been assessed under the 1995 Act. Our experience is that very few young carers who are receiving support from young carers' services in Scotland have been assessed under the Act. We would hope that more young carers will have their needs assessed as a result of local authorities implementing GIRFEC, and would like to see something in the regulations which recognises the imminent change to

assessing children and young people's needs as detailed in the Children and Young People's Bill.

**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)**

Mostly

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

We recognise that this list is not exhaustive and appreciate the flexibility this will give to support where charges are waived. **However, we believe there is some clarity needed over the status of universal services which are already provided free of charge by a range of third sector organisations, specifically carers' centres and services. Information and advice, emotional support, training and advocacy are available to all carers at all stages of their caring journey, whether or not they are eligible for or have undergone a Carers' Assessment and whether the service is provided directly or indirectly by a local authority.** It is clearly set out in the National Carers Strategy that carers must have access to up to date, good quality information and advice whenever they need it. Many people with caring responsibilities will benefit greatly from information, advice, advocacy and signposting, even though their caring situations may not seem particularly 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 are pleased to see the recognition in paragraph 11 that support with household tasks and gardening can be provided to carers. However, providing this type of support to a carer is not to free up their time to provide personal care to the cared-for person, but rather to reduce some of the burden a carer experiences in addition to caring or that impacts on their ability to provide care. It may also assist in freeing up time for the carer to help improve their wellbeing and quality of life.

We suggest that paragraph 11 reads:

11. Many carers have multiple responsibilities over and above their caring role and may need assistance with practical aspects of their lives to support their health and wellbeing. For example, it would be perfectly reasonable for a local authority to provide or commission help with housework and gardening to help reduce physical and emotional stress on the carer. When this support is provided to carers, it will be free of charge.

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

Yes	No
	X

**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.**

**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
	X

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

Whilst we recognise the limitations on local authorities in providing taxis and driving lessons for carers, particularly the need for agreed financial limits on driving lessons, it is difficult to define what 'exceptional circumstances' are.

Primarily, if a carers' assessment identifies a need for a carer to access a service or venue that is only accessible to them by taxi, then it is only right that their taxi fares are included as part of the support. The example given in the draft regulations is of a carer who lives in a remote part of Scotland and does not have access to alternative transport. It needs to be recognised that it is not only remote and rural parts of Scotland where access to public transport is limited – even in cities and large towns, bus and train services can be inconvenient outside of peak travel times and the inconsistency of public transport travel times can cause problems for carers who have to return promptly to relieve replacement care providers. Rural and remote areas may not have any access to public transport and therefore the use of taxis or private cars will never be exceptional circumstances for them.

**We would prefer that 'appropriate circumstances' be used rather than 'exceptional' or 'special' circumstances.** These terms can become barriers to carers for whom it is quite reasonable because of location and/or their caring circumstances to use a taxi. Supporting a carer to learn to drive could also have multiple benefits in supporting their carer in their caring role, e.g. ease of transport to appointments and reducing isolation. It may also support a carer's general wellbeing, by enhancing their employment prospects.

The examples provided are useful to illustrate different ways that carers can benefit from support with transport, but local authorities must always be prepared to consider appropriate ways in which support with transport can be overcome.

**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
X	

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

We welcome the proposal that support to the carer in the form of a short break will not be charged for, and that the whole cost of a short break (including taxi fares if required) will be met by the local authority. 71% of respondents to our online survey also agreed that the local authority should meet the entire cost of the break, and reiterated that carers who cannot work full time because of their caring responsibilities (and in many circumstances, those who are able to work) would not be able to afford any kind of break without assistance.

*"I do not have extra cash to fund breaks, yet I am saving the council thousands each week as my daughter requires a 2 to 1 support package, 24/7"*

**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
X	

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

Many people with caring responsibilities would like to have a break together but are not able to do so because they are not able to access the same levels of support as they would at home. Additionally, if the carer has to carry out their typical caring responsibilities whilst on the break, they do not get the full benefit of a break. It is good that the extra costs of being able to have a break together, such as specialist equipment, additional agency care, specialist transport or accessible/specialist accommodation, will also be waived.

**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
	X

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

Informal replacement care, or care in emergencies, may often be provided by friends or relatives. However, we have significant concerns that the guidance indicates this should be the default position. Unpaid carers are not required to provide care, whereas the local authority has a statutory obligation to provide care and support to those who need it. Whilst some carers may prefer to receive care from a friend or family member when their regular unpaid carer is not available, there may be many reasons why this is not appropriate, including but in no way limited to complexity of care needs, inability of friends or family to provide care on a regular basis, or no appropriate friends or family to provide care.

Simply put, this position trivialises the role of the unpaid carer. Carers are experts in those they care for and often possess a huge skills base, becoming proficient and efficient in providing care due to the time they spend caring. Often this can include medical skills such as administering injections, caring for stomata, catheters and feeding tubes, and physiotherapy. Family and friends will not have the skills required to take this care on, nor should they be expected to. If they do have the skills, willingness and ability to provide care, they are probably already doing it.

It also places undue stress and pressure on the carer if they are expected to arrange replacement care. They may feel guilty if the care provided by the family member is reluctant, poor quality or in any way not ideal – this can lead to family arguments and breakdown of relationships. It is also a risk that well-meaning family members can underestimate the care that is needed, particularly for people with a learning disability, mental health condition or neurological illness; many carers reported bad experiences of family members providing replacement care for them because whilst the person who stepped in was well-meaning, they were not sufficiently able to provide care in the required way.

53% of respondents to the online survey did not agree that it was reasonable to ask friends and family to provide replacement care.

*“Our 30 year old son has complex needs and requires help with personal care. It is inappropriate for his only sister who lives abroad to be expected to do this. We have very few relatives and all are too old/unwilling to cope with his needs. Friends evaporate as soon as they are asked to help in this way.”*

*“My wife is afraid of other people, even those that she knows”*

*“I cannot ask my 30 yr. old son to look after his sister because it is very inappropriate e.g. toilet and washing needs, dressing etc. He also works full-time based in Nottingham but travels abroad a lot for work... All grandparents are dead except for my mother who is 83 and she herself gets support from me.”*

*“Not everyone is suited to a caring role - just because someone is family does not change this. Forcing someone into a role in which they were not comfortable would*

*not be good for health of cared-for person, or provide the mental break that the carer needs.”*

The consultation report provides many more examples of occasions when it would be impractical or inappropriate to involve family, friends, neighbours and volunteers as replacement carers.

Regarding the circumstances of ‘social isolation’, if replacement care is restricted to only those who have become socially isolated, preventative opportunities to reduce the number of carers and people with care needs who become socially isolated in the first place will be missed. The definition of social isolation in the draft regulations also will not cover situations where the carer and cared-for person do have families, friends and neighbours, but none of them are willing or able to provide care. We believe that this will be the case in many situations and it is not clear how this would be interpreted. It would be a grave error for the regulations to state the default position is to expect unpaid carers to approach unwilling or unavailable family and friends to convince them to provide replacement care.

We would propose that ‘social isolation’ is removed from this section, and that both the availability and appropriateness of replacement care provided by friends and family is discussed as part of an assessment. Where it is identified that no such replacement care is possible, the local authority must arrange or provide adequate replacement care that is free of charge to the carer.

**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.**

It remains concerning that there is no legal obligation on local authorities to provide support or services to carers in response to the outcome of a carers’ assessment. If local authorities are not bound by duty to provide support, even when they have assessed a carer as needing the support, it raises fundamental questions as to whether these regulations will have any effect on carers at all. We appreciate that local authorities provide support for carers and will always signpost to other sources of support such as carers’ centres, but in these austere times there is a real risk that where local authorities are not required to provide or arrange support, they will prioritise funding to their statutory obligations and this will limit the amount of funding that goes to preventative support and services for carers.

Regarding the points made in paragraphs 19-21, around charges for supplementing the agreed levels of support and charging of carers outwith their role as carers, whilst we recognise there are circumstances where charges cannot be waived, it should be recognised that there may be occasions where it would be counter-productive to charge the service user, such as if the application of a charge would prevent such a break.

We recognise that carers may be charged for services that are not related to their role as carers, and that their income may be taken into account if their partner is assessed for some services, and that this is outwith the scope of these regulations and guidance. However, we feel it is important that supporting guidance recognises the ambiguities in this area of the law and that further work is being undertaken by CoSLA and its partners in clarifying the law. Current guidance on charging advises local authorities to consider whether the carer (as a supported person) has difficulty in meeting the charge due to their financial circumstances and advises that they consider the full impact of all combined charges on the wellbeing and independence on both carer and service user (*National Strategy and Guidance for Charges Applying to Non-residential Social Care Services 2012/13*).

**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](mailto:alun.ellis@scotland.gsi.gov.uk) by **Wednesday 10<sup>th</sup> July 2013**.