

Carers (Scotland) Act 2016

Consultation on timescales for adult carer support plans and young carer statements for carers of terminally ill persons

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EXECUTIVE SUMMARY

The Carers (Scotland) Act 2016 (“the Act”) came in to force on 1st April 2018.

The intention of the Act is to ensure that Scotland’s estimated 745,000 adult carers and 44,000 young carers are identified and supported on a more consistent basis; to enable them to continue to care, if they so wish, in good health and to have a life alongside caring.

In relation to young carers, the intention is that young carers should have a childhood similar to other children and have the same future opportunities.

The Act sits within the wider context of the Scottish Government’s aim to build a fairer Scotland and strong sustainable economy; tackling inequalities in society; and delivering public services in communities. In particular, our Programme for Government 2018/2019 focuses on the values of kindness, dignity and compassion as being core to the kind of Scotland we want to see. Our National Health and Wellbeing Outcome 6 also highlights the importance of supporting carers and recognises the potential impact of caring:

“People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing.”

The Act extends and enhances the rights of unpaid carers in Scotland, by giving **all carers** the right to an adult carer support plan (ACSP) from their responsible local authority¹ or young carer statement (YCS) from the responsible authority². An ACSP and YCS is a document prepared by this authority setting out the carers personal outcomes, identified needs and support to be provided to meet those needs. Local authorities have a duty to provide support to carers where their identified needs, as detailed in the ACSP or YCS, meet the local eligibility criteria (unless those needs can be met by universal services or extra support for the cared-for person). Early identification of carers is key to successful implementation of the Act, so that carers can access support early in their caring journey, to help prevent problems.

The Act requires Scottish Ministers to set timescales for preparing adult carer support plans and young carer statements for carers of people who are terminally ill with a life expectancy of up to 6 months. Authorities are already required to offer an ACSP or YCS to every carer they know about. In line with our focus on early identification, we therefore expect many carers of people who are terminally ill to have had an ACSP or YCS well before the 6-month definition is reached. We know that authorities already prioritise ACSPs and YCSs for these carers, so we expect the time limits to be set will act as a backstop rather than a target.

¹ The local authority for the area in which the cared-for person lives.

² This is normally the local authority where the young carer lives but in special cases can be a health board or a grant-aided or independent school.

This consultation seeks views on:

- the overall outcome these regulations should seek to support and the principles they should follow;
- when the timescales in the regulations should be triggered, i.e. when the clock should start;
- time limits for holding the first substantive conversation with the carer to start preparing an adult carer support plan or young carer statement; and
- time limits for completing an adult carer support plan or young carer statement.

The proposals in this consultation have been informed by research by Marie Curie, *'Getting it right for carers supporting someone at end of life'*³, which investigated and considered the needs of carers in these situations.

The consultation has also been developed with input from a task group involving representatives from Palliative Care Scotland, Marie Curie, Macmillan Cancer Support, Association of Palliative Care Social Workers, Children's Hospices Across Scotland, Carers Trust Scotland and COSLA.

Consultation responses will be analysed and considered with input from the task group to help inform the final regulations and associated guidance.

This consultation is open for a period of 12 weeks. (18/01/2019 – 12/04/2019)

We invite your views to each of the questions below.

³ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/marie-curie-and-macmillan-getting-it-right-for-carers-final-report-november-2018.pdf>

QUESTIONS

THE CARERS (SCOTLAND) ACT 2016 - PROPOSED TERMINAL ILLNESS REGULATIONS

1. Overall outcome and principles for regulations

Background

Sections 7 and 13 of the Carers (Scotland) Act 2016 are as follows:

7 Adult carers of terminally ill cared-for persons

(1) The Scottish Ministers must by regulations prescribe timescales for the preparation of adult carer support plans in relation to adult carers of terminally ill cared-for persons.

(2) For the purposes of this section and section 13, a cared-for person is terminally ill at any time if at that time the person suffers from a progressive disease and death in consequence of that disease can reasonably be expected within 6 months.

13 Young carers of terminally ill cared-for persons

The Scottish Ministers must by regulations prescribe timescales for the preparation of young carer statements in relation to young carers of terminally ill cared-for persons.

For the purpose of these regulations, the Act defines terminal illness as where, “*the person suffers from a progressive disease and death in consequence of that disease can reasonably be expected within 6 months*”.⁴

The Act gives all carers the right to an adult carer support plan or a young carer statement (as appropriate). The requirements for adult carer support plans and young carer statements are set out in the Act and associated statutory guidance⁵.

Local authorities are responsible for offering and preparing adult carer support plans and are normally responsible for young carer statements. Many authorities have made arrangements for local carer organisations to prepare these plans or statements on their behalf. The adult carer support plan or young carer statement will explain the carer’s personal outcomes and identify any support required to achieve these outcomes.

⁴ This is consistent with the definition of terminal illness used for social security benefits administered by the UK Government Department for Work and Pensions. It is different from the definition set out in the Social Security (Scotland) Act 2018, which will apply to the delivery of disability assistance in Scotland.

⁵ Carers (Scotland) Act 2016 Statutory Guidance: <https://www.gov.scot/publications/carers-scotland-act-2016-statutory-guidance/> (Part 2, Chapter 1 and Part 2, Chapter 2)

Our existing statutory guidance on adult carer support plans and young carer statements explains that they “*ought to be prepared within reasonable timescales taking into account the urgency of needs for support*”. Because of the particular urgency of supporting carers looking after someone who is terminally ill, the legislation quoted above requires time limits to be set for preparing plans for them.

As explained above, we expect many carers of people who are terminally ill to have had an ACSP or YCS well before the 6-month definition is reached. We know that authorities already prioritise ACSPs and YCSs for these carers, so we expect the time limits to be set will act as a backstop rather than a target.

In deciding on the content of these regulations, it is helpful to consider the overall outcome and principles which they should support.

Proposal 1

We are proposing the following **overall outcome** for the regulations to support:

- Adult carers and young carers of a terminally ill person receive an ACSP or YCS and associated support in an efficient and timely manner.

We also propose the following **principles** to be taken into account in developing these regulations:

- The time limits we set should not compromise the quality and personalisation of support for carers of people with a terminal illness.
- The time limits we set for this group of carers should take into account the impact this may have on prioritisation of other urgent cases.
- The time limits we set should not prevent adult carer support plans and young carer statements being completed quicker, in line with existing good practice.
- We should minimise bureaucracy for both professionals and carers.

QUESTION 1

1) Do you agree with the overall **outcome** and **principles** proposed?

Yes / No

Please explain your answer.

2. What triggers the time limits set by these regulations (i.e. when does the clock start)?

Background

Local authorities (and Health and Social Care Partnerships) may identify a carer of a terminally ill person in a number of ways.

- A carer may inform the local authority of their situation.
- A local authority may receive information or a referral from a professional such as a home care assistant, district nurse, health visitor or GP.
- A local authority may receive a referral as part of preparation for hospital discharge of the cared-for person.

To 'start the clock' on the time limits, the regulations could require particular types of evidence, such as a DS1500 form⁶, to confirm the terminal illness diagnosis of the cared-for person. However, we are concerned that such an approach would lead to delays and create unnecessary additional work for the professionals involved and for carer.

Proposal 2a

Instead, to avoid potential delays, we are proposing that the time limits should be triggered, ***when the authority receives information to indicate that a carer is caring for a person with a terminal illness***. This could encompass any of the situations listed above.

As part of this approach, we will develop guidance for authorities to accompany the legislation on approaches to identifying carers in this situation and evidence they might draw on (in line with the 6-month definition noted above)⁷.

Further background

When the authority receives information about a carer in this situation, he or she may not be ready to participate in an adult carer support plan or young carer statement. Immediately following the diagnosis of a terminal illness, it is understandable that carers are often unwilling to focus on their own needs until the support needs of the cared-for person have been addressed.

The regulations will need to take account of these situations and ensure that these carers can benefit from the accelerated time limits for ACSPs and YCSs when they are ready to participate.

⁶ A DS1500 provides essential information about a patient's prognosis and can be used by a patient to apply for social security benefits from the Department for Work and Pensions under special rules.

⁷ Our guidance will link to the forthcoming 'Guidance for doctors completing benefits assessment under special rules in Scotland (BASRIS) form for Terminal Illness', to be published by the Chief Medical Officer.

Proposal 2b

We therefore propose that the time limits would also be triggered, ***when a carer who is caring for a person with a terminal illness requests an adult carer support plan or young carer statement.***

QUESTION 2

2a) Do you agree with the proposal that the time limits in regulations would be triggered, ***when the authority receives information to indicate that a carer is caring for a person with a terminal illness?***

Yes / No

Please give reasons for your answer

2b) Do you agree with the proposal that the time limits in regulations would also be triggered, ***when a carer who is caring for a person with a terminal illness requests an adult carer support plan or young carer statement?***

Yes / No

Please give reasons for your answer

3. Separate timescale for first substantive conversation with the carer in preparation of an ACSP or YCS

Background

An adult carer support plan or young carer statement can be completed following one conversation or may need several, depending on individual needs and the complexity of the case. It may also require the input of different organisations, particularly in deciding about support to meet a carer's identified needs, which can include support for the cared-for person. These circumstances can mean that more time is required for an effective ACSP or YCS to be completed.

Many of the benefits of an ACSP or YCS would normally emerge from the first substantive conversation with the carer. This would normally involve developing an understanding of the outcomes that are important to the carer and their individual needs; and ensuring the carer is aware of sources of support and advice and their options for future care planning.

We want the timescales we set to ensure this first stage happens quickly to help ensure effective and timely intervention, in line with the overall outcome we are proposing for these regulations. We also want timescales which take account of the complexity in some cases, and do not compromise the quality of the ACSP or YCS.

Proposal 3

We therefore propose to set two separate time limits:

- a shorter time limit for the first substantive conversation with the carer in preparing the ACSP or YCS; and
- a longer time limit for the completion of the ACSP or YCS.

QUESTION 3

3) Do you agree with the proposal to set separate time limits for the first substantive conversation with a carer (as part of the preparation of their ACSP or YCS) and for completion of the ACSP or YCS?

Yes / No

Please give reasons for your answer

4. Timescale for the first substantive conversation in preparation of an ACSP or YCS

Background

We want carers of terminally ill people to receive timely support, but the timescales we set also need to take account of carers' individual circumstances and their readiness to participate. Immediately following the diagnosis of a terminal illness, carers may be unwilling to focus on their own needs until the support needs of the cared-for person have been addressed. At this very early stage, the carers' needs may also be hard to identify.

In setting these time limits, we need to bear in mind:

- our proposed overall outcome that these carers receive timely support;
- the principle of not compromising the quality of support for carers; and
- the principle of taking account of the impact on prioritisation of other urgent cases.

Rather than proposing a specific time limit at this stage, we are seeking views on three alternative timescales. These have been informed through dialogue with Local Authorities and Health and Social Care Partnerships regarding their current practice and timescales for prioritising similar cases.

It is important to note that any timescale prescribed would need to be subject to the carer's willingness to participate.

QUESTION 4a

4a) Adult carer support plans - Please give your views on the pros and cons of requiring the first substantive conversation for the ACSP to take place within the following alternative timescales.

Time limit	Pros and cons
2 days	
4 days	
6 days	
Other (please specify)	

What is your preferred time limit? Please give your reasons.

Additional background – Young carers

All the issues discussed above are relevant to setting a time limit for the first substantive conversation in preparing a young carer statement.

Additionally, young carers of people with a terminal illness can be particularly vulnerable due to their age and pressures of balancing their caring role and education.

We are therefore requesting separate views on the pros and cons of alternative time limits for the first substantive conversation in preparing a young carer statement.

QUESTION 4b

4b) Young carer statements - Please give your views on the pros and cons of requiring the first substantive conversation for the YCS to take place within the following alternative timescales.

Time limit	Pros and cons
2 days	
4 days	
6 days	
Other (please specify)	

What is your preferred time limit? Please give your reasons.

As highlighted previously, once a carer has been identified by a local authority they may not be ready to participate in the ACSP/YCS. In such cases local authorities would agree future actions with the carer, this may be to delay the first substantive conversation and agree a further date, or, agree for the carer to contact the local authority once they wish to take the offer of an ACSP/YCS forward.

In such cases, timescales for completing the first substantive conversation and the ACSP/YCS would start once the carer had confirmed they were ready to participate.

Counting non-working days?

Background

In setting a time limit of a few days for the first substantive conversation with the carer, we will need to decide whether public holidays and weekends will be counted. There is certainly the potential for the authority to receive information during weekends or public holidays to indicate that a carer is caring for a person with a terminal illness.

This decision needs to consider our proposed overall outcome that these carers receive timely support; as well as the practicality for authorities in mobilising support on non-working days. We also need to bear in mind our principles of:

- not compromising the quality of support for carers; and
- taking account of the impact on prioritisation of other urgent cases.

QUESTION 5

5) Please give your views on the pros and cons of whether the first substantive conversation time limits should count non-working days or working days only.

Days	Pros and cons
Include non-working days	
Count working days only (excluding week ends and public holidays)	

What is your preferred option? Please give your reasons.

Timescale for completing the adult carer support plan or young carer statement

Background

In addition to setting a time limit for the first substantive conversation, we also propose to set a time limit for the completion of the ACSP or YCS for carers looking after someone who is terminally ill.

Completing the ACSP or YCS means that the carer has all their needs identified and decisions about support made and recorded, regardless of how complex their circumstances are. The time limit we set should support the proposed overall outcome that these carers receive timely support. These will be time limits, so will not prevent the ACSP or YCS being completed more quickly, in line with existing good practice. We will also need to take account of the potential for some caring situations to require support from different agencies and organisations, which could take time to coordinate and deliver. We also need to bear in mind our principles of:

- not compromising the quality of support for carers; and
- taking account of the impact on prioritisation of other urgent cases.

Again, rather than proposing a specific time limit at this stage, we are seeking views on three alternative options. These have been informed through dialogue with Local Authorities and Health and Social Care Partnerships regarding their current practice and timescales for prioritising similar cases⁸.

The legislation will also need to take account of the fact that in some cases authorities will be reliant on other organisations inputting before they can complete an ACSP or YCS. This will mean including a caveat that *authorities must take reasonable and practical measures to complete plans/statements in the prescribed timescales*. This caveat will be expanded in guidance to accompany the regulations.

QUESTION 6

6a) Adult carer support plans - Please give your views on the pros and cons of requiring the **ACSP** to be completed within the following alternative timescales.

Time limit	Pros and Cons
2 weeks	
3 weeks	
4 weeks	
Other (please specify)	

⁸ In coming up with options, we also considered the timescales followed to complete other assessments such as the Adult Support & Protection Risk assessment and GIRFEC Child Plan assessment.

What is your preferred time limit? Please give your reasons.

Additional background – young carers

All the issues discussed above are relevant to setting a time limit for completing a young carer statement.

Additionally, young carers of people with a terminal illness can be particularly vulnerable due to their age and pressures of balancing their caring role and education.

We are therefore requesting separate views on the pros and cons of alternative time limits for the completion of a young carer statement.

6b) Young carer statements - Please give your views on the pros and cons of requiring the **YCS** to be completed within the following alternative timescales.

Time limit	Pros and Cons
2 weeks	
3 weeks	
4 weeks	
Other (please specify)	

What is your preferred time limit? Please give your reasons.

RESPONDING TO THIS CONSULTATION

We are inviting responses to this consultation by 12/04/2019.

Please respond to this consultation using the Scottish Government's consultation hub, Citizen Space (<http://consult.gov.scot>). Access and respond to this consultation online at <https://consult.gov.scot/health-and-social-care/carers-of-people-who-are-terminally-ill/>

You can save and return to your responses while the consultation is still open. Please ensure that consultation responses are submitted before the closing date of 12/04/2019.

Alternatively, you can e-mail your response and the completed Respondent Information Form, which is also available separately on the Scottish Government website (see "Handling your Response" below) to: carerspolicy@gov.scot

If you are unable to respond online, please complete the Respondent Information Form (see "Handling your Response" below) and send it to:

Carers (Scotland) Act 2016
Consultation on Terminal Illness Regulations Timescales
Carers Policy Branch
Scottish Government
St Andrews House, GE.15
Regent Road
Edinburgh
EH1 3DG

Handling your response

If you respond using the consultation hub, you will be directed to the About You page before submitting your response. Please indicate how you wish your response to be handled and, in particular, whether you are content for your response to be published. If you ask for your response not to be published, we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

If you are unable to respond via Citizen Space, please complete and return the Respondent Information Form included in this document.

To find out how we handle your personal data, please see our privacy policy : <https://beta.gov.scot/privacy/>

Next steps in the process

Where respondents have given permission for their response to be made public, and after we have checked that they contain no potentially defamatory material, responses will be made available to the public at <http://consult.gov.scot>. If you use the consultation hub to respond, you will receive a copy of your response via email.

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us. Responses will be published where we have been given permission to do so. An analysis report will also be made available.

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to the contact address above or to : carerspolicy@gov.scot .

Scottish Government consultation process

Consultation is an essential part of the policy-making process. It gives us the opportunity to consider your opinion and expertise on a proposed area of work.

You can find all our consultations online: <http://consult.gov.scot> . Each consultation details the issues under consideration, as well as a way for you to give us your views, either online, by email or by post.

Responses will be analysed and used as part of the decision making process, along with a range of other available information and evidence. We will publish a report of this analysis for every consultation. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.



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