

Carers (Scotland) Act 2016

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

August 2019

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

SUMMARY

The Carers (Scotland) Act 2016 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.

The Act requires Scottish Ministers to set timescales for preparing adult carer support plans (ACSP) and young carer statements (YCS) for carers of people who are terminally ill with a life expectancy of up to 6 months.

The consultation on timescales for adult carer support plans and young carer statements for carers of terminally ill persons sought 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;
- whether the time limits for the first substantive conversation should include non-working days or working days only; and
- whether there should be different time limits for adult carers and young carers.

The consultation was 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.

The consultation opened on 18/01/2019 for 12 weeks and closed on the 12/04/2019.

- 46 responses were received.
(47 responses were submitted on line, but 1 response contained no data)
- 23 individuals responded.
- 23 organisations responded.
 - 16 Statutory organisations.
 - 7 Non Statutory organisations.

The responses to the consultation have been analysed in this paper and discussed with the task group to help inform the draft regulations and associated guidance.

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.

Consultation Paper Question 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 carer should take into account the impact this may have on prioritisation of other urgent cases.
- The time limits we set should not prevent ACSP and YCS being completed quicker, in line with existing good practice.
- We should minimise bureaucracy for both professionals and carers.

Question 1: Do you agree with the overall outcome and principles proposed?

We received 46 responses to the question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
Agree	44	92%	22	15	7
Disagree	2	8%	1	1	0

The overwhelming response from the majority of responses were that they agreed with the overall outcome and principles proposed.

The pros and cons identified most frequently were as follows:

Pros

- A large number agreed with the outcomes and principles under the condition that this was conducted in a timely manner.
- Several stated that these principles were clear.
- Several suggested that it was important to respect the needs and wishes of people with a terminal illness and that local hospice care and support should be included in the plans if appropriate.
- Both the outcome and principles are logical as a timely manner is appropriate in this situation.
- Several felt that the regulations would only assist a small proportion of carers, so prioritisation would not create problems for other carers.

Cons

- The outcome described is merely reiterating existing good practice rather than introducing improvement.
- Principle can only be undertaken meaningfully at council/partnership level and not at government level.
- The approach would only be fair if plans for other carers are conducted at the same speed.

Consultation Paper Question 2

Question 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?

We received 45 responses to this question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
Agree	37	82%	19	12	6
Disagree	8	18%	4	4	0

There was a clear majority in favour of this proposal across all sectors. Where responses identified reasons for their agreement, by far the most popular was:

- Enabling early support for the carer. (12 responses)

Of the 8 responses disagreeing the clear reason for the majority, including all 4 from statutory organisations, was:

- Need to wait until carer has decided they are ready. (6 responses)

A further 3 responses which agreed with this proposal made the same comment.

Question 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?

We received 45 responses to this question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
Agree	41	91%	19	16	6
Disagree	4	9%	4	0	0

There was a clear majority in favour of this proposal across all sectors. Where responses identified reasons for their agreement, the most popular were:

- Enabling early support for the carer. (13 responses)
- Clock only to start when carer agrees to support plan. (9 responses)

Of the 4 responses disagreeing with the proposal, all were from individuals. There were no clear trends in the reasons they gave.

Consultation Paper Question 3

*Question 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?*

We received 46 responses to this question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
Agree	39	81%	18	14	7
Disagree	7	15%	5	2	0

There was a clear majority in favour of this proposal across all sectors. Where responses identified reasons for their agreement, the most popular were:

- Not a simple process would require more than one conversation, possible multiple meetings to conclude ACSP. (23 responses)
- Early identification/conversation required to manage quick / critical support. (14 responses)
- Carer requires time to consider needs and engage appropriately. (13 responses)

Of the 7 responses disagreeing the clear reasons were:

- Individuals (5): Felt the process should be as quick as possible due to terminal diagnosis. One felt the initial conversation should be the ACSP without further stages to the process.
- Statutory (2): Timescales are already embedded in good practice, which take into account a range of different carer circumstances. May not be appropriate for carers to engage within these timescales. Timescales which are not linked to carers' circumstances could have a potential negative impact on the quality of the plan.

Consultation Paper Question 4

Question 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.

2 days , 4 days, 6 days or 'other'.

We received 46 responses to this question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
2 days	8	18%	3	1	4
4 days	11	24%	6	3	2
6 days	14*	30%	10	4	0
10 days	2	4%	0	2	0
14 days	2	4%	1	1	0
No time limit	9**	20%	3	5	1

* 3 responses stating 'other': 5-7 days have been counted as 6 days above.

** 1 unanswered response with comments criticising the arbitrary nature of time scales has been counted as 'no time limit'.

The pros and cons identified most frequently for each category were as follows.

2 days	<p>Pros:</p> <ul style="list-style-type: none"> • Certainty over the requirement of this to happen, reassurance. • Gets things moving quicker for the carer if these conversations happen sooner (reduce stress / get support in place quicker). • Quickly identifies critical support. <p>Cons:</p> <ul style="list-style-type: none"> • When the diagnosis is very sudden this could be too quick for the carer, unable to focus and identify needs, other priorities. • Quality of conversation superficial, planning not thorough. • Challenge to get staff and then support in place (particularly rural areas). • Potential for delay to other priority cases, should be based on need not arbitrary timescale. <p>2 days was most favoured by non-statutory organisations, with focus on timely support, with less consideration as to whether this would be meaningful or whether the carer would be able to cope. Some individuals felt this may be too early for the carer to have meaningful conversation.</p>
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<p>4 days</p>	<p>Pros:</p> <ul style="list-style-type: none"> • Gives carers more time to come to terms with diagnosis, but allows their needs to be discussed and support put in place relatively quickly. • More reassuring for carers as they are aware of support available. • More practically manageable for Carer Centres to support. <p>Cons:</p> <ul style="list-style-type: none"> • Still could be too soon for carer unable to focus and identify needs, other priorities. • Taking longer to get critical support, when situation could be changing quickly due to speed of terminal illness. • Could still be a challenge for support / services. Appropriate staff may not be available. <p>4 days was the second most popular option. Comments were similar to those for 6 days (see below) with the additional point: 'would provide more reassurance for carers that support is available and catch crisis situations quicker'.</p>
<p>6 days</p>	<p>Pros:</p> <ul style="list-style-type: none"> • Gives carers more time to come to terms with diagnosis, but allows their needs to be discussed and support but in place relatively quickly. • More practically manageable for support staff/services. <p>Cons:</p> <ul style="list-style-type: none"> • Taking too long to get critical support leaving carer in crisis. • The situation changing quickly due to speed of terminal illness. • Carers feel unsupported/not a priority and less likely to engage. <p>6 days was the most popular option. With the majority of responses supporting 4 to 6 days, the main focus was on:</p> <ul style="list-style-type: none"> • Carers being in a position to engage and make process meaningful. • Support staff / systems / services realistically being able to provide support.
<p>Other</p>	<p>The majority of responses not opting for the 2, 4 or 6 day categories argued that there should be <u>no time limit</u> because local systems already prioritise urgent cases depending on the individual circumstances. They also argued that time limits do not support a person centred approach.</p> <p>Pros:</p> <ul style="list-style-type: none"> • People are individuals and have unique situations so therefore there should be no single time limit. • Carers are given more time to consider needs. <p>Cons:</p> <ul style="list-style-type: none"> • If a longer timescale then should maybe have an upper limit 14 days.

Question 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:

2 days , 4 days, 6 days or other.

We received 41 responses to this question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
2 days	7	18%	3	0	4
4 days	9	23%	5	2	2
6 days*	9	23%	7	2	0
10 days	4	10%	0	4	0
14 days	1	2%	0	1	0
No time limit**	11	23%	3	7	1

* Includes 2 statutory orgs responses which stated (5-7 days).

** Includes two which were left unanswered but indicated no time limit in comment.

The pros and cons identified most frequently for each category were as follows. Many comments were the same as those for ACSP time limits. Additional points are highlighted in italics.

2 days	<p>Pros:</p> <ul style="list-style-type: none"> • Certainty over the requirement of this to happen, providing reassurance. <i>Possibly more important for young carers as more vulnerable.</i> • Gets things moving quicker for the carer if these conversations happen sooner (reduce stress / get support in place quicker). • Quickly identifies critical support. <p>Cons:</p> <ul style="list-style-type: none"> • When the diagnosis is very sudden this could be too quick for the carer, unable to focus and identify needs, other priorities. • Quality of conversation superficial, planning not thorough. • Challenge to get staff and then support in place (particularly rural areas). • Potential for delay to other priority cases, should be based on need not arbitrary timescale. • <i>Young carers may not be primary carer, not as easy to contact.</i> • <i>The most appropriate support worker may not be available.</i>
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<p>4 days</p>	<p>Pros:</p> <ul style="list-style-type: none"> • Gives carers more time to come to terms with diagnosis, but allows their needs to be discussed and support put in place relatively quickly. • More reassuring for carers as they are aware of support available. • More practically manageable for Carer Centres to support. • <i>The most appropriate worker more likely to be available, may be back at school for example.</i> <p>Cons:</p> <ul style="list-style-type: none"> • Still could be too soon for carer unable to focus and identify needs, other priorities. • Taking longer to get critical support, when situation could be changing quickly due to speed of terminal illness. • Could still be a challenge for support / services. Appropriate staff may not be available.
<p>6 days</p>	<p>Pros:</p> <ul style="list-style-type: none"> • Gives carers more time to come to terms with diagnosis, but allows their needs to be discussed and support put in place relatively quickly. • More practically manageable for support staff/services. <p>Cons:</p> <ul style="list-style-type: none"> • Taking too long to get critical support leaving carer in crisis, <i>particularly if young carer and they are primary carer.</i> • The situation changing quickly due to speed of terminal illness. • Carers feel unsupported/not a priority and less likely to engage.
<p>Other</p>	<p>As for ACSPs, the majority in this category suggested <u>no time limit</u>.</p> <p>Pros:</p> <ul style="list-style-type: none"> • People are individual and have unique situations therefore there should be no time limit. • Carers are given more time to consider needs. <p>Cons:</p> <ul style="list-style-type: none"> • If a longer timescale then should maybe have an upper limit 14 days.

Comparison with responses for ACSP

Only 41 Responses for YCS compared with 46 for ACSP. 5 were left unanswered, either blank or felt they could not comment. Of the 41 responses:

- 34 answered the same as the ACSP (83%).
- 3 suggested reduced timescales (6 days to 2 days; 6 days to 4 days; and 14 days to 6 days).
- 2 who had given a timescale for ACSP stated that timescales for YCS should be in line with child planning.
- 2 suggested increased timescales (2 days to 10 days; and 6 days to 10 days).

Consultation Paper Question 5

*Question 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?***

We received 41 responses to this question.

Response	Total	% of total	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
Count Working Days Only (excluding weekends and public holidays)	26	63	12	13	1
Include non-working days	15	37	8	2	5

Most individuals and statutory organisations were in favour of counting working days only. Most non-statutory organisations favoured counting non-working days. Some responses highlighted that decisions on this issue are closely linked to decisions on the number of days. The pros and cons identified most frequently were as follows:

Count non-working days	<p>Pros</p> <ul style="list-style-type: none"> • The timescales for carers are easier to understand and should be turned around quickly. • May lead to quicker assistance. • Several suggest that non-working days are irrelevant to a person who may only have 6 months to live. • Could be useful in rural areas due to geography. <p>Cons</p> <ul style="list-style-type: none"> • Whilst the NHS do, the social care work force do not usually work weekends. • Could impact on over-stretched services. • Many organisations will have difficulty responding on bank holidays and weekends.
Count working days only	<p>Pros</p> <ul style="list-style-type: none"> • Workers are more likely to achieve targets set and at higher quality. • This is a more achievable ambition with current resources. • Local authorities could adhere to timescales more easily. • This is better structured and more staff/agencies can be involved. • More manageable for all parties. • Clear expectations on all parties. <p>Cons</p> <ul style="list-style-type: none"> • There may be difficulty delivering on tight timeframes. • This could cause crisis/anxiety for carers. • There was concern that this could potentially result in long timescales to ensure compliance. • This may delay development of statement, with the perception that power lies with statutory services.

Consultation Paper Question 6

*Question 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:
2 weeks; 3 weeks; 4 weeks; other.*

We received 46 responses to this question.

Response	Total	% of all	Breakdown		
			Individuals	Statutory organisations	Non-statutory organisations
Immediately	1	2%	1	0	0
2 weeks	15	32%	9	0	6 ³
3 weeks	10	22%	5	4	1
4 weeks*	11	24%	2	9	0
No time limit OR case by case**	9	20%	6	3	0

* Includes one statutory organisation which replied: Other, one month.

** Includes two which were left unanswered but indicated no time limit in comments.

The pros and cons identified most frequently for each category were as follows:

2 weeks	<p>Pros:</p> <ul style="list-style-type: none"> • Good for quick intervention and support. • Realistic given nature of caring for palliative illness and potential rapid changing circumstances. • Achievable for non-complex cases. <p>Cons:</p> <ul style="list-style-type: none"> • Too short for complex cases involving multiple agencies. • Carer doesn't have sufficient time to consider their own needs. • Cared-for person's care needs may not be determined. • Not enough time to gather all information required. • Carers/services under pressure to rush a plan which may compromise quality and effectiveness. • Carer may not be able to cope emotionally. <p>2 weeks was mainly favoured by individuals and non-statutory organisations. Most individuals provided limited comments on the pros and cons of this timescale, comments focussed on early intervention and quick support, due to the potential speed of decline.</p> <p>Non statutory organisations felt 2 weeks would be preferred and</p>
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³ One of these responses is the national carer organisations (NCO) group response which includes multiple opinions and perspectives on the most appropriate time limit. The response overall has indicated 2 weeks as preferred but individuals comments sent to the NCOs vary.

	<p>enough time to complete plan. Some raised concerns of plans potentially being rushed and the need to take account of individual circumstances, with one suggestion of 'ideally 2 / 3' weeks.</p> <p>No statutory organisation felt that 2 weeks was an appropriate timescale for completion of the full plan. Comments said that it was too short for carers to reflect on their needs and come to terms with the situation. Pressure to complete plan in this timescale could compromise quality, putting carers under pressure, particularly in complex cases. Most preferred either 3 or 4 weeks.</p>
<p>3 weeks</p>	<p>Pros:</p> <ul style="list-style-type: none"> • Not as driven by timescale and a better pace for carer. • Enough time to build a relationship with the carer and family and identify issues. • Realistic timescale to complete a thorough plan of support. <p>Cons:</p> <ul style="list-style-type: none"> • Carers might find this quite long without support. • Difficulties may arise due to the changing nature of caring for someone with a terminal illness. • Potential challenge for complex, multi-agency cases. • Insufficient time for carer to reflect on their needs fully. <p>3 weeks was preferred by a significant minority of individuals and statutory organisations. Many saw 3 weeks as a compromise, with 2 weeks feeling rushed and 4 weeks too long without support. Some statutory organisation reflected this could provide enough time to identify need, start to put support in place and be undertaken at the carer's pace.</p>
<p>4 weeks</p>	<p>Pros:</p> <ul style="list-style-type: none"> • Allows time for comprehensive assessment. • Allows time for carers to be flexible. • Some precedents at local level for 28 days for an assessment. • Allows time for resources to be targeted correctly. • More complex cases could be completed. <p>Cons:</p> <ul style="list-style-type: none"> • Situation may decline rapidly with palliative illness and needs change significantly. • Carer finds process too lengthy at a difficult time. • Carer without support for too long. <p>The majority of statutory organisations favoured 4 weeks. Their comments focussed on allowing time to build relationship with carer, carers having time to reflect on their needs and comprehensive plans leading to getting the right support. Non-statutory organisations felt 4 weeks would be too long due to the potential rapid decline of cared-for person and changing circumstances.</p>

Other	<p>A significant minority of individuals and statutory organisations were in this category. The majority of these responses argued that there should be <u>no time limit</u> either because it does not recognise the nature of palliative illness or it would put undue pressure on carers.</p> <p>Issues about overall quality of support with any timescale still remain.</p>
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Question 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:*

2 weeks; 3 weeks; 4 weeks; other

We received **36 responses to the question** on the preferred time limit, with 10 people declining/unable to give a preferred option.

Response	Total	% of all	Breakdown		
			Individual	Statutory organisation	Non-statutory organisation
Immediately	1	3%	1	0	0
2 weeks*	15	42%	7	2	6 ⁴
3 weeks	6	16%	3	3	0
4 weeks	10	28%	2	8	0
No time limit / case by case	4	11%	2	2	0

* Includes one left unanswered but indicated the same as adult carers in comment.

2 weeks	<p>Pros:</p> <ul style="list-style-type: none"> • good for quick intervention • realistic given nature of caring for palliative illness • more essential for young carers due to their age <p>Cons:</p> <ul style="list-style-type: none"> • too short for complex cases involving multiple agencies • young carer doesn't have sufficient time to consider their own needs • services under pressure to rush a statement • too rushed for a young carer • school holidays may mean workers are off <p>2 weeks was mainly favoured by individuals and non-statutory organisations, however 2 statutory organisations also preferred 2 weeks. Comments were similar to ACSP and also focussed on the vulnerability of young carers and the need for quick support. One individual commented that children often need longer to reflect and process what change means for them, so this may be too quick.</p>
3 weeks	<p>Pros:</p> <ul style="list-style-type: none"> • Not as driven by timescale and a better pace for young carer • Enough time to build a relationship with the young carer and family

⁴ One of these responses is the national carer organisation (NCO) group response which includes multiple opinions and perspectives on the most appropriate time limit. The response overall has indicated 2 weeks as preferred but individuals comments sent to the NCOs vary.

	<ul style="list-style-type: none"> • Cons: • Young carers might find this quite lengthy • Difficulties may arise due to the changing nature of caring for someone with a terminal illness • Potential challenge (i.e. too quick) for complex, multi-agency cases <p>3 weeks was preferred by a significant minority of individuals and statutory organisations. One said a complex YCS could be completed within this time. Other comments highlighted time for young carers to collect their thoughts and more time to gather information.</p>
4 weeks	<p>Pros:</p> <ul style="list-style-type: none"> • Allows time for comprehensive assessment • Allows time for young carers to be flexible and fully supported <p>Cons:</p> <ul style="list-style-type: none"> • Young carers may feel under-supported • Situation may decline rapidly with a palliative illness <p>4 weeks was the most popular option among statutory organisations. Comments focussed on allowing time to build relationships with young carers and potentially wider family members to ensure YCS is right. Also ensuring the right professionals are involved in supporting young carers and planning process. With plans being able to reflect views and opinions of different teams/agencies; and allowing time to properly consider more complex needs of youngsters.</p> <p>Some comments also noted that issues about overall quality of support with any timescale still remain.</p>
Other	<p>A significant minority of individuals and statutory organisations were in this category. The majority of these responses argued that that there should be <u>no time limit</u> either because it does not recognise the nature of palliative illness or it would put undue pressure on young carers. Some said immediately and some did not give any explanation or substantive comments for choosing “other”.</p> <p>Suggestion that 4 weeks is preferable to allow young carers to consider their needs but that guidance should stipulate the YCS should be completed as soon as possible (i.e. as soon as the young carer is ready).</p> <p>Some specific issues raised about school holidays.</p>



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