



Response from the National Carer Organisations to:

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

About the national carer organisations

The National Carer Organisations are brought together by a shared vision that all Scotland's unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Scotland, the Coalition of Carers in Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Carers Trust Scotland, the Scottish Young Carers Services Alliance, Crossroads Caring Scotland and Shared Care Scotland.

Methodology

The National Carer Organisations summarised the government consultation paper and circulated the information in the form of a survey. We made this survey available to carers and other interested parties via our mailing lists and social media. In addition it was highlighted to participants at the Coalition of Carers members meeting in March 2019 and included in the information packs on the day.

In total we received 69 responses to the survey. 37 were from carers (30) or former carers (7), 20 were staff from a third sector organisation, 1 was from a member of staff from a statutory organisation and 10 were from a staff member with a caring role.

This submission is based primarily on the responses to our survey. A full report of the survey is included as part of our submission.

Do you agree with the overall outcome?

We asked respondents to our survey if they agreed with the outcome '*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 received the following responses

Yes	85.51%	59
No	11.59%	8
Don't Know	2.90%	2

Overall respondents agreed with the outcome, however a few respondents felt that it was too 'vague' *'Too vague. Timely is not specific enough'* or could be open to interpretation 'what's the definition of 'timely'??'

Another suggested that 'urgent' should replace 'efficient' to better reflect the need for timescales to be as short as possible. *'They should specify a time, what is efficient-I feel urgent is more appropriate as it's what is required'*

One also suggested that the phrase 'if they choose' should be added to the outcome

Do you agree with the principles proposed?

We asked respondents if they agreed with the proposed principles. We received the following responses

Yes	97.1%	67
No	1.45%	1
Don't Know	1.45%	1

The response to the principles was overwhelmingly positive, with only one respondent saying they were not in agreement with them.

In particular, several respondents commented that they agreed with the principle to '*minimise bureaucracy*' Although one respondent commented that bureaucracy was already a concern *'Bureaucracy has already taken over many aspects of working with carers. Pressure to complete carer assessment and support plans within 20 mins over the phone has been suggested as being more than enough!!!'*

Overall people expressed the view that while short timescales are important and bureaucracy needs to be minimised, it is essential that quality is not compromised. *'mustn't stint on quality'*. Concerns were expressed by one respondent that increased demands may affect the quality of ACSPs and YCSs *'Presently I see the quality of ACSP under threat due increasing referrals and decreasing resources'*

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? Do you also 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 asked respondents if they agreed with this proposal. We received the following responses

Yes	76.81%	53
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No	13.04%	9
Don't Know	10.14%	7

While the majority of respondents agreed with this proposal, several thought it was lacking in detail and without having sight of the guidance, or having more specific information on the approach that would be set out in guidance, it is difficult to comment on this proposal with any authority.

In particular, respondents raised the concern that the guidance may be open to interpretation. *'Is guidance enough? Is guidance open to interpretation?'*

In most cases the first point of contact for carers is a GP or other medical professional. Several respondents to our survey highlighted the important role they play in identifying that a carer is looking after someone with a terminal illness and signposting carers to support.

They also suggested that GPs, or other medical professionals should also have a responsibility to inform carers of their rights in these circumstances and that where they did, this should also prompt the clock starting in relation to the timescales defined in regulations. *'Is it enough for the ACSP to be triggered if the authority receives information to indicate that a Carer is caring for a person with a terminal illness. Many Carers won't be in touch with or referred to the authority in this instance and may well just be in touch with NHS services.'* and *'Can't medical authorities contact social work to recommend a start date'*

Given the integration of health and social care and the greater role of Integration Authorities, we feel this is something the Government should consider. Certainly the regulations or guidance should be clear about the critical role and responsibilities of health staff.

It is essential that carers and representative organisations are fully involved in development of the proposed guidance. We feel there are several questions outstanding in relation to this proposal, including the following:

- What information would be accepted as proof?
- Who would be authorised to provide the information?
- Who will be responsible for sourcing the relevant information and what if this takes time? or incurs a cost?
- If the carer, who is looking after someone with a terminal illness, requests an ACSP or YCS, how will they be expected to evidence that the person they care for has a terminal illness? Or does this only apply where evidence is in place and has been accepted by the LA, but the carer has chosen to defer until a later time?

In relation to the definition of terminal illness and the required evidence, our preference would be for this to align as closely as possible with the definition that has been developed by Social Security Scotland:

'the definition of terminal illness for the purpose of disability assistance, will be based on the clinical

judgement of a registered medical professional, removing any reference to a time-restriction.'

We understand that the Carers Act defines terminal illness more narrowly as:

'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.'

However, we feel it is important to learn from the substantive work which has been undertaken by Social Security Scotland and to reflect this in the guidance which will accompany the regulations, in so far as the legislation permits.

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 asked respondents if they agreed with this proposal. We received the following responses

Yes	58.82%	40
No	29.41%	20
Don't Know	11.76%	8

The majority of respondents agreed with this proposal, although there were some contrasting views. Some carers expressed a desire to make process as simple as possible and they felt this would be more likely to be achieved with one timescale *'Carer has enough to deal with, so process should be as easy as possible'* and *'Two timescales are added stress for carers'*

Others felt that the process of developing an ACSP or YCS with a carer should not take too long and should be achieved in one meeting *'completion at one sitting saves time and worry'* and *'Production of a ACSP or YCS should not be a protracted process.'*

However, other respondents thought that the two timescales recognised that different local authorities have different processes in relation to initiating and completing ACSPs and YCSs and therefore two timescales were required *'There has to be separate timescales, each authority have such different resources / procedures in place, to tie both into the one timescale would compromise statements in Q2'*

Many respondents also pointed out that conversations are not always simple due to the complexity of carers' lives and the various impacts their caring role can have on them. This is particularly the case for carers looking after someone with a terminal illness. It therefore may require multiple meetings *'Because a conversation about an ACSP/statement may take time before the carer is able/wants to complete - this timescale should account for this'* and *'At such a difficult time, carers may need support to engage with the process'*.

Adult carer support plans / Young carer statements - 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.

We asked respondents for their views on the proposed timescales. We received the following responses

2 days	33.87%	21
4 days	20.97%	13
6 days	19.35%	12
Other	30.65%	19

There was a fairly even spread of answers to this question, with 2 days being the most popular response and Other as the second most popular response.

Those who responded with 2 days focused on the need for carers to receive support as soon as possible *'The sooner the better for all concerned'* One respondent suggested that initial contact could be by phone, confirming that the carer wishes to take up the offer of an ACSP/YCS and agreeing a date to meet. They therefore felt that in these circumstances the short timescale should be achievable.

Those who responded with 4 or 6 days did so because they felt that this was a reasonable timescale to allocate a worker and make contact with the carer.

Those who responded with Other put forward a variety of suggestions, many of which fell within the proposed timescales of between 2 to 6 days. Some respondents suggested a longer timescale with the maximum suggested time period being 2 weeks, suggested by 3 respondents.

One respondent suggested less than 24 hours, while another stated they did not agree with timescales.

Several respondents raised concerns that the timescales would need to reflect the pace at which the carer wished to proceed and that some people may require time to come to terms with the diagnosis.

In some cases respondents were concerned about the ability of staff to respond within short timescales due to lack of capacity and the current pressure on resources *'At present carer centre staff are swamped as they are the 'Go to agency'. Social work staff are passing nearly all work to local carers centres. This demoralises staff and makes people afraid to approach social work'*

It appears that the respondents did not all have the same interpretation of what the first timescale would apply to. Several seemed to think that it would involve contacting the carer, perhaps by phone and arranging a time to see them. This group tended to favour a shorter timescale.

Those who interpreted the timescale as the start of the ACSP/YCS, where they would meet with the carer for a longer conversation, tended to indicate a longer timescale would be necessary.

We therefore feel it is important that the regulations clarify what is intended by the phrase ‘the first substantive conversation’ and they make it clear whether a phone call and setting a time to meet would fall under this definition.

The National Carer Organisations view is that the timescale at this stage of the process should be as short as reasonably possible. Our preference would be for 2 working days, as we are aware that 2 non-working days may fall over the weekend, which would make it very challenging for services to respond and may result in the carer having to interact with more than one staff member, which is not desirable in the circumstances.

The only exception to this should be where the carer wishes to postpone their ACSP or YCS, or move at a slower pace. Staff should not feel under pressure to meet deadlines if the carer is struggling to come to terms with the diagnosis and needs time to process this. The regulations need to build planned delays into the process, where, they are prompted by the carer.

These may be at the point of first contact or at any time during the process. Particularly since if the diagnosis is recent and unexpected the carer’s focus is likely to be on the treatment and medical appointments that may be required for the person they care for, which will almost certainly take precedence.

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 asked respondents for their views on counting non-working days. We received the following responses

Include non-working days	60.32%	38
Count working days only	46.03%	29

A small majority of respondents indicated that they believed the timescales should include non-working days. Their reasons mostly related to the need for carers to access support as quickly as possible, without delay and the observation that people’s caring roles are not restricted to working hours.

Responses included *‘Time is of the essence’* and *‘A day is a day when caring for someone who is terminally ill’*

Some also pointed to other systems, such as DWP which take account of non-working days *‘It enables everyone to understand and be able to count accordingly to processes which happen this way already, e.g. DWP’*

Those who favoured only counting working days were mostly concerned with the timescales being achievable and needing to take account of services only operating during working hours.

Responses included 'this is unfair to services which operate Monday to Friday and will lead to staff and carers suffering in other ways ways ' and 'Staff are entitled to AL and also may be off sick. The Government needs to be realistic when setting time scales'

Given that many local authority areas have devolved their responsibility for undertaking ACSPs and YCSs to third sector organisations, we are concerned that these smaller organisations will not have the capacity to respond to short timescales which include non-working days. Unlike local authorities they do not provide out of hours or emergency services, as the focus of their work is preventative support.

Responses from Carers Centres included '*Only working days as this would impact significantly on the capacity of carer centres and young carer services delivering ACSP's and YCS ' and 'Most Carers Centres are only open Mon-Fri so counting non working days would not be helpful'*

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

We asked respondents for their views on the proposed timescales. We received the following responses

2 weeks	44.26%	27
3 weeks	13.11%	8
4 weeks	19.67%	12
Other	22.95%	14

The majority of respondents, nearly half, thought that ACSPs /YCSs should be completed within 2 weeks.

Their reasoning was primarily to ensure carers are supported within the shortest timescale '*It is important carers are not under pressure at a trying time, therefore plans should be dealt with and support put in place as soon as possible'* and '*It will be a very stressful situation the carer is in and therefore time is of the essence to ensure appropriate assistance is put in place as quickly as possible to support them.'*

Those who suggested a longer timescale of 3 or 4 weeks primarily focused on the impact on staff and the organisations undertaking ACSPs and YCSs '*The complex nature of some cases and the very real pressure being put on front line staff to deliver effective and personalised plans.'*

Some also indicated that longer timescales were required because of the pressures on the carer's time

and their availability to meet with staff *'carers lives are busy, so need time to schedule gaps , it also gives time for carers to process report's and 'carer availability likely to be a factor'*

Several respondent who replied with Other suggested shorter timescales, with the most common being one week. One respondent suggested that the emphasis should be on evidencing the reasons why some ACSPs or YCSs may take longer to complete. For example, carers ability to engage, complexity of the situation, health and family crisis.

The National Carer Organisations position is that we believe that timescales should be as short as is reasonably possible. However, as before we believe the process needs to be able to account for delays which arise either because the situation is complex and requires multiple meetings with the carer, or the carer wishes to postpone the process or proceed at a slower pace.

Additional Comments

We also wish to highlight several issues which have the potential to be unintended consequences of the regulations, or may act as barriers to the successful implementation of this legislation.

Accessing Support

Our understanding is that the regulations will only cover the development of an ACSP or YCS for carers. They will not cover the time period it will take for services to be put in place. We are concerned that while a carer may access a support plan promptly there may be lengthy delays before appropriate support is put in place. Where this is the case the short timescale to complete an ACSP or YCS will be of little merit.

We are also concerned about the availability of suitable support for carers in some areas. Market shaping in relation to carer support is still in its infancy in many areas and while good practice is progressing there is no guarantee that suitable services will be available for carers looking after someone with a terminal illness who has an assessed eligible need.

Carer Pathway to Support

We are concerned that the pathway to carer support is not yet clear in many areas, where local authorities have not yet agreed which agency, or staff within an agency are responsible for undertaking ACSPs or YCS.

This is particularly true of YCSs, where even young carer services are unsure of the carer pathway for young carers to access a YCS. This issue was raised by a respondent to our survey *'Re YCS, there appears to confusion to who takes the lead in preparing the YCS'*

Identifying carers

Acknowledging that someone is near the end of their life can be very emotive and distressing for both the person who is terminally ill, their family and their carer/s. It can therefore be a difficult subject for

staff to address and there may be some reticence in them raising this with the carer and ensuring they are aware of their right to an ACSP or YCS within a defined timescale.

In most cases it would be hoped that the carer would already be known to services and will have had their needs assessed, but this may not always be the case, particularly where:

- The carer may not be identified until they reach a crisis point
- The person they care for may just have been diagnosed with a condition which will lead to a quick deterioration
- Their circumstances may have changed, and the person's care needs increased, leading to them seeking support

As outlined earlier, in most cases the first point of contact for carers is a GP or other medical professional. Several respondents to our survey highlighted the important role they play in signposting carers to support, particularly where they are caring for someone with a terminal illness.

Given the integration of health and social care and the greater role of Integration Authorities, we feel that health professionals need to have their role in identifying carers looking after someone with a terminal illness more clearly defined.

Certainly the regulations and guidance should be more specific about the critical role and responsibilities of health staff in relation to the implementation of these duties.

Staff training and informing carers of their rights

In terms of carers knowing their rights, a survey undertaken by the Coalition of Carers in Scotland in November 2018, revealed that 51% of carers had not heard of the Carers Act and only 16% of carers were fully aware of their rights under the Act.

It is therefore essential that all staff who are in contact with carers receive training to ensure they understand the rights under the Act and pass this information on to carers in a systematic manner, including information on local carer pathways and signposting to local carer support. This should include GPs, hospital staff and other health professionals.

It is important that staff do not presume that as carers are in contact with multiple services that they will already have an awareness of their rights.

In relation to supporting carers of someone with a terminal illness, staff may also require support and training in relation to how to raise this issue in a sensitive and compassionate way.

Support after the person has died

Support to carers must also include support after the person has died. This should be reflected in the regulations and any subsequent guidance. As one respondent commented *'It is self evident and with time being limited then having a ACSP & YCS is essential. But I would like to think that time would be*

available for reassessing and support planning post death should be included as with the best of intentions the impact of a caring role and death cannot always be accurately anticipated.'

Capacity of local carer organisations

As several respondents indicated they have concerns about the ability and capacity of local carer organisations to respond to short timescales.

In many areas the local authority has devolved responsibility for undertaking ACSPs and YCSs to local carers centres. This has been seen as a positive step and their intervention is generally highly evaluated by carers.

However, carers centres are generally not set up to respond to crisis situations or very short timescales and they do not offer out of hours services as local authorities do. They tend to have relatively small staff teams and often only two or three workers are responsible for undertaking ACSPs or YCSs.

Local partnerships will have to consider the logistics of local carers centres undertaking these new responsibilities and whether they have the capacity to do so. In some areas they may require additional support or resources to enable them to respond appropriately.

We believe this issue is particularly concerning as the information we have received from carers centres indicates that since the Carers Act came into force their referrals have increased by an average of 26%.

In spite of this, not all carers centres have had an increase in funding to ensure they have the resources to enable them to cope with increasing demands. For 1 in 3 centres their funding has remained the same and for 1 in 10 their funding has decreased in the last year. These areas are already struggling to cope with additional demands.

Monitoring

We believe there will need to be careful monitoring of these regulations to ensure that timescales are complied with and any barriers to implementation are identified as early as possible and addressed. We are also concerned that aspects of the guidance could potentially be open to interpretation. It is therefore important that the guidance is as clear and unambiguous as possible and its implementation is also monitored.

Carers with protected characteristics and carers from rural and island communities

There are particular challenges for carers with protected characteristics in accessing support. It is therefore essential that each area undertakes an equality impact assessment of their proposed process to respond to the defined timescales for carers of someone with a terminal illness accessing an ACSP or YCS.

There are also particular challenges for carers living in rural and island communities in meeting defined timescales, such as the ability of staff to respond quickly when covering large geographical areas and the availability of local support.

It is essential that these rights are accessible to carers from all communities and in all geographical areas, however this may require additional development and resources.

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