



Coalition of Carers in Scotland (COCIS) - Right to Respite Session

On the 23rd June COCIS held an online member meeting which included a session on the recommendation in the Feeley report that carers have a right to respite.

*Carers need better, more consistent support to carry out their caring role well and to take a break from caring With regular access to quality respite provision. **Carers should be given a right to respite** and a range of options for respite and short breaks should be developed.*

The session began with introductory presentations, after which members took part in discussion groups and then participated in a polling session.

This paper includes a summary of discussions and responses to the polls, along with comments from the Chat Box

Discussion Groups

61 people attended the meeting and there were 5 discussion groups altogether. This is a summary of the key points, grouped together by theme

Question 1. How would a right to respite support better outcomes and help address barriers to accessing support	
Theme	Responses
Benefits to knowing your entitlement	<ul style="list-style-type: none"> • Automatic right to respite - not making a case for respite time and again! • Arranging respite can seem like a military campaign, with the stress and challenges involved in getting arrangements in place. Then afterwards there can be consequences with the behaviour of the cared-for person, which can be impacting by the loss of routine 'the mop up afterwards'. Knowing what respite was in place in advance, without having to 'fight' for it, would really help with the stress and produce better outcomes for carers • Carers need in writing what respite they are getting -it helps them to plan. Knowing that you are receiving regular respite helps with stress levels • Pressure would be off Carers if they knew they had an entitlement from the start of their caring role / at point of hospital discharge where applicable

	<ul style="list-style-type: none"> • Carers feel a sense of guilt. If there is a right then the decision is made for you. The right removes the guilt • We don't all want to take the break but we may still want the opportunity to take that break. The thought of the break may help the management of stress and anxiety.
Better resourcing for respite	<ul style="list-style-type: none"> • In Fife we are about to start with a programme of SDS funding specifically for carers. The problem is this all needs to be paid for and the money simply isn't there • As carers we should not worry about where the funding comes from. That is a political matter. We need to focus on what matters to support carers and funding aside, the support isn't even there. • The options for respite are available but we need the funding to pay for it.
Financial support to take a break	<ul style="list-style-type: none"> • Respite isn't affordable for some people, carers may need financial support to take a break • Care charges should be stopped
Supporting carers wellbeing – current gaps in service	<ul style="list-style-type: none"> • Carers are increasingly isolated during Covid • Elderly parents are taking their adult children on holiday with them as there is no one who can step in to provide the respite care.

Question 2. What might a right to respite look like?	
Theme	Responses
The role of carers centres and incorporating preventative support	<ul style="list-style-type: none"> • Carers centres deal well with non-critical need. For critical need local authorities need to take the lead • Carers centre do the preventative, holistic service provision. There needs to be more investment in carers centres • Respite assessments should be performed by local Carers Centre
Elements of a good break	<ul style="list-style-type: none"> • The break has to be beneficial for the cared-for person as well and the carers needs to be confident that they are safe ' I don't mind letting go, if I am confident there is someone there to catch them' • Staff who are trained are needed – Carers have to know the level of care the cared for needs is provided and guaranteed before they can relax • Respite must be person centred and preventative
Support for specific caring groups / circumstances	<ul style="list-style-type: none"> • Carers in rural areas struggle with respite. For example, one family had to pay for a long taxi journey in order to access a break and couldn't afford it • Rural communities with low population means a lack of PAs / helpers etc

	<ul style="list-style-type: none"> • Young carers need to be viewed separately, they may need respite even if they only care for a few hours • BAME – not many carers in this community identify themselves as unpaid carers. They are not happy about cared for people going into residential care – they feel guilty and shamed • Be aware of the profession of the carer and the demands on them if they are working – carers in employment require different times of respite – caring is not a 35 hour leave at 5pm post – it's 24/7 and requires accommodation
Deciding eligibility - Process	<ul style="list-style-type: none"> • ACSPs are a blunt tool for respite- would need to be looked at and revised for this purpose • Remove bureaucracy - How do we get through the layers of bureaucracy and get rid of complexity – constant battles • Has to be personalised to the unpaid carer • Early intervention key – have a person centred care plan in place which relieves stress for the cared for and the carer • Different situations require different levels of support – apply person centred care applicable to the circumstances – it cannot be mechanistic • Who has a right to judge whether or not respite is needed and how much is needed? • Arrange at the beginning and review as care needs change -again cared for could be good for a short time then the need for emergency care comes in • Not every carer wants a break from caring. Asking the carer what they want and need for a break is important, including what they want by a break from caring, and whether they want one. • Carer respite should be an automatic part of any support package
Who should be eligible for a right to respite?	<ul style="list-style-type: none"> • The Feeley report identified the need for equality. There needs to be standard amount, like an annual leave entitlement. 'Everyone should have a right to respite' based on a human rights approach • All carers should have the right to respite • Offering some help to all carers even those who provide less hours of care • Those with a high level of caring responsibilities should be prioritised • With a human rights-based approach is the right to respite the right question? Is it not the right for all people to live a life they choose to which includes the right to personal time, not to provide care (all the time), the right to balance my role?

	<ul style="list-style-type: none"> • ALL CARERS should be offered respite
Legislation	<ul style="list-style-type: none"> • Must be enshrined in law to identify who is responsible for delivering the right. It also needs to be funded to cover the cost of respite or short breaks or respite including replacement care. • Amend the Carers Act • Having a right is only good if it is backed by resources
Delivery Mechanisms	<ul style="list-style-type: none"> • Who will the gate keepers be? Carers Centres or L.As? What are the gates going to be? Remove L.As from being gate keepers, they use funding from the Carers Act to balance their books.
What the right to respite entitle you to?	<ul style="list-style-type: none"> • 4 weeks respite • Vouchers

Question 3. What should happen next	
Theme	Responses
Carers involvement	<ul style="list-style-type: none"> • Carers need to be involved in the early stages of planning • A starting point needs to be understanding what a break means to carers – start to define the definition. This needs to start with carers themselves.
Increasing the marketplace and provision	<ul style="list-style-type: none"> • Difficulty in recruitment at the moment – cannot get agencies to provide staff this is a huge issue and impacts on the right to respite • We need to start training people? A human rights based approach also needs to recognise that caring roles are not for everyone so who are we training to be a paid or unpaid carer? Who is it that we are training to provide the replacement care so a carer can take a break?
General Comments	<ul style="list-style-type: none"> • Monmouthshire provides the right to 4 weeks respite to all their carers including replacement care. This model should be explored • End to all the talking – TAKE ACTION! • We were talking about Care 21 in 2005 and still in the same boat • Resources need to be implemented, clarified • FUND THE RIGHT TO RESPITE

Polling sessions

Below is a summary of the responses to the polls. Many of the themes are the same as those raised within the discussion groups

1. Who should be eligible for the right to respite?
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All carers	85% (41)
Only carers caring for longer hours	0
Only carers where the need is identified in an ACSP	10% (5)
Other (let us know in the Chat)	2% (1)
Don't know	2% (1)

2. Should the amount of respite be?	
A flat rate – everyone should be entitled to the same amount of respite	2% (1)
There should be more respite for people with a more intensive caring role	9% (4)
A guaranteed minimum entitlement for all – but topped up based on assessed need	81% (38)
Other (let us know in the Chat)	6% (3)
Don't know	2% (1)

3. What needs to happen for a Right to Respite to work? (comments added to Chat Box)	Number of Responses
Money / Resources Of these 8 specifically mentioned Ringfenced Funding <ul style="list-style-type: none"> • <i>'Fund the Right' - without money behind it nothing will happen.</i> 	26
Marketplace – increased provision <ul style="list-style-type: none"> • <i>Available, appropriate replacement care throughout Scotland to enable carers to take a break</i> 	3
Partnership Working <ul style="list-style-type: none"> • <i>LA and Carers Centres/services working in partnership</i> • <i>Proper partnership working between carers centres, local authorities and unpaid carers. Clarity about roles.</i> 	3
Personalised decision making and support <ul style="list-style-type: none"> • <i>Person centred and as and when required rather than waiting to crisis .</i> • <i>All decisions should be personalised</i> 	3
Carer involvement – further discussion <ul style="list-style-type: none"> • <i>Start a conversation as to what a right actually means. Does it mean the right to something funded by the tax payer? Or can we be more creative in our definition</i> • <i>Capture as many voices and perspectives as possible from carers and to gain more insight on what would work for people</i> 	2

<p>Legislation</p> <ul style="list-style-type: none"> • <i>Legislation and commitment to carers from all agencies and govt</i> • <i>We need the Act (Carers Act) amended</i> 	2
<p>Other Comments</p> <ul style="list-style-type: none"> • <i>All LA's need to get on board - needs funding and logistics/availability in place</i> • <i>Recruiting trained staff!</i> • <i>Should be human rights based</i> • <i>Training required for people who support cared for person.</i> • <i>A right to respite doesn't necessarily mean a right to receive anything.</i> 	

Contact Information

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