

rest assured?

a study of unpaid carers' experiences of short breaks

July 2012



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foreword

This report completes a two-part research project that was undertaken to improve our overall knowledge and understanding of short breaks provision in Scotland. *It's about time: An overview of short break planning and provision in Scotland* (Shared Care Scotland/Reid Howie) was published in 2010.

The findings that have emerged across both pieces of research reveal there is still a long way to go before national outcomes to protect the health and wellbeing of carers, and to enable them to retain a life outside caring, are realised for the majority of Scotland's unpaid carers. With less than one in every two carers surveyed in this research accessing short breaks, there is still much to be done.

We recognise the challenges facing the statutory sector with a rising demand for services and unprecedented pressure on public spending. We also recognise the important steps taken by government in recent years to increase short break provision. However we are confident further progress can be made if we adopt a more proactive approach to forward planning, by embedding good practice and by working together to overcome the obstacles, highlighted by this research, which prevent carers accessing the breaks they deserve. The prize will be healthy, happy sustainable caring relationships and the prevention of unnecessary additional spending in years to come.

We are extremely grateful to our research partners, the Coalition of Carers in Scotland and MECOPP for their help with this work. Special thanks go to IRISS, and in particular Ellen Daly, for her considerable efforts in analysing the results of the survey, interviews and focus groups and for writing most of this report. And finally, this research would not have been possible without the participation of the many carers throughout Scotland who gave their valuable time to take part in this study and for sharing their personal stories. We hope the report that follows does justice to their contributions.

Don Williamson
Shared Care Scotland

about the project partners

IRISS is a voluntary sector organisation with a vision to promote positive outcomes for the people supported by Scotland's social services. IRISS works to enhance the capacity and capability of the social services stakeholders to access and make use of knowledge and research for service innovation and improvement.

Shared Care Scotland is a charitable company that works to improve the quality, choice and availability of short breaks (respite care) provision across Scotland for the benefit of all unpaid carers and people who use services.

Coalition of Carers in Scotland is a network of autonomous local carer-led groups, centres and projects. The Coalition is lead by an Executive Committee made up of carers and staff from local carer organisations.

MECOPP provides a variety of services to black and minority ethnic carers and communities locally, regionally and nationally including advocacy, respite, a resource library and a training service.



1. executive summary

This report describes the findings of research carried out between August and December 2011 into the experiences of unpaid carers in accessing and using short breaks (respite care). The study explored, from the carers' perspective the benefits of short breaks (provided by formal services and family and friends), good practice in planning and provision, deficits and areas for improvement. Research findings are based on 1210 responses to a Scotland-wide survey distributed through carer organisations, four focus groups involving 36 carers and 13 interviews.

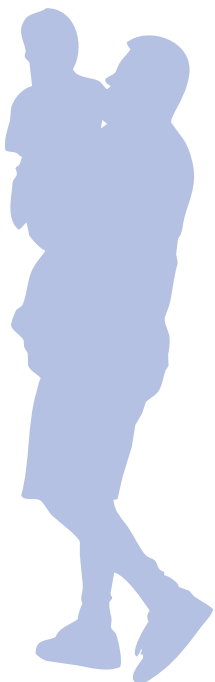
Key findings from the study:

- Over half of the survey respondents felt that caring had negatively affected their interests and hobbies and their mental wellbeing. Over 40% reported that caring had negatively affected their family life, friends, finances, physical wellbeing and career. Similar findings emerged from the interviews and focus groups. However, a third of respondents said that caring had a positive impact on their hobbies, family life, physical wellbeing and friendships.
- Short breaks were considered fundamental to carers to help alleviate the physical and emotional demands of caring and to sustain the caring relationship, preventing admission to residential care.
- Over half (57%) of survey respondents had not taken a break from caring. Sixty-three percent of black and minority ethnic (BME) carers had not had a break from caring.
- Those who had taken a break were most likely to be satisfied with the quality of the break, the choice, support to organise it and the length. Respondents were most likely to be dissatisfied about the frequency of breaks.
- Over half of respondents (56%) noted that the level of their breaks had stayed the same over the last two years. Twenty-five percent of respondents noted that the frequency of their breaks had decreased. Those most likely to report a decrease were providing care to a parent. Twenty percent of respondents said that the level of their breaks had increased over the last two years.
- Forty-three percent of those who had not had a short break identified that this was because they did not know how to access short breaks.
- Other barriers to participants taking breaks from caring included:
 - Difficulty with the planning process
 - A lack of appropriate and personalised provision
 - Guilt
 - Uncertainty about eligibility

- Carers suggested that short breaks could be improved by:
 - Being provided as an early intervention rather than at crisis point
 - Having increased choice, flexibility, frequency and length of short breaks
 - Having more information about carers' entitlements and availability of short breaks
 - An increase in appropriate and personalised short breaks, including culturally suitable services for BME carers
 - Better planning processes including a single point of contact and dates for short breaks secured well in advance

In response to the research findings, seven key improvement areas and suggested actions have been identified. These areas focus on:

1. Planning for improvement
2. Involving carers in decisions about the future development of short breaks
3. Extending the reach of short breaks
4. Improving information and advice about short breaks
5. Meeting the challenges and opportunities presented by Self-directed Support
6. Helping families and communities to support each other
7. Measuring the reach and impact of short breaks



2. introduction

IRISS (The Institute for Research and Innovation in Social Services) worked with Shared Care Scotland, the Coalition of Carers in Scotland and MECOPP (Minority Ethnic Carers of Older People Project) to research the views and experiences of unpaid carers about short breaks, also known as respite care.

Unpaid carers are individuals who care for a friend, relative or neighbour without receiving paid income other than income received through the benefits system.

For the purposes of this research, **short breaks, breaks from caring or respite care** all refer to a carer and the person they care for being supported – mainly through the provision of a service - to have a break from their normal routine and the demands of their caring situation. Breaks can also be supported through more informal arrangements, for example with family members or friends stepping in to help. The break should be planned and delivered in such a way to achieve positive outcomes for both the carer and the person with care needs.

Outcomes refer to the impact of support on a person's life and not the outputs of services. Outcomes are changes or benefits for individuals who access support and those of their unpaid carers.

Aims of the research

This project aimed to gather the experiences of unpaid carers in accessing and using short breaks in their area. The study also sought to:

- Identify the characteristics of good practice in short break planning and provision from the carer perspective
- Uncover evidence of carers reporting outcomes in relation to short breaks supporting the caring relationship, promoting health and wellbeing, and helping to widen opportunities (for themselves and the people they care for)
- Find out about carers' levels of satisfaction with the amount, quality, timing, frequency and appropriateness of services or support offered/received
- Highlight any evidence of improved choice, flexibility and personalisation of services
- Gather feedback on the availability of timely, up-to-date information on assessment procedures, eligibility criteria and entitlements relating to short breaks
- Identify perceived deficiencies/shortfalls in services

This project is stage three of a broader research agenda:

1. A review of local authority approaches to service planning and provision within adult services¹
2. A mapping exercise to identify the range and availability of different models of respite care and short break services
3. A survey of carers' experiences of respite care and short break services

Stages one and two have been completed and the findings published in *It's about time* (Shared Care Scotland/Reid Howie, 2010).

Details of the method used to conduct this research, including survey design, sample and dissemination and the approach taken to focus groups and interviews, can be found in appendix two.

Contextual information including key research and relevant social policy can be found in section six of this report.



¹ The For Scotland's Disabled Children Liaison Project has carried out a mapping exercise of short break services for disabled children available at: www.fsdco.org.uk

3. findings

The survey findings reported in this section are based on the number of respondents who answered each question rather than the overall total number of survey respondents.

3.1 profile of carers who completed the survey

The survey provided some demographic information about respondents. Eighty-four percent were over 45 years of age. Only four respondents were under 18 (0.4%), therefore, young carers are under-represented in this study. Forty-five percent were retired. Six percent identified as black and minority ethnic. Seventy-two percent lived in urban areas. Forty-four percent of respondents cared for a partner/husband/wife. Seven percent of respondents said they provided care for more than one person. Over a quarter (28%) of those caring for more than one person cared for their partner and a parent. Twelve percent of respondents cared for someone with a physical disability with an additional 32% caring for someone with a physical disability in addition to at least one other condition. Forty-three percent cared for someone with more than one condition. Sixty-seven percent reported caring for more than five years. Over half (55%) of respondents provided 100 or more hours of care per week.

3.2 the impact of caring

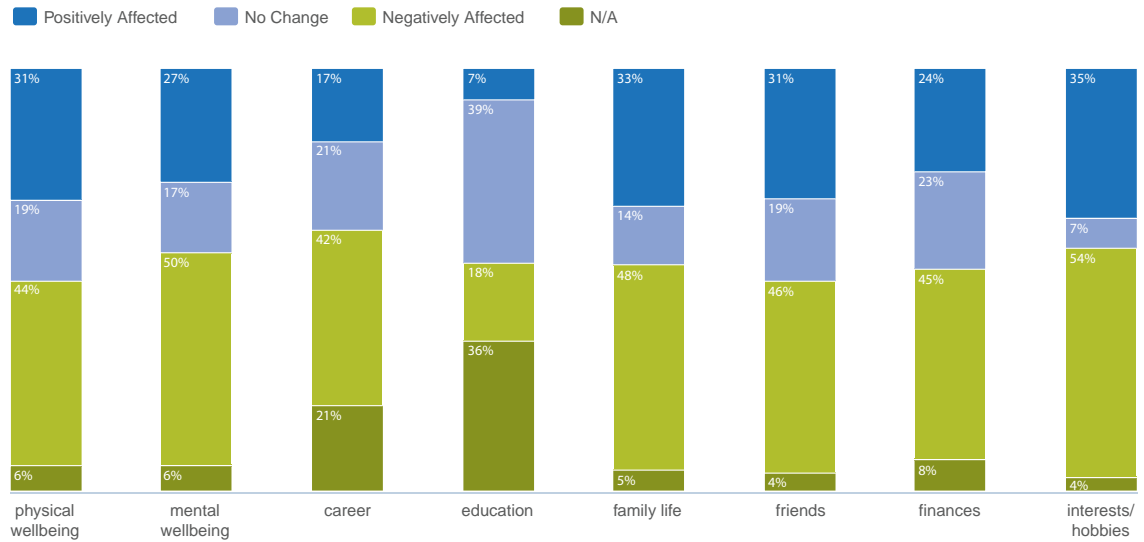
Personal and social lives

The survey found that over half of respondents felt that caring had negatively affected their interests and hobbies (54%) and their mental wellbeing (50%). Over 40% of respondents reported that caring had negatively affected their family life (48%), friends (46%), finances (45%), physical wellbeing (44%) and career (42%). The only aspect of personal and social life to have been negatively impacted by less than 40% of respondents was education; only 18% reported as being negatively affected. Most respondents (39%) said that their education had been unchanged. This finding could relate to the age range of respondents; many may have been out of education for some time.

Findings from *Care 21: The future of unpaid care in Scotland* (Scottish Executive, 2006a) uncovered similar findings, with more than half of carers in their survey reporting lack of sleep, tiredness, stress, anxiety, irritability and depression. The *Care 21* research also suggested that the incidence of physical and mental health related problems were more likely where more hours were spent caring. Other findings about the impact of caring involved many carers feeling that their free time was restricted, that it had a detrimental effect on family life and increased feelings of isolation and loneliness. More recently, research undertaken by Carers Scotland (2011) found that 96% of respondents to their survey reported that caring had negatively affected their health and wellbeing.

Despite these negative impacts, it is also important to note that around a third of survey respondents in this study said that caring had had a positive influence on their lives, particularly on their interests/hobbies (35%), family life (33%), physical wellbeing (31%) and friends (31%).

Figure 1: Impact of caring on personal / social life



Source: Review of short breaks 2012 <http://s.iriss.org.uk/short-breaks>

There were no noticeable differences between genders; both men and women said aspects of their personal and social lives had been negatively affected. There were also no key differences between those who spent 0-19 hours caring a week and those spending over 100 hours caring in a week. Respondents across the 'hours spent caring' categories said caring had negatively affected all aspects of their personal and social lives (except their education). The only exception to this were those caring for between 0-19 hours a week who were most likely to indicate that there had been no change to their financial situation.

There were some variations depending on the length of time respondents had been carers. Those who had spent less than six months caring were most likely to report 'no change' to their family life. Those who had cared for six months to a year said that their physical wellbeing and interests/hobbies had been positively affected by caring and that their financial situation had not changed. This same group reported equal percentages of positive and negative affects to their career (27%), mental wellbeing (38%) and friendships (38%).

Age appeared to be a factor on the impact that caring had on the personal and social lives of respondents. Overall, those in age categories 60-69 and 70+ reported more positive effects of caring on their lives than those in age categories: under 18, 18-24, 25-34, 45-59. About half (between 48% and 52%) of those aged 60-69 reported that their physical and mental wellbeing, family life, friendships, finances and interests/hobbies had been positively affected or had not changed. Over half (between 57% and 70%) of those aged 70+ reported a positive impact or no change to their physical and mental wellbeing, family life, friendships, finances and interests/hobbies. Those aged between 60-69 and 70+ were most likely to have been caring for between five and ten years. Those aged 35-44 were most likely to report negative impacts of caring on their physical and mental wellbeing, career, family, friendships. Again, this age group was most likely to have been caring for between five and ten years.

In terms of the effects of caring on personal and social aspects, there were some notable differences between those who had experienced a short break and those who had not. Overall, those who had experienced a break from caring rated the impact on their personal and social lives more negatively than those who had not taken a break. For example, 50% of those who

had taken a break said that their physical wellbeing had been negatively affected, compared to 54% percent of those who had not taken a break who felt that their physical wellbeing had been positively affected or had not changed. Fifty-eight percent of those who had taken a break felt their mental wellbeing had been negatively affected by caring. In contrast 49% of those who had not taken a break said that their mental wellbeing had been positively affected or had not changed. Over half (54%) of those who had taken a break said their family life had been negatively affected compared to 49% of those who had not taken a break who felt that their family life had been positively affected or was unchanged. Similar trends were evident across the other aspects of personal and social life including friendships, interests/hobbies and career.

It is interesting that those who have taken breaks report aspects of their personal and social lives more negatively affected than those who have not taken a break. It is unknown if those taking breaks from caring are doing so because they are experiencing higher levels of stress in their personal and social lives, or if the breaks they are taking are too infrequent or too short to alleviate the impact of caring. It is unclear if those who have not taken a break have less need for them because they experience fewer negative affects of caring on their personal and social lives. These findings also cannot account for individual resilience or coping strategies.

There were some differences to personal and social aspects depending on the carer's relationship with the person being cared for. Forty-three percent of those caring for a partner/husband/wife said their physical wellbeing had been positively affected and 48% said their interests/ hobbies had been positively affected.

While the survey findings give a useful sense of the scale of the issues associated with being a carer, aspects of participants' personal and social lives were explored in greater depth through focus groups and interviews.

Physical and emotional impact

A dominant theme that emerged as a result of the focus groups and interviews was the physical and emotional impact of caring. Exhaustion and lack of sleep were widely reported:

It is a sheer exhaustion thing, because I don't sleep ...I think it's just because I've been that used to having to be there for H if anything happens to him...

(Interview 7 – mother caring for young son)

...it's really exhausting. So it's 24 hours for seven days or something like that. And I get worried that I might not be up to it.

(Interview 8 – father caring for adult son)

Those caring for spouses and parents expressed feelings of profound loss for the cared for person and of their previous relationship. One carer talked about 'the stranger that's living with you' (Edinburgh focus group – daughter caring for mother); another described it as 'like a bereavement' (Dunfermline focus group - wife caring for husband).

...he is not the man I have loved all those years, and yet there is still bits of him that is still the same old A.

(Interview 6 – wife caring for husband with dementia)

...M seems like two people to me now – the M I know and the M I haven't a clue about.

(Edinburgh focus group – husband caring for wife with dementia)

And I've lost my mum, you know, she's still there in body, but she's not... apart from being heartbreaking, it's frustrating as well...

(Edinburgh focus group – daughter caring for mother)

Where participants provided care for more than one person they described a significant increase in their levels of emotional and physical stress:

I mean, I've also got a father with dementia that I have to go and support him as well so it just feels like I never have time off.

(Interview 3 – mother caring for young son)

My mother is 90 and lives with us... I have also got... a terminally ill sister with cancer who is on her own...

(Edinburgh focus group – daughter caring for mother and sister)

...I've got other responsibilities, I've got young kids too... I look after my man... my wee grand-daughter, she's got disabilities too.

(Glasgow focus group – mother caring for son)

What was particularly poignant was participants' descriptions of their caring role as all consuming and how it changed their identity:

...you lose yourself in being a carer – although it's a label, it actually becomes who you are – you are the carer, and that is what actually defines you...

(Edinburgh focus group - daughter caring for mother)

...I am neither a widow, nor a wife really... I am a carer, to my husband I am a carer, nothing else.

(Interview 10 – wife caring for husband with dementia)

...I think the last six months has made me realise that as well as being H's mum, I'm still me, and that I've forgotten all of that since he's came on the scene.

(Interview 7 – mother caring for young son)

Although participants talked about the strains of caring they also spoke positively about the people they cared for and their commitment to the caring role:

Because you love them, you would do it for anybody. You know what I mean, it just comes naturally, no way you're going to say you're no going to do it.

(Glasgow focus group – mother caring for adult daughter)

...I don't regret it at all, because he is my champion... he is so stoic – he must be aware of some of the things that are inhibitions to the way he lives his life, and I think he's incredibly brave. He is brilliant, really, but it's tiring.

(Interview 8 – father caring for adult son)

Mental wellbeing

The impact caring had on mental wellbeing was a common theme. Several carers described experiencing mental health problems including depression:

I mean I always have had a problem with depression but my psychiatrist believes that it is my son who is keeping me depressed.

(Interview 11 – mother caring for young son)

...it's that [breaks from caring] and the fact that I work, it keeps him out of full time care because I think otherwise I would be suicidal.

(Interview 10 – wife caring for husband with dementia)

In some cases, mental health problems also affected siblings of the cared for person:

...she actually nearly had a nervous breakdown last year and she has had to re-do her year again at school, she should have left school by now but she is still there, she is re-doing her last year, and Young Carers has turned her life around.

(Interview 11 – mother caring for young son)

Family life

Participants described the impact of caring on their family life. They talked about relationship breakdown with partners and the impact on the siblings of the cared for person. Participants who were parents to other children often expressed guilt at not being able to give them more attention. This guilt could be a trigger for seeking breaks from caring:

...my husband and I separated... mostly to do with the pressure of having an autistic child... we couldn't have a normal family life... my husband couldn't handle it, my daughter was upset all the time, it was a really bad family situation, we had to have some sort of break from it otherwise things go pretty pear shaped really.

(Interview 11- mother caring for young son)

She [carer's daughter] really got quite pushed to the side... we didn't have the time... G was 24/7... it's a shame that we missed out a wee bit on her growing up... it's always a struggle... to kind of share yourself around... and she usually always is the loser... she's just got to be and that's just the way it is.

(Interview 12 – mother caring for adult son)

...to be honest if I hadn't had a younger daughter, I don't know that I would even have requested respite to start with - but because he was so intense and we couldn't do a lot of things with her...

(Edinburgh focus group – mother caring for adult son)

Social life

Impacts on participants' social lives included not being able to pursue personal interests, hobbies or see friends. For some this was a difficult issue to deal with and increased feelings of isolation:

I used to be in my darts team, come in about maybe one o'clock in the morning, put the music on, my man would get up, we'd have a wee dance. I broke down last month, I put on one of my 60's songs, and I couldn't stop greetin... I just realised my life had changed, because that just won't happen again.

(Glasgow focus group – wife caring for husband and adult son)

...my son, he won't go in anybody else's house except his carer's... so I can't go to see any of my friends if he is around.

(Interview 11 – mother caring for young son)

I always found with my son's disability, the epilepsy part's hard, but I think sometimes the autistic side is harder because it's how the world perceives it, you know?... if somebody's acting strangely you get a whole different response. So therefore you don't want to go out, you avoid a lot of life...

(Interview 12 – mother caring for adult son)

Employment and finances

The survey showed that most respondents were retired (45%). Fourteen percent said they would like to work but were unable to due to caring responsibilities. Of the 33 respondents who provided further information, a recurring theme was that their own health problems, sometimes linked to the stress of caring, prevented them from working:

- *Currently off sick due to stress caused by lack of support*
- *Have taken one year off due to health problems (mental health) caused by caring for son*
- *Would like to work but unable to at present due to personal injury*

Carers in the focus groups and interviews who were employed felt that work was fundamental to their sense of self and also provided a much needed break from the caring role. Other participants struggled to juggle a job and caring. Some had experienced loss of income, loss of opportunities for promotion and in some cases had to give up work entirely due to their caring responsibilities:

...I can relax and enjoy the job I am doing, which I do, and I love it, and it makes me feel a person – that is what keeps me going, because I feel a person in my own right, otherwise I am nothing but his carer. [...] Having the job has allowed me to do what I am doing without going off my head.

(Interview 10 – wife caring for husband with dementia)

...I have lost two fifths of my income to care for him and I've lost my prospects of promotion because of that so I have lost a lot of earning ability and I'm on my own with all the finances for that.

(Interview 3 – widowed mother caring for young son)

There is also the financial part as well with caring for my mum full time, so I can't go out to work, so I am relying on my carer's allowance and my income support...

(Dunfermline focus group – daughter caring for mother)

Participants often made comparisons between their unpaid caring role and the paid workforce of carers in terms of a lack of paid holiday and sick leave:

At yet in the normal world, paid people coming in to care, they have holidays, they have sick leaves, they are only allowed to work so many hours.

(Edinburgh focus group – mother caring for adult son)

We're not allowed to be ill. What happens then?

(Dunfermline focus group – wife caring for husband)

Additional financial pressures reported by carers in the study included higher demands on household utilities and modifications to their homes to be able to continue providing care at home:

...washing machine is never off, the tumble dryer never off. [...] The heating is on more, it's a total nightmare.

(Interview 13 carer 2 – daughter-in-law caring for mother-in-law)

We had to get one of the bathrooms changed into a wet room just in September... so she could stay on a permanent basis...

(Edinburgh focus group – daughter caring for mother)

These findings corroborate research carried out by Carers UK (2008) about financial pressures on carers which found respondents of their survey struggling to pay utility bills, experiencing increased debt and fuel poverty.

3.3 impact of short breaks

Short breaks were defined in the survey as 'a carer and the person they care for being supported to have a break from their normal routine and the demands of their caring situation'. When respondents were asked if they had ever had a short break from caring, 43% (522 people) answered that they had received one; over half (57%, 688 people) had not. BME respondents were less likely to have had a break; 37% BME respondents had had a break whilst 63% had not. Barriers to breaks from caring are explored in section four of this report.

Sixty-one percent of those aged 35-44 had not had a break. Fifty-three percent of those aged between 45 and 69 had not had a break. Sixty-two percent of those over the age of 70 had not had a break. In terms of work status, those most likely to report having a break were in part time employment, students or self-employed. 65% of men and 54% of women had not had a break from caring. There were some differences between those living in urban and rural areas. Over 60% of those in urban areas had not had a break. Between 50%-55% of those in small towns and rural areas had taken a break from caring.

The focus groups and interviews explored in depth the impact of short breaks on carers and the people they support. Although not all involved in interviews and focus groups had taken a break from caring, they talked about the impact they imagined a break would have on their lives and those of the person they care for. However, the imagined effects were very similar to actual experiences reported by participants who had taken breaks. Participants tended to focus on the benefits of short breaks to their physical, emotional and family life.

Breaks provided invaluable opportunities to alleviate the physical and emotional demands of the caring role, similar to findings uncovered in the *Care 21* research. Common responses to this study were about 'recharging the batteries', having a chance to 'chill out', 'time to myself', a chance to catch up on quality sleep and a change from 'the routine' of caring. It was agreed in the focus groups and interviews that breaks were also fundamental to participants in terms of their identity outside the caring role and helping them carry on:

It's wonderful because I just feel as though I am living again, instead of just being a total carer.

(Interview 3 – mother caring for young son)

...it does help you cope... you know, shortness of temper, you know, frustration... and the thing, when you have had respite and then don't have it, I can then look back and say 'my God, that really saved our life', and I mean that literally, you know, saved our family and everything.

(Edinburgh focus group – mother caring for adult son)

...my whole life revolves around M, what's good for her, that I kind of lose myself. And I think that is what I would look for from respite – to discover who I am...

(Edinburgh focus group – husband caring for wife with dementia)

Breaks also helped carers sustain their relationship with the cared for person, giving them an opportunity to top up vital reserves of patience and tolerance. This is particularly important to ensure cared for people are treated with respect and dignity, and to minimise any risk of them experiencing abusive behaviour from those they rely on for care. Some participants described the positive impact of replenished reserves of patience on the cared for person's behaviour:

Definitely patience – if I don't treat M a certain way and patiently and all the rest of it and don't react to certain situations, things are much better, behaviour is much better.

(Dunfermline focus group – mother caring for teenage son)

I probably think I could tolerate H more. I mean, that might sound bad, but I think maybe if I had more time to myself, and relaxed, then when I came back I would feel, well hopefully fresh, and I would be able to take on the every day challenges... you know, cope with them better, instead of feeling like every week's the same, you know, you're on this treadmill but nothing ever changes.

(Interview 7 – mother caring for young son)

Carers in the study frequently talked about the anticipation of having a break as being part of its positive impact, highlighting the importance of the process of planning short breaks:

...a lot of having respite is pacing yourself and knowing that, you know, you are going to get a break in three weeks, or even you are going to get a few hours at the end of the week. You can focus and work towards that. But when you haven't got that date there, it does increase your stress levels.

(Edinburgh focus group - mother caring for adult son)

...just the thought of getting away, away from my house, just seeing different things, just the idea you are going somewhere. You have that to look forward to.

(Interview 4 – wife caring for husband)

Breaks from caring also provided an opportunity to spend time on other relationships outside the one with the cared for person, including partners, children and friends. However, while this did provide a break from the caring role, it didn't always provide a rest or a chance for carers to get time to themselves. Carers frequently talked about using breaks from caring as a chance to spend time with their other children, or in some cases, to provide respite for siblings of the cared for person:

It's actually more of a break for my other son, because C is the one that H takes his anger out on. So I think that was another reason for respite, was to give C the break from H more probably than me.

(Interview 7 – mother caring for young son)

...it's more a sort of time with my younger daughter more than respite for me.

(Interview 9 – mother caring for adult son)

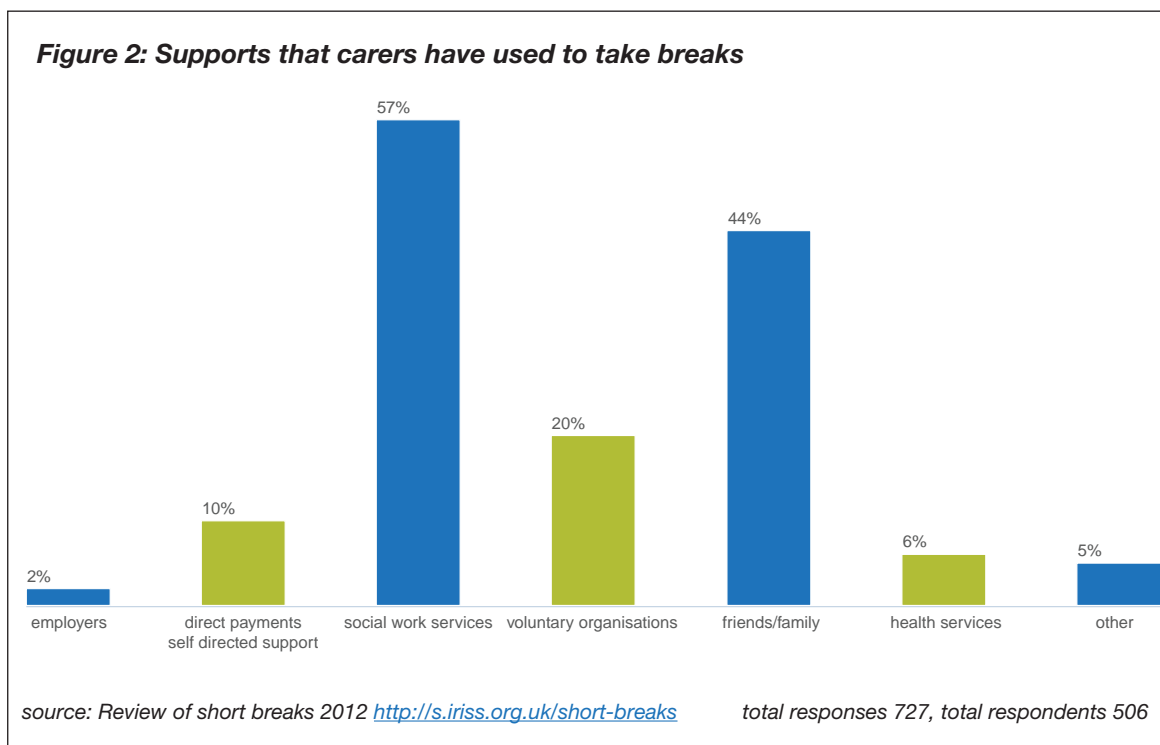
...me and my husband would be shattered after respite, because we fitted in so many activities for my daughter... So it was just a different sort of being shattered.

(Edinburgh focus group - mother caring for adult son)

3.4 experience of short breaks

Supports used

Forty-three percent of respondents (522 people) had received a break from caring. Those that had taken a break used support from a number of sources outlined in figure 2 (also appendix 1, table 2). Respondents could identify if they had used more than one service/support; 36% (180 people) identified more than one.



57% of those surveyed indicated that they had used social work services to take a break; 28% had used social services exclusively with an additional 29% using social services in conjunction with at least one other support (eg friends, voluntary organisations, health services, Direct Payments).

Forty-four percent had used friends and family to take a break from caring; 19% had exclusively used this form of support with an additional 25% using friends and family in conjunction with at least one other support. Only 2% had used health services exclusively, with a further 4% using health services in combination with at least one other support.

Of those BME carers who had taken a break from caring, 29% said they had used the sole support of social work services to take a break. An additional 13% of BME carers used social services and at least one other support (primarily friends and family or voluntary organisations). Twenty-nine percent used the sole support of friends and family to take a break with an additional 17% using friends/family together with social services or voluntary organisations. In 2006, the *Care 21* research found that the most common method of respite care was a nursing or residential home and that 29% relied on family and friends to take a break from caring.

Several accounts from the focus groups and interviews suggested that where the cared for person received a short break from formal services these were viewed positively:

She is well looked after, she thoroughly enjoys going, and she is even happier when she comes home.

(Dunfermline focus group – father caring for adult daughter)

But he enjoys it when he is there, never wants to go, but when he gets there, he has an absolute ball and I love every second of it.

(Dunfermline focus group – mother caring for teenage son)

T absolutely loves them [short breaks], the carers are very good to him and he loves just getting away...

(Interview 9 – mother caring for adult son)

However, carers' preferred choice was often for the cared for person to have a break with other family members:

And it was okay because it was family and I think that made a big difference – I knew she would be okay, that she would be happy being spoilt by them.

(Edinburgh focus group – husband caring for wife with dementia)

I don't think he would be able to cope to go with people he didn't really know ...my mum takes him swimming, my dad takes him to rugby, you know he does a lot of things, he sees other members of the family as well, so I think that's much preferable than to go to something organised with someone else.

(Interview 11 – mother caring for young son)

For those carers who relied upon family or friends to take a break, they talked about their worry that this support would dwindle because of ageing relatives:

And I don't take the risk – she's 86 now, I can't take the risk that he will whack her. So it means that that's another thing that I don't... I can't really use...

(Interview 8 – Father caring for adult son)

...as he gets older, it gets harder because the people who have helped to care for him are getting really old now, so that back-up that I've had all his life, is diminishing.

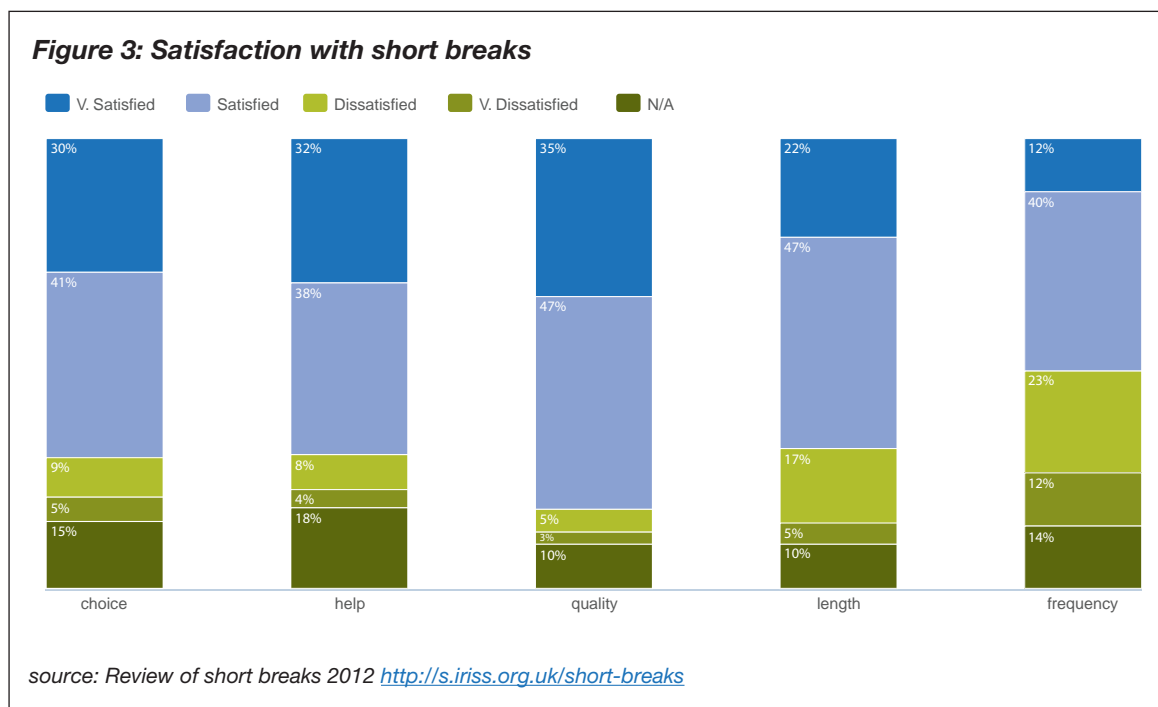
(Interview 12 – mother caring for adult son)

...my mother-in-law usually takes my son, but I mean they are getting older, well my father-in-law is in his 80's and my mother-in-law now has dementia and Alzheimer's.

(Interview 2 – mother caring for adult son)

Satisfaction with short breaks

When asked how satisfied they were with different aspects of short breaks, most survey respondents indicated that they were satisfied as illustrated in figure 3 (and appendix 1, table 3).



Carers surveyed were most likely to be satisfied or very satisfied with the quality of the break experience (82%), the choice of breaks available to them (71%) and the support they received to arrange the break (70%). Sixty-nine percent of respondents were satisfied or very satisfied with the length of breaks. Respondents were most likely to be dissatisfied about the frequency of breaks, 35% were either dissatisfied or very dissatisfied suggesting many did not receive breaks as often as they would like.

A similar picture emerges when we look at the BME respondents, who were most likely to report that they were satisfied with all aspects of their breaks, except for the frequency. Fifty-eight percent of BME respondents identified that they were dissatisfied or very dissatisfied with the frequency of their short break.

Participants' satisfaction with short break services was further explored in the focus groups and interviews. This uncovered a number of themes including what carers consider are the indicators of quality in short break provision, the importance of length and choice of breaks, the impact of changes in provision, and how carers feel about the future of short break services.

Quality

What was of paramount importance to the carers in the study was the wellbeing of the cared for person and the short breaks provided to them being appropriate and life enhancing. Carers' first priority was that the cared for person was safe, well looked after and happy. This also alleviated feelings of guilt at leaving them:

I thought what we had was excellent for my dad. He was well looked after and we felt confident enough for him to be in there and we knew that he was being treated well.

(Dunfermline focus group – daughter caring for father)

Carers particularly valued short breaks that provided opportunities for the cared for person to engage in social activities. Carers of young people frequently talked about the benefits of them being part of a peer group and developing social skills:

...it's a group of his own age and roughly his ability, so he feels like one of the boys and one of the gang and also when he comes back he's got lots of things to talk about.

(Interview 9 – Mother caring for adult son)

I think being with other people... it's teaching him social skills... especially having the autism.

(Interview 12 - Mother caring for adult son)

Two interviewees who were single mothers felt paid carers acted as important role models for their young sons:

...he really likes it, and his carer is the centre of his universe basically, well he's kind of a role model because he hasn't got his dad around...

(Interview 11 – mother caring for young son)

I think it is really good because they tend to have a male carer who comes and so it's really a good positive role model for him because obviously with his dad being dead we are limited with male role models that he has so it is really helpful to have that.

(Interview 3 – mother caring for young son)

For carers who had taken short breaks with the cared for person, what supported them most was getting some help with the caring role, such as help with meals, to make the break mutually enjoyable:

...the caring role is lightened... the burden of entertainment is shared, and the fact that the meals are prepared for them, and someone else is doing the washing up. So all of the stuff, the kind of routine grind of the day, is taken away and they can just enjoy being on holiday together...

(Dunfermline focus group – granddaughter caring for grandfather)

We actually taken my son down with us, and also my wee granddaughter, and my daughter... so we went as a family unit. And it was... it was brilliant. [...] it was absolutely fantastic... because the meals, no having to do the... just even the simplest things... that we all get up and do... we're like robots... having that routine interrupted in a good way...

(Glasgow focus group – mother caring for young son)

Another aspect of quality related to the relationship carers had with paid carers. Participants talked about the importance of having a positive relationship with paid carers but also that paid carers had a consistent relationship with the cared for person. What was clear from discussions with carers was that they really valued having a personal, trusting relationship with paid carers:

I don't want a stranger coming into my life. And I think a lot of people might feel like that. [...] It's just trust. You have to know that the person that's been cared for is going to like them, going to have a connection...

(Interview 12 – mother caring for adult son)

I have got consistent carers on a regular basis, he knows them and he knows what is happening with them and the only time we have hiccups is when there is a change of carers.

(Interview 3 – mother caring for adult son)

They also described positive experiences of services which were both appropriate and personalised to the needs of the cared for person. This theme seemed to be more prominent where participants provided care for children or young people:

...it's brilliant, it's appropriate and they have put him into a group with a couple of lads his age.

(Dunfermline focus group – mother caring for teenage son)

...So it's important if they are looking at having respite breaks that it's not just about taking the children to something suitable for children with Special Needs.

(Interview 3 – mother caring for young son)

...the holiday the carers' group can give them is far superior to a family holiday... they do ask the clients what they want and what they like and they get feedback from the holidays... a form will come in and ask me did he enjoy it and is there anything we can do to improve it [...] they pretty much are tailored to his needs which is what it should be...

(Interview 9 – mother caring for adult son)

Only two carers in the study had experienced Self-directed Support or Direct Payments and both had polarised views. One found it 'brilliant' and that it offered 'more control' (Interview 11 – mother caring for young son) while the other reported that it led to increased paperwork, stress, uncertainty and ultimately to a reduction in funding (Glasgow focus group – mother caring for adult daughter).

Length

Carers had mixed views about the length of short breaks. Some felt that any length of break had a positive impact, while others felt strongly that the length of the break was fundamental:

Even if it's a long weekend, rather than a week's nice but it doesn't matter just as long as you can get away from cleaning and the four walls.

(Interview 4 – wife caring for husband)

It's limited, I don't feel like I can make the most of that time, because it's such, as I say it's not even 48 hours.

(Dunfermline focus group – mother caring for teenage son)

...I kind of think if you are working at such a high stress level, it can take such a long time to sort of chill out, that often by the time they are ready to come back, that is when you have started actually feeling yourself relax.

(Edinburgh focus group – mother caring for adult son)

Interestingly, one participant talked about how having an infrequent break actually had a detrimental effect on her ability to cope with the caring role. This links to the findings of the survey, in that those that had taken a break from caring, still reported negative impacts of caring on aspects of their lives:

Well when you have to cope all the time you just do, but if you suddenly don't have to cope, you suddenly relax and all your coping mechanisms kind of go away, and then when he comes back I kind of go to pieces because I can't cope because I have left it behind, so I have to readjust, it takes me about another week to readjust and it's really hard.

(Interview 11 – mother caring for young son)

Choice

Although those survey respondents who had received a break were overall satisfied with the choice available, carers in the focus groups and interviews explained that they often felt their choices were limited:

...I am quite conscious of the fact that there isn't enough resource out there, and there isn't enough back up, you know, there is not any choices – you have no choice in it.

(Edinburgh focus group - daughter caring for mother)

Basically it meant feeling so guilty when I was going away and where they wanted to put him. I just didn't like that but the way the lady said it too, well that is it, there is nothing else.

(Interview 4 – wife caring for husband)

Findings from the BME focus group identified similar feelings about a lack of options; they took what local government provided/offered to them.

Changes in break provision

Of those respondents who had experienced short breaks, over half (56%) reported that the level of short breaks they had received over the last two years had stayed the same. Of the respondents who said the levels of breaks had stayed the same, 36% provided care to a partner/husband/wife.

Overall, 25% of respondents noted that the frequency of their breaks had decreased. Most likely to report a decrease were those providing care to a parent (32%). Twenty percent of respondents said that the level of their breaks had increased over the last two years. Those most likely to report this were those caring for a partner/husband/wife (34%).

Of the 45% of survey respondents who said that their level of short breaks had increased or decreased, many gave details as to why they thought this was the case. Some respondents lacked the confidence to trust the caring role to others. Others found breaks too expensive or that the cared for person was reluctant to take one. Examples from the survey include:

- *Difficult to organise breaks as he is so specific about what he would like to do. Finding accommodation is expensive.*
- *Confidence that others can cope and my husband is well and able to choose how much help he needs.*
- *From 1st April we changed to Direct Payments and respite changed from 28 to 44 nights. We did ask for increase. Did not expect as many but will gladly use them.*
- *Mum resents any other carers and nursing home etc. No one can provide the care that I do. I have to agree. Lack of training, commitment and understanding any carers we have encountered and even the ambulance service have dropped dramatically in my estimation.*
- *Because I realised that unless I got time away I would become sick and die. I made it happen for me because it is a survival issue. I risked it.*
- *Unsuccessful application with carers centre where I am registered because I had a short respite break with another service. Since being registered at carers centre I have been unsuccessful with every application for respite care.*

Carers reflected in the focus groups and interviews on the impact that changes in provision had on the cared for person. In some cases, participants linked a reduction in short breaks to a deterioration in the cared for person's behaviour:

...95% of the time is horrendously hard work, and 5% of the time he was becoming violent and violent to the extent we had to ring the police to deal with him. And I mean we had two major incidences, and both of them followed a period where he had had no respite whatsoever for three months...

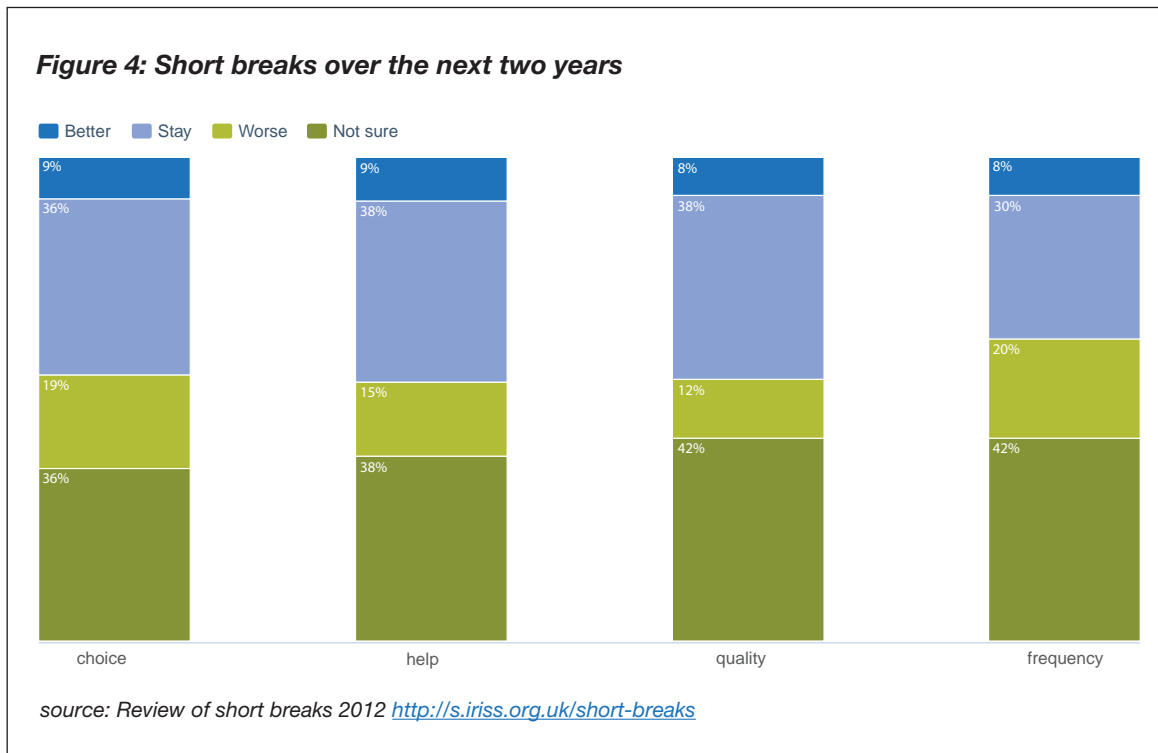
(Edinburgh focus group – mother caring for adult son)

...that's when you see him going a wee bit no well... So they take him away before Christmas. But this year it's no happened. And I can see it happening... this week's been terrible... really grating him [...] this week has been quite a nightmare.... He's peeing himself again which he's no done for years.

(Glasgow focus group – mother caring for adult son)

The future of short breaks

In terms of thinking about the future, survey respondents were asked whether they felt the choice, help/support to arrange breaks, quality or frequency of short breaks would get better, worse or stay the same. Most respondents said they were 'not sure' about the future of the quality and frequency of breaks. An equal proportion of respondents felt that choice and support to arrange breaks would either stay the same or were 'not sure'. The uncertainty about the future is also perhaps reflected in the high number of participants who did not answer the question. The majority of BME participants also expressed that they were 'not sure' whether choice, support to arrange, quality or frequency would get better, worse or stay the same over the next two years.



The focus groups and interviews revealed some uncertainty and at times pessimism about the future of short break provision and support for carers:

They are slowly improving, I still think they have a long way to go. I feel like people are like second class citizens really, they don't get enough support from the government...
 (Interview 1 – mother caring for young daughter)

Carers seemed acutely aware of reduced financial resources and the impact this would have on the availability of short breaks. There was evidence of concern about the shift to Self-directed Support and Direct Payments placing an additional demand on the carer:

I am a bit pessimistic about it, I don't like the trend, the way it's going, I think what they will possibly try to do now is by Direct Payment that you would have to just fund your own, and for a carer it's very difficult, it's another thing to worry about and have to bother about. For me the situation is excellent because it's done for me and I get the choice if I want him to go and if I don't want him to go.
 (Interview 9 – mother caring for adult son)

I don't see it becoming easier because everywhere you look there's cuts... it's going to be even harder, you know, a bigger waiting list... will you even qualify?

(Interview 12 – mother caring for adult son)

When asked what their ideal future short break provision might look like, participants commonly expressed very modest needs and expectations given the scale of the caring commitment and its impact on their lives:

Two days B&B, and not do any housework. That sounds like respite to me...

(Interview 12 – mother caring for adult son)

Well I would be quite happy maybe every six or eight weeks, a couple of nights would be great...

(Interview 10 – wife caring for husband with dementia)

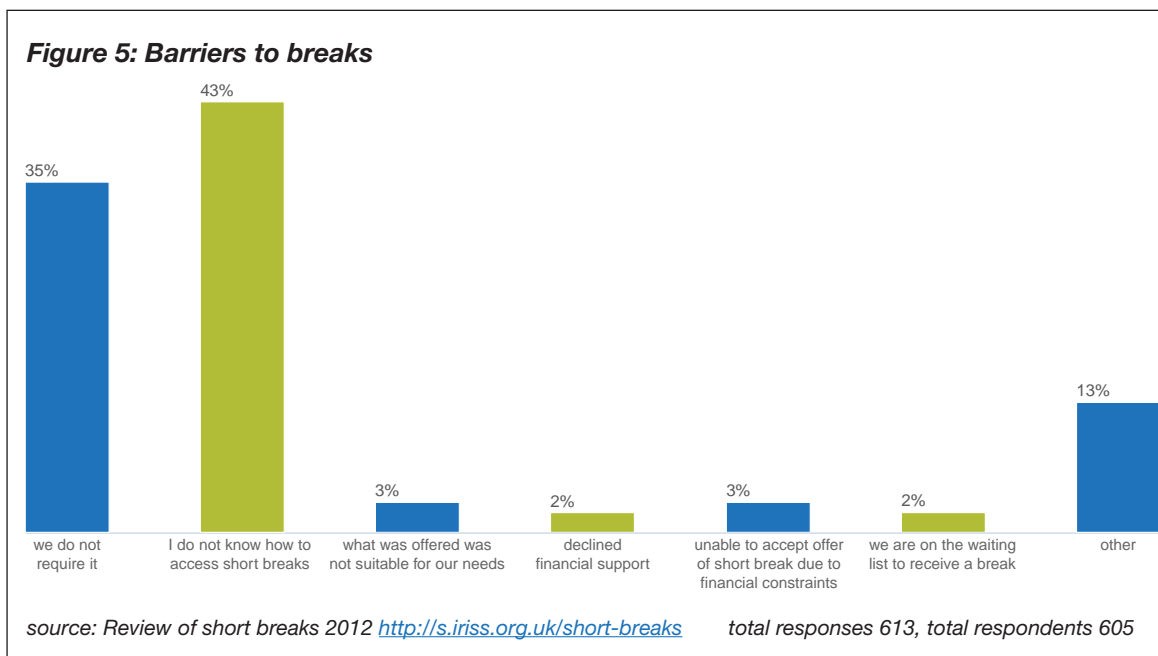
I am not looking for massive amounts... but it would be really nice if three or four times a year I could have one or two overnights where I could plan to do something like go away for a weekend.

(Interview 3 – mother caring for young son)



4. barriers to accessing short breaks

Over half (57%) of survey respondents had not had a short break. Forty-three percent said that this was because they did not know how to access short breaks as illustrated in figure 5 (also appendix 1, table 5). This is surprising given that the sample for the study was drawn from carers already in touch with carers' organisations. In contrast, 35% of respondents had not taken a short break because they did not require it. Those most likely to say this were retired (61%). In 2006, *Care 21* found that 39% of carers had not had a break from caring. 14% stated that not knowing how to access short breaks was the reason, with another 14% saying they did not require it.



Of the 255 respondents who said they did not know how to access short breaks, half (50%) were providing care to a partner/husband/wife.

Not knowing how to access short breaks was the most common barrier across the different caring situations (eg caring for a partner, child, parent etc) and across the categories of cared for person (eg physical disability, learning disability, long-term condition, old age etc). This was also the most common barrier for those up to the age of 59. Those between 60 and 70+ were more likely to have not taken a break because they did not require it.

Seventy-nine survey respondents provided further details about why they had not had a break, providing an insight into many barriers. These ranged from difficulty in accessing and booking short break services, not being aware they were entitled to breaks, not being offered a break, anxiety about leaving the caring role to others, and preferences for breaks provided by friends and family rather than formal services. Some respondents said the person they care for was against using formal short break services. Other barriers mentioned in the survey included:

- *Can't get any social work support because I seem to be coping*
- *As I care for both my wife and my parents, no co-ordination, as to meeting both separate needs. And if they do I still have children to look after*
- *Been that long now - lost interest, inclination and cash*
- *Breaks I asked for were fully booked*
- *Enquired about respite. Told it had to be booked a very long way off and might not be available*
- *Father will not accept help from strangers*
- *Social work haven't completed assessment*
- *I rely on family support therefore do not wish to have a short break*
- *Would not place my relative in a respite care place*

Of the BME respondents, 47% who had not had a short break also reported that they did not know how to access short breaks. Some expanded on other barriers. These were mixed; some BME carers not did not want to access short breaks services whereas others were unsure how to:

- *Am not yet confident to leave my caring role to someone else while I take respite for myself*
- *I need to care for my parents and family*
- *No money and not sure where to get help*
- *Not sure about procedure to apply*

Many of the barriers to taking breaks from caring highlighted by the survey respondents were reflected in the findings of the focus groups and interviews. Key barriers surfaced in the focus groups and interviews included a lack of information about carers' entitlements to breaks, difficulty with service providers and the planning process, a lack of appropriate provision and guilt.

Lack of information

A lack of information and understanding about short breaks was a prominent theme throughout the focus groups and interviews. Many carers talked about not knowing their entitlements and the difficulty in finding out information. However, sometimes carers were aware of short breaks and respite but still felt confused about how to access it:

But last year we were offered respite, but for respite you have to give a reason, I think the reasons are for me, why I need the respite, I am not quite sure, but speaking to the social worker we decided the reason was it would give me more time with my daughter...

(Interview 9 - mother caring for adult son)

Carers also talked about a lack of information from GPs and social work services, and often took responsibility for finding out information for themselves:

What we have found is that nobody tells you anything, anything you find out is you actually just find out talking to somebody and a chance remark, because it's nobody's job to tell carers anything, even the GP doesn't have to tell you about carers groups or DLA [Disability Living Allowance] anything like that.

(Interview 9 - mother caring for adult son)

...unless you know your rights, what you are entitled to, social work don't tell you anything.

(Interview 13, carer 2 – daughter-in-law caring for mother-in-law)

You find out things by accident don't you?

(Glasgow focus group – wife caring for husband)

The BME focus group participants also felt carers often have no knowledge of how to access short break services. Similar findings about carers discovering information by chance or word of mouth were evident in the *Care 21* research.

Battling to be heard

A considerable barrier was the difficulty carers experienced when engaging with statutory social services. In discussions with carers, it was common for them to describe accounts of doing battle with social services to get a break from caring. Stories of fighting 'tooth and nail' were numerous:

...I had to kick, scream, shout to get what I have got, and even then I was told that these places were so hard to come by, and they are quite often kept for emergency cases. But my point was who is to say that I am not going to become an emergency case if I don't get it?

(Dunfermline focus group – mother caring for teenage son)

...we had to put together a business case, which if I hadn't had a business background, I wouldn't have been able to do... It was an endless fight with the council – I mean literally every day.

(Edinburgh focus group – daughter caring for mother)

Some participants' experiences were of a system where they had to fight to be heard, which they were often too exhausted to do:

I don't know how they decide if I'm going to get it or if I'm not going to get it. I think the way it works the now, my own opinion is the ones that shout the loudest, get. So I think in that sense, it's unfair because I think probably the people that are maybe under the most pressure are the people that aren't shouting the loudest..

(Interview 12 – mother caring for adult son)

...I worry for people that aren't as assertive or have such good support from their friends than me... social services just say no, you can't have any respite, if I hadn't fought for that, I worry about people who can't fight like that.

(Interview 11 – mother caring for young son)

Participants' difficulties often focused on processes involved in the organisation and planning of short breaks. Carers commonly described the planning processes to access short breaks as impersonal, time consuming, overly bureaucratic and stressful. In some cases, this discouraged them from seeking help altogether:

I think most people would say that bit's probably the hardest part of caring. It's not the care, you know, it's everything else that comes in. It's the filling in forms constantly [...] it's easier to just watch them yourself than go through the process...

(Interview 12 – mother caring for adult son)

...the stress I went through leading up to that, I don't even know if it was worth it to send her there to be honest with you.

(Glasgow focus group – mother caring for adult daughter)

...somebody's somewhere wae a bit of paper who hadn't even met me who hadn't even come out to visit me had decided 'you don't need this anymore' [...] And they're constantly going to change it, or cancel it, or take it off you...

(Interview 12 – mother caring for adult son)

In some cases, organising breaks with statutory social services involved struggling to get a social worker and/or a lack of staff consistency, adding to the time and stress placed on carers:

...I wrote to an MP – that is how I got a social worker...

(Dunfermline focus group – mother caring for teenage son)

So you keep phoning, phoning and you cannot get the person who is dealing with you [...] then if you get another social worker they don't have a clue who you are talking about, what their needs are and then it starts the process from scratch again.

(Interview 13, carer 2 – daughter-in-law caring for mother-in-law)

...You need somebody that knows you and knows your situation, to be fighting your corner, and you don't want to see somebody different every other meeting... So right even at the first stage I think you've got an awful lot of barriers to reaching your goal.

(Interview 12 – mother caring for adult son)

A commonly held view was that carers' experience of planning and accessing short break services depended largely on the individual social worker. There were mixed views about social workers with both positive and negative examples. In some cases social workers were instrumental in securing breaks for carers, in others, the social worker was seen as the main barrier to accessing breaks:

...my social worker has said himself 'you need more respite, I will try and get you more.'

(Interview 11 – mother caring for young son)

I used to have a great social worker; I've now got a terrible social worker [...] Initially the first social worker that I had they tried to persuade me to get respite... then the new social worker took over and she is just interested in cutting back the hours.

(Interview 3 - mother caring for young son)

Lack of appropriate provision

Another key barrier uncovered through the focus groups and interviews was a lack of appropriate provision for the cared for person. In some cases, what was offered was unacceptable because it was of poor quality or because it was age-inappropriate, resulting in carers turning down the services offered (though only 3% of survey respondents said they had turned down short breaks services due to unsuitability):

Once we hit the adult services... massive problems there because although we were approved funding, there wasn't anything to spend it on because there is nothing appropriate.

(Edinburgh focus group – mother caring for adult son)

...they were going to put him in an old folk's home and I said no way, he's not going in there. He is only 59 and if they put him in with people with dementia... That was basically all the social worker said they had, there was nowhere for people who needed care to go...

(Interview 4 – Wife caring for husband)

It looked to me like a kind of care home... you know the way you get an old folks home [...] thought he'd be bored here, you know? What would be the point of that?

(Interview 12 – Mother caring for adult son)

In other cases where inappropriate services were offered, this was seen as being due to inadequate assessment of the cared for person by the social worker:

...I was really appalled at what she [the social worker] expected my husband to move into... I said to her, you assessed my husband and you know that was not the place for him - I would never have put him over the door. [...] Honestly, I wouldn't put my cat in there.

(Interview 13, carer 1 – wife caring for husband)

So, he [the social worker] come up to the house, he never even seen my daughter, my daughter was coming in from her wee centre, he seen her for a couple of minutes before he went out of the door. So he doesn't even know my daughter...

(Glasgow focus group – mother caring for adult daughter)

Guilt

Powerful feelings of guilt were common in the carers in the focus groups and interviews. This often inhibited them from seeking or taking a break from caring and / or enjoying the breaks they did take. Some felt taking a break amounted to 'admitting defeat' or 'not doing the best you can'. Others talked about getting support as accepting 'charity' or being 'too proud' to ask for help. In some cases, carers also expressed difficulty with other family members:

I think my ex-wife would make much of it... if I were to indicate that I was getting some respite within the time that I had him, she would go and do her nut.

(Interview 8 – father caring for adult son)

I think that's my big stumbling block, is guilt when it comes to H and leaving him. You know, probably my family would make me feel more guilty thinking I'm that I'm going away and leaving him.

(Interview 7 – Mother caring for young son)

If the cared for person had a negative attitude towards short breaks or respite, this often exacerbated the guilt carers felt in leaving them. Participants described instances where the person they cared for 'flatly refuses to go' to short breaks or doesn't appreciate the carer needs a break. For some, this is the main barrier to accessing breaks from caring:

I've gone through situations where I'm really exhausted, and he doesn't realise... and that's really a barrier because you can't make him understand that sometimes you need to be away from him.

(Dunfermline focus group – wife caring for husband)

I would have appreciated a bit of help, as an intermediary, with my parents and my mum in particular, to persuade her that it's a good idea...

(Edinburgh focus group – daughter caring for parents)

Identifying as a carer

Another barrier suggested by this research was that in some cases, participants did not identify as carers. While some people strongly identified as carers, others were unsure if they were 'carers' or simply the spouses, parents and children fulfilling a natural role for their loved ones. This has implications for whether a person providing care will be aware of, or will seek support, including short breaks:

I said 'I think I'm a carer' and she says 'oh you should see somebody' and I said 'I've never seen anyone'.

(Glasgow focus group – wife caring for husband affected by stroke)

Further, carers in the study were unsure about how difficult their situation needed to be to warrant them taking a break. They frequently made comparisons between their situation and those of other carers, imagining others had more pressing needs than them:

I always think that there's people worse off than me... that would need things more than that.

(Interview 7 – mother caring for young son)

...there's a lot more people than me out here, I can't be too demanding [...] I feel that I am the person that is getting the favour [...] I'm grateful, and I just know that out there, there must be a great demand, so I am grateful for what I get.

(Interview 10 - wife caring for husband with dementia)

...other people's situations seem so much worse, they have went through so much worse – I shouldn't be feeling like this worrying all the time.

(Edinburgh focus group – daughter caring for parents)

5. improving the short break experience

When asked if there was anything that could be improved about their short break experience survey respondents made a number of suggestions. These highlight a number of practice issues and seek to address many of the barriers identified through this study. Respondents suggested improvements in choice and flexibility. Examples from the survey included:

- *The chance to take different dates you are offered.*
- *Availability of emergency respite care. Increase in number of beds available. More flexibility relating to check-in and check-out times.*

Requests for increased consistency and control, as well as improved planning processes were also made:

- *Would be nice to know when the respite carer was being changed and to be informed about who would be coming in.*
- *Yes it would be helpful if we had an assigned social worker rather than having to be passed to different people who don't understand our family situation.*
- *My mother went into a care home for a few days last June... I tried to book early but everything was left to the last minute adding to the stress and strain of everything - until two days before we were unsure if she would get a place even though I have booked three months earlier.*

Accessibility of short breaks and an increase in information were also prominent:

- *The council have less respite beds available this year than last year. One respite bed is 30 miles away which added to cost of getting my husband there in an electric wheelchair... I would prefer respite to be local.*
- *More information on what breaks are available and to what extent the Direct Payments can be used to achieve some variety of respite.*

There were similar but notable differences in the improvements suggested by the BME respondents. In particular, they requested longer, more frequent breaks, better choice of locations, help with travel costs and better quality of halal foods.

In response to the question as to whether there were any other services or supports respondents would like to access in the future, 363 (30%) provided more information. Again, carers said they needed choice, information, flexibility, an increase of appropriate and innovative short break services and support to address the physical, mental and financial impact of caring. Carers in the *Care 21* research also identified advocacy, emotional and financial support, better information, more flexibility and less bureaucracy as ways to improve their lives.

BME respondents also suggested other improvements including befriending services for parents to overcome language or cultural barriers, bilingual staff, breaks tailored to cultural needs, interpreting services to address medical issues and access to Direct Payments.

The focus groups and interviews further explored what carers felt would help improve their experience of short breaks in the future.

Early intervention

Carers consistently emphasised that short breaks are for them a form of early intervention. They were very aware that without breaks, the carer and the caring situation risked breaking down, resulting in costly residential care or admission to hospital:

...respite, I am sure, helps people go on and on and on... but I think they have had no respite whatsoever, they can end up having very miserable lives, and perhaps people end up going into full time residential care before necessarily they really needed to...

(Edinburgh focus group – mother caring for adult son)

...if it wasn't for J [the paid carer], C would be in care.

(Interview 11 – mother caring for young son)

I think short breaks are extremely necessary, for every reason really, and what happens if a carer says 'I'm not doing this anymore'? I mean that sounds awful, but what if you stand up and say 'sorry, I'm going, I'm out', what would happen?

(Glasgow focus group – daughter caring for mother)

The levels of desperation some carers experienced before seeking or getting help were a far cry from early intervention. Some carers described only getting support once they were in crisis or at breaking point. One carer described it as 'begging to a certain extent' (Interview 13, carer 1 – wife caring for husband). Another commented:

I think a lot of carers perhaps get to such a stage they can't even help themselves, because they are so physically and mentally shattered...

(Edinburgh focus group – daughter caring for mother)

A strong message from carers in the study was that identifying them early in order to offer information and support before they reach a crisis point is essential in improving their situation:

...an automatic system where people are identified at maybe very early stages, that at some point in the future this person is going to need support.

(Edinburgh focus group – daughter caring for mother)

I think they [carers] need an easier route to it, because if you're really stressed, really hard work, it's really hard to focus on how do I go about getting that, how would I get respite, oh I need to phone social work... it's a hard route - when things are really very hard. And that's when it comes to light, when you need it, it's not when it's good.

(Interview 12 – mother caring for adult son)

Carers talked about the importance of timing in receiving information and opportunities for health professionals to intervene at the point of a diagnosis:

You got a diagnosis, and you left... I think that's where the gap happens. There's nobody stepping in at that point. They're not referring you then to a social work department or to a social worker or to an organisation from there... And I think that's a big gap because that's when you're going to get on the rung of the ladder, right at day one, before things get so stressful because you're out there doing it on your own... to make it better it has to come in really early.

(Interview 12 – mother caring for adult son)

In fact, there was evidence in the focus groups and interviews that social workers and health professionals were in some cases instrumental in helping carers to realise support was needed:

It was N, H's social worker, that arranged the respite care. She thought that it was time somebody maybe phone me, because... well I had taken attempted overdoses six times and done self-harming... and she thought that I maybe needed a wee bit help.

(Interview 7 – mother caring for young son)

...it was my GP who'd actually said, 'look, you need it'. Because I think at that time I was probably quite near a breakdown, and I just thought, 'wow, imagine letting someone else watch your child, a stranger?'

(Interview 12 – mother caring for adult son)

And I says 'well I look after my sister's boy, he's 34 now, my husband, and I look after my grand-kids...', and the lassie says 'that's an awful lot to look after', and I just looked at her, and I couldn't stop greetin... and it just dawned on me.

(Glasgow focus group – mother caring for adult son, husband, grandchildren)

Information

Carers expressed very positive experiences of carers centres and found them a good source of information and support:

They [the carers centre] are very good, give you information and stuff like that...

(Interview 1 – mother caring for young daughter)

I just don't know where I would be without the Carers Centre...

(Glasgow focus group – wife caring for husband)

However, carers in the study consistently said they thought health professionals and social services could do more to provide information to prevent carers slipping through the net. Participants of the BME focus group also felt strongly that there was a need for the widest possible stream of information on what help is available in community languages to be distributed at appropriate outlets such as MECOPP. BME carers also suggested respite care information could focus on self-help, healthy exercise and diet to help carers better support themselves and more information about services available to people with different types of visa.

Better information provision and advice were also identified by 17% of carers in the Care 21 research as something which would improve their lives.

Better planning

Carers in the focus groups and interviews felt that the planning process involved in accessing short breaks could be vastly improved. Many found that it added to the considerable stress that they were already under. Where carers had accessed short breaks, the inflexibility of the planning process and inability to plan very far ahead impinged on their enjoyment of any breaks they received. The planning process is critical; participants in the study talked about the anticipation of having a break as a key part of helping them continue in the caring role. This highlights how important it is for carers to be able to plan their breaks ahead of time. When asked what one thing that they would change about the experience of short breaks, carers often cited the planning process:

I mean if you could get maybe a year in advance dates, that would make a huge difference to me.

(Dunfermline focus group – mother caring for teenage son)

I would like to maybe have a plan, like I would maybe like a weekend every 8 weeks, I don't know if that would be feasible... I would quite like to say well I've got a weekend off and you could do that.

(Interview 13, carer 1 – wife caring for husband)

And flexibility – there is no flexibility in the system, absolutely none.

(Edinburgh focus group – daughter caring for mother)



6. context

In order to put the findings of this study in context, it is helpful to reflect on previous key pieces of research and relevant policies relating to carers and short breaks.

In 2004, the (then) Scottish Executive commissioned research into the experiences of unpaid carers. The findings were published in *Care 21: The future of unpaid care in Scotland* (Scottish Executive, 2006a) and presented stark evidence about the impact of caring. The report highlighted that 'giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options' was a priority (Scottish Executive, 2006a p10). The *Care 21* report presented a detailed picture of the experience of carers and made 22 recommendations. The Scottish Executive published its response to the *Care 21* research shortly after publication in which it accepted 'the need for a strategic approach to respite provision for carers' (Scottish Executive, 2006b p3) and committed to an assessment of respite provision in Scotland. It also emphasised the importance of redesigning local services towards preventative, personalised respite care. *Care 21* was influential in the development of *Caring together: The carers strategy for Scotland 2010-2015* (Scottish Government, 2010a).

Guidance on short breaks (Respite) was produced by the Scottish Government and the Convention of Scottish Local Authorities (COSLA) in 2008. It emphasised the importance of robust planning for short breaks to help improve support and outcomes for unpaid carers. The guidance recognised that 'short breaks are an essential part of the overall support provided to unpaid carers and those with care needs, helping to sustain caring relationships, promote health and wellbeing and prevent crises' (Scottish Government, 2008 p1). The guidance highlighted a number of factors based on research as being important to providing choice and personalisation of short breaks for carers including:

- Access to short breaks of different types and in different settings
- The option to have a break with or without the cared for person
- Access to short breaks at different times of the day / week
- A choice in length of break
- Flexibility over when short breaks are arranged
- Confidence in the quality of care provided

The guidance went on to describe a set of indicators of good short breaks including that they²:

- Are based on thorough assessment of service users' and carers' needs, on-going review and clear communication
- Are appropriate to the needs and circumstances of the carer
- Are appropriate for the age, sex, culture, and level of need of the care recipient
- Maintain or improve the wellbeing of the care recipient
- Are delivered by appropriately trained and caring staff
- Include suitable transport where necessary, so that this does not become a barrier
- Are affordable
- Are reliable

Personalisation

In recent years, social policy in Scotland has focused on a shift towards personalised health and social services, which puts people who receive support and their unpaid carers at the centre of service design and delivery. The *Self-directed Support Strategy* (Scottish Government, 2010b) and the *Self-directed Support Bill* are key drivers of personalisation. A focus on outcomes rather than outputs is a principle that underpins a personalised approach to social services.

Part of the *Caring together* strategy focuses specifically on short breaks, emphasising the importance of 'flexible, personalised short breaks provision, leading to better outcomes for carers and the people they care for' (Scottish Government, 2010a p77). A separate strategy was developed for young carers in the form of *Getting it right for young carers: The young carers strategy for Scotland 2010–2015* (Scottish Government, 2010c), which also stresses the importance of developing personalised short breaks and helping support young carers minimise the adverse affects that caring can have on them.

It's about time

It's about time: An overview of short break (respite care) planning and provision in Scotland, published in 2010 by Shared Care Scotland/Reid Howie, focused on the way local authorities in Scotland approached the planning of short break and respite care services. The research identified a number of key findings including:

- Personalisation was a key focus of many local authorities though the pace of implementation varied. Related to personalisation was an increase in more outcome-focused assessment and a growing use of Direct Payments, although the numbers of users is relatively low
- Access to alternative, more personalised options can often depend on the knowledge, experience and attitude of the person assessing
- Many local authorities sought to prevent carer breakdown and admission to hospital or long-term care through improved assessment, regular reviews, telecare and the delivery of mainstream services
- Local authorities had mixed success in rolling out carer assessments

2 From Scottish Government (2008, p11) Annex A

- Issues were identified relating to transitions between children's and adult services and adults and older people's services relating to changes in eligibility and a lack of appropriate services being available
- Ethnic minority carers face a number of barriers to finding out about and accessing respite services

The report also suggested that in addition to evidence in the *Care 21* report and the Scottish Government guidance on respite care, that potential impacts of breaks from caring may include:

- Preventing family breakdown, with the psychological, social and economic costs that accompany this
- Preventing some emergency admissions to hospital
- Helping to address the issue of bed blocking (whereby someone stays in hospital because there is no other suitable place where they can go to be looked after) and delayed discharge from hospital
- Preventing, or at least delaying, admission to long-term care

Reshaping care for older people: A programme for change 2011-2021 (Scottish Government, 2011) also acknowledges that there is currently 'insufficient support for unpaid carers, many of whom are older themselves, that limits their vital contribution to the health and well-being of the people they care for and restricts their own capacity for a healthy life' (Scottish Government, 2011 p8). Informed by the views of people who use support and their carers, *Reshaping care* highlights the need for 'greater support for unpaid carers such as short breaks, information and advice, tax breaks and entitlement to periods of leave from work' (p13).

SNP manifesto commitments and government policy

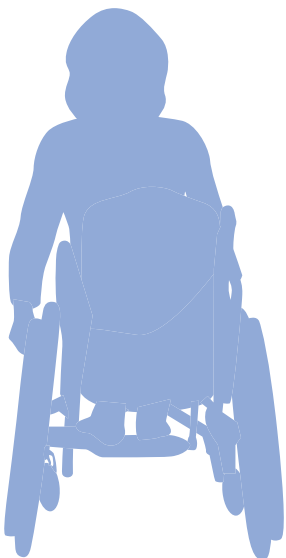
In 2007, the newly elected SNP government entered into a Concordat Agreement with local government, marking a sizeable shift from national to local decision-making with a reduction in centrally directed funding, and a greater focus on outcome-focused planning. Within the agreement there was a commitment to make progress towards delivering an additional 10,000 weeks of respite by 2011.

The SNP also made a manifesto commitment to introduce a 'guaranteed annual entitlement to breaks from caring for those in greatest need' by 2011. (This commitment has yet to be delivered and the government will reassess the timescale for delivery in July 2012.)

In October 2011, the Scottish Government published statistics on the amount of provision of respite in local authority areas across Scotland. The statistics are presented in 'respite weeks provided or arranged by local authorities' and then further broken down into 'respite nights' and 'respite days' for three age groups: 0-17, 18-64 and 65+. The data indicates that there was a total increase in provision of just over 10,600 weeks over the period of the Concordat Agreement, although data comparisons have proved difficult due to different local interpretations of respite information. Shared Care Scotland has provided a summary analysis of the data collected from local authorities between 2007/08 and 2010/11 showing the overall changes in respite weeks over this period for each age group and by area. Although there is an overall increase in respite services, this data 'does not tell us how many people benefited from short breaks, the number

waiting for a break, or the quality, choice or appropriateness of the services offered' (Shared Care Scotland, 2011). The Scottish Government has set up a Working Group involving local authorities, Shared Care Scotland and carers to look at these issues.

The Short Breaks Fund was launched in November 2010, with the first projects receiving a share of nearly £1m in March 2011. The fund supports the development of short break services and help for carers and their families to arrange their own breaks. Since, there has been a further £3m provided by Scottish Government up to the end of March 2012. In February 2012 the Government announced a further £3m for 2012/13 to support short breaks and respite care through third sector providers.



7. conclusion

As a result of this study, we know caring has a considerable impact on the physical, mental, emotional, social and family lives of unpaid carers. Their finances and employment opportunities can also be affected. These findings make the case for why breaks from caring are a vital part of supporting unpaid carers, to help them continue caring, but importantly, to have a life outside the caring role. Many of the findings in this study corroborate the picture drawn by the *Care 21* research in 2006.

When carers do get a break, they tend to view all aspects of these positively, except for their frequency. They use a range of services to help them take breaks from caring, primarily social services, but friends and family also play a key support role. However, this research suggests that there is a considerable amount of unmet need – more than half the carers in the study had not taken a break from caring – due to numerous barriers including:

- A lack of information and awareness about how to access short breaks
- Poor experiences of processes to access short break services including practice issues with social services staff
- A lack of appropriate, timely and flexible short break services

Many impacts of caring and barriers to breaks were evident across the different groups of carers in the study, suggesting that these issues are widespread and systemic. In terms of improvement, carers in the study identified increased choice, personalisation, frequency, flexibility and early intervention as priority areas. These suggestions resonate with the aspirations and commitments outlined in the *Carers strategy* and the *Guidance on short breaks*. Despite this apparent agreement between carers and policy makers on what is required to improve short break planning and provision, evidence from this study suggests that a considerable gap remains between the support carers need and what they are receiving.

8. next steps

The following key improvement areas have emerged from the research. We have tried not to sound too prescriptive, as we believe solutions need to be developed and owned locally. However we hope the ideas that follow provide a useful starting point for local discussion around how short breaks are provided, and what can be done to make things better. Local authorities and their planning partners will play a key role in taking this forward with their stakeholders and we are keen to support these efforts in whatever way we can.

Planning for improvement

The voices of carers who contributed to this report provide compelling evidence of the significant impact that regular, appropriate breaks can achieve in supporting families, preventing ill health and sustaining caring relationships. However our findings lead us to conclude there is still a long way to go to reach the 'life outside caring' and 'caring in good health' outcomes set out in the Scottish Government's and COSLA strategy for Scotland's unpaid carers. Too many carers still struggle to access the short breaks they need, when they need them.

The findings from the *It's about time* research (Shared Care Scotland/Reid-Howie, 2010) into the planning and provision of short breaks revealed a lack of systematic forward planning of short break provision in local areas and we believe this may, in part, explain a lack of progress in some areas.

What can be done?

- We believe long-term, sustainable progress on short breaks is more likely when there is a **robust improvement plan** in place at local level. Ideally this plan needs to be informed by a **thorough understanding** of the short break needs and wishes of carers and care recipients of all ages, based on accurate information about the services currently available, levels of take-up and the amount of unmet need.
- **Vision and strategic leadership** will be critical to ensure there is the high level commitment to change and this is communicated within the organisations involved. Implementation should be overseen by a named 'lead' at senior management level.
- Being accountable and keeping people informed of progress will also be important. This could be achieved through the publication of an **annual short breaks improvement statement** setting out specific plans, targets and resources for short break services in the year ahead, explaining the range of services that will be commissioned and how these will address the needs of carers and care recipients in the given area.
- Joined-up working within and across organisations is vital to coordinate efforts, streamline processes and make the best use of all the available resources. Recent developments to take forward greater **integration of health and social care**, to establish more strategic partnerships with the third sector and the launch of funding programmes backing integrated working such as the Change Fund, all provide new opportunities and resources for a more coordinated expansion of preventative, personalised short break provision.

Involving carers in decisions about the future development of short breaks

The quality of the contributions to our survey clearly demonstrated that many carers have considerable knowledge and experience about what does and doesn't work for them and the people they care for when it comes to short break services. They understand what mix of services will serve them best and have an important insight into how short break services should be monitored and evaluated.

What can be done?

- We believe the principles of **'co-production'** apply to short breaks and that the best outcomes are achieved when carers and care recipients are able to fully participate in decisions about the design and delivery of their short breaks either directly or, if necessary, through a trusted advocate.
- Some carers and care recipients will also be able to participate at a more strategic level too by contributing their knowledge and experience to **help shape the future development of short breaks**. Support and training should be provided to enable this involvement on an ongoing basis.

Extending the reach of short breaks

Some of the stories described in this report highlight once again that many carers have difficulty in taking the initial step in asking for help, and struggle on despite risks to their own physical and mental health and, in time, their capacity to continue caring. Professionals within statutory and voluntary support organisations, therefore, have an important role to play in reassuring carers that they should feel able to have a life outside caring and that external support, perhaps in the form of a short break service, is sometimes necessary to achieve this. Many of the most 'at risk' carers may be outside the local carer support infrastructure, with only short, fleeting opportunities where they may be identifiable – at hospital admission or discharge, visits to GPs or pharmacies for example.

The research once again highlighted the lack of short break services that cater for the needs of carers and care recipients within black and minority ethnic (BME) communities.

What can be done?

- We believe more can be done to use national and local promotion and advertising campaigns to help **increase public understanding of caring**, to help people to self identify their caring role and to provide signposting to sources of information and advice.
- Further embedding **carer awareness within health and social care workforce training** programmes will help to highlight the important role they play in the early identification of carers. This should also include an understanding and awareness of the particular challenges faced by **BME carers**, as well as carers within other equality groups.
- **Building relationships** with local organisations working with **BME communities** will be important, and enlisting their help to design short break supports which meet the particular needs of BME carers and care recipients.
- Specific **inputs on short breaks within workforce training** will help to promote awareness of the different ways people can be supported to have a break, as an alternative to more traditional 'respite' or 'care bed' approaches.

- The more informal allocation of relatively **small amounts of provision that can be managed flexibly** may be enough to sustain people, preventing or delaying the need for higher levels of support. The use of a '**short break vouchers**' scheme, for example, may enable carers and care recipients to 'test the water' and experience the benefits of short breaks, without the need to undertake a full assessment. There may be scope to explore the prescription of breaks using vouchers through GP practices.

Improving information and advice about short breaks

Many respondents told us that coping with caring responsibilities leaves little spare 'energy' to search for information about breaks from caring, or to research the different and perhaps more appropriate short break services that may be available. Some people told us that they would not know where to start looking for this information. Families within black and ethnic minority communities are particularly at risk of missing out because of insufficient effort to convey information in their language through their networks.

We also heard from many carers who were unaware that they may be eligible to receive financial support to help them have a break, or at the very least advice and information about services, including accessible mainstream services, they may be able to arrange for themselves. This research highlighted the considerable budgetary pressures faced by carers and consequently the worry of paying for a break may be significant barrier to people asking for help.

Our research also highlighted the frustration felt by carers when faced with complex assessment processes that appeared to serve the administrative needs of organisations, rather than the support needs of the client. The complexity of these systems often discouraged people from seeking assistance.

Carers also highlighted the very positive effect of being supported by a well informed, helpful and proactive health or social care manager.

What can be done?

- We believe that there is an urgent need for local areas to **review the availability, accuracy and accessibility of their information about short breaks** - across caring and equality groups – and to respond to any gaps and deficiencies found.
- Local areas should ensure that there is **information on local authority websites** about the range of short break services available, including accessible mainstream services, and how people access these.
- In addition, local authorities should have clearly written **eligibility information** readily available which explains the criteria used to allocate and review short break support to families and where they can go for more information.
- Frustration can be reduced by providing clear, easily understood documentation, by avoiding duplication of form filling and generally **simplifying - as far as possible** - the process of seeking support to enable breaks from caring.

Meeting the challenges and opportunities presented by Self-directed Support

The expected shift towards Self-directed Support (SDS) with the carer, and the care recipient, assuming more control of their care package will offer much greater opportunities for personalised solutions, including short breaks. Carers with experience of personalised short breaks were extremely enthusiastic about the positive difference this made to their life and the person they cared for. However, the survey responses suggest people may need encouragement and practical assistance to take their first step. The uncertainty about future provision may also produce a fear of 'letting go' of established arrangements, even where these are, perhaps, not delivering the best outcomes.

What can be done?

- We believe carers and care recipients should have the opportunity to develop the **skills and knowledge** they need to help them make the best use of the opportunities SDS provides, including opportunities for more flexible, personalised short breaks. Information providers and advocacy organisations will have a key role to play in this respect, helping to build confidence.
- Carers and care recipients **will need new 'tools'** to help them decide what supports they require, including breaks from caring, and to help them find their way to the services that can deliver this support the way they want. The publication of local directories of service provision will not only help people source information but also encourage them to consider different options.
- The **sharing of good practice examples of Self-directed Support** will help to promote alternative and innovative ways that people can achieve good outcomes. Methods of gathering and transferring this good practice will need to be developed. Carers and care recipients should play a key role in disseminating this learning.
- The success of Self-directed Support will depend on the **availability of a wide range of provision serving different needs** for people to choose from. In particular smaller community-led services may become less sustainable in the short term and will need transitional support and advice until they adapt to this new funding environment.

Helping families and communities to support each other

With less than half (44%) of carers in this survey receiving any form of family support to have a break, there are potentially more opportunities to assist families and friends to support each other.

What can be done?

- There is scope to use **online technology** and **social media** to connect families and friends to arrange help with trips to the shops, GP or hospital visits or other routine tasks.
- **Linking families in similar circumstances** together may provide opportunities for more informal, reciprocal offers of help to develop. House swapping arrangements for holiday breaks may be a possibility where people further afield can swap houses with the same adaptations and equipment.
- Time banking, community connectors, local area coordinators or other similar initiatives could also play an important role in helping to involve wider communities in building a **'circle of support'** around families with caring responsibilities to help share the care.

- With support, the planned **extension of Self-directed Support to carers** should open up new opportunities for carers and their families to create and manage their own flexible solutions to achieving a break, making the best use of the 'assets' available.

Measuring the reach and impact of short breaks

The findings of the *It's about time* research (Shared Care Scotland/Reid-Howie, 2010), supported by the research findings contained in this report, portray a rather 'uneven' picture of short break provision across Scotland. However, our detailed understanding of this is poor because of inadequate, inconsistent or even non-existent data information systems in local areas, with little evidence of rigorous approaches to service evaluation. Consequently, it is difficult to evidence locally the extent to which service planning is achieving the best outcomes for people for the costs incurred. Information about poorly served groups and levels of unmet need is also hard to quantify because of missing data.

What can be done?

- We believe that local areas should take steps to **review the performance data currently available about short breaks** and the extent to which this is used, or could be used, to inform decisions about future provision. Local studies to gather information on levels of satisfaction with different services and to record people's preferences for alternative forms of provision would all help to create a firm foundation on which future services can be planned.
- A more consistent approach to data gathering to help with the evaluation of short break provision would be beneficial. **We believe carers and care recipients are best placed to determine the most appropriate performance measures against which services should be measured.** (This research provides a starting point for this work by identifying certain indicators of service satisfaction.)
- **Further development of national performance data** on short breaks will be necessary to more reliably evaluate the impact of government policy to improve the availability of preventative, flexible short breaks and to ensure improvements were reaching carers throughout Scotland. The Scottish Government's working group on 'Respite Weeks' could be remitted to take this forward with the engagement of key stakeholders, including carers.

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appendices

The following supporting resources can be found on the IRISS website at:

<http://s.iriss.org.uk/short-breaks>

- Scotland-wide survey
- Database of all survey data

appendix 1: tables of survey data

Table 1 (Figure 1) Impact of caring on personal / social life

	Positively Affected	No Change	Negatively affected	Not sure/ applicable	Total
Physical wellbeing	322 (31%)	199 (19%)	452 (44%)	65 (6%)	1038 (100%)
Mental wellbeing	271 (27%)	169 (17%)	506 (50%)	63 (6%)	1009 (100%)
Career	146 (17%)	179 (21%)	355 (42%)	175 (21%)	855 (100%)
Education	54 (7%)	289 (39%)	138 (18%)	268 (36%)	749 (100%)
Family life	322 (33%)	136 (14%)	479 (48%)	52 (5%)	989 (100%)
Friends	304 (31%)	192 (19%)	449 (46%)	42 (4%)	987 (100%)
Finances	227 (24%)	214 (23%)	417 (45%)	71 (8%)	929 (100%)
Interests/ Hobbies	379 (35%)	74 (7%)	581 (54%)	37 (4%)	1071 (100%)

Table 2 (Figure 2): Supports used by carers to take a break

Contributors	Number	% of respondents	% of responses
Employers	10	2%	1%
Direct Payment / Self-directed Support	50	10%	7%
Social work services	287	57%	39%
Voluntary organisations	100	20%	14%
Friends/family	224	44%	31%
Health services	32	6%	4%
Other	24	5%	3%
Number of responses	727		
Number of respondents	506		

Table 3 (Figure 3): Satisfaction with short breaks

	V. Satisfied	Satisfied	Dissatisfied	V. Dissatisfied	N/A	Total
Choice of break	131 (30%)	182 (41%)	40 (9%)	23 (5%)	67 (15%)	443 (100%)
Help to organise the break	140 (32%)	166 (38%)	34 (8%)	18 (4%)	79 (18%)	437 (100%)
Quality of the break experience	153 (35%)	207 (47%)	22 (5%)	13 (3%)	43 (10%)	438 (100%)
Length of breaks	94 (22%)	204 (47%)	73 (17%)	20 (5%)	43 (10%)	434 (100%)
Frequency of breaks	50 (12%)	168 (40%)	96 (23%)	50 (12%)	60 (14%)	424 (100%)

Table 4 (Figure 4): The future of short breaks

	Better	Stay	Worse	Not sure	Total
Choice	83 (9%)	355 (36%)	188 (19%)	348 (36%)	974 (100%)
Help to arrange	82 (9%)	342 (38%)	139 (15%)	349 (38%)	912 (100%)
Quality	70 (8%)	343 (38%)	111 (12%)	378 (42%)	902 (100%)
Frequency	71 (8%)	271 (30%)	186 (20%)	382 (42%)	910 (100%)

Table 5 (Figure 5): Barriers to breaks

Reason	Number	% of respondents	% of responses
We do not require it	210	34%	29%
I do not know how to access short breaks/respice	262	43%	51%
What was offered was not suitable for our needs	21	3%	3%
Have asked for a break but have been declined financial support	11	2%	2%
Have not taken up the offer of a short break due to financial constraints	20	3%	3%
We are on the waiting list to receive a break	10	2%	1%
Other	79	13%	11%
Number of responses	613		
Number of respondents	605		

appendix 2: method

Overview

The research was carried out from August to December 2011. Research methods included a Scotland-wide survey, focus groups and interviews. The survey enabled the research to reach carers across a wide geographic area and to gather demographic and quantitative data. The survey also provided a way to recruit for further research to gather qualitative information through focus groups and interviews. The focus groups allowed the researchers to explore key issues in more depth and enabled participants to discuss their personal experiences with other carers in a group. The interviews, most of which were conducted by phone, provided an opportunity for in-depth discussion but also meant the research could involve carers who may have been unable to attend focus groups including those in rural areas.

Survey: design, sample and distribution

The survey was developed by the project partners with input from members of the Scottish Government's Carers Reference Group. The survey was in postal and web-based format.

A sample of carers centres was selected from the Coalition of Carers in Scotland network. This sample was taken from local generic carer organisations providing services to carers from all client groups and focused on the larger centres in each local authority. Each centre was contacted for their help to randomly distribute the surveys to carers on their mailing lists. Distributing the postal survey through carer centres was a preferred method because centres hold the contact details of carers and have regular mail-outs of their newsletter in which the survey could be included.

Given budget constraints, the project team estimated that approximately 7000 surveys could be distributed. The rationale for this number was that if there was a response rate of one in five (which the *Care 21* survey received) that this would result in a generous number of survey results from which to draw conclusions.

The number of surveys sent to each centre for distribution was based on the number of carers in the local authority area and the approximate number of carers on each centre's mailing list. Statistics on the number of carers across Scotland and in each local authority area were taken from the Scottish Household Survey (2007/2008).³

The number of postal surveys to be sent to each centre was calculated using percentages of carers in each local authority area and sending this percentage of the total number of surveys (n=7000) to the carers centre(s) in that area. For example, 3.66% of Scotland's carers live in the Renfrewshire local authority area. 3.66% of 7000 surveys is 256 and therefore the centre in Renfrewshire was asked to randomly distribute 256 surveys through their mailing list of 2500 carers. A decision was taken that a minimum of 250 surveys would be sent to each area, again, to help ensure a minimum of 50 responses based on a 1 in 5 response rate. For example, 2.88% of carers live in North Ayrshire. This percentage of 7000 is 202 surveys, which was boosted to 250. Where centres had fewer than 250 carers on their mailing list, every carer on the list was sent a survey (eg Shetland have 70 on their list, Orkney, 200 on theirs). Several centres provided

3 The Scottish Household Survey (SHS) is a cross-sectional survey designed to provide reliable and up-to-date information on the characteristics and composition of Scottish households at a national and sub-national level. <http://www.scotland.gov.uk/Topics/Statistics/16002>

support to carers across two local authority areas (eg North and South Lanarkshire, Falkirk and Clackmannanshire, Edinburgh and Midlothian). Where this occurred, carer populations for each area were combined and the requisite number of surveys sent to the carer centre for distribution.

Other methods of distribution included posting information about the research, including downloadable copies of the survey and a link to the online version, posting on the project partners' websites, and in their e-bulletins and newsletters.

Accounting for the boost of survey numbers to 250 where necessary, as well as some additional requests for surveys from local authorities and other organisations, the total number of postal surveys sent was 9184.

BME carers

MECOPP distributed surveys to a random sample of their carers, and through a number of other organisations, focused on supporting minority ethnic and lesbian, gay, bisexual and transgender people. In order to address language barriers, where necessary, carers were supported to complete the survey by support staff from these organisations. A nominal fee was paid to these organisations for their support staff's time.

Response

The number of paper surveys distributed was 9184; 8989 via carers' centres and a further 195 requested from local authorities. Participants were given the option of filling out the paper questionnaire that was sent to them – of which 1071 (89%) of participants did – or to complete it via the online link – of which 139 (12%) of participants did. A total of 1210 survey responses were received.

Focus group sample

Survey respondents were given the option to complete their contact details if they would be interested in being involved in further research (focus groups or interviews). The call for participation in focus groups received a low response rate, which is understandable given carers' commitments. Some focus groups were arranged through carer centres with others organised through direct engagement with survey respondents. Travel costs and costs for substitute care to be provided for the cared for person were offered.

Four focus groups were held. One in Glasgow, two in Edinburgh and one in Fife. One of the Edinburgh focus groups was for black and minority ethnic carers only. For this focus group, language support, facilitation and scribing of key points were provided by MECOPP.

In total, 36 carers attended the focus groups. Focus groups were typically an hour and a half long. All focus group discussions were audio recorded and transcribed. The topic guide for the focus groups was developed by the project partners in line with the research aims and areas of interest. Each group was divided according to whether carers had experienced a break from caring or not. The rationale for splitting the groups was to ensure each group had a chance to fully explore these different experiences.

Interview sample

To ensure the research included those from different geographic contexts, each postcode provided by the respondents was scored according to the Scottish Neighbourhood Statistics urban-rural classification⁴. This classification system distinguishes between urban, rural and remote areas within Scotland. Once each postcode from the respondents was classified, a random sample of each classification was invited to take part in a telephone interview.

A total of 13 interviews were conducted (10 by telephone, three in person). The interviews were in-depth and semi-structured. Questions were based closely on those in the focus group topic guide. Interviews took between 15 and 45 minutes. The face-to-face interviews took an hour each. All were audio recorded and transcribed.

Ethics

Consent was implicit in the voluntary completion of the survey by respondents. The survey contained introductory information about the purpose and scope of the research, the project partners, confidentiality, and anonymity as per standard practice outlined in the Social Research Association Ethical Guidelines. The contact details of the lead researcher were also provided for any questions or concerns. Survey respondents self-selected to be considered to take part in further research by volunteering their contact details. At the beginning of each focus group and interview, the same contextual information was provided. In addition, verbal consent was obtained for methods of capturing focus groups and interview content (eg audio recording and transcription). Project partners from Shared Care Scotland and the Coalition of Carers in Scotland, acting as facilitators and interviewers, were on hand to address any sensitive issues. In the case of the Dunfermline and Glasgow focus groups, the carers' centre managers also attended. Participants were debriefed at the end of each focus group and interview. They were provided with details of how to contact the project partners for any follow-up issues or questions.

4 <http://www.sns.gov.uk/>



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