

Partnership Carers survey, December 2010

Do you need a break from caring?

Executive summary

The ability for Carers to access a break from caring for a family member has been reported consistently as a key issue by carers in helping them to support individuals to live in their own home. This survey aimed to understand further what local carers felt about existing respite provision and gaps in services.

198 responses were received, from carers, covering a diversity of caring situations, including multiple caring roles, with 140 (over 70%) providing at least 50 hours per week of care. Most respondents lived within West Berkshire, but some were 'distance carers'. 86% of respondents lived with their cared-for. 73% of respondents were female and only 3% from an ethnic minority. 50% used home care, 38% had help from relatives. 34% used day care services and 20% used a sit-in service.

Some carers reported coping very well and others reported being close to breaking point, with all shades in between. Some reported they experience excellent carer services and others were at the extreme opposite end of a broad spectrum of experiences.

Only 43% of carers felt they were getting the right amount of daytime respite and, similarly, 55% felt they needed additional overnight respite. The majority of respondents reported needing respite mainly in order to be able to carry out simple, basic, everyday activities and to get enough rest, with half also wishing to take a holiday. Cost was reported as the biggest barrier to meeting respite needs in nearly half the responses. Care quality was an issue for 30% of respondents. Whereas respite capacity is reportedly insufficient, some respondents also indicated that other, more affordable solutions would work for them.

Some patterns emerged. The need for overnight respite packages of 'four times a year' and breaks of '1-2 nights' and '7 nights' were most frequently mentioned. However, the wider evidence suggests that each client may require an individual respite package.

Looking ahead, responses indicated that carers envisage more opportunities to go away, and 20% see more opportunity for their cared-for either to be able to go on holiday or, to a lesser extent, to receive care in their own homes. The demand frequency for care home or for respite centre breaks remains important to about 25% of carers, but demand for these options appears likely to remain static.

All conclusions and recommendations should be read within the limitations of the research methodology, also noting that of the 'estimated 2,000' local carers providing 50+ hours per week of care, only 140 respondents to this survey claimed to meet that definition (7%).

Recommendations

1. Overall provision and funding of both daytime and overnight respite should be increased, with a particular focus on avoiding situations where carers are unable to continue caring.
2. Stronger efforts should be made to ensure that carers are more aware of the available respite services.
3. The main priorities for additional respite capacity are, in order of priority:
 - at –home services lasting one night,
 - sitting services during the day and
 - day centres.
4. The capacity of the overnight at-home respite services should be reviewed based on targeted research with prospective clients.
5. The capacity of the daytime sitting services should be reviewed based on targeted research with prospective clients.
6. The proposed reduction in West Berkshire Council's day services capacity should be reviewed specifically for those clients with family carers. Those who are identified as greatest risk of reaching breaking point should receive priority service.
7. Specific reviews should be carried out in connection with apparent shortages in the following specialist respite services:
 - Overnight and residential services for young people with dementia
 - Activities services for the young-cared-for
 - Specialist live-in care for those with dementia
 - Future concern over closure of specialist MS Centres
8. Efforts to reach to the 'hard to reach' should remain undiminished and, wherever possible, be strengthened.
9. All services providers need to be more vigilant to identify when carers become 'former carers', to avoid inappropriate ongoing communications.
10. Maintaining and improving care quality and ensuring respite services are affordable to clients are key priorities to meet, across all recommendations.

Introduction

Census data indicates that around 12,000 West Berkshire residents (8.4% of population) provide unpaid care to family, friends or neighbours. Nearly 2000 people in West Berkshire provide significant amounts of care (over 50 hours a week) for an adult family member or close friend.¹

The ability for Carers to access a break from caring for a family member has consistently been seen as a key issue by carers in helping them to support individuals to live in their own home.

A recent national statutory survey undertaken by West Berkshire Council '**Caring for others survey 2009 -10**' highlighted that although the number of carers that actually received a break was relatively low, (approx 32%), qualitative comments reinforce that those that did saw the service as important for themselves and for the person they care for and valued the service they receive. There were no questions within this survey that asked the Carer why they had not received a break or indeed if they wanted a break, or the type of respite services they would benefit from. This was an area that many partners wanted to review further.

A survey was developed in partnership with the organisations listed below² to further understand issues in relation to respite care received both during the day and overnight.

The survey aimed to understand further:

1. What local carers felt about existing respite provision and gaps in services.
2. Views of overnight respite and gaps in provision of service.
 - If other options or services were made available, what would the take up be?

An advantage of agencies working in partnership to develop and deliver this survey was the ability to pool information about carers across agencies. This aimed to reduce duplication, costs of mail out, increase chance of active participation in the survey and for all partners to benefit from the analysis of the survey to provide a clear evidence base to understand current needs and inform future planning of services.

¹ West Berkshire Council District Profile 2010

² **The following organisations participated in this survey:**

- *Multiple Sclerosis Society Newbury & District*
- *West Berkshire Neurological Alliance*
- *Princess Royal Trust for Carers*
- *West Berkshire Council*
- *Crossroads Care Newbury & District*
- *West Berkshire Disability Alliance*
- *West Berkshire Independent Living Network*
- *Alzheimer's Society West Berkshire*

Methodology

The survey was conducted via a postal self – completion questionnaire.

The questionnaire was developed in partnership by the organisations involved - See Appendix A for a copy of the final questionnaire.

Sample:

It was recognised that there was a duty to meet the requirements of the Data Protection Act in order for each organisation to legitimately share the details of the carers they support. The survey was felt to be in the best interests of carers within West Berkshire to inform the effective development of carers services within West Berkshire. John Holt (Neurological Alliance) agreed to act as Data Controller and manage the data provided by each organisation. The only data to be shared was the name and address of the carer, some organisations only shared postcode data. Great care was taken to ensure the data was transferred and stored safely and securely, with all personally identifiable information destroyed by the data controller after the survey had been completed.

The survey was printed centrally and sent to each organisation to add address labels and send out to designated post codes as set out by the Data controller.

The survey questionnaire was sent the week commencing 30th November 2010 with a stamped reply envelope. Carers were asked to complete and return the questionnaire.

Completed surveys were returned to West Berkshire Independent Living Network, a contact number (John Holt) was provided if carers needed help answering the questions. Any queries received were passed to organisations for review / appropriate follow up.

The results were entered onto the online survey tool Survey Monkey.

Response rates to the survey

The survey went out to 900 carers.

198 Carers responded, a response rate of 22% which gives a confidence levels of +/- 6%. The usual confidence limits to make a survey statistically valid are 5% so although conclusions can be drawn from the results of this survey, care needs to be taken when generalising these results.

Despite efforts to avoid duplication there were a number of responses that indicate individuals had received more than one questionnaire; therefore the overall sample size may be lower thereby increasing the percentage response rate.

Throughout this report the percentage scores for each question reflects the percentage of the total number of people answering the question, rather than the total number of people returning the survey. This means that in some cases the statistical validity is poor.

Many qualitative comments have been included in the report as supporting evidence. It should be noted that multiple comments for the same theme have not been included.

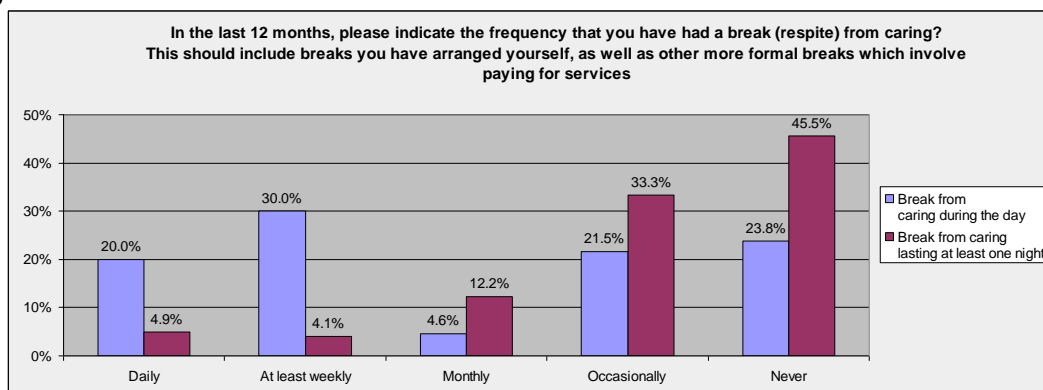
Results

Section 1 – Understanding your current ‘respite’ needs

This section asked a number of questions to understand current respite received and whether carers felt this met their need.

Frequency of breaks from Caring

The graph below indicates the frequency of breaks respondents received, either during the day or overnight.



Breaks during the day: 50% of Carers report that they receive a regular break from caring either daily (20%) or weekly (30%).

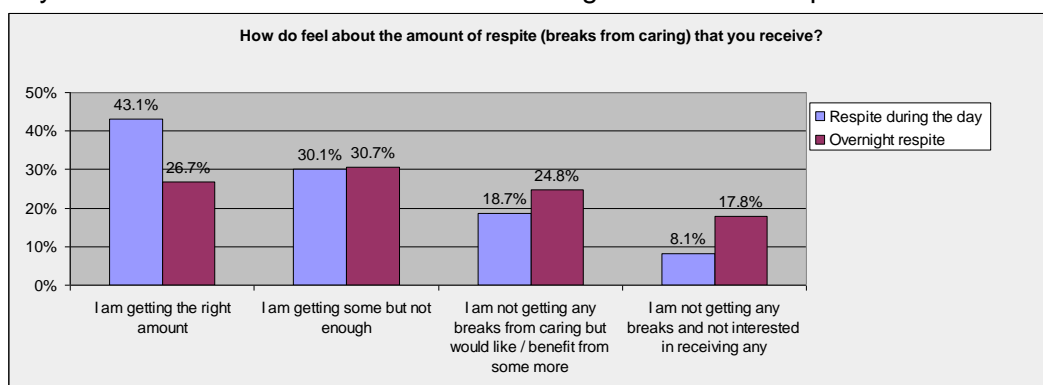
23.8% report that they never receive any breaks from caring. *This is lower than those reported in the 2009 -10 WBC survey but may be as a consequence of the targeted survey (carers that felt respite was not an issue for them may not have responded)*

Overnight breaks: 45%, a significantly higher number of respondents, do not receive any overnight breaks. Those that do receive overnight breaks tend to receive this much less frequently, 33% report that they receive overnight breaks occasionally.

Anomaly – the graph indicates 4.9% of carers reporting overnight breaks were received daily, this may be from carers who do not currently live with the cared for.

Views from Carers on the level of respite received

The survey asked whether Carers felt this was the right amount of respite.



Breaks during the day: Only 43% of carers felt they were getting the right amount of respite.

30% of Carers felt that they were ‘getting some breaks but not enough’

A significant proportion, 18.7%, indicated they are not getting any breaks and would benefit from some.

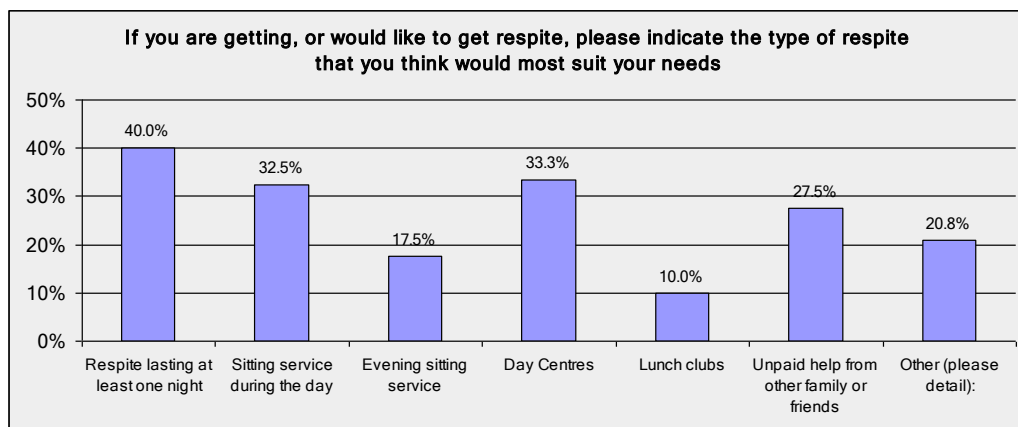
Overnight breaks: Just over a quarter, 26.7%, felt they were getting the right amount of overnight respite

A further 25% of carers not currently receiving overnight respite felt that they would benefit from some. It is worth noting that there are a proportion of carers that do not receive any breaks, particularly overnight breaks (18%) and are not interested in receiving any.

Type of respite needed

When asked the type of respite that would most suit their needs, the most frequent responses were:

- Respite lasting at least one night (40%)
- Sitting services during the day (32.5%)
- Day centres (33%)
- Unpaid help from family / friends (27.5%)

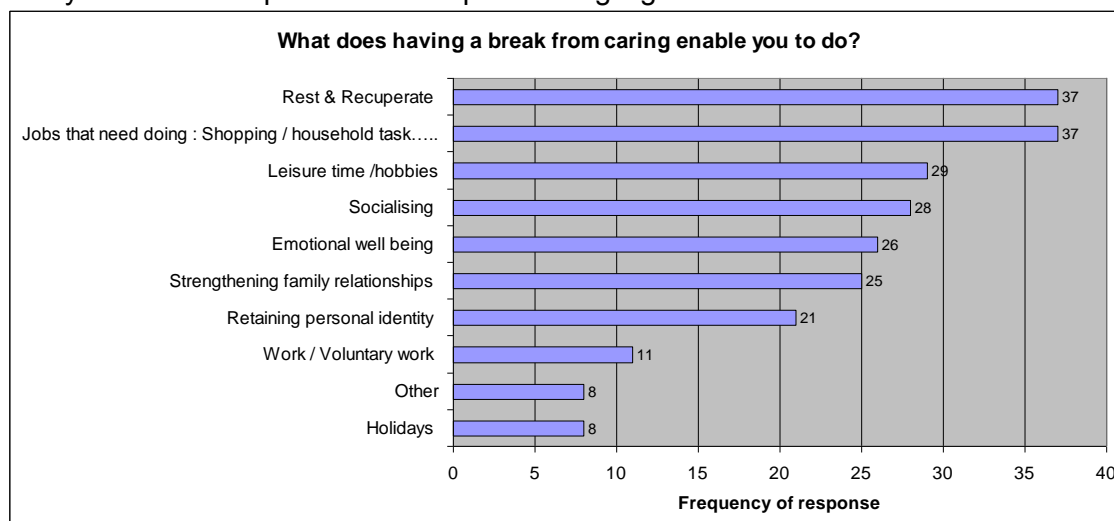


Other responses included: 'cleaning', specific reference to more time away and 'holidays'; 'Specialised treatment/leisure sessions for relative' and 'Play scheme for children in wheelchairs with learning difficulties'.

What does having a break from caring enable you to do?

There were numerous comments in response to this question.

Analysis of 'text' responses to this question highlighted a number of common themes:



Examples of qualitative comments received reinforce the strength of opinion and value that carers place on breaks from caring to allow them to continue in this role. These include:

Opportunity to rest & recuperate

'Re-charge batteries to enable me to carry on caring'; 'Unwind'

'Knowing mum is safe I can go out shopping or meet friends. It is great to relax for a while and recharge the batteries'; 'Rest, relax; "Relax from being on constant alert'

'Rest and recuperate giving longer benefits to myself and person under care';

'Time to relax in a different environment and re-charge the batteries'

'Have a much needed rest and a good night's sleep.'

'Recharge my batteries, be a normal family, give attention to my other child, have 8 hours sleep without being disturbed, give my bad back a rest. Do things that non-carers take for granted'

Jobs that need doing: Shopping / household tasks / appointments...

'To carry out basic needs such as cleaning the house, making phone calls, shopping';

'Get on a bus to Newbury to shop for food and other essentials, cooking, clean homes, do washing, decorating, home repairs, keep garden tidy, personal care for myself, medical treatment. I can do none of these things unless my patient is away ...';

'Shopping, doctors, dentists appointments';

'Having a break from caring for my wife enables me to do odd jobs about the bungalow, e.g. washing, ironing, keeping the garden tidy and in the summer period mowing the lawn.';

'catch up with chores I can't do with my cared for around.';

'Go shopping with peace of mind knowing that my husband has someone with him'

Leisure time /hobbies

'enables me to have 'me' time for hobbies'; "Taking some form of exercise'; 'Playing croquet in a club'; 'go to the cinema'; 'Taking some form of exercise.'; 'Bird watching'; 'Ride my bicycle and keep fit.'; "Write some of my books'.; 'Walk in the country'; 'Writing, essays, information, more gardening', Tending my allotment.'; 'Play tennis';

'Undertake activities with family & friends not easily achieved whilst caring as activity may be unsuitable. Change an otherwise very routine led life.'

Socialising

'To have occasional days out with my friends'; 'Relax and see friends and have a normal life for a weekend once in a while'; 'Go out and do the things I want to do.'

'Shopping, meeting friends, just not having to think about caring for anyone for a few hours.'

'It enables me to meet others to talk, relax and keep up to date with current affairs.'

'Time to have fun and fully relax, without thinking about others"

'In short: to live a little; i.e. to go into town to have time to sit down for a cup of coffee'

"... I can have a morning shopping or the occasional day out with one of my clubs. These away days give me a tremendous boost as I can have meaningful social interaction and visiting art exhibitions, National Trust properties etc is so stimulating and a break from the daily caring role.'

Strengthening family relationships

'Gives me time to be with my husband. time for us as a couple is limited';

'Concentrate on my two younger children- take them out alone'

'Without respite we have no freedom to do things which we would choose to do or spend time alone or with friends'.; 'Visit friends and relative' ;'Have time for my own family, being able to do things for me'

'Spend time with my daughter and focus on her needs. Spend time as a couple with my husband....Respite allows us to do ordinary family activities together.'

'Spend time with my husband, friends, and family'; '...spend time with my wife.'

Emotional well being

Keeping sane' ; 'not having to worry'; 'peace of mind' ; 'To switch off from the stress/boredom'; 'Not worry as much'; 'It would help me unwind as at the moment I have depression';

'Be able to do something for yourself and not have to worry'

'It enables me to take exercise which is essential (swimming) for relief of my sciatica and benefits my physical, spiritual and general well-being....without this I would be 'shut in', static, depressed and unable to do my work which is invaluable to others'

'It gives me a fresh look at things are feel I can cope better after a break.'

Retaining personal identity

'being my own self'; 'time to be me'; 'normality'; 'it gives me a bit of a normal life';

'Be myself and do things that I want to do'; 'live a normal life and get out of the flat';

'To attempt to 'be me', Think for myself'; 'to have a small window of life away from Alzheimer's';

'Have a life'; 'feeling there is a life outside of caring!'

'Get needed perspective. Plan, evaluate to move forward.'

Work / Voluntary work

'I work full time. This acts as a break. I can switch off mentally'; 'Volunteer work';

'To attend work, no care provision to have any break'; 'It enables me to do my part time work(teaching)'

Holidays

'Go away from home for a weekend break'; 'walking holidays'; 'Go on holiday'

'Everyone needs a break. Looking after my mother I thought it would be so easy to be able to have holidays, weekends away etc. So difficult.'

'To have a holiday/ weekend breaks without leaving my mother on her own'

Other

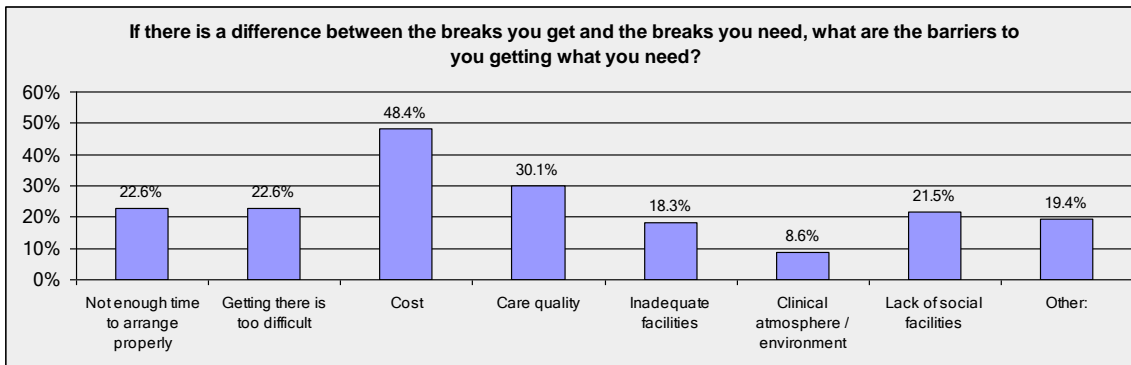
*Facilitates choice: 'go to bed when I want to' ;
 'Plan, evaluate to move forward.'*

Concerns were highlighted regarding the closure of WBC day centres:

'The news about the closure of Ormonde Centre has caused me a lot of anxiety and worry about my mum's future wellbeing & how we will afford to pay for home care'

Barriers to receiving respite / breaks from caring

Respondents were asked if there was a difference between the breaks they receive and the breaks they need, and what the barriers are to getting what they need.



The most significant issue appears to be cost; almost 50% of carers identified this as a potential barrier.

30% identified care quality as a concern;

Over 20% indicated 'getting there'; 'time to arrange' and 'lack of social facilities' were barriers to getting the respite care needed.

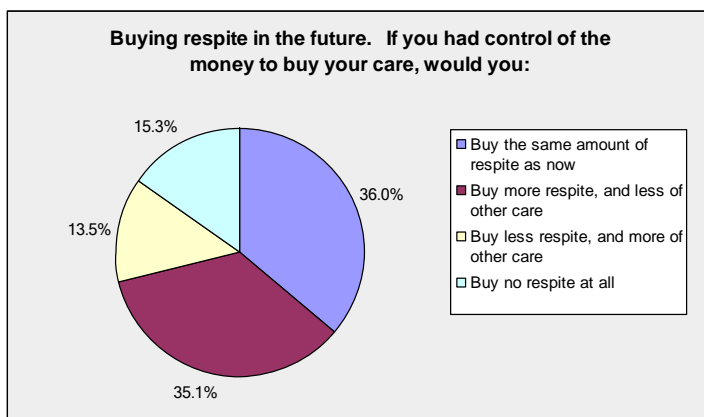
Buying respite in the future.

In recognition of the move towards the personalisation of services and the focus on the ability for individuals to have more choice and manage their own support, carers were asked if they had control of money to buy their respite care how they would spend this.

Interestingly only 36% indicated that they would keep the status quo and buy the same amount as they currently receive.

35.1% indicated that they would buy more respite but 13.5% indicated that they would actually buy less respite than they would do now. One comment received highlighted – 'I would balance it out to make the money go further'.

Consistent with previous responses a proportion of respondents indicated that they would not buy any respite.



Section 2- Overnight Respite

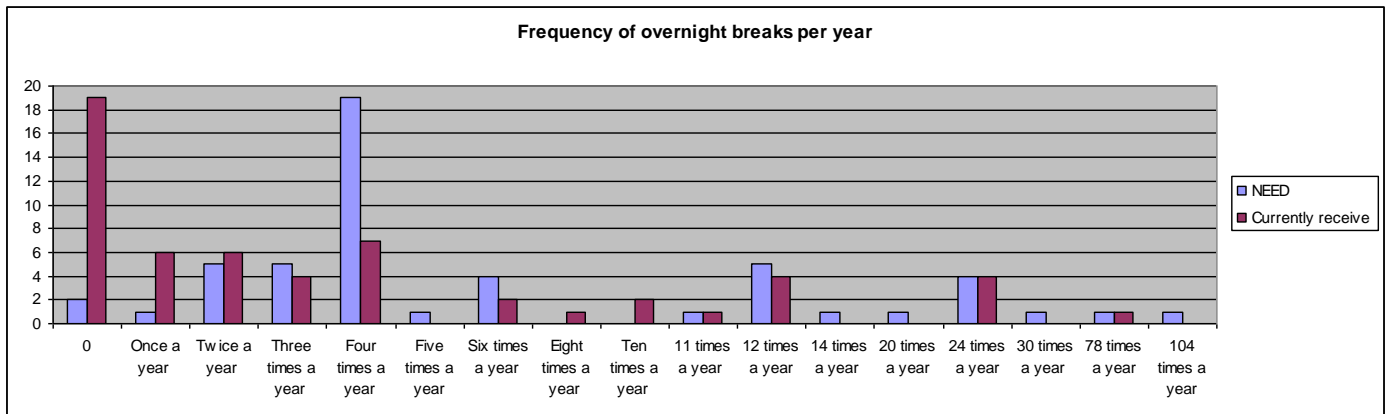
The next section focused specifically on understanding Carers 'overnight' respite needs. "Overnight respite" was defined as any break which includes one or more overnight stays - this could be just one night, a weekend, or for several days at a time.

Respondents were asked to only answer this section if they have or are in need of overnight respite, consequently the number of responses for each question is lower. (between 60 – 90 responses)

Frequency and duration of overnight breaks

Respondents were asked to indicate the number of overnight breaks they

- actually received and
- they felt they 'needed' both in terms of times per year and length of break



'Need' for overnight respite is higher than overnight respite actually received.

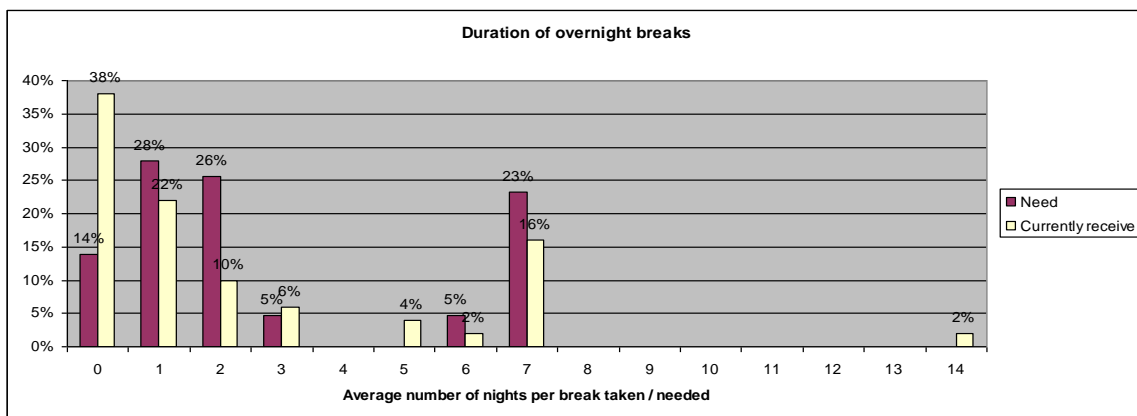
Frequency of breaks (per year)

The graph above indicates that there are a number of people that receive no breaks that actually feel that they need a break. Interestingly in terms of frequency per year, the main focus of need appears to centre around 'four times a year'.

Duration of overnight breaks

Analysis of duration of overnight breaks was made by averaging the number of nights per break (total number of nights per year / total number of breaks per year). The graph below indicates both the average duration of breaks taken and average duration of breaks needed.

Two areas of 'need' emerge: 1 or 2 overnight breaks (long weekends) and breaks lasting for 7 nights (1 week)



NB – Difficulty in analysis of some responses due to some inconsistency, which seems to suggest that people had interpreted the question differently. Those answers that were inconsistent were discounted

Again, there were numerous qualitative comments to explain the apparent difference between overnight respite care received and actually needed.

A number of common themes emerged:

Lack of suitable care available

'Care homes can be very inflexible and insist on longer breaks.'

'Now have a different carer who is not confident enough to take responsibility for my son overnight.'

'...no suitable overnight respite care for a younger person with dementia'

'There are few people who will stay overnight with my mother.'

'We are unable to find suitable respite for our daughter that she enjoys and we are happy with, which results in only occasional breaks which are very short.'

'I don't use all the respite I could because of the lack of a suitable carer, i.e one that can do activities with my son that are suitable for his age (carer too old).'

Cost of care too high / lack of available funding

'This will reduce to about 7 nights next year as you have reduced our funding;'

'Cost of care while I am away.'

'I would just love to be able to have a break sometimes without it costing so much money.'

'All money in budget has to go to care, no money available for respite break'

'We cannot afford respite nor does this West Berkshire care to support us with! We have been let down badly'

'For the amount of care I need for respite the funding I receive will only cover one week per year.'

No ability to make arrangements / difficulty asking for help

'I find it hard to ask all the time; I have no means by which I can arrange overnight respite.'

'I have to set up so many arrangements / people to cover daytime / night time care for my husband'

'Guilt';

'Don't know how to get overnight respite.'

Family support – The importance of family members was highlighted both in providing respite care and in some cases the difficulties this causes, and the perception from some that no one else can provide respite other than family members

'My brother is the only one who is prepared to do the overnights and now mum needs personal care he does not feel able to give it.'

'Because we have always managed as a family my brother our sister and their families have mum so I can get away but at present my sister's ill health is making things difficult'

'Respite is provided by family members if possible.'

'We can only achieve a holiday occasionally if we drive her to family in the North of England, not practical for a short break.'

'We get a few days away 2-3 days at the time at a relative's home.'

Unwillingness of cared for to attend respite

'It is very hard taking someone to a care home that they do not want to go to'

'Mum won't want strangers in. She would get anxiety attacks. Can't do that to her'

'...And also the person we are caring for accepting!'

A number of comments were received from carers who do not currently receive respite but would like and felt they would benefit from overnight respite.

Reasons for overnight respite.

Respondents were asked to consider the main reasons for you or the person spending night(s) away. 45% indicated that it enabled them to have a holiday.

A significant proportion, 44%, indicated reasons. These fell into the following categories which are similar themes from previous questions:

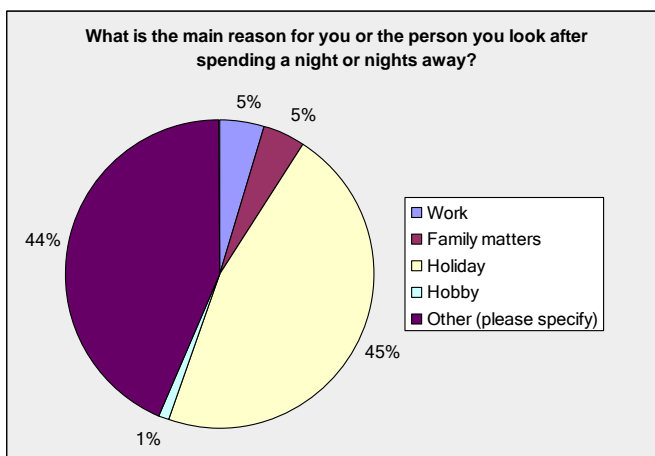
Need to have a break / rest from day to caring : *'To have a proper break; a necessary break from the strain of 24/7 caring'; 'Catch up on sleep, never have an undisturbed night'; 'I can't cope without a break.'*

'I do not need any nights away - just days. be free to get out of the house.'

A combination of the above reasons;
'Family matters and holiday'; 'Holiday and hobby'

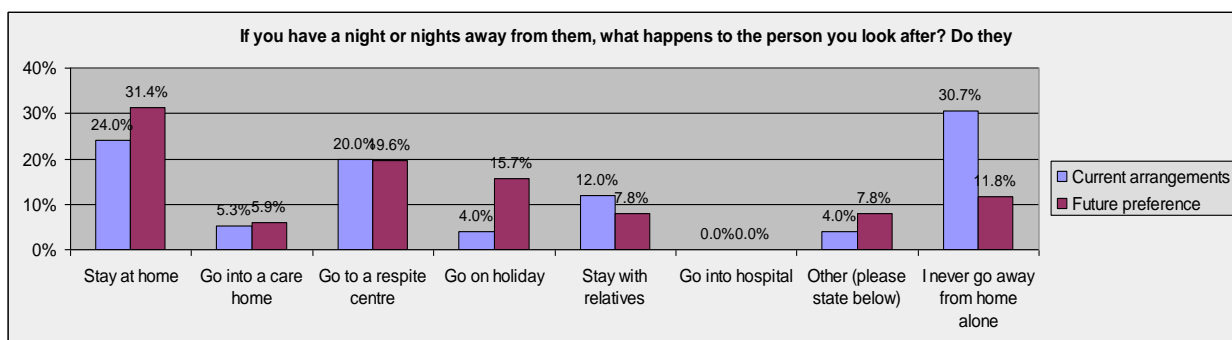
Difficulty in having a break: *'Impossible'*
'Do not have any nights away at present'

Other reasons: *'For her to build independence.'; 'Visiting friends'*
'Rest for us & also expand activity for the dependant.'
'Hospital.'



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'other'
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Respondents were asked what happens to the person you look after?



Other comments referred to the following options

'Specific facilities in relation to the individual needs: i.e. Castle gate'

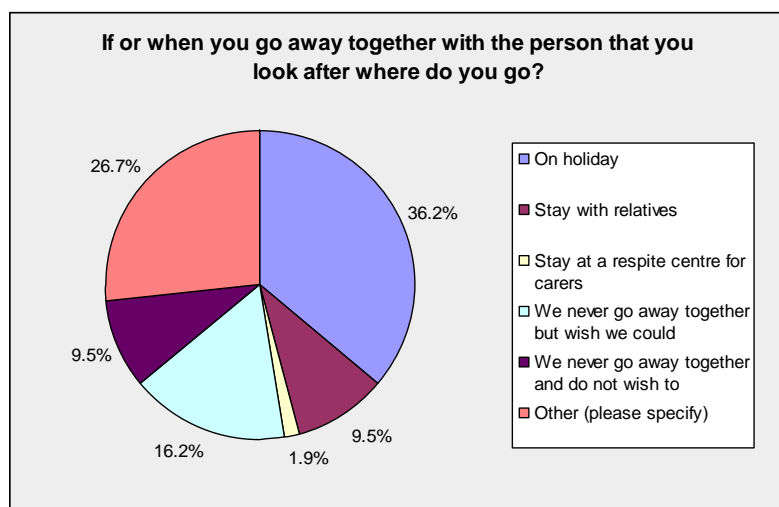
'A combination of family support and staying at home'

'Pay agency for a night so my husband can stay at home.'

'We go away together.'

'Acknowledgement that families / relatives do not have disabled facilities so this makes things difficult.'

If or when you go away with the person that you look after where do you go?



A significant proportion of responses stated 'other', however when analysed the **majority** of other comments indicate that it is actually a combination of the two: 'Go on holiday and / or stay with relatives'

Other comments refer to the fact that going away is 'too difficult / no available place' or provide specific examples:

'To our static caravan, New Forest';

'We go to St Dunstan's Home for the blind. Day outings';

'On holiday and stay at a respite centre for carers.'

Finally, respondents were asked to provide any other further comments about overnight respite. Comments related to the following areas:

Family Support

'I only ask my brother. I don't know who else to ask.'

Our daughter and husband take us on holiday.

Stay with relatives but that is no break!!

Concern for future respite

'Situation likely to get worse next year if Brambles MS respite centre closes'

'We will not have hols in future. Too much arranging and stress for me as carer. Occasional day out with carer will have to do.'

Lack of respite received

'I need holidays with my husband and 6 year old son. We cannot take my mother of 90 years'

'In 15 years my husband and I have been away for 3 overnight breaks.'

'My daughter has a mental illness and I have not had any respite care in five years'

'Have only had one break together last four years, for a week in the UK. Had to hire a s/c cottage due to wheelchair so not much of a break for carer, more just a change of scene.'

Importance of ensuring the right respite for cared for person

'I would love to go on holiday with my husband. That way I know he would be safe with me.'

'Very important that it is an enjoyable respite for the dependant as I can enjoy the time if I am happy he is also.'

'My husband goes to Helen Ley Care Centre where the care is unsurpassed & totally reliable. From this care home he is able to have visitors who live in the area and he feels completely at home there. All his needs are catered for so that he comes home stimulated and healthy.'

For myself to benefit from a respite stay it needs to be at the same place and continuity of staff. Anything other would result in my daughter not being happy and would be more of a problem when returning home and any further respite'

Numerous comments about individual situations and need for specific respite available

'Needs to be of high quality, high staff ratio, specialist trained dementia staff. A suitable environment for an otherwise fit, healthy, younger person with Alzheimer's, not a sitting service.'

'There needs to be more good quality respite for Learning Disability clients offering various different options and choice. It also needs to be affordable especially if being purchased from a personal budget.'

'An important concern is that my wife 'needs watching' and in the past has been allowed to wander off down the road. This can arise because she is very independent and has difficulty communicating. She can give the impression of being capable when in fact she may be in danger. She is vulnerable and not properly assessed by the care home she attended '

'Current arrangements work (Castlegate) but am keen to ensure my son has access to outings & activities as part of respite as he is very active & not sure if appropriate provision exists through adult services.'

'If I have to work overnight I have to get an emergency carer in at my own cost.'

'If we go on holiday it is still hard work with a disabled son.'

'My teenager is an epileptic so needs respite with medical backup.'

Unwillingness / difficulty for cared for be away from home

*'*** does not like the idea of going away from home. He has Alzheimer's and any change confuses him.'*

'I wish I could go away with my husband but as he has dementia he gets easily disorientated and agitated away from home which can be difficult and stressful to cope with.'

'My husband does not feel happy in care homes. So it upsets us both when he goes to one for me to have a break.'

'The problem we have is that our son refuses to go to the care offered and so we have great limitations for respite'

Section 3: About the person you care for

Questions in this section focused on the Carers profile and services that the 'cared for' person receives to support them.

Length of time Caring

Table 1 indicates the length of time Carers that they spend each week looking after or person they care for. The majority 70.9% indicate they spend over 50 hours a week caring.

Table 1

Number of hours	% of responses	
Up to 20 hours per week	10.4%	indicate helping the
20 - 49 hours per week	18.7%	
50 hours + per week	70.9%	50 hours a

Age of Carers

Table 2 indicates the age of the Carers. 48% of carers are aged over 65

Table 2 – Age of Carers

Age of Carer	Response Total	%
18 - 34	3	2.1%
35 -44	9	6.4%
45-54	27	19.2%
55 -64	34	24.1%
65 - 74	31	22.0%
75 -84	33	23.4%
85+	4	2.8%
Total	141	100.00%

Age of Cared for

Table 3 indicates the age of those cared for. 63.57 % of those cared for are individuals overall 20.7% are over 85.

Table 3 – Age of cared for

Age of person you look after	Response Total	%	
Under 18	13	9.3%	over 65,
18 - 34	12	8.6%	
35 -44	4	2.9%	
45-54	9	6.4%	survey
55 -64	13	9.3%	the
65 - 74	22	15.7%	person
75 -84	38	27.1%	
85+	29	20.7%	
Total	140		

It should be noted that some partners sent the to carers of both adults and children. Clearly, needs of carers in relation the age of the they care for may vary, but due to the low numbers it is not possible to split the results.

Carers were asked to state the first part of their e.g. RG14, responses were received from the

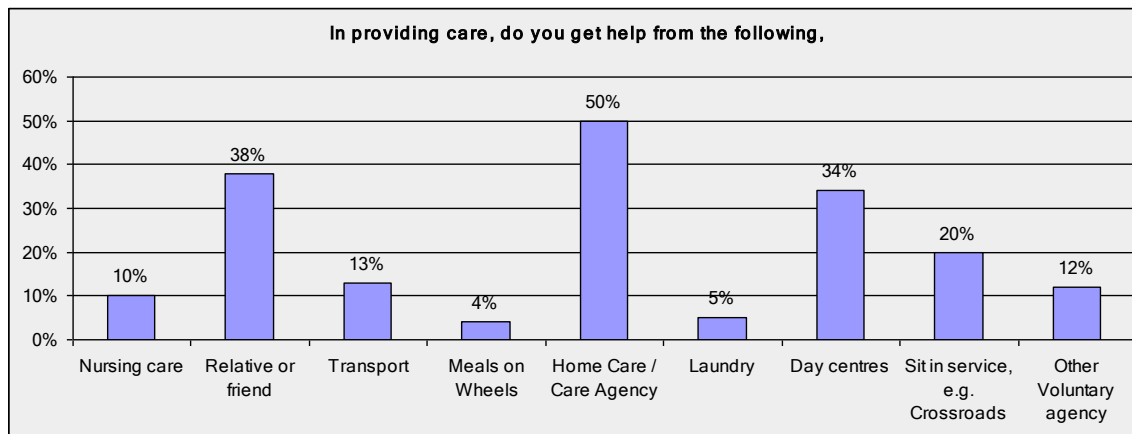
Postcode	No of responses	
SP3	1	postcode following.
SO16	1	
RG7	23	
RG8	13	
RG9	1	
RG4	1	
RG31	16	
RG20	7	
RG18	13	
RG17	31	
RG14	34	
CR2	1	
CO10	1	

Carers profile

- **Gender** - Responses indicated that 73% of respondents were female , 27% male
- **Ethnicity**: 97% of Carers responding to this survey identify themselves as White (British, Irish, Traveller of Irish Heritage, Gypsy/Roma, any other White background)
- The majority of respondents indicated that they 'live with the person they care for (86%)

Help / support received

Carers were asked to indicate what support / help they received in their caring role. The graph indicates that Carers receive a range of services to support them in their caring role.



The most frequent support or services received are:

- 1- Home Care / agency (50%)
- 2- Help from a relative or friend (38%)
- 3- Help from a day centre (34%)
- 4- Sit in service (20%)

There is clear indication that these services or support helps carers manage in their caring role

Qualitative comments

The final question of the survey provided the opportunity for carers to inform us of anything else about the respite needs that 'you or the person you look after need now or may need in the future'

There were numerous detailed replies, many detailing personal circumstances and specific references to current situations and difficulties faced. It is impossible to include all comments within this report but below is a summary of key emerging themes and examples of comments received.

Positive feedback

'My husband was hospitalised in RBH, then Walnut Centre, then RBH, then West Berks Hospital. The respite care that was given was of great help to me and him. We would have found it very difficult to cope then and now....Advice from PALS at RBH in December 2009 was excellent and the rehabilitation respite care was of great value

***** gets one day a week in a day centre with which we are very happy.'*

'My dear wife passed away. She had been in the care home at Willows Edge and very well looked after for two years. Congratulations on the work you are doing to help carers'

'found respite care in West Berkshire was excellent and very successful. It enabled me to go on holiday with minimal worry. Day centre and Crossroads are wonderful. I was disappointed at West Berkshire's decision to cut funding for respite'

'feel very happy with the type of respite I get. My daughter is very happy with her family respite and so I have no help from family or friends. My respite family are like family to her. They are also flexible to look after her when I am most in need.

Without the support I have from the respite family and regular respite I would not have been able to look after my daughter. A service I couldn't go on without.'

Family support

I get help from a relative or friend every three months.

Our two daughters come twice a week.

Personal & emotional distress caused by caring

'Caring becomes harder the longer you do it The person who is being looked after doesn't realise how difficult it is or even what it is that you do to enable them to survive comfortably. I know that I am getting to the point where it is too much'

'Need desperately respite care at a respite centre in order to get regular respite. On the brink of collapsing!!!'

'Often I get very anxious and depressed and would never cope with any less day care or night respite.'

'need at least the amount of respite I am currently receiving but think it is unfair I will have to bear the full costs of it. This terribly unfair system is causing me to worry about my own mental and physical health issues. It's time to take greater care of carers!!'

'Caring is 24/7 seven days a week.'

'am finding the situation very tiring & need to be able to relax sometimes.'

*'I looked after my wife ***** for fourteen years, Since then after having a bad fall she has been in seven different hospitals and homes. . She has been away for more than four years and is still in a care home which has completely broken my heart.'*

Request for more respite

'Looking after a parent or loved one – is not easy. I never thought I would find it so difficult just to have a holiday. I thought respite would be more on hand. When I went for one week in July it was as though I was asking for a whole year's break, not one week....'

'....I would like to be able to rest more often worry-free and also to be able to give more attention to the rest of the family. For my son, who I'm caring for, I would like him to have fun on holidays or just going out and enjoying himself.

'Just a break to go fishing or outdoor activities'

'Personally I just need a break from the incessant routine'

'I have been trying very hard to get help with no success'

'Carers need good long blocks away from the person they care for. You need this to unwind and switch off from the carer role. The odd hour is next to useless as it does not allow you to relax. You always have one eye on the time.'

Concerns about future requirements

'It is impossible to tell what may be in the future.'

'At the moment neither of us needs respite but of course that may change in years to come.'

'I am finding household tasks difficult due to increased arthritis in hands and side effects from tablets affecting legs and feet.'

'In the future we may need help with transport to doctors or hospital.'

'If I'm ill what will happen to my husband?..'

'In the future, home help every day. Plus more day centres (more days).'

'Considering use of meals on wheels to lighten care workload.'

Cost of respite care

'It is very very expensive if you have no funding. I have no pension'

'With the government cutbacks I now have to source my own care package and respite for my husband!!'

'Information is extremely poor and when people help comes there are plenty of wise words little action with less monetary help/ I applaud what you are trying to do. But you really do need financial backing'

Finding appropriate services.

'Respite needs to be a flexible provision e.g. different provision at different times to suit the situation. Allocation of respite should be capable of purchasing from a menu of choices.'

'needs social activities to be with peers desperately. There just isn't anywhere that suits his needs. He needs help to become more independent away from the family.'

'I need a suitable care home which my husband would find appropriate and be happy in.'

'We do not qualify for respite. My son is 23 and has dyspraxia, behaviour problems and some difficulties in getting/keeping employment. There seems to be no support or provision for people like him or for parents like us - we fall through every gap I would prefer an ad hoc service as and when it is needed.'

'Mum has never wanted to go to day centres. They would make her more confused – she has dementia.'

'It would also be nice to have a companion to come out with mum and me to look after her when I have to pop to the dentist or into the dentist, rather than leave her at home.'

'I find it hard to find suitable dementia respite care for my husband – he is relatively young at 74 and was very traumatised by first experience of respite (in dementia surroundings) where he felt 'locked in' and watched over by 'guards'.

'The person I care for has needs that cannot be fitted into a regime which makes buying in carers an impossibility.'

We use a luncheon club once a month. Day centres would be a good idea, at least it would keep my mum entertained. Instead of sleeping in the chair at home'

'My son needs to begin to experience life away from the family home in order to become more independent. When things get difficult it would be nice to know there was a break available.'

'Residential respite care is something I have considered and discounted due to the upset to my caree's routine that would result from being away from his familiar environment. The stress of preparing him to go to a residential respite centre and then trying to re-establish his routine afterwards would negate any benefit I might have from a total break from caring. My only other option is live-in respite care, the cost of which is prohibitive. This form is aimed at those who live with their caree and provide 24/7 care but there are lots of carers who do not live with or provide 24/7 care for their caree - but who still desperately need a break from being constantly on call and responsible for the well-being of a loved-one.'

Reference to range of service used, and importance of these

Numerous references to the range of services carers used including:

Crossroads; Home Care; Sit in service; Nursing care; Link Up; Combat Stress (Charity)

Personal budget buys taxi transport four days a week.

Memory strategy group; carers meeting every month.

Pangbourne Voluntary Drivers are very useful.

Kidz Club in school holidays; Mencap

Hydrotherapy and other exercise classes and advice from Parkinson's UK.

Chiropody and Podiatry.

Meals on wheels

Eight Bells for Mental Health.

'Day centres, 5 days a week day centre care very important.'

Concerns re day centre closures

'my husband relies on Windmill Court to get respite on two other days. We are devastated to hear it is closing. What's the point of a personal budget if the center isn't there to spend it on?'

'Closure of Ormond Centre - will mean we have 3 days a week now totally empty & mum has no care, no social activities, no company - we are going to really struggle to fill these huge gaps & I worry she will end up back in hospital in no time.'

There were also a number of comments that relate to the distribution of the survey

Duplicate mailings – Despite best efforts to reduce duplicate mailings a number of Carers received duplicate survey forms, some receiving three survey forms with a request to sort out mailing list

Lapsed Carers – Responses were received from a number (over 25) carers requesting that they are removed from mailing lists as they are no longer a carer due to their spouse / family member dying.

Change in circumstances

A number of carers indicated that they no longer a carer, primarily because their 'cared for' had gone to residential / nursing home and were returning the questionnaire as they no longer felt that the responses were relevant

'Sadly my husband is in a nursing home and respite care no longer applies.'

All agencies need to consider how they update their databases

Conclusions

The survey provides useful information to understand Carers perceptions and views about respite services, both during the day and overnight, that they receive to enable them to have a break from caring.