

## What works in relation to carers' breaks?

(A rapid review of the evidence prepared for Coventry  
as part of **ripfa**'s one-to-one support)

Short breaks for carers have emerged as an important part of the provision of social care. Whilst past policies may have acknowledged the vital care given by informal carers, current policies aim at ensuring that carers are not only acknowledged but given the support they need to keep caring. A central part of this support is the provision of a short break for carers. In the coming years, budgets for short break provision will be increased, and the increased use of direct payments will make short breaks more achievable. It is therefore important to look at the research available on short breaks for carers, what the policies and policy guidance say, what carers say about short breaks, and what information there is concerning best practice for short breaks.

**A note on terminology** Until recently, short breaks were known as "respite care". The shift to the replacement of respite with "short breaks" came amidst recognition that "respite care" has negative connotations for many of those who receive care (as well as for carers who do not like to feel that they need respite). The implication of the term "respite" is that the person being cared for is a burden. The implication of short break is that both parties are benefiting, having a break from usual routine. Along with the change in terminology has come a change in approach which sees an emphasis on benefits to both parties in the short break.

### Policy background, support and guidance

Although the emphasis in this piece is on what works in carer's breaks, it is helpful to start with a look at the policy background, which gives guidance to how service planning for provision of short breaks should be approached. Central to all policies on short breaks is a definition which emphasises the importance for both parties. The Care Service Improvement Partnership (CSIP) gives a useful definition of a short break as being "any formal service with the purpose of providing a break from the usual routine for the person with dementia and/or their carer" (CSIP 2008).

UK government policy on carers has become more involved since the changes in community care in the early 1990s. Prior to this, social care models were built on the premise that support would be needed when informal care broke down. The new approaches to social care saw the importance of carers, and it was increasingly recognised that support to carers was needed. The 1999 "Caring for Carers" paper was the first policy paper to set this out. It set out the need for information, support and care for carers. The greatest emphasis was placed on care, and the provision of short breaks (then referred to as "respite") was given prominence. This was backed up by proposed strategies for carers which provided grants for short breaks. The 1999 Royal Commission on Long Term Care, although focusing on possibilities for funding of care, also included elements on how to fund carer needs.

Since this burgeoning interest in support to carers, there has been a strengthening of the carer networks, and new policies can be built on finding out what carers really want and feel. In the most recent policies on carers, is a vision that "carers will be able to

have a life of their own outside of their caring role" (UK Government 2008), and that short breaks are the key to this. This is based on consultation with carers who stated that provision of breaks were among their highest priorities. In order for breaks to be a successful experience, the government states that services for short breaks need to be integrated and personalised, two key concepts throughout the literature on short breaks. Short breaks need to be well-organised and planned so that people can plan with them in mind, as well as be tailored to individual need, and that personal budgets can be used to meet these needs. Other key features of short breaks mentioned are that they should be well-organised and planned so that people can plan their time around them.

Whilst 2008 saw the launch of new policies on carers from the UK government, there were also new commitments to short breaks in Scotland. The Scottish Government committed to delivering 10,000 additional respite weeks by 2011 and announced the introduction of guaranteed entitlement to respite care for those in greatest need by 2011. Along with these came new guidance on short breaks (Scottish Government 2008).

This guidance is more detailed than that available from the UK government but with the same emphasis on the importance of personalisation and integration of services. The documentation examines issues of planning in greater depth, stating clearly that the same rigour applied to planning services should be applied to planning short breaks. This is something to emerge also from some of the research available – provision of breaks should be seen as part of service delivery rather than as something separate. If taken as part of service delivery as a whole then planning for breaks is given equal importance in terms of resource allocation and organisation. As such, short break provision needs to be built into strategic planning which should be done in an integrated/joint manner between health and social services. Joint planning needs to consider resource use and allocation possibilities from across services for short breaks. For example, some short breaks may need input from NHS boards (for example when the person cared for requires intense health care needs or active rehabilitation), whilst others stay within local authority social care. Plans need to include clear allocation of resources and responsibilities.

## **Evidence base for respite care**

As stated earlier, policy developments have grown from recognition of the huge amount of work done by carers, as well as increasing evidence from carers. Whilst it is often difficult for carers to find the time to be involved in research projects, there have been a number of studies done with identify what carers need and how they experience short breaks.

There is much evidence of the numbers of carers and the support they give. Informal care is the most important source of care for most older people in the UK, with one survey of those receiving domestic help carried out in 1999 showing that 80% relied exclusively on informal help. A study carried out by Tihanyi and Cormac (2006) quotes the 2001 census which found there to be 5.8 million carers nationally. This is not taking into consideration those who do not define themselves as carers. The peak age for carers is between 50 and 70. The study by Tihanyi and Cormac examined the mental and physical well-being of carers. 71% of those spoken to said caring responsibilities made them feel worried. 32% said that caring had made them feel depressed. 11% felt tired a lot of the time. A further study carried out in 2002 by Carers UK found that 70% reported feeling mentally and emotionally drained, 61% felt physically drained and the same felt frustrated. Equally high percentages reported feeling anger, loneliness, guilt and disturbed sleep. Physical health problems include hypertension and lower immune response as well as increased risk of heart disease.

As stated earlier, short breaks are seen as a method to counteract some of these negative impacts. The Scottish Government guidance outlines the following benefits of short breaks to carers.

- They help carers to safeguard their health (physical and emotional), to enable carers to continue caring
- They can prevent social isolation
- They can help to overcome a crisis
- They make time for the carer to spend with family and friends
- They help people develop independence and prepare for a time when the carer cannot continue caring.

So this provides us with an overview of the types of benefits that can emerge from short breaks, but increasingly, decision-makers require clear evidence of impact. **What impacts do breaks have on carers?** Three thorough systematic reviews of evidence have recently been carried out on this topic in a bid to find out if there is clear evidence of benefit to carers. But it is rather a complicated subject to study, so the research base is unclear. Experiences and impacts of breaks on carers are very individual and dependent on many different factors. As such comparison across carers is difficult. The information available is often of more anecdotal and individualised than required for doing more "scientific" cross-case analyses, but this type of information is just as valid in terms of recognition of types of benefit.

Whilst one of these systematic reviews (Mason et al 2007) says that there is little effect of clear impact on carer burden and mental and physical health, the other two point to particular benefits. The review carried out in 2009 by Elizabeth Victor identifies clear satisfaction with the short breaks experienced and strong evidence that the breaks allowed carers to have a rest and experience physical and emotional relief, as well as do everyday jobs, pursue social activities and interests and sometimes employment. The study identified the following as instrumental in improving mental well-being: experiencing emotional and physical relief from caring, having time to put into management of other activities of daily life, and having time to maintain and develop other social interests and networks.

Whilst there was evidence of improved emotional well-being, there is also evidence that breaks could cause carers to experience negative emotions such as anxiety and sadness at being separated from the person they care for, and most notably, guilt about using the services. This is something which emerges again and again in discussions on carers and short breaks. But if these negative feelings towards short breaks could be overcome, there is evidence that the breaks enabled some carers to continue in their caring role who would otherwise have sought other options. That said, there was mixed evidence on the relationship between service user and subsequent institutionalisation of the person receiving care. For some it allows individuals to keep caring longer, whilst for others it is a step on an inevitable journey towards permanent residential care.

This information is derived mostly from qualitative studies, those that have discussed experiences in depth with carers. Interestingly, quantitative evidence, which relied on statistics and survey findings produce more negative findings. This is probably due to the complexity of the issues at stake, a complexity that does not fit well to the simple answers given to a quantitative study such as a survey. A review of quantitative studies on carers experiences of short breaks carried out by Shaw et al (2009) therefore found that carer burden was not massively reduced in the long-term and that there was no effect on anxiety given by respite. The study found that caring as a way of life makes for long term social isolation and respite does little to change that. It also noted the guilt associated with using respite care. There were also surprising negative impacts on quality life, the reasons for which are unclear. The study suggests it could be that respite is only used when things have got really bad and are only going to get worse, or

that the break clarifies for the carer how difficult their life is. This study also found that respite use increased institutionalisation. Again, this could be because respite is used when a situation has got to that position anyway, or that respite is used as a stepping stone to institutionalisation.

## **Making short breaks successful for carers**

Particular factors were identified by Victor (2009) as key to the short breaks being successful for carers. Primarily, carers expressed the needs to feel confident about the nature and quality of the alternative care that the carers' relative or friend received during the break.

In particular, carers were concerned about the amount and nature of activities provided, the personalisation of the care, the opportunity for additional medical care and general environmental factors. Also of concern was the quality of staffing care – training and expertise, personal qualities, continuity and sufficient numbers. Other factors for success were based on the planning process. The carer felt happier with the short break if thoroughly involved in planning, and in particular, if their knowledge and relationship of the person being cared for was clearly recognised. Breaks were also more successful if flexible enough to meet the timing needs of the carer.

These findings were echoed in another study, by Shaw et al. (2009). In the qualitative part of the study, they investigated the issues relating to uptake of respite care by carers. Key findings were:

- Carer attitudes to caring and respite
- Caregiving relationship
- Knowledge of and availability of services
- Acceptability to and impact of respite care on care recipients
- Hassles resulting from use of respite care
- Quality of respite care
- Appropriateness and flexibility of service provision

The study found that **respite needs to provide a mental as well as physical break and in order for respite to provide this, carers need better information about services, support early in the caregiving career, access to a range of services with flexible provision, reliable transport services, continuity of care, good quality care that provides benefits for recipients and appropriate activities in personalised care.**

A useful study carried out by the NHS in 2004 went one step further in identifying the value of different types of respite care for carers of people with dementia.

**Day care:** Highly valued by carers, as they see benefits for both themselves and the person with dementia. There is some evidence that day care attendance might have a preventative effect on entry to long-term care. Some studies show improvements in physical health, stress and psychological wellbeing, whilst others didn't, but the study recognises that this is a very difficult thing to accurately assess.

**In-home respite (someone coming in to the family home to "sit "with care recipient").** Highly satisfactory. Carers stated that they would like it more frequently and for longer periods. Evidence suggests this type of respite could help to maintain family routines and roles as well as the care recipients' sense of self.

**Host family respite:** Little evidence, but what there is reports positive outcomes for both carers and care recipients. Many of those being cared for, report preferring being in a family home rather than in a residential home.

**Overnight respite away from home including care home and hospital:** Other types of breaks were more beneficial than these. They were difficult to organise and carers felt more guilt about using them. There is some evidence that care recipients sometimes return home in a worse condition, but also evidence of benefits from medical support during the stay.

## Short breaks in practice

Deciding on an approach to take to short breaks means starting with defining an approach to carers and respite care. Linda Pickard (2001) looked at the different approaches to respite for informal carers as discussed at policy level. She identified three different ways of seeing carers and respite care. On the one hand, carers can be seen as "co-workers", who provide a vital support and as such should be supported with almost worker-type rights. At this level they would be given allocated time off, as it is important that they keep working. They can also, however, be seen as "co-clients" – a group who needs support in the same way that those they care for do. In this sense, respite is needed to stop them from getting ill and making demands on services, but it also makes them quite an expensive group to recognise. And lastly, carers can be "superseded", which means that care is provided in a "carer blind" fashion – in other words, when care is planned for an individual, it is done so as if the carer were not there. In theory this means increased service provision for the individual, no support for the carer and therefore no need for respite. Cost analysis of this approach have been carried out which show that the increased cost of service provision would be no more than the cost of respite for carers, and certainly less than the cost of institutionalisation needed if care fails.

At different times, carers have been viewed in these three different ways. In terms of respite, being viewed as co-worker, the carer has the right to have time off, but also is understood as almost obliged to keep working. Being viewed as co-client also has its difficulty, as many carers dislike greatly the idea that they are under any burden or in need of support. They view caring as something they want to do, or at least should be viewed as happy doing. The third approach, of superseding the carer, is problematic in its unrealism. Although increased service provision would often be beneficial, the caring role will continue. People who share lives will care for each other, and that caring will therefore once again become unrecognised.

This is an interesting way of looking at caring and short breaks, as it brings to light some of the key issues faced in accepting and providing help. There are many complexities involved, and this categorisation highlights the fact that putting carers into one category or another will not solve the problem. Short break provision needs to be above all personalised, created to meet the needs of the individuals involved. But services cannot be planned without some common starting point. There is therefore a need to build up a picture of **what is needed in short breaks**, and looking at the needs for breaks expressed by carers is a good place to start.

A study carried out by the NHS Service Delivery and Organisation R&D Programme (2004) into effective respite for carers found particular issues important to carers. Many carers voiced the need for a broad range of services, including in-house respite. The list of options needs to be flexible, able to meet diverse needs, as well as being easily accessible and affordable where paid for. Very importantly, benefit systems and assessment procedures need to be clarified and simplified. People need to understand criteria for eligibility and the assessment process they will be going through. Many carers would prefer that the assessment for short-term breaks is part of an on-going review process. Breaks also need to maintain the well-being of the care recipient, to ensure peace of mind for the carer as well as a positive experience for the care recipient.

Respite care should not be seen as secondary – the services provided need to be done so by high quality staff.

These particular issues emerge from other such studies, with many emphasising strongly the need to create breaks which are beneficial to both parties. The issue of guilt felt by many carers in using short break services should not be under-estimated, and to many, the fact that the care being provided in their place is of high quality and of benefit to the person cared for is the way in which they “allow” themselves to take advantage of the services. The issue of personalisation and choice also emerges strongly in most such studies. People’s lives are complex and needs vary a great deal. Carers need to feel that the short break really meets their needs in terms of benefiting the cared for, as well as giving them the type of break they need. The issue of information provision is also vital. In many cases, carers don’t know that they are eligible for support, or that there are different types of breaks available.

## Recommendations for respite care

So what makes for successful respite care? The **Scottish Government Guidance on Short Breaks** provides a useful list of indicators of good short breaks. They should be:

- Based on thorough assessment of service users' and carers' needs, on-going review and clear communication
- Appropriate to the needs and circumstances of the carer
- Appropriate for the age, sex, culture and level of need of the care recipient
- Maintain or improve the well-being of the care recipient
- Delivered by appropriately trained and caring staff
- Include suitable transport where necessary
- Affordable
- Reliable.

In terms of service planning, evidence points towards the great value of involving carers and service users in identifying the types of breaks needed, as well as eligibility criteria, information needs and feedback. Shared Care Scotland Best Practice Guidelines (2008) focuses on the following:

- Clarity of decision-making – Local authorities need to produce a set of eligibility criteria to explain how they will assess people's needs – carers and SUs should be involved in the development of these criteria
- Better planning – Local authorities are encouraged to develop a Short Break Service Strategy or Plan with help from health, voluntary sector orgs and other stakeholders. Joint work leads to more joined-up services and more effective use of resources
- Listening to carers – is key to ensuring the services meet their needs. Carers should be involved in developing their own services as well as break services generally in their area.

Another set of best practice guidelines, this time from **CSIP (2008)**, include both carer and service user requirements for successful breaks, as well as issues relating to service process and planning:

- Breaks need to have a focus on outcomes for the person being cared for as well as outcomes for carers.
- The need for short breaks should be an integral part of the care plan
- There should be easy access to planned and unplanned events requiring the support of short term care
- Effective assessment should underpin the process
- Short breaks should be part of plan to prevent personal crises as well as responsive to emergency situations.
- Should be integrated into other services provided and be seen as part of the menu of options
- Information flow needs to be simple and consistent
- Continuous feedback about services is very important to make them work.

The **UK Government Inspection Standards for Short Term Breaks** sets out six standards which cover the following:

- Standard 1 – service delivery/outcomes for SUs – arrangements for short term breaks need to be responsive to the needs and preferences of SUs and their carers. Services should be of good quality and reliable. Services need to recognise and address the sometimes conflicting needs of service users and carers and seek to sustain and enhance service user independence.

- Standard 2 - there need to be clear, effective and sensitive arrangements in place for receiving referrals for short term breaks. Access to services, once agreed, needs to be as straightforward and free of bureaucracy as possible.
- Standard 3 - All arrangements should be made with the assumption that both SUs and carers participate in planning and decision-making. Arrangements need to be flexible, sensitive to need and recognise need for short breaks to be satisfying.
- Standard 4 - Strategy should be in place that ensures potential SUs, carers and SSD staff know about the range and availability of short term breaks, the eligibility criteria, charging policies and how to apply.
- Standard 5 - There need to be measure in place to ensure equal opportunity, in terms of provision of breaks which meet the range of needs expressed by different populations.
- Standard 6 - All management arrangements should be developed to deliver the best value short breaks possible which are responsive to the needs of the population.

The Scottish Government guidance states that personalisation is key to successful short breaks, and that therefore there needs to be a wide range of options availability. Different types of option include: access to different types of short breaks, to breaks with or without the cared for person, to short breaks at different times of the day/week, to choice in the length of break, to flexibility over when short breaks are arranged and confidence in the quality of care provided. Another important point here is that breaks should be viewed as preventative and planned early, as this is the most effective way of ensuring they help in preventing crises. Emergency crisis support systems also need to be in place. Self-directed support is an important option for people to have greater flexibility, choice and control over arrangements.

## **A final note on person-centred care**

There has been increasing interest in the idea of **user-friendly respite care, based on the model of person-centred care**. Within this paradigm, the emphasis is on how to create breaks of benefit to the service user, but this shift also benefits the carer. As stated earlier, for many carers, of primary importance is that the break experience is beneficial to the person they cared for. In theory, user-friendly breaks create such an experience, which in turn will benefit the carer.

Although this is not the place to go into the theory and practicalities of user-friendly respite care, what may be useful is to finish this paper with a list of examples of user-friendly respite care which work for carers as well as for those being cared for.

### ***Midlothian Council – producing person-centred breaks***

In Midlothian the Local Authority worked with a respite steering group made up of service users and carers to explore people's needs from a short break. As a result of this, they started providing weekend or week long breaks with specialist hotel provision. They then developed a respite coordination service across all community care groups. Another focus has been on developing a systematic way of picking up on people's needs through the Single Shared Assessment and Carers' Assessment processes.

### ***Smart Breaks – brokerage service - Midlothian***

This has been quoted as best practice by a number of different bodies in England as well as Scotland. It is a short breaks brokerage service. They "use commitment to person centred planning to help and support people who have care needs to plan a more meaningful break. (They) work together with the disabled person and their families in a planning process to design a break that meets the individual's own interests and needs." (Fitzpatrick & Wood 2007) Working with service users and carers, they design breaks

and options and provide information on possible sources of funding, helping with forms if necessary.

Other brokerage services are also being tried out as it is increasingly recognised that personalised planning of short breaks is very complicated. A model being used in Toronto, Canada, has a co-ordination service for the agencies and organisations providing respite service which people can contact directly for assistance in identifying the best respite option.

### ***Short Breaks Bureau – Perth & Kinross Council***

This is another type of detailed brokerage or “travel agency” service. Following assessment to work out the eligibility, a staff member of the Short Breaks Bureau will meet the family to explain what they do, how the breaks system works and what they will be doing next. They will then follow that up with another meeting to discuss the needs and wishes of the service user and their carers, what they want from the break, ideas they may have and what help and support may be needed. The Bureau will then look for holidays or breaks which will best suit the circumstances. Findings will then be presented back to the family where a final decision is made, dates are decided on and finances are arranged. Following the break, the Bureau will meet the family to carry out an assessment of their experience which can be built into their own breaks next time as well as to guide the experiences of others.

### ***Use of direct payments***

Using direct payments to pay for short breaks is an increasingly popular option, but requires the use of extensive support in order to plan a break which everyone is happy with. The types of brokerage services outlined above play a vital role here. The following examples of how direct payments can be used are provided by the Valuing People Support Team. One service user saved up her direct payment support to be able to pay for supported holidays and employment of a PA during those holidays as well as more regular community support to go to clubs and other activities. Another service user employs full-time carers every six weeks to go with him to the family’s holiday home with his family, enabling them to spend time together without his parents acting as carers. In another case, the service user paid a volunteer’s entrance and expenses to take him stock car racing twice a month, something he very much enjoyed but could not attend without help.

### ***Hotel in the Park, Tower Hamlets***

This is a hotel, where people with learning disabilities are guest rather than service users, taking a short break in their home city. This was born from the views of service users and carers who wanted breaks to be more like a holiday than any form of “care” service. The hotel is made up of seven en-suite rooms, two of which are completely adapted and include overhead tracking and hoists. All rooms have their own television and music centres and meals are prepared by a chef to be eaten in own rooms or in the dining hall. Guests are referred through social services and allocated a number of nights per year. Importantly, it has not cost the Local Authority anymore to run this service than a usual residential short break service.

### ***West Sussex Adult Placement Scheme***

This scheme supports people with learning difficulties to stay with individuals, couples or families for long or short periods of time. Twenty carers provide breaks for approximately 60 people. These breaks take different forms, with some involving the service user simply taking part in the activities of the carer’s family, whilst others see the service user being fully supported to plan their own holiday activities, or using the stay as a B&B type service. There are a range of carers and facilities available to be able to provide for different needs. This is one of the Department of Health’s Individual Budget pilot schemes.

### ***Natural Breaks – Merseyside***

This is a community based break, the focuses of which tend to be around particular community-based activities where people learn something new and meet new people. Natural Breaks works with those who have previously been considered too demanding of service providers to be given access to respite provision. In the "Social and Leisure" service of Natural Breaks, staff work with individuals who need one or more person to support them. They support the person with a disability to get out regularly and join in something such as college class, sports, voluntary work and evenings out. These outings are regular and frequent. The "Out and About" service sees a support work spending time with 3 individuals, enabling them to access leisure activities together.

### ***Ling Trust, Carrog Mill, North Wales: Tailor Made Holidays.***

The Ling Trust owns three holiday cottages in North Wales to enable people with learning disabilities and their families to take a tailor-made holiday together. Families can either bring their own supporters or have support provided for the holiday period. Part of the scheme is focused on training and supports people to learn independent living skills locally.

### ***Clayton Road short break centre, Newcastle upon Tyne.***

This short break centre is focused on enabling people with learning disabilities to have a break in which they can relax, learn something new and live an "ordinary" life. "Everyone is different. We hope to make sure each person gets the kind of help they need." They encourage people to make their own decisions about how to spend their time whilst there, whilst being helped to make friends, learn things and be as independent as they want to be. There is an emphasis on service users having a say in how the centre is run.

### ***Emergency breaks***

Within the West Sussex Adult Placement Scheme mentioned above, one of the families is paid a retainer to accept people on an emergency basis if needed. There is also an in-house floating support service which can help in people's home in an emergency and an older carers' worker who helps carers make plans for emergency situations.

The Sefton Carer's Centre has a Carers Emergency Respite Team which will provide an instant response in the case of an emergency which prevents a carer from continuing to care. Support can be provided up to a maximum of 48 hours, and further help will then be given to find more care if needed. This service includes an advance care planning component, which means that when a carer registers with the service they ensure that everyone is clear about what need and support would be needed in the case of an emergency.

### ***Breaks in Hertfordshire***

Hertfordshire has produced their own menu of short breaks. These include

- Four befriending schemes for people living with family carers.
- Activity schemes (where people go out in small groups evenings and weekends, etc), college breaks schemes,
- Help at home schemes.
- "Break away" schemes (i.e. holidays).
- A scheme where respite services go into homes to enable carers to take a break.
- A gym scheme, whereby people with learning disabilities access a mainstream gym, so giving carers a break.
- An arts workshop.

They have a "flexible pot" which can be used (up to approximately £500 per family) to provide anything that gives a family a break (e.g. holiday, weekly sitting service and so on).

## Conclusion

Short breaks are needed to ensure the welfare of carers, both in terms of maintaining their mental and physical well-being, as well as in ensuring they can continue to provide their vital caring support. Evidence on the impact of respite on carers is difficult to gather, as impacts are individualised and complex. However, many studies do provide evidence of benefits to carers in terms of relieving anxiety, stress and giving space in which to just live their lives. There is also, however, evidence of guilt related to the use of short breaks, something which provision of breaks needs to consider. Despite research which contradicts itself in terms of identifying benefits, in consultations carers have emphasised how important short breaks are, and policy has taken this into consideration both in the UK and Scotland, providing increased funds to short breaks and guidance to strategic planning.

In terms of what carers want from breaks, the following are particularly important:

- Breaks which benefit those they care for as well as themselves
- Assessment for short breaks to be part of regular care planning.
- High quality care provision
- Flexible options
- Involvement in planning of the short breaks
- Clear assessment processes
- Reliable advanced planning
- Easily accessible information

Service provision should be planned with input from service users and carers, with extensive consultation undertaken to define the types of services required. Service user and carer involvement should also be sought to define eligibility criteria, as well as in individual planning and feedback to assess the impacts of short breaks. The approach taken to short breaks should be integrated, with joint planning of resource allocation across health and social care. Short breaks should be seen as preventative, with early planning being key to ensuring crises are avoided.

A number of different types of short breaks are available, and increasingly innovative approaches are being used in the move towards "user-friendly" short breaks – breaks which meet the needs of service users. These new models of user-friendly short breaks are useful to look at in terms of what works for carers, as the primary wish of carers is often that the break is suitable for and enjoyed by the person they care for.

## References

Coalition of Carers in Scotland, Shared Care Scotland (2008) **Give us a break – turning commitments into action.**

<http://www.sharedcarescotland.com/publications/publications/GiveUsaBreak.pdf>

I Cormac & P Tihanyi (2006) **“Meeting the mental and physical healthcare needs of carers”** Advances in Psychiatric Treatment Vol 12 162 – 172

<http://apt.rcpsych.org/cgi/reprint/12/3/162>

C Shaw, R McNamara, K Abrams, R Cannings-John, K Hood, M Longo, S Myles, S O’Mahony, B Roe and K Williams (2009) **“Systematic review of respite care in the frail elderly”** – Health Technology Assessment

<http://www.hta.ac.uk/fullmono/mon1320.pdf>

Care Service Improvement Partnership (2008) **Creative Models of Short Breaks for People with Dementia**

<http://www.mentalhealthequalities.org.uk/silo/files/short-breaks-pdf.pdf>

**Clayton Road Short break centre for people with learning disabilities**, Newcastle

- <http://www.newcastle.gov.uk/core.nsf/a/claytonroad#believe>

Essex Social Care Policy and Research Team (2006) **The Provision of Respite Breaks in Essex** Essex County Council

<http://www.essexcc.gov.uk/vip8/ecc/ECCWebsite/content/binaries/documents/Appendices - full version2.pdf>

J Fitzpatrick & A Wood (2007) **A Guide to Short Breaks – supporting family carers and people with learning disabilities to have short breaks that work for them.**

Valuing People Support Team.

[www.valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=2244](http://www.valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=2244)

HM Government (1999) Inspection Standards for Short Term Breaks for People with Physical Disabilities and Older People.

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4035624.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4035624.pdf)

HM Government (2008) **Carers at the heart of 21<sup>st</sup> Century families and communities.**

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_085338.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085338.pdf)

A Mason, H Weatherly, K Spilsbury, H Arksey, S Golder, J Adamson, M Drummond and C Glendinning (2007) **“A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers”** Health Technology Assessment

<http://www.hta.ac.uk/fullmono/mon1115.pdf>

R McConkey & J McCullough (2006) **“Holiday breaks for adults with intellectual disabilities living with older carers”** Journal of Social Work 2006,6: 65

NHS Service Delivery and Organisation Research and Development Department (2004) **A Proper Break: effective respite services for carers of people with dementia**

<http://www.sdo.nihr.ac.uk/files/adhoc/48-briefing-paper.pdf>

Perth & Kinross Council (2007) **Short Breaks Bureau – What’s it all about?**  
<http://www.pkc.gov.uk/NR/rdonlyres/E6B30EE8-67BB-47FE-98D8-FEF1B857871E/0/Bureaubrochurev4080710.pdf>

L Pickard (2001) **Carer break or carer-blind? Policies for informal carers in the UK.** *Social policy & administration*, 35 (4). pp. 441-458.

Scottish Government (2008) **Guidance on short breaks.**  
<http://www.scotland.gov.uk/Resource/Doc/245982/0069419.pdf>

E Victor (2009) **A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence.** Princess Royal Trust for Carers.  
<http://static.carers.org/files/systematic-review-15-jan-3840.pdf>