

## Summary Report

### Your Chance to Influence Short Breaks for Carers

**Tuesday 7<sup>th</sup> September 2011  
Birkenhead Pavilion**

The Department of Health announced new resources of £400 million would be made available to the NHS over four years to enable more carers to take breaks from their caring responsibilities. The NHS Operating Framework 2011/12 made clear that:

*PCTs should pool budgets with Local Authorities to provide carers' breaks, as far as possible, via direct payments or personnel health budgets. For 2011/12, PCTs should agree policies, plans and budgets to support carers with Local Authorities' and local carers' organisations and make them available to local people.*

The carers short breaks event was a follow up to this announcement as it aimed to involve carers from diverse backgrounds to ensure they could influence the development and design of short breaks for Wirral carers, particularly with reference to hidden and vulnerable carers.

The involvement of Wirral Carers Association and Wired (Carers Support Service), ensured invitations were sent to a wide range of carers who have caring responsibilities that included people with learning disabilities, physical disabilities, mental health conditions, long term conditions, drug and alcohol related symptoms, people who are nearing the end of life, dementia or Alzheimer's. Invitations were also disseminated to BME, younger carers, older carers and lesbian, gay, bisexual and transgender (LGBT) community groups as it is often reported that these population groups do not feel they are able to influence the development of services to ensure they meet their needs (Wirral Joint Strategic Needs Assessment 2011).

Invites were also sent to carers voluntary and community sector organisations to ensure their views as service providers would also inform where there are current gaps in service delivery and also inform on their experience of working with carers from diverse backgrounds and understanding some of their needs.

Over twenty carers and ten carer organisations attended, together with carers support organisation Wired, the Chair of the Carers Association Ken McDermott, six NHS and LA officers along with the Chair for NHS Wirral, James Kay and the Carers Champion and local Councillor Sheila Clarke.

Councillor Clarke opened the event and set forward the agenda for the day, James Kay discussed the Department of Health announcement of new money and how we need to hear the views and voices of carers to inform how we take forward carers and short breaks as a joint approach with our LA colleagues. Ken McDermott (CA Chair) provided a real life view of what it is like to be a carer, the impact this has on you mentally, physically and emotionally throughout different stages of your caring role. A presentation was provided by Rick O'Brian, Head of Service, Access and Assessment, Adult Social Services for Wirral, which discussed key policy areas that inform the short breaks programme for carers nationally and locally along with a review of the Department of Health Carers Short Break Demonstrator sites which concluded with a view of what carers short breaks could look like for Wirral carers.

The remainder of the afternoon focused on three themed workshops, which were spread across four round table discussions and focused on the following three themes:

- **Workshop 1 - What do you think Carers short breaks are?**
- **Workshop 2 - What do you think the current gaps are?**
- **Workshop 3 - What would you like carers breaks to be?**

**Workshop 1** - The round table discussions illuminated a range of examples around what they believed short breaks are currently (appendix 1) particularly with regard to carers being given the opportunity to have a break outside of their every day caring role, which enables them to “have some me time”, this was reflected across other workshops and a key theme was identified which suggested carers often feel guilty for taking a break and that short breaks should be developed to ensure carers feel confident in taking their break, knowing the person they care for will be looked after safely.

Short breaks should be flexible and fit around the carer and those they care for. The delivery of short breaks can range from one hours provision to one week’s provision and is different among carers, it should be around choice and control.

**Workshop 2** - A range of examples were provided and overall the key issues tended to focus on there not being enough good and relevant information available for carers to support them in making some key decisions around short breaks. Further concern was raised towards the term ‘carer’ and the context in which it is used as many carers do not see themselves as a carer, they are just looking after a loved one, a family member, friend or neighbour.

Further gaps in provision were discussed in relation to carers at crisis point in their caring role, current emergency response services are unable to meet this need as the service is not available to all carers and is not a 24/7 service. A carer’s emergency response service should be one that is available all year round and is able to respond to carer’s emergencies or crisis if they present. Clarity amongst carers and professionals of what the difference is between a short break and respite should also be made, this is confusing currently.

There is potential to create further gaps in provision of services once the GP Clinical Commissioning Consortia’s are up and running, which many discussed as going back to post code lottery of services.

Services that carers currently receive are not flexible to their needs or those they care for and this is an area that really needs to be addressed. Carers discussed not feeling in control or that services did not always cater for their diverse needs based on age, gender, ethnicity and caring responsibilities etc

GP’s are often the first point of access for carers to be identified yet they don’t appear to be proactive in identifying carers early and it is often when carers are at crisis point when their role as a carer has broken down.

**Workshop 3** - This final workshop aimed to gain an understanding towards what carers would like short breaks to be. Overall this raised some creative and innovative examples of short breaks, ranging from home sitting services, gardeners, training, aromatherapy sessions, dancing, drumming classes, art sessions to longer term provision that enabled the carer to take a weekend break or overnight breaks, theatre trips etc. The provision of breaks would need to be consistent and ensure that the carer really did have a life outside of their caring role.

The opportunity to take short breaks would need to be advertised widely across carer organisations, shops, community centres, libraries, doctor's surgeries, hospitals and other NHS and Adult Social Service venues and Local Authority organisations such as One Stop Shops. Further promotion could also be made through local radio stations, local press and community news letters.

More promotion to be provided within the workplace to ensure carers who work are also aware of the short breaks programme.

### **Summary/conclusion**

Each table nominated a spokesperson to feed back on all themes discussed within each workshop (Appendix 1). This was followed up with questions and next steps in taking this forward.

Further questions focused on:

- When will this go live?
- How will decisions be made
- How will we feedback on future developments
- How will we continue to involve and consult with carers

Carers and carer organisations were informed that a Task and Finish Group will be set up and this will feed back to the Carers Development Committee, Carers Association and also through the Carers News Letter. Carer representation will be sought for the Task and Finish Group who will work to inform further on developments for short breaks as detailed in the 2011/2012 Operating Framework for Short Breaks for Carers.

# Appendix 1

## Your chance to influence Carers Short Breaks

Tuesday 6 September 2011

The Pavillion, Birkenhead

### Workshop 1 – What do you think Carers short breaks are?

- Opportunity to have a break from their caring role
- Opportunity to do things for themselves
- A chance to do things they want to do
- Confidently leave your caring responsibilities at home
- Chance not to feel guilty
- Chance to regain your independence and identity
- Preparation for the future
- Chance to relax

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- Range from 1 hour to .....
- Flexible according to carer need, which can fluctuate
- Can be hugely difficult to engineer on your own
- Not necessarily breaks or short – may be goods as well as services
- An individual recharging plan
- Not necessarily away from cared for person
- Subject to cultural differences

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- Weekends/days out/coach trips
- Relaxation/holistic therapy.
- A complete break away, e.g. 1 week or more with and without cared for person
- Access to education/self development
- An opportunity to do something for the carer – knowing cared for person is safe/secure without carer
- Peer support/sharing experience and knowledge – reducing carer isolation
- Training days (condition specific, e.g. stroke, MS, etc)

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- Little holidays
- Sleep overs
- Hours to suit the carer
- 2 hrs to a whole weekend
- Stay at home break
- Budget for couples to have a break
- Carers paid for
- Pool budgets

## Workshop 2 – What do you think the current gaps are?

- Information about what is available
- Recognising that you have caring responsibilities
- How do you link into support services?
- Educating healthcare professionals about the stress and underlying anxieties carers have
- Knowing the difference between a short break and respite care (longer periods)
- Transition services from children's to adults
- How do carers who don't qualify for a personal budget access short breaks?
- No continuity across the localities for carers' support (Post code lottery)

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- Quality/availability of care provided
- Timing of delivery of care, e.g. care calls at inappropriate times of day/eve
- Complexity of self assessment forms/and/or quality of imagination of assessor
- Getting information about help for carers
- Keeping carers informed of new developments/changes/events, etc.
- Bureaucracy
- Service delivery doesn't always full expectation
- Speed (or lack of) getting carers services in place
- Education of professionals – “what it is really like for carers in practice”
- Carers around the table during decision making process
- Forward planning, e.g. knowing information about events early

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- Identifying hidden carers
- Service providers not including carers on register and ensuring they get a carers needs assessment
- Service providers not ensuring information understood by carers, including knowledge of the system
- Knowledge of previously successful requests

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- Identification of carers
- Budgeted to couples
- Training personalised
- Continuity of support workers
- Flexibility of care
- Register of services available
- Availability of advice
- Gap in provision
- Lack of day provision
- More integration
- Lack of information

### Workshop 3 – What would you like carers breaks to be?

- Free
- Eligible for all carers with no qualifying criteria
- Promoted and marketed
- Meaningful, e.g. length of break
- Personalised
- Fun
- Opportunity to socialise with anyone/other carers
- Chance to try new hobbies/meet new people
- Easily accessible
- Process easy to navigate (personal budget)
- Faith in the service for the cared
- Guilt free
- Early preventative support (in caring role)
- Available 24/7
- Delivered in a dignified way
- Treated with dignity by professionals
- When assessed, assessed for need not what the budget is
- Anticipation – looking forward to the break
- Chances to improve emotional and physical well being

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- Enjoyable/entertaining
- Relaxing/personally enriching
- Yoga/meditation
- Education on, (a) how to cope, (b) our cared for persons condition
- Group therapy
- Decent quality of carer service provision
- Break away for carer and cared for person (holidays together) to reduce carer anxiety
- Using carer register for better communication – publication of upcoming events and opportunities
- Having support from your own personal support worker
- Organised activities, e.g. dancing, zumba, drumming, art/craft sessions
- Chances to relax and keep fit
- Ring fenced protected plans for carers/consistency of delivery of service
- Priority given to young carers needs

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- Clearly understood by all concerned
- Renamed
- Well publicised
- End point of a planned process involving:
  - Adequate notice
  - Information, re previously funded items link with other carers
  - Facilitated discussion (maybe involving support broker)
  - Feedback
  - Ongoing support
  - Review and tweak
  - Measure of effectiveness of intervention

- Include service user
  - Extend to those with extensive/multiple caring role irrespective of service users needs
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- As much choice as possible
  - Emergency cover response
  - Planned program for future break
  - Fast response to request
  - Care worker as well as respite care
  - Known information easily available
  - Early GP referral for provision of short breaks and hospital
  - Care free
  - Pooled resources for carers and users
  - Community group involvement
  - Theatre breaks
  - Bus pass availability
  - Taxi availability
  - Transport support
  - Befriending service