



seven million
reasons to care

Making Respite Real in Mental Health

**A Guide to Respite Care for
Professionals and Carers**



Introduction

Carers are often key to ensuring the people they care for are properly supported and links with professionals are effective, as outlined in the Triangle of Care.¹ It is therefore important to ensure that carers are able to continue to support the person they care for. Respite care and carers breaks are crucial to enable them to do this.

Respite care is usually accessed through an assessment of the service user's care needs by the local authority or it may be identified as a need in a carer's assessment. However, many carers of people with mental health problems experience issues accessing respite care and there is ongoing confusion about what respite care in mental health is.

This guide aims to clarify:

- What respite care is in mental health.
- The difference between respite care and a carers break.
- How to access respite care and a carers break.
- The different ways respite care can be used to benefit both carers and the service user.

It contains information for carers of people with mental health problems, service users and professionals from a range of services.

Although the terminology and legislation referred to in this guide applies to England the principles and rationale are applicable across the whole of the UK.

About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners, through our unique online services and through the provision of grants to help carers get the extra help they need to live their own lives. With locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is of a world where the role and contribution of **unpaid** carers is recognised and they have access to the trusted quality support and services they need to live their own lives.

1 Carers Trust (2013), *The Triangle of Care: Carers Included: A Guide to Best Practice in Acute Mental Health Care Second Edition* (Carers Trust).

What is respite and what is a carers break?

This leaflet looks at two ways carers can access a break:

- Respite care.
- Carers breaks.

Respite care

Respite is usually a service provided to the person with care needs.

Respite care can be provided in traditional ways, for example through support workers coming into the home to provide support, or through residential stays where the person being cared for spends time away from home. However, these models of respite do not always meet the needs of carers and services users in mental health.

Respite care can also involve the carer and the service user having a break from routine *together*, for example going on a weekend away.

Respite care should be pre-planned wherever possible. It is both a means of providing carers with a break as well as a change of scene or routine for the service user. This should be considered when an assessment of need is completed for the service user, carer or both.

Carers breaks

Carers breaks are different to respite care. These services are usually provided to the carer.

The aim is to give carers a break from caring and enable them to do something for themselves. They are designed to be tailored to a carer's specific needs which are identified in a carer's assessment.

What would respite care mean for me? A carer's view

James is 48 and cares for his daughter Alison aged 26 who is a mental health service user. James has arthritis and Alison has a number of health conditions including mobility issues and is blind. James would like respite care that would enable him and Alison to go away to the countryside where their relative lives, once a month or every few months together, either for a day or a couple of days. This would:

- Give them both a break from their regular routine.
- Enable them to spend quality time together as father and daughter.
- Enable them both to see other family members.
- Enable them to receive support from other family members.
- Enable them both to socialise.
- Ensure both could also benefit physically, mentally and emotionally from walking in the countryside and in the fresh air.

This sort of respite care would require financial support but the long-term benefits would be significant. It also combines respite care and carer breaks demonstrating that they can be used to complement one another.

How to access respite care and a carers break

How to access respite care

Respite care can usually be accessed by the service user receiving an assessment as it is usually regarded as a service for them, rather than a service for the carer. However, a local authority could choose to provide respite care, in order to help the carer if this was identified in their carer's assessment as something they needed, even if the person with care needs in their own right did not meet eligibility criteria.

Many service users only receive services from their mental health service so may not be referred to their local authority and therefore will miss out on respite care. It is important for health professionals to make this referral.

How to access a carers break

To access a carers break funded by the local authority, a carer needs to have a carer's assessment. However, the assessment may also identify respite care as a need for the carer.

What is a carer's assessment?

A carer's assessment is a carer's opportunity to tell social services about the things that could make caring easier for them. The assessment will help decide what services could be provided to help them. See www.carers.org/carers-assessment or contact your Carers Trust Network Partner for more information.

Accessing both respite care and carers breaks together

In many cases, the needs assessment for the service user and the carer's assessment can be combined, if both people want this.

The assessment and support plans should link up so that the needs of the service user and the carer are both considered when planning what support is needed.

How are respite care and carers breaks paid for?

How is respite care paid for?

As respite care is often regarded as a service for the person with care needs it may be provided through a personal budget after an assessment of the service user's needs. However, it can also be identified as a need for the carer in their own carer's assessment. Contact your local carers service for support and guidance.

The Care Act (2014) introduced new rights for carers in law in England and has set out guidance on what carers can be charged for. It is best to seek guidance from your local carers service for full information but in principle a carer cannot be charged for a service provided to the person being cared for even if the carer will benefit from it, for example respite care. However, the person being cared for may be charged for this service.

The local authority must carry out a financial assessment of the carer or the service user for any chargeable services.

For more detailed information visit: www.carers.org/care-act.

How is a carers break paid for?

To access a carers break funded by the local authority, a carer needs to have a carer's assessment to ascertain their needs. However, the assessment may also identify respite care as a need for the carer. This may be paid for through the personal budget of the person with care needs.

Different types of respite care

Traditional types of respite care

There are a number of more traditional types of respite care. These include:

- A support worker who comes to provide replacement care in the home for a few hours a week.
- Specifically designed residential respite care facilities for services users which can include crisis houses and specialist respite care residential centres.
- Opportunities for service users to take a break away from their daily routine, for example some organisations provide funds for disabled people and carers to access a break.

However, even when carers are able to access funding for respite care these traditional types of respite care do not always meet their needs or may not be in their local area.

In addition, if the service user goes away for respite care it is important that the carer's needs are considered.

Meeting the needs of both the service user and the carer

Peter, aged 36, cares for his wife Janet, aged 34, who has a diagnosis of personality disorder. They have five young children. Peter works part time having had to cut his hours due to his caring role. Janet has what is described as respite care built into her care plan, whereby she goes to stay in a supported placement once every few months. Peter explained that this does not give him respite at all, in fact it makes his life harder as he then has to take sole care of the children and continue to work.

(continued)

He often feels resentment (which he doesn't like to feel) as his wife gets respite from the situation but he does not.

A whole family approach could have benefitted Peter as well as Janet. By providing a cleaner and help with childcare, for example Peter would also have felt that he had benefitted from the break.

Innovative solutions for mental health respite

Respite for someone with a mental health problem doesn't always need to incur a large or in some cases any financial cost. Many service users are able to support themselves independently and the carer merely needs reassurance that the person they care for is safe and well while they have a break from their caring role. For example, a phone call from the service user's Care Coordinator or a couple of pop-in visits to the service user from the Home Treatment Team may be all that the carer needs to feel reassured.

With a move towards personal control and choice, personal budgets can offer carers and service users with access to respite options that meet their specific needs and lifestyles. It is important to note that respite funding is linked to the service user/or person being cared for so this need should be considered when an assessment is provided by the local authority. Future need should also be taken into account – often it is not considered until someone is in crisis and it can prove challenging to source appropriate respite funding at short notice.

Supporting carers in crisis and planning for the future

Amanda, aged 50, cares for her brother, Phil, aged 46, who she lives with and who has a diagnosis of schizophrenia. There is limited local support as their other brother Graeme lives a long distance away. Over a few months, Phil's mental health deteriorated resulting in Amanda needing to be at home with him more while also balancing a demanding job.

Eventually, Phil was admitted to hospital and the hospital referred Amanda to the local Carers Trust Network Partner. They explored her needs and she explained that what would be most helpful would be if Graeme was able to come to visit them so they could share Phil's care for a while on discharge from hospital.

The Network Partner referred Amanda for a carer's assessment. In addition, it suggested she applied to the local authority's direct payment for carers scheme. This would help her pay for Graeme to travel by train to stay with her and her brother to enable her to take a break from her caring role.

Overcoming challenges for carers in accessing respite care and carers breaks

Why do carers experience challenges accessing respite care in mental health?

Carers Trust conducted a short survey in 2014 to research the understanding of respite care in mental health among professionals, carers and service users.²

They were asked who they thought respite care was for, how respite care is accessed and what respite care is. The results demonstrated the confusion and lack of understanding of respite care in relation to mental health. The majority of those responding to the survey were either carers or professionals (38% and 44% respectively). Some key responses were:

- 54% didn't know how to access respite care.
- Only 12% identified correctly that respite care was accessed through a community care assessment.
- 31% thought it was accessed through a carer's needs assessment.
- 23% didn't know how to access respite care at all.

On a positive note, 67% believed that service users and carers should benefit from respite care and 23% thought service users, carers and professionals could benefit from it.

Commissioning services

It is important for commissioners of respite care services to ensure they consider the needs of mental health service users and carers. Considering linking respite care and carers breaks together when commissioning may ensure that carers' and service users' needs are better met.

2 Carers Trust (2014), *Respite in Mental Health Care* (Carers Trust).

Key tips for professionals to help carers access respite care and carers breaks

Professionals involved with service users and carers in mental health should consider the following:

- Funding for respite care is linked to the service user's social care needs and is not normally regarded as a service for the carer. However, the change in the Care Act means that respite care may be accessed if identified as a need in the carer's assessment (although of course the carer does derive some benefit).
- When developing a care plan for a service user, it is important to consider potential respite needs in advance. Carers should be involved in the development of the care plan. Carers are often able to help to predict the kind of crisis that may occur in the future and the kind of response that will be helpful.
- Consider including respite care needs when developing a discharge plan.
- Ensure the carer is aware that they may be able to obtain funding for a carers break and ensure they are referred to the appropriate service to enable them to access this.
- Respite care should be designed and provided to ensure everyone benefits – the person being cared for, carers and other family members – rather than just the person being cared for.
- Consider the language you use to describe and offer respite care as conventional models of respite care may be off-putting to some service users and carers.

Key tips for carers to help carers access respite care and carers breaks

- Discuss with the person you care for how and why respite care and carers breaks could be used to ensure both of you remain well.
- Ask about a carer's assessment and how you are able to access a carer's break.
- The person you care for may not appear to have any specific social care needs so may not be referred for a community care assessment by the local authority. However, you may both benefit from respite care and it (as well as a carers break) may be accessed through a carer's assessment. Ensure that you request this assessment to enable you to access respite care.

Key tips for service users

- You shouldn't only be offered one type of respite care, for example a day centre. Instead, it should be personalised to your needs and wishes.
- If you are not offered an assessment by the local authority it is important to ask for one. Also, ensure the person who supports you is aware of their rights to request a carer's assessment and to access support including a carer's break.

Useful resources

Carers Trust

How to find your local carers service

You can find your nearest Carers Trust Network Partner by using our Find your local service facility at www.carers.org or calling 0844 800 4361. Carers can also access Carers Trust's online help and support services. Email support@carers.org for more info.

Babble

Visit babble.carers.org or email youngcarers@carers.org

Babble is Carers Trust's new online community where young carers under 18 can find others in a similar position, chat, have fun, share experiences and access information and support online from an expert team.

Matter

Visit matter.carers.org or email matter@carers.org

Matter is for carers aged 16–25. This online service enables young adult carers to post photos, update statuses, ask for help and share their thoughts and comments from wherever they are.

Carers.org

Visit Carers.org or email support@carers.org

Carers.org is for adult carers, with users aged 18 to 80+, with a focus on sharing knowledge and finding solidarity, backed by access to expert and authoritative welfare information.

Rethink Mental Illness

www.rethink.org

Detailed guidance on mental health for service users and carers.

Mind

www.mind.org.uk

Information on mental health, rights and support.



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