

Do you care for an adult with a long term neurological condition?

Would you like to influence the development of services that enable carers to participate in activities of their own choosing?

We have been commissioned by the Department of Health to carry out this study across the UK. The study aims to find out whether people who care for adults with long term neurological conditions can get the **respite/replacement care** services they need in order to have more freedom outside their caring role. We also want to know about people's past experiences of this type of care and what, in their view, a 'five star' service would be like.

There is an explanation of what we mean by **respite/replacement care** on the next page.

Who can take part in the study?

We would like to hear from carers who spend several hours a day caring for an adult with a long term neurological condition. For example:

- Progressive conditions such as:
 - Multiple Sclerosis
 - Parkinson's disease
 - Motor Neurone Disease
 - Huntington's disease
- Sudden onset conditions such as:
 - Stroke
 - Head or spinal injury
 - A brain infection such as Meningitis or Encephalitis

If you decide to take part we will ask you to complete a postal questionnaire and return it to us (you will not have to pay postage) or, if you prefer, you can complete the questionnaire online. Most questions involve ticking a box, circling a number or writing a short sentence. How long the questionnaire takes to complete depends on the person completing it, but in a pilot test most people took less than one hour.

Some people may find it upsetting to answer questions about the difficulties they face. On the other hand, our previous research has found that participating can help people to understand their caring situation better. What you (and the other carers who take part) tell us will be used to develop guidelines for health and social services so that future services can be designed to meet the needs of the people who will make use of them.

Completed questionnaires will be stored in locked filing cabinets in locked offices. Online questionnaires will be password protected. Only the research team will have access to the data. Anything you write will be treated confidentially and no individuals will be identified. If you agree to take part you can withdraw at any time without giving an explanation. Your health and social services will not be affected, regardless of whether or not you choose to take part.

What is the difference between respite and replacement care?

Going back for many years, the term **respite care** has been used to describe services that:

Temporarily assume responsibility for someone in need of care and support so that the person who usually provides it can take a break for rest and relaxation.

But nowadays it is recognised that many people who take on a caring role would like to be able to participate in a range of other activities over and above taking a break for rest and relaxation. These could include:

- Paid employment
- Further education or training
- Voluntary work
- Spending time with other people
- Sport or exercise

The term **replacement** care is increasingly being used to refer to any type of service that takes over from the main person who usually provides care for any reason in the short or longer term.

Types of replacement care

There are several different types of **replacement care**.

Some of them are services which are available outside the home such as:

- Day centres that provide therapy or activities for the person cared for, but that also give the person who cares some time to themselves.
- Residential settings, where the person cared for can go to for short periods of time ranging from a couple of days to a week or more so the carer can take a break

Other services are available in the home such as:

- Regular short visits from paid carers
- Day or overnight sitting services that allow the carer to have some time for themselves
- Befrienders who may take the person cared for out for the day.

If you want to take part in this study please follow the link to the online form on the webpage.

If you have any further questions, please feel free to contact:

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Thank you for taking the time to read this information sheet