

Caring for someone with ME/CFS

Most of us lead busy lives, but for the six million people in the UK who care for relatives, partners or friends, the pressures can be enormous. Every year two million people become carers, according to the charity Carers UK, so the thing to realise is that you're not alone.

The charity Crossroads estimates that around 175,000 young people under the age of 18 live in this way. It says 1 in 8 people in the UK are carers.

Recognising that you are a carer is the first step to getting the support you need to look after your relative, partner or friend with ME/CFS.

Locally, in East Lancashire, there are two charities (see links below) which provide help and support to local carers – Carers Link in Hyndburn and the Ribble Valley and Carers Contact in Burnley, Pendle and Rossendale. Blackburn with Darwen Council also provides information to carers in those two towns.

What is a carer?

So what is a carer? A carer is someone who, without payment, helps or looks after or supports a relative, partner, friend or neighbour who could not manage without their help.

Are you a carer?

Many carers do not recognise that they are carers or realise the impact that caring is having on their lives. If you look after a relative, partner, friend or neighbour, without payment, whether full time or perhaps just to do their shopping, then you are a carer. Blackburn with Darwen Council estimates there are 13,000 unpaid carers in the borough.

New to being a carer?

Carers UK says the first step is to recognise you're a carer – whether you're a mum, dad, husband, wife, partner, brother, sister, friend or neighbour. No-one likes to be labelled, but realising you are a carer is the first step to getting the help and support you need.

Carers UK gives ten steps for new carers. These are:

- Recognise you're a carer
- Include your family and friends
- Tell your GP
- Tell social services
- Tell people at work
- Claim your entitlements
- Find your nearest carers group or centre
- Look after yourself
- Think about the future
- Support the main carers charities such as Carers UK

Their full booklet on what to do if you're a new carer is packed with lots of advice and

information and can be downloaded from:

<http://www.carersuk.org/>

Caring for ME

A study by Sidsel Elisabeth Kreyberg, reported in the journal of charity Invest in ME (<http://www.investinme.org>) says ME/CFS is a demanding , long-term illness which takes up a great deal of friends', relatives', partners' or neighbours' time and where all live with a great deal of uncertainty, not only for the future, but for what every single effort can bring on – the daily as well as the extraordinary ones.

CFS/ME has a profound effect on every part of life. Many carers have told UK charity 25% ME Group that they felt their world had been “turned upside down” and they had feelings of “despair”.

In the words of MP Tony Wright, the ME sufferer faces a double burden: “They must cope with an illness that to a great extent destroys their lives and suffer the prejudice and ignorance that has followed this illness around”.

ME is “a profound challenge on every level”.. It can be very hard indeed to care for someone whose illness goes on for days, weeks, years, even decades.

One of the hardest lessons is learning how to live with the illness rather than the expectation of a “cure”, for this can impose intolerable pressures on both parties.

The 25% ME Group's Carers Pack V2 explains clearly the difficulties carers of people with ME/CFS face and is packed with advice for caerers and is superbly written and informative and we would recommend that all new carers download it from the following link:

<http://www.25megroup.org/Information/Carers/carers%20pack-2.pdf>

Further information

The two local charities, Carers Contact and Carers Link, plus Blackburn with Darwen Council's website for carers can be accessed at the following addresses:

<http://www.bprcvs.co.uk> – Carers Contact (Burnley, Pendle, Rossendale)

<http://www.carerslink.net> - Carers Link (Hyndburn and Ribble Valley)

<http://www.blackburn.gov.uk/server.php?show=nav.277> – Blackburn with Darwen Council

The government's Carers Direct website is packed with information for carers including how to claim carer's allowance and is available at:

<http://www.direct.gov.uk/en/CaringForSomeone>

Two of the main charities for carers in the UK are Carers UK and Crossroads:

<http://www.carersuk.org> – The Voice of UK Carers (Carers UK)

<http://www.crossroads.org.uk/> - Crossroads, caring for carers

You may also find the following websites useful or helpful whether you are a new carer or have been looking after someone with ME/CFS for a long time:

<http://www.carers.org/> - Discussion board for carers

<http://www.carersinformation.org.uk/> - Information for "informal" ie unpaid carers in the UK

<http://www.25megroup.org/Information/Carers/carers%20information.htm> – 25% ME Group information for carers

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