



'The letter' has arrived...

In Issue 21 of Carers in Mind this time last year, we introduced the new benefit reforms that were being introduced by the coalition government. Recently, we have been contacted by a number of families asking for advice as 'the letter' for a Work Capability Assessment has arrived and people are worried. It is really important people feel fully supported in this process to prevent it from having a negative impact on their health and wellbeing.

There is dedicated support available through Richmond Aid's Benefit Service which can be contacted on **020 8831 6080 / 6070** or email at benefits@richmondaid.org.uk. Support can also be accessed from the Citizen's Advice Bureau. You can also call the Rethink Advice Service or the National Mind infoline. If you have a care co-ordinator, you can ask for them for help.

We have found that the Rethink factsheets offer good and comprehensive advice - the full factsheets can be downloaded from their website or we can give you paper copies if you do not have access to a computer. We have feedback from families who have used these sheets and they found them extremely useful. Below are some extracts from the Rethink sheets - they recommend people take their time as there is a lot of information to take in:

If you have applied for Employment and Support Allowance (ESA) because you are not well enough to work, the Department of Work and Pensions (DWP) have to decide

whether you do qualify for this benefit. The test they use to decide this is called the Work Capability Assessment (WCA).

To qualify for ESA, the DWP have to decide that you have limited capability for work.

- ★ They do this by asking you to complete a Work Capability Assessment (WCA).
- ★ You will be sent an ESA50 questionnaire which asks you questions about your ability to manage everyday tasks.

what do we do?!

- ★ It is important to fill this in as accurately as possible, you can get help with this from an advice agency.
- ★ You are also likely to be asked to attend a medical with a doctor or nurse contracted by the DWP.
- ★ If the DWP decide you don't have limited capability for work you cannot continue to receive ESA.
- ★ It is possible to appeal this decision but you only have 1 month to do so.

Limited Capability for Work

In order to qualify for and receive ESA the DWP has to be satisfied that you have limited capability for work. You will automatically be treated as though you have limited capability for work if you are a hospital in-patient and in some other limited circumstances.

In some cases, the DWP may be able to decide that you have limited capability for work based on the information provided in your initial claim for ESA along with the doctor's note provided. If they can't they will send you an ESA50 questionnaire. ***In practice most people will receive an ESA50.***

In order to qualify for ESA you need to score 15 points in total across the whole questionnaire. It is possible to score a different amount of points for the different questions.

The ESA50 Questionnaire

On page 2 of the form it asks if you need any special help in getting to a medical assessment - this is an opportunity to identify any needs you may have to get to the assessment.

The first 10 questions deal with physical health. The mental health related questions are in Part Two of the questionnaire. Depending on the nature of your mental health problem, not all of the questions may be relevant to you. Rethink lists some things you may want to think about for each of the mental health specific questions.

If you are able to get a letter or report from a healthcare professional who knows you well which also states why they think you have limited capability for work then you should attach this to the ESA50 questionnaire when you send it back. A letter simply confirming your diagnosis isn't as useful as a letter explaining how your condition affects your ability to work, or what could

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NHS Richmond has allocated respite funding for families and friends living in the borough of Richmond who are supporting someone with mental health problems.

The aim of this funding is to support you to focus on your own health and wellbeing by taking some time out for yourself. If you are experiencing stress and/or anxiety, or your health and wellbeing is affected in any other way by your caring role - you can apply for an individual payment of £350, or £500 as a couple.

Do you find that supporting someone with mental



health problems can leave you feeling depleted and frazzled?

You don't have to use this grant to take a holiday or break. You can put it towards counselling, complementary therapy treatments such as massage, healing, aromatherapy etc. You could use it for yoga, relaxation, meditation, exercise, martial art or dance classes; or perhaps gym or tennis and sports club membership – a season ticket for your favourite sport!

Would you like to take up a creative activity such as art, design, cookery, needlecraft, photography or creative writing? Perhaps a college course, or series of classes?

Carers in Mind can assist you in making an application. We can help you to complete the forms and submit your application.

Ruth Stroud

Improving mental health services

Primary care psychological therapies

NHS Richmond is commissioning a new primary mental health service which will include provision of psychological therapies service for people with depression and anxiety disorders. These therapies are also known as talking therapies.

We asked for views about how future psychological therapies services would look locally. Thank you to everyone who took part in the survey or attended the discussion group at 32 Hampton Road. Some of the common themes from the feedback include:

- ★ Reducing waiting times
- ★ Improving access (location and appointment times)
- ★ Outreach into the community
- ★ Choice of therapies
- ★ Quality of treatment
- ★ Quality of therapists and staff

A report outlining the results of the survey and how the feedback has informed the service specification for the new service will be available shortly. The current psychological therapies service provided by the Priory will continue until the new service is in place which is planned for April 2012.

Adult acute inpatient beds and rehabilitation services. The Richmond Adult Mental Health Strategy 2010 set out recommendations to redesign rehabilitation services by increasing services in the community and appropriate floating support and to redesign the commissioning of adult acute inpatient beds across South West London.

NHS Richmond is now developing proposals to achieve these recommendations, taking into account national policy and guidance, local health needs, clinical evidence and input from carers and service users.

NHS Richmond is therefore undertaking an independent clinical review of local rehabilitation services to identify what local community based rehabilitation services could look like in Richmond. An independent consultant psychiatrist will also be undertaking a needs assessment of inpatient beds across South West

London to recommend the required number and type of beds across the area and related community based support such as home treatment services. RB Mind is working closely with the NHS alongside other local partners including service users, carers, Kingston Advocacy Group, Imagine, Richmond LINK and South West London & St George's (SWLStG's) Mental Health NHS Trust to develop these proposals.

To help with this work NHS Richmond will be working with Carers in Mind and other mental health carer groups to hear from carers who have recent experience of local inpatient, crisis & home treatment or rehabilitation services. Once the proposals have been agreed NHS Richmond plan to hold a 12 week public consultation in March on its proposals for adult acute inpatient and rehabilitation services. The consultation will be a further opportunity for you to have your say on the proposals. We will share more information with you about the consultation nearer the time.

In the August 2011 issue of this newsletter we stated that "NHS commissioners have agreed that there will be no new admissions to Riverside Lodge with immediate effect." This is no longer the case as NHS Richmond has decided that it will not be restricting admissions into this service and that it will remain open until the new rehabilitation services are in place.

*Caroline O'Neil
Engagement Manager, NHS Richmond*

Carers in Mind alongside RB Mind has fed back concerns that people have shared with us about some of the outcomes of previous consultations for the development of local mental health services. We have requested that in future consultations it is made clear what can and cannot be influenced by families and friends and service users. We also have expressed a need that future consultations will need to clearly communicate the scope of changes proposed, their expected costs, benefits and impact.

Kim Willson

When Jon Cousins confessed to his two closest childhood friends that he suffered from bipolar disorder, they were stunned. They had known him for four decades or so, but he had hidden his illness so diligently that no one close to him suspected he was anything but contented.

Behind his outward success, Cousins had always experienced severe bouts of depression interspersed with spurts of creative highs, when he would work through the night and act on new ideas – the "manic" part of living life as a manic depressive, as bipolar disorder was formerly, and still is commonly, known. "I didn't mind the highs at all," says Cousins "I was just very creative during those periods and I like working. But to operate like that all the time would burn me out." And the low points? "They were abjectly awful. Completely terrible. Terrible, terrible, terrible. I wouldn't go out. I would draw the curtains, wouldn't answer the phone and make excuses not to meet people. This would go on for a number of weeks."

Cousins had asked his doctor for help on several occasions. He spent his late thirties on antidepressants and was referred for psychotherapy several times. Neither approach worked. "I hated the therapy so much that when I came out I treated myself to an LP every week," he says. "That way I could look forward to the session finishing." On one occasion he returned from holiday to discover his therapist, who had promised to reveal exactly what was wrong with him at their next session, had died while he was away. He was overjoyed to be spared further examination, and wriggled out of being set up with another therapist.

When, in 2006, he noticed that his high periods were becoming less frequent and the low periods were longer and darker, Cousins returned to the NHS. He was unprepared for what followed: a psychiatric nurse referred him to a psychiatrist, and he was faced with a wait of months for a diagnosis. It was December and he left the appointment feeling lower than ever before. He knew he didn't want anything the NHS could offer him to deal with his problems: he hated therapy and didn't want to submit to medication and risk losing the high periods in which he flourished. He contemplated suicide as he

moodscope.com

walked across a railway bridge. "It was a tough Christmas," he remembers.

The worst bit was the wait. The following February, he met a psychiatrist who said she suspected he suffered from cyclothymia, a mild form of bipolar disorder, considered to be on the "bipolar spectrum". Stephen Fry is a famous sufferer, and two of Cousins' friends, independently, had said to him they thought he might have it too, after they had seen Fry's BBC programme, *The Secret Life of the Manic Depressive*.



The psychiatrist asked him to go away and record his moods before his next appointment. Not sure of how best to do this, Cousins turned to Google and came across a test called *Panas* – the Positive and Negative Affect Schedule. Ever the ad creative, he adapted the test into a set of playing cards. Each one of 20 represents a different mood and is graded from one to four, so Cousins could give himself a four one day for "alert", but a zero for the cards marked "proud" and "excited". He plotted his progression on a graph. In May he met another psychiatrist, who confirmed the cyclothymia diagnosis from the mood charts. This was a blow, even though it meant Cousins was no longer in limbo. "Once you've questioned your own sanity so much, you then start to question your own insanity," he says.

But the psychiatrist was baffled and amazed by the way Cousins had recorded his moods. At first he couldn't believe that this patient had devised the playing card method and made them him-

self; he then moved on and said that they should be made available to other people. "That was when I

first started thinking of Moodscope," says Cousins.

Moodscope began to develop when it was put online. Cousins asked his friends to monitor his own progress and join in if they wished. Four years later, it works as an online community for people suffering from mental health problems and has more than 16,700 devotees. The Institute of Psychiatry is carrying out a pilot research project into Moodscope, analysing 20 patients already using mental health services.

The other important aspect to Moodscope is its "buddy" system. Users can nominate one or several friends to keep track of how they're doing. Each day the chosen buddies are simply emailed the score of the user so they know what sort of day their friend is having. It is then up to them to act on this information, perhaps with a phone call or email. "It is up to people to come up with their own routines," explains Cousins. "I've got four buddies. One's in Israel and he only ever emails if my mood dips, and then it's just a question mark. I email back to explain, and by the time you've explained, you've understood yourself what the problem was. Others email me every day with a sentence and a few words."

One user, who has suffered from depression since childhood, says using Moodscope helps her to stop a down period in its tracks. "It's not immediate," she says. "But seeing my graph working its way down somehow helps me stabilise and move back towards a neutral place. I can begin to slow down my thoughts and activity before impulsiveness leads me to risky behaviour."

Though he considers himself cured, that doesn't mean he feels 100 percent all the time. "It hasn't completely stopped me being depressed and it certainly hasn't stopped me having low moods. We all have low moods and we're all going to feel bad at times. That's a part of 21st-century life. What Moodscope has done is give me a tool to manage those low moods, and shown me how to get help from other people."

From: Bipolar Disorder: My ever changing moods, by Sophie Morris. The Independent, March 2011



Enjoying and Coping with Major Festivities

Seasonal and religious festivals provide an opportunity for families and friends to come together to strengthen their relationships, celebrate their culture and reaffirm their faith.

These times are special and fun but can sometimes be stressful and hard work when a member of the family has mental health problems. Here are some coping strategies and ideas, provided by families using SWLStG's services, to help you deal with these occasions:

LOTS OF HYPE, STRESSFUL BUSY SHOPS

Make lists!

Stagger shopping times or request homemade presents – this may help those with low incomes feel less pressure and more able to give.

Consider doing things differently this year. Some suggestions:

- ★ have a Christmas picnic
- ★ get right away (don't celebrate!)
- ★ get others to cook a course
- ★ stay in bed watching old films
- ★ attend religious ceremonies to break up the season

STAFF AWAY, SERVICES AND ACTIVITIES CLOSED

Renew prescriptions early, ensure they are made out correctly and last until well after public holidays end.

Encourage service users to help with pre-, during and post- festival activities.

Find out what is open – free council newspapers can provide this information.

Check you **know crisis line numbers** and how to get help if you need to.

Share your concerns with your care-coordinator.

Compile a list of things to do and share this with family members.

ROUTINE DISRUPTED

Try to **maintain as ordinary a routine as possible**. If you can't - try to avoid being overly critical if some people don't feel like joining in.

Make sure your request for help is heard and is specific. Try looking at the person directly, saying exactly what you would like them to do and explain the benefits this would bring.

Have a break or take time out.

Examples:

- ★ go to another room/space
- ★ take the dog for a walk
- ★ visit a neighbour for an hour or so

FAMILY MEMBER FEELS LEFT OUT OR UNDER PRESSURE

Share plans about who will be visiting and when.

Try to negotiate **what activities your family member could be involved in.**

For example: "do you would want to join us for the main meal and then have time to yourself?" or "who would you rather sit next to?"

Before the family get together, **practise conversation ideas** to help you handle difficult relatives.

Stagger visitors' arrival and leaving times through the holiday so you don't have to cope with too many people at once.

Catherine Gamble, Nurse Consultant, SWLStG's NHS Mental Health Trust.

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happen to your health if you were asked to start looking for work.

Will I have to go for a medical assessment?

The DWP may be able to decide whether you have limited capability for work from the information given in your ESA50 and any extra evidence provided, however **in most cases you will also be asked to attend a medical assessment.** The assessment is carried out by a doctor or nurse from a company called Atos Healthcare.

They might ask you whether you *can* do something, like use a telephone. Although you may well be physically able to use one, *do* you actually do so? Make sure they are clear about that difference and if your condition prevents you from actually completing the task they ask you about.

Remember: it is possible to take someone to the assessment with you if you wish. This could be someone formally involved in your care like a social worker, or an informal carer like a friend or relative. They may have information about how your condition affects you day-to-day that they could share and they should not be stopped from doing so.

What happens next?

After you have returned the ESA50 questionnaire and attended the medical assessment, the DWP will make a decision about whether you have limited capability for work and can continue to receive ESA.

If you don't agree with the decision it is possible to ask for the decision to be revised, and then if you still don't agree you can appeal. You can use a form called a GL24 to submit an appeal which you need to send by recorded delivery so you are sure it has been received within the strict timescale.

Don't forget there is help there for you with this process.

If you would like a copy of the newsletter in large print or you need any help accessing information from the internet - please let Kim or Ruth know.