

NEWSLETTER

August-September 2006

CLINICAL GUIDELINES PUBLISHED (which was NICE)

The most important event for us over the past couple of months has been the publication of the NICE Guidelines for treating our condition. Jackie gives her own reaction inside this newsletter. While it doesn't guarantee us the best treatment or the most sympathetic medical staff, it does bring together the best advice and information based on evidence.

There is much I could comment on (and no doubt will over coming months!) but from the MDF point of view my favourite quote has to be "Patients, family and carers should be informed of self-help and support groups and be encouraged to take part in them, particularly at initial diagnosis, and regularly after that. Such groups may provide information on early warning signs, treatment and side effects, and support in time of crisis." Yes!

Another aspect that pleases me enormously is the stringent criteria for diagnosis in adolescence. People will know my concern that, especially in the US, more and more children and young people seem to be diagnosed. If adhered to, this will prevent a young person being slapped on Olanzapine the first time he or she throws a toy out of the pram.

In July, Clare Gaskell, Chief Pharmacist with the Trust joined us to answer questions about medication. As usual, it was a lively and interesting session. As a supplement to the session I asked whether any everyday activities can interact our medication. As you will see inside, Clare has kindly sent us some information based on the research of a colleague.

Finally, I know that many of you like to hear the experiences of other people with the condition. Many thanks to those who contributed to the 'The best/worst thing I ever did for my bipolar'. Now read on...



After a couple of years on Olanzapine, Gary found the healthy living advice a little bit hard to adopt.

Cambridge Independent Advocacy Service

A free, independent and confidential advocacy service for adult users of the mental health services in Cambridgeshire

Tel: 01223-218500

LIFELINE

The Cambridge Mental Health Helpline is available 7-11pm every day.

Call Freephone on:

0808 808 2121

THE BEST THING I EVER DID FOR MY BIPOLAR...

... was admitting that I really did have it and so deciding that I could start to recover. *(Roger)*

... was continue to meditate and practice yoga. The ability to have a small psychological 'distance' that comes about from meditating and the ability to witness the acrobatics of my mind, rather than become completely absorbed by it has enabled me to live a closer to 'normal' life. *(Michael)*

... was to admit to a GP that I suffered very badly with depression and that it affected my quality of life severely. This led to being put on medication that has transformed my everyday life and made me a much happier and more stable individual. The other good thing I did was acknowledge that I do suffer with the illness and take steps to start managing it rather than letting it control me. *(Kyra)*

... was to fight for diagnosis and medication which has changed my life (for better) *(Kim)*

... was visit my parish priest - when I stopped believing I was cursed or damned for my own failings things started improving. I couldn't tell you whether God has brought about the change but I find that believing that there is a higher being (God) to ask for help makes me feel less isolated and helpless, both things that distract me from negative thoughts and give me what appears like inner strength. *(Carina)*

... was change psychiatrist to one who believes in moderate doses and listens to one's preferences, who keeps careful notes, and who helped me to see that I should try an atypical antipsychotic for a long period alongside lithium, to stave off recurrent bouts of severe mania. *(Jean)*

... was to give up work. I regretted it very much at the time and it still upsets me to think about it, but I haven't had more than a 'blip' since and the benefit to my family has been huge. I'm beginning to get a bit twitchy about my life now, five years on, and am thinking about taking a part time course at CRC next year. *(Jackie)*

.. was go to the volunteer bureau and get a voluntary job working with people with learning difficulties on an organic farm. Working outside helped my mood and helping people worse off than myself helped me to climb out of the pit of depression and self pity. *(Rebecca)*

... was find out what it was and seek medical advice. I'd been admitted twice before, the first time in Barcelona and totally out of the blue, and the second time in Fulborn, also a complete surprise. Then I did some CBT which was probably the most constructive thing I've done. *(Huw)*

THE WORST THING I EVER DID FOR MY BIPOLAR...

... was denying that there was anything much wrong with me for about 18 years! *(Roger)*

... was experiment with drugs earlier in life. My mind has always been very creative and fluid and drugs did not suit me at all even though my stubborn and curious nature had me try a whole bunch before I realised this fact. I had several 'bad trips' which are basically brief psychotic episodes. If I could change anything I would not have explored drugs. If I could influence anything now I would encourage kids not to experiment with drugs as, in my experience, it may be fine for the majority and not carry too major consequences, but for the few it is tantamount to Russian roulette and can bring on all sorts of extreme, perhaps avoidable, suffering. *(Michael)*

... was firstly to eat a lot of very sugary foods leading to mood swings and putting on a lot of weight (can't blame the olanzapine entirely!) which has damaged my self-esteem and self-confidence. The second thing was to choose to be in a non-supportive relationship where my partner denied that I had any sort of problem and did not try to help me. I have proved over the last two years that I remain more stable when I am not in a controlling relationship and one that doesn't acknowledge how my moods can fluctuate at times. *(Kyra)*

... was not sleeping *(Kim)*

... was to go hospital when very depressed. A friend advised and helped but I found myself isolated, given no support and discharged while I was still gripped by an imminent fear of killing myself. It has left me with a guilty secret from my parents who I was too scared to confide in and a huge sense of shame, along with having crossed the line between having been able to cope as an out patient and the need for in patient care, which I feel was a little benefit. Perhaps, had I been high and not depressed I would have found a different situation. *(Carina)*

... was, some months after coming off a high dose of antipsychotic, to believe I had recovered; I lost weight and started talking, spending, pursuing a relationship manically, eventually being sectioned. *(Jean)*

... was attempting to resit the year at university without admitting that I had a problem and getting help with it. I had to drop out for a second time. *(Rebecca)*

... was believe it wasn't affecting me. I spent 6 months in depression wondering what would come next, reading all about "everyone else's problems" until I accepted it was my problem. *(Huw)*

NEW NAME; SAME GAME

The more observant amongst you will note from the title page that we are now calling ourselves. 'The Cambridge MDF BiPolar Self Help Group' in line with the current national image. Same organisation. Same people. Same condition. Whilst I'm prepared at long last to concede that 'Bipolar' is becoming the most common term for this condition, it bothers me a little that MDF no longer makes clear what the 'MDF' bit actually means. In a couple of years we'll have to start explaining that we're not people who use a certain type of material to build our kitchens with.

Forgive me if I haven't made all of our stationery and publicity compliant with this odd title yet. I'm working on it.

As an aside, I thought it wonderfully arrogant and a touch naïve that the NICE Guidelines say this condition was "once known as 'manic depression'" as if that term was now lost in history. It still is called 'Manic Depression' by a lot of people.

BIPOLAR ON THE BOX

I've just heard that the long awaited documentary about MD by Stephen Fry is to be broadcast in two parts on Mon 18 and 25 Sep on BBC TWO at 9pm. From all I hear it should be worth watching.

There will also be a BBC website that goes with the programmes. I don't have the web address yet but I do know that if you look hard enough you'll come across some sound bites from a certain MDF group facilitator and other 'real' people with MD. I'll let you know when it goes live.

BITS AND PIECES

I was interested to see in Science Daily a report indicating that a 'new' treatment model was working well and very cost effective. A psychiatrist monitored the condition and prescribed the medication while a Nurse Care Co-ordinator held weekly group sessions looking at early warning signs, coping skills and action plans. Patients receiving that treatment gained more relief from symptoms and felt more productive at work and better able to manage relationships.

There sounds to be a good deal of similarity with our Self Management Courses and adds confirmation that this sort of group approach is worthwhile.

I was also fascinated to read in The Scientist that Lithium may work by pulling cells into a more regular circadian rhythm. It seems to make sense as Lithium is known for its timekeeping qualities in watch batteries. We also know how bad irregular sleep habits are for the condition.



FREE - CONFIDENTIAL - INDEPENDENT - IMPARTIAL

Cambridgeshire
Citizens Advice Bureaux
local rate: **0845 241 2555**

TURNING POINT FOR CARERS

If you support an adult with a mental health problem in Cambridgeshire or Huntingdon you can get information, advocacy and support.

Ring 0845 601 7881

LIFECRAFT

Mental health information service is open
from 12noon-5pm Mon – Fri

Tel: 01223-566957



The language of the Guidelines scarcely did justice to the torrid rollercoaster that Mildred saw as her destiny.

MEDICATION AND EVERYDAY ACTIVITIES

Thanks to Clare Gaskell, Chief Pharmacist with the Trust for the following information:

Many of us remember that medicines can interact with each other but sometimes we forget that they can also interact with other things. The table below gives you an idea of how the four main medicines that are prescribed for people with bipolar disorder may interact with some everyday things. As always, if anything in the table causes you concern or you want to ask further questions please contact me. In some cases, if there is no problem at the moment then altering your medication may create one - some of these things you should know about just in case you do decide to stop doing something suddenly e.g. drinking caffeine or restricting your salt intake. In many cases this may be just reassurance that these things are not having an impact on your medication or vice versa.

Drug	Lithium	Carbamazepine	Sodium Valproate	Lamotrigine
Smoking	No direct effect	No proven effect	No known effect	No known effect
Caffeine	Consistent caffeine has no effect but abrupt withdrawal can increase lithium levels.	No effect on carbamazepine but there may be less effect from caffeine.	No known effect	No known effect
Alcohol	May produce a slight increase in lithium levels (maybe due to dehydration?) Increased drowsiness	Increased drowsiness	Increased drowsiness	Maybe increased drowsiness
Exercise	The general benefits of exercise outweigh the risks of dehydration after exercise, especially if adequate hydration during and after exercise	No known effect	No known effect	No known effect
Salt/Diet	High amounts of salt can decrease lithium levels but also salt restriction can increase levels. Can cause increased appetite and weight gain.	Drinking grapefruit juice can increase carbamazepine levels	Can cause increased appetite and weight gain.	No known effect
Sunshine	No known direct effect	Possible increased sensitivity to sunlight	No known effect	Possible increased sensitivity to sunlight

The table is a simplified version of some research that Simon, one of the pharmacists at Fulbourn Hospital has undertaken, references are available for each of the statements. In addition, other medicines that you may be taking could interact with these things e.g. clozapine and smoking so please contact me if you would like any further information.

Clare's contact details are:

Clare Gaskell, Chief Pharmacist, Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, Kingfisher House, Kingfisher Way, Huntingdon, PE29 6FH
Tel 01480 398522 or 0781 8453287 Email clare.gaskell@cambsmh.nhs.uk

If you'd prefer to contact Clare though me, you're very welcome.

The NICE Guidelines on Bipolar Disorder – by Jackie

On 25th July the NICE guidelines for the treatment of bipolar disorder were published. NICE stands for the National Institute for Health and Clinical Excellence; it produces guidelines on the benefits and best use of new medicines, technologies and the treatment of many specific illnesses.

The aim of their work is to make sure that wherever we live and whoever we are treated by, we will all get the best possible treatment for our condition. It provides a resource for us to understand our treatment and the support options that are available, plus extensive and clear guidelines for our doctors to follow. Hopefully in our case it will contribute towards earlier and more accurate diagnosis and a more considered choice of treatment rather than the hit and miss approach many of us have experienced in the past!

The 28 page booklet designed for patients and carers is very clear and well informed. It has lots of good advice on contentious subjects like medication in pregnancy and bipolar in teenagers. There are a lot of 'shoulds' in it – but then knowing what you 'should' be getting in the way of care will help you actually get it. There are even lists of questions for you or your carer to ask your doctor to make sure that you get the right treatment.

The guidance for healthcare professionals is a hefty 76 pages. It emphasises patient choice, good communication and information and involvement of carers, though only if the patient wishes them to be informed.

There are lots of solid, specific recommendations like not prescribing anti-depressants long-term because of the risk of switching to mania, not prescribing valproate to women of child bearing age and best practice when coming off medication. I was surprised to read 'Lithium should not be initiated routinely in primary care for bipolar disorder' – until I worked out that this meant GPs should not initiate treatment, rather than shrinks. Interestingly, (refer to previous newsletters!) it does not like the term mood stabiliser, and instead uses 'anti-manic medication' and 'prophylactic medication' for Lithium etc. It has advice on the special requirements of elderly people with bipolar – for example interactions with the many other medications such people often end up taking for other conditions. It says that pregnancy and contraception should be discussed with all women of child-bearing age, just in case.

Interestingly, they recommend that long-term treatment should continue for 2-5 years after the last episode. I get the impression that a lot of doctors around here recommend staying on the pills for a lot longer than that.

It has advice on diagnosis – I was pleased to read that GPs are recommended to ask about hypomanic symptoms in patients with recurrent depression. That would have got me diagnosed about 20 years earlier! The section on

diagnosis in children and adolescents seems to try to avoid over-diagnosis; it stresses the need to demonstrate euphoria for at least 7 days, and warns against relying on irritability as a symptom.

The advice mentions the value of self-help groups, self-management, and advance statements. All patients should be given written advice on lifestyle changes that may help them stay healthy and extra support after stressful life events such as job loss. The very first recommendation under 'mania' is to give advice on cognitive-type ways to calm things down – keeping to a routine etc. They promote psychological treatment for depression if drug treatment doesn't work, cognitive therapy for patients with chronic or recurrent depression and advice on exercise, routine etc for all depressed patients. It makes the important point that psychological therapy is most helpful in patients who are relatively stable

It should be noted that although these guidelines are produced after considering research, no-one can write anything without some kind of bias towards their own ideas. We have heard the professional opinion that they over-state the value of antipsychotics and in particular olanzapine in the treatment of bipolar.

Even so my judgement is that there is a lot of really good stuff in this. I just hope all our mental health teams have time to read it and, even more problematically, the money to implement it...

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The NICE Guidance can be found online at:

<http://tinyurl.com/m6crg>

It comprises the three documents 'NICE Guidelines' for Professionals, a 'Quick Reference Guide' for Professionals (but very useful for the informed lay person) - Ref N1076 - and 'Information for the Public' – Ref N1078. There are also some more specialised documents about costing and implementation.

Paper copies of the full guidelines are not available yet. Single copies of the other two items can be obtained free quoting the reference numbers above by e-mail from: doh@prolog.uk.com or by 'phone from 0870 1555 455.

The 'phone number is one of those rip-off national numbers that cost more than they need to and makes them a profit. Don't get too chatty! I can order them for you by e-mail if you'd like.

I could print anyone copies of the full (76 page) Guidelines if they wish but I'd need to charge 4p per page to cover my costs. The Quick Reference Guide is probably adequate for most people in the group.



CAMBRIDGE

MDF BIPOLAR

SELF-HELP GROUP

MAKE SURE YOU RETAIN THIS PAGE FOR REFERENCE

MEETINGS AUGUST TO DECEMBER 2006

There are links to maps on our website or just ask and I can send one.

Meetings at Hilltop, Primrose Street, Cambridge

We have small groups ('punters' and carers in separate groups if attendance justifies). Hilltop car park is at the end of Greens Road, down a little slope. Come for refreshments at 7.30pm for a 7.45pm start.

September 25th, October 23rd, November 27th, No meeting in December

Meetings at St Matthew's Parish Hall, St Matthew's Road, Cambridge

There is usually a guest speaker or group discussion on a relevant topic. There is street parking around the area but watch out for double yellows and residents' bays in some places. Come for refreshments and informal chat at 7.30pm for an 8pm start.

September 11th – Judy Dean, Project Manager with the Trust will lead a discussion into the Recovery values' in Mental Health. Judy has researched the needs of service users over some years and the influence of the growing 'Recovery' movement can be seen on the website: <http://workingtogetherforrecovery.co.uk/>

October 9th – Dr Neil Hunt will put into perspective the subject of violence amongst service users. Dr Hunt is a Consultant Psychiatrist and wrote the book 'Bipolar Disorder – Your Questions Answered'. This meeting will be open to the public as our offering to World Mental Health Day

November 13th – To be arranged.

December 11th - To be arranged.

<u>CONTACTS</u>	Phil	Jeannette	Viv	Joanna
	0845 434 9780	01223 563269	0845 434 9780	01223 574266
Preferred times: (We can't guarantee being in when you call but will get back if you leave a message)	7pm-9pm weekdays 10am-9pm weekends	7pm-9.30pm weekdays	7pm-9pm weekdays 10am-9pm weekends	Weekends
New Members	*			
Ring for a chat	*	*	* (Carers)	*
Correspondence to: Phil Alsop, Secretary, 6 Beechwood Ave, Melbourn, Cambs SG8 6BH. E-mail: mdf(AT)mdfcambridge.org.uk Website: www.mdfcambridge.org.uk				
We are a local group of the national MDF The Bipolar Organisation , Castle Works, 21 St George's Road, London SE1 6ES Tel: 08456 340 540. Fax 020 7793 2639. E-mail: mdf(AT)mdf.org.uk Registered Charity Number 293340				