

NEWSLETTER

New Year 2010

ASK THE PHARMACIST (NOW!)

Before I start encouraging you to read beyond page one, I must draw your attention to next Monday's talk at St Matthew's. We look forward to another visit from an informed and popular speaker.

Dr Clare Gaskell is chief pharmacist for the local mental health trust. She will be speaking about drug-drug interactions between bipolar medications, and between bipolar medications and drugs for other conditions. Many of us have had personal experience of how such interactions can affect physical and mental health and it is an important topic.

It should be a really interesting evening as she is always right on top of the latest research and happy to answer people's general questions, too. That's Monday 11 January 7.30 for 8.00p.m start. All other details are on the back page.

IN THIS ISSUE

A major way to get anywhere with our illness is by sharing knowledge between fellow sufferers. I'm particularly pleased that we've been able to bring together the experiences and views of some of the membership on a couple of topics. The first relates to the changes underway in the provision of our mental health services. For those of us who need long-term support, the prospect of a reduction in CPN provision has to be one of the main concerns. Phil has produced a compact summary of members' views and of ways that the Trust's proposed changes could be improved through better consultation. These suggestions deserve our approval.

The self-management article is a summary of members' difficulties with the combination of bipolar disorder and alcoholic drink. A big thanks to the many contributors for sharing experiences and practical tips.



Christmas was Christmas, but Doctor Santa always left extra medication to cover New Year

Driving a car is for many of us the most dangerous thing that we do. The licence to drive held by anybody with a long-term illness is subject to medical assessment and review by the DVLC at regular intervals. The conditions relating to mental health sufferers are a bit of a minefield and this month's Ask The Doctor points us in a necessary and safe direction.

Jackie has given us a rundown on Edward's thought-provoking presentation to our group on the theme of Genius and Madness. To round things off, we have a couple of book reviews. Edward has had a look at group favourite Liz Miller's book on her MoodMapping programme.

I've reviewed a practical guide (for bipolar sufferers and those around them) that is actually well targeted and easy to read. Maybe someday I'll get the newsletter looking that way!

DUMPED BY YOUR MENTAL HEALTH TEAM?

Many of us have had a CPN (Community Health Nurse) or other member of the Community Mental Health Team to monitor our well-being over the years. Contact is usually through home visits that allow much more time than GP or Psychiatrist appointments. Other than family members, that person is in the best position to spot our worsening moods, to support us effectively and to negotiate with others in the system on our behalf.

Jane, for example, said: "I found having a CPN to make a huge difference. He was extremely knowledgeable and could work out how much medication I'd taken just by looking at my face. A visit might consist of a ten-minute chat, or an hour, or a phone call to my husband and waiting with me for several hours until he got home, or persuading me to go into hospital and taking me there himself. I am absolutely certain that having a CPN reduced the length of my hospital stays, though probably not the total number of admissions."

Malcolm writes: "The problem is that I deteriorate very gradually and it is only when I reach the point of being unable to go out and buy food that I realise that something has to be done and I seek help."

What has happened over the past couple of years or so is that this contact has been withdrawn – often suddenly and without it having been communicated.

Jane's experience was: "What really annoys me is that I wasn't told I didn't have one any more. I rang up the team with a problem after being well and therefore out of contact for some months only to find out that my CPN had left. Nobody had bothered to tell me, and nobody had told me that I'd been classified as no longer needing one any more. At around the same time I was also discharged by my psychiatrist. I have spent the last few years managed only by my GP. She's great, but I have this nagging feeling that sooner or later I am going to fall back into the system and there will be absolutely no continuity of care."

Malcolm described it thus: "I was signed off as an outpatient some time ago; then I was signed off by my occupational therapist a couple of years later. The rationale in both cases seemed to be a move by the NHS to short, focused interventions (rather than proof that the patient is well) after which I was effectively dumped."

In these days of belt-tightening, it is right to question the use of highly trained staff on an open ended, long-term basis. This is especially true for us when we can be well for long periods. It also seems reasonable to divert some staff into the shorter more focused interventions. However, good customer care (and common decency) suggests it should be done in a careful, planned and well communicated way.

We have often made this point to the Trust in meetings so it was very disappointing and frustrating to be recently told:

"We clearly need to look at this. We are reviewing pathway implementation this week, with teams. We will also review the number of referrals received against predicted."

The opportunity for the Trust to look at this has been there for some time. What we ask the Trust to do as a matter of urgency is:

- To review the implementation of pathways (the new Team structures) and communicate the result publicly. In particular the needs of those with lifelong recurrent and severe conditions should be considered.
- To make manifest the criteria for allocation of long-term support.
- Where support is stopped or reduced:
 - to ensure an explanation is always given, face to face if at all possible;
 - to plan for the change over a few meetings, if necessary;
 - to offer fallback help wherever possible;
 - to notify the individual of avenues of appeal;
 - to notify the individual of rights including advocacy and PALS;
 - to leave the individual with a plan, written if possible, for how they will manage from then on, including emergencies.

Phil

ASK THE DOCTOR - DRIVING

Once we have got a licence to drive a car we usually assume that we have this for good. Many of us are reliant on driving for transport, particularly if we live outside the city. If we have a special licence for a lorry, a bus or a taxi, we may rely on this to earn a living and so feel that this is a right not a privilege. However we know that driving a vehicle is the most dangerous activity that most of us do and the situation in which we are most likely to seriously injure another person. There are three thousand deaths and a quarter of a million people are injured on our roads in the UK each year.

It is on this background that doctors have a responsibility to mention to you that your illness may affect your ability to drive and that you as the patient have a responsibility to notify the DVLA (Driver and Vehicle Licensing Authority) about this.

The rules apply to all serious illnesses not just psychiatric illnesses. For example if you have a heart attack or a stroke you must notify the DVLA.

If you are suffering from depression or anxiety but this is not severe then you should take advice from your doctor about whether you should drive. It will usually be reasonable for you to continue unless you are taking a medication that can affect your driving. The most serious medication problems appear to arise from benzodiazepine drugs such as diazepam (Valium) or lorazepam (Ativan). Also combinations of medication (including antidepressants) with alcohol can make it more likely that you will have an accident.

If you have a more severe depression, which includes significant memory or concentration problems, agitation, behavioural disturbance or suicidal thoughts then you should stop driving.

If you suffer from mania (and the DVLA includes hypomania in this) then you should stop driving, take advice from your doctor and inform the DVLA. It is *your* responsibility not your doctor's to inform the DVLA. The DVLA will then ask your doctor for information about your illness and they will consider re-licensing when are satisfied that the patient:

- (a) Has remained well and stable for at least 3 months
- (b) Is compliant with treatment
- (c) Has regained insight
- (d) Is free from adverse effects of medication which would impair driving
- (e) Subject to a favourable specialist report.

If you are getting repeated episodes then they will want you to be stable for at least 12 months.

The DVLA will always contact your doctor and ask for a report, so you must expect this and tell your doctor. The DVLA recognises that those with bipolar disorder are also more likely than average to have problems with alcohol and drugs and so they will routinely ask you and your doctor about this. You should discuss this with your doctor so they have all the information they need to fill in the form.

Most people with bipolar illness are able to keep a licence but are subject to a yearly review. If you are taking your medication reliably (which can be shown by blood tests with lithium) and remaining well then this usually becomes a routine process. If you have a very unstable or severe illness or are drinking heavily or not taking treatment regularly then you may well find it difficult to get a licence back.

If you do not tell the DVLA about your illness then you may be driving illegally and if you have an accident you may find that you are not covered by your insurance. If your doctor thinks that you are ignoring advice to inform the DVLA, especially if they think you may not be fit to drive then they

may inform the DVLA directly. This would be very unusual - I have done this only once in my career - and would put you in a difficult position with the DVLA and make it much harder to regain your licence. It is much better and usually not as difficult a process as you might think if you contact the DVLA sooner rather than later.

If you do hold a special licence for example for your work as a lorry or taxi driver then the rules are much more stringent but it is even more important that you discuss this with your doctor and contact the DVLA.

The DVLA's medical rules for drivers can be viewed at:

<http://www.dft.gov.uk/dvla/medical.aspx>

Dr Neil Hunt

GENIUS AND MADNESS

A short summary of Ed Pain's October talk

What is Madness? It is an outdated term that embraces psychosis, mania and hypomania. Psychosis is defined as a break with reality and includes paranoia, hallucinations, delusions and incoherent speech. It can be associated with substance abuse. Mania and hypomania we are familiar with! Some people find it to be associated with seasonal changes, and again manic-like symptoms can be promoted by substances such as cocaine and ecstasy. 61% of Type 1 bipolar patients have histories of substance abuse. The suicide rate in bipolar patients is notoriously high.

Does madness aid creativity? Is it associated with genius? Part of the problem is deciding which historically creative figures may have had mental illness, and of what kind. Some clues are whether their productivity is seasonal, whether there is evidence of drug abuse, suicide attempts, asylum stays or family history of mental illness. Kay Jamieson has studied this in her book *Touched With Fire*.

Then we also have to define genius. Wikipedia describes genius as having:

- a systematic and orderly approach to problem solving
- a sense of wonder with an ability to look at things in a fresh, almost childlike way
- the ability to keep an open mind and a flexible attitude on all subjects
- the ability to concentrate with greater depth and intensity than the average person

The flight of ideas and increased activity associated with mania and hypomania could certainly contribute to some of these factors.

Genius has also been defined as being people with an IQ of more than 140 (0.25% of the population), but the test

tends to favour generalists and scientists, not creative artists.

Historical figures that are thought to have had bipolar disorder include Isaac Newton, Van Gogh, Shelley, Beethoven and Winston Churchill. A more recent example is David Nash – winner of the Nobel Prize for Economics – who had paranoid schizophrenia.

So why does society link madness with genius? An interesting question!

Jackie

SELF MANAGEMENT - ALCOHOL

In the last issue, we brought together members' thoughts about telephone use and related self management. For this article, it's the turn of alcohol. This is especially relevant over the festive season, but of year-round concern to us all. About two-thirds of bipolar folk have some history of alcohol or substance abuse, with alcohol being by far the most frequent problem.

Most of those of us who have had trouble with booze appear to share a common problem. We are very much aware that alcohol makes matters worse, but when unwell find ourselves in trouble again. Member B observed that when well he only drank at social occasions and even then only in moderation. An episode, either up or down would lead to excessive drinking: "It's like a compulsion". Alcohol affects perceptions and in doing so can often lead us to consider it as a convenient and effective self-medication.

Alcohol plays a dangerous role in that it worsens our existing mood fluctuations. At the same time, we hope to use it for emotional relief. This is, of course a vicious circle. When depressed, member C used it to numb the pain and get some sleep. Others have seen it as an anti-anxiety tool, a temptation when either high or low.

Alcohol and hypomania is a potent and highly unpredictable cocktail. While alcohol can be perceived as a means of relaxing and unwinding, several of us found that an increased elevation of mood was enjoyable, even exhilarating. Member D admitted that being hypomanic and hitting the bottle could lead to dancing in the kitchen in the middle of the night. I myself have experienced such dancing as a prelude to more damaging activities. But that's another story!

There are other complications. Emotional stress can encourage drinking in anybody, but that tendency can be more harmful to bipolar sufferers. No hangover is totally physical; the emotional "down" can be worse and more protracted for us. Member E observed that the emotional hangover could actually be worse on the *second* day after a binge.

The combination of medication and alcohol is a complex issue far wider than our discussion. Perhaps that's a question that we can next week put to Chief Pharmacist Clare Gaskell at her talk to our group next week on Monday 11 January.

So how do we self-manage? Step One is the recognition of the nature of the problem. It seems that many of us have had problems and some of us realise that we still have a problem on our hands. Family and friends can often find it impossible to be objective. Our main hope lies in education about our illness and its treatment. Self management can play a important role in the latter.

The link between alcohol and "average" mood may be clear, but it is not always obvious to us. Many people actively monitor their consumption. Member F pointed out that alcohol consumption can be included in a mood diary. I was once encouraged to monitor mood against the previous night's alcohol consumption when I was still considered to be unipolar. It was a very sobering experience. Frank discussion with a CPN, GP or psychiatrist can be useful: they tend to err on the side of caution!

Many of us express the view that sharing experience with other sufferers is the best way forward. We may drink during bipolar episodes but that doesn't necessarily make us alcoholics. One member found an AA meeting unhelpful because underlying mental illness issues were not acknowledged. Alcohol abuse is more likely a symptom rather than a problem in itself.

If we can't completely remove alcohol from our lives we need to manage it. A variety of suggestions were made on the controlling of alcohol consumption. The simplest – and perhaps the most effective – involve reducing access. Member C pointed out that building a social life around a pub was not a good idea! Don't keep any more than a small amount of alcoholic drink in your home.

Try alcohol-free days. This requires self discipline, but you can find it easier if you can get others to "pull you up" on this. In my own case, a challenge from my psychiatrist was eagerly taken up by the section of my personality marked "proud"! Two members reminded us that drinking a lot more water proved beneficial to moods.

You can also try watching the strength of your drinks. I myself just don't drink spirits. When in the pub ask for one of the weaker beers or wines: Bar staff are used to this request, especially from drivers. Check the strength of wines that you buy. Whatever you do, don't buy a wine box. Yes, you can have a little, but can you see how little it was? I doubt you'll weigh the box before and after!

Jon

BOOK REVIEWS

Living With Bipolar: A practical guide for those with the disorder, their family and friends. Lesley and Michael Berk, David Castle and Sue Lauder. Vermilion (Ebury publ.)

This is a very accessible guide to bipolar disorder. The strong mood swings associated with the illness are disturbing for both sufferers *and* the people around them. It is not unusual to find a self-help book aimed at both groups but I think that this book benefits from two contributing parties: the authors, and their main source of inspiration – us!

Two of the authors are psychiatry professors of high standing; one of them being president of the International Society of Bipolar Disorders. Their research credentials are good. The other two are very established clinical psychologists who also have experience in teaching and research. So that's a pretty high-powered quartet of medical health professionals.

The authors found that they were getting a clear message about a type of book wanted by the patients in their treatment programmes. It should contain the latest research findings combined with practical hands-on recommendations relevant to managing the illness. Who better than “us lot” to help give it a practical focus? The authors fully acknowledge this.

After a full explanation of the illness, the book runs through medication and psychological treatments. Self management tools, especially monitoring and coping methods are covered in detail.

The importance of maintaining your relationships with family and friends is also acknowledged. Coverage is well presented for both sides. The final chapter is written specifically for the partners of sufferers. It is easy to overlook, but you should also aim for a good working relationship with your GP or other main professional support. They may be the expert on the illness itself, but you are the one who understands best how it affects you.

This book actually does what it says on the tin. It is informative and practical, very clearly written. It provides detailed introductions to most matters but will also be a good source of reference. Each chapter ends with a useful summary of key points. I'll definitely keep it the next time I thin my library. For related online information, see:

www.eburypublishing.co.uk/bipolar/

You can buy direct, or from the usual stockists.

Jon

MoodMapping: Plot your way to emotional health and happiness. Dr Liz Miller. Rodale (Macmillan)

The author, Dr Liz Miller is herself diagnosed with Type I bipolar disorder and writes for MDF The Bipolar Organisation's Pendulum magazine. She also appeared last year on Comic Relief with Ruby Wax to raise public awareness of mental health problems. Before becoming ill, she worked as a neurosurgeon and now works part-time as a GP and in Occupational Health. Despite her diagnosis and three mental health sections, she remains well and has happily lived without medication for the last eight years so she certainly has some experience to share in this area!

Liz has come to our group twice. Her first talk examined how recording your mood can provide cues to better self management. She returned last year to look at how your mood can be influenced by the food you eat. At that talk, we heard that her mood mapping technique was to be released as a book in October last year.

The book offers a completely new view on mood charting and how you can help yourself find greater stability with self management. The basis of the book is Liz's concept of MoodMapping. The MDF's Self Management course encourages recording your daily mood on a scale of one to ten but MoodMapping proposes that mood is governed by two independent causes: your energy level and how positive or negative you feel.

The book comes in two parts. The first leads you through a 14-day programme that uses MoodMapping as the core to assessing how you feel when considering areas of your life that can affect your mood such as your surroundings and relationships. By Day 11, you know how to work out how you feel and the factors that affect it. The final four days of the programme look at ways to change your mood.

The second part gives tips on managing the moods of groups and others before finally discussing mood disorders. I must say that I really enjoyed reading this book and found it first gave me the tools to work out how I felt before trying to change it!

MoodMapping is stocked by Waterstones in Cambridge and by Amazon.

Edward



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MEETINGS

Remember that not all meetings now are exactly on second or fourth Mondays so check dates carefully. Up to date info is always on the website and we can e-mail reminders to those of you who so choose. There are also links to maps on our website or just ask and we can send one.

LIFTS – Lifts may be available if you're stuck for getting to a meeting. Let us know if you're in need.

Meetings at Hilltop, Primrose Street, Cambridge

We have small groups. Hilltop car park is very near the end of Greens Road, down a little slope. Come for refreshments at 7.30pm for a 7.45pm start.

The next four meetings will be on January 25th, February 22nd, March 22nd and April 26th

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 yellow lines and residents' bays in some places. Come for refreshments and informal chat at 7.30pm for an 8pm start.

Monday January 11th 2009 – PCT Chief Pharmacist Clare Gaskell on drug-drug interactions between bipolar medications and also with medication for other conditions. An informed and popular speaker, Clare will, as usual be happy to answer our questions.

CAMBRIDGE MDF BIPOLAR SELF-HELP GROUP ~ CONTACT DETAILS

You can telephone: **08456 340 540** or **0207 798 2600**. These numbers go to the national MDF The BiPolar Organisation offices in London. They will tell callers about our group and pass messages on to us if necessary.

Please send any correspondence to us:

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Emails can also be forwarded to the following. Replace '(AT)' in the addresses with '@' (It's to reduce spam):

Jackie: [jackie\(AT\)mdfcambridge.org.uk](mailto:jackie(AT)mdfcambridge.org.uk) - especially about meetings and activities

Edward: [edward\(AT\)mdfcambridge.org.uk](mailto:edward(AT)mdfcambridge.org.uk) – especially about mailing lists, website and lifts.

Jon: [jon\(AT\)mdfcambridge.org.uk](mailto:jon(AT)mdfcambridge.org.uk) - especially about the newsletter.

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