IN THIS ISSUE

Summer may be over but we have six pages of articles and news to warm you. Many of you don’t manage to get along to our quarterly talks at St Matthews, but we do try to bring you a good write-up. Dr Ramana’s July talk on depression was so comprehensive that I myself got a bit lost along the way. A big thanks to Phil for selecting the highlights that will be of particular interest for us bipolar folk!

Dr Hunt attended the 2012 CINP neuropharmacology (drugs for the brain) conference, this year in Stockholm. As our understanding of genetics advances it appears likely that an individual’s genetic characteristics could indicate the best medication. The implications for ‘personalised medication’ could be quite radical.

I’m very pleased to publish a fascinating article specially written for us by Group member Jenny Tillotson. Jenny is a Senior Research Fellow in Fashion & Textiles at Central St Martins College of Art & Design and a Visiting Scholar at Cambridge’s Department of Chemical Engineering & Biotechnology. Her work has taken her into a unique and unexplored world where creative design meets scientific principles. The outcome? her invention of interactive clothing fabrics that can assist emotional wellbeing via the sense of smell.

This is truly a ‘science fashion’ story. But what makes this article special for us is Jenny’s account of how her bipolar diagnosis and personal circumstances have inspired, and now drive, her work. Do follow the web links for lots more information on her projects, as well as better illustrations than I can bring you!

Aunty P’s ATOS satire gives way to the serious problems of Work Capability Assessments. The biggest sufferers are those who are being pushed to leave the protected ESA Support Group, and those who may completely lose their ESA. Serious mental health problems are getting worse. Please read the comments at the end of that article.

HILLTOP MEETINGS – the Latest News

You may already know that the Hilltop Day and Carers Centre on Primrose Street will be moving to the Horizon Resources Centre on Coldhams Lane. We plan to go with them. The news is that the building work at the Coldhams Lane site is taking longer than we had expected.

We will therefore be staying where we are for our meeting on Mon 24 September and for those in October and November. We will keep you posted with further news.

OCTOBER TALK

The next talk at St Matthews is on Monday 8 October. Our speaker will be our long-standing friend Clare Mundell, the CPFT Chief Pharmacist. Clare will be giving us her popular ‘Q&A’ session and will be pleased to answer our medication questions. This can be especially useful for folk just starting with medication. As usual, come along for a cuppa from 7.30; talk starts at 8pm.
FASHIONING EMOTIONAL HEALTH

This is the story of my Scentsory Design® research at Central Saint Martins College of Art & Design, where I work as a Senior Research Fellow in the School of Fashion & Textiles. I am regularly asked where I got the idea for my research, but rarely do I tell the truth because of the stigma I have experienced over the past two decades. Instead I say the idea came whilst volunteering as a ‘buddy’ for the Terrence Higgins Trust, offering emotional support for people living with HIV and AIDS – but that is only half of the story.

In 1991, I graduated with a degree in Fashion Communication from Central Saint Martins, which led to a career as a fashion stylist in the media (pop promos, editorial, TV). While I was a student I went to Japan looking for work and came back having met my future husband Marc Rolland, who was the menswear designer for Thierry Mugler (‘sci-fi’ creator of best-selling perfume ANGEL). He introduced me to the wonder of science fiction – and this is where my ‘science fashion’ story began.

A few years after graduating, I became very ill and was diagnosed with Bipolar II Disorder. I experienced deep depression, manic highs and chronic insomnia; it was a very chaotic and scary period and I was told “never tell anyone”. The illness had a catastrophic effect on me as a stylist as I was suddenly incapable of communicating with anyone, particularly in the fashion industry - ironic really, given that fashion is a form of expression, a desire to interact and communicate. Marc encouraged me to look at science and think of fashion in a completely different light; more towards an emotional force for giving ‘positive energy’. Inspired by a 1980s quote from Thierry Mugler on the future of fashion being “more about wellbeing and less about well-showing”, I took this statement to heart, launched myself into the world of wellness and went and did a PhD at the Royal College of Art.

My goal was simple: to create a ‘Smart Second Skin’ that could be worn as a protective layer to enhance my mood, offer emotional support and help me communicate better. Thanks to Professor John Miles at the Royal College of Art who supported my sensory research (and saved my life!) I invented futuristic ‘wellness fabrics’ based on our most evocative sense and primitive communication system – the olfactory sense.

Marc also has bipolar. As a successful designer in the fashion industry (Salvatore Ferragamo, Brunello Cucinrelli), he has had a dramatic impact on my work over the past 20-odd years. It has not been easy; however the bonuses that my type of bipolar gives, such as the wider range of emotions and creativity, even the hypomania at times, outweigh the negative aspects (depression, pain, anger, rage, sadness, social anxiety, fatigue, low self-esteem) and it has all played a major part in my Smart Second Skin vision. With our experience as radical thinkers, sensitive designers and long-term users of health services, our ambition is to start a design-led ‘Science Fashion Lab’ in Cambridge linked to Haute Couture in Paris.

Fifteen years after completing my PhD and giving birth to our three beautiful children (Madeleine 15, Thaddeus 11 and Zéphyr 10), the demand to improve quality of life, coupled with the fast acceleration of technologies, has led to a growing trend of ‘wellbeing’ and personal health monitoring tools. During those fifteen years, I have worked on numerous wellness projects from my Smart Second Skin clothing, that emits scent by mimicking the neurobiological delivery system found under skin, to the eScent® personalised user-worn delivery device, capable of dispensing wellbeing scents in response to a stimulus. In 2000, I also worked for an MIT Media Lab start-up company promoting ‘wearable technologies’ inspired by Star Trek (think ‘tricorder’ and ‘communicator’).

Fashion will always have the glitzy ‘well-showing’ element, but it is rarely used as a platform for ‘wellbeing’, and this is where I am using my bipolar diagnosis to inform my research into this interface of creative design and scientific principles. However I am fully aware that I must tread carefully due to the sensitivity of the condition.

I am now using my experience as a catalyst to find new ways to balance the physiological, psychological and emotional states through smell and intelligent monitoring technologies. I do this by seeking out leading experts in biotechnology, electronic engineering, psychology and design who share my vision and passion. One of my projects is on point-of-care diagnostics and mobile personal devices with Professor Chris Lowe, a leading science entrepreneurial academic at the University of Cambridge, where I also work as a Visiting Scholar in the Department of Chemical Engineering & Biotechnology. What drives me? My kids. With further research emerging of an increased risk of inheriting bipolar (50-75%) from two bipolar parents, I want to invent a simple but effective way to manage a better life by reducing stress and improving sleep, and therefore limit the risk of a potential acute bipolar episode.

I am pioneering a new discipline of electronic scent-emitting devices that could have a major impact on emotional wellbeing and the way we experience things in everyday life. Smell has the power to evoke emotion because olfactory substances impact directly with the limbic system in our brain. Nowadays, technology only reaches out to sight, sound and touch senses to enhance users’ experiences; however, due to technological constraints, there has been limited use of scents to enhance a user’s olfactory experience. I am attempting to change this through my research in the Textile Futures Research Centre at Central Saint Martins, and at the University of Cambridge.

Scentsory Design® is a ‘science fashion’ project that unites emerging technologies, Complementary and Alternative Medicine (CAM), wellbeing and ‘emotional fashion’ with the ancient art of perfumery and the therapeutic power of essential oils. CAM is used by two million adults as an over-the-counter alternative to stress-relief and sleep products. There is increasing evidence in the growing field of ‘aromachology’ (the study between scent and psychology founded by the Sense of Smell Institute in 1989) that certain plant-based essential oils can reduce stress by influencing mood, physiology and behaviour, emotional states and improve sleep. For example, it is widely known that citrus can alleviate stress and lavender can sedate.

Using the science of aromachology as the anchor, this project stems from the realms of science fiction by projecting strange new connections between different disciplines in science, art and pop culture. It explores interactive fragrance technology (i.e. scent-on-demand) that goes beyond (passive) scratch and sniff, burning incense and (alcohol-based) perfume bottles. Often compared with the military police in Star Trek: The Next Generation who sniffed aromas from sensory emitters embedded in uniforms to change their state of mind, Scentsory Design® invents a new method to deliver scent from ‘intelligent’ mood-enhancing clothing. By creating an ‘active’ scent symphony that is tailored to fit your mood throughout the day, this is a new wearable concept in electronic perfumery that stimulates the sense of smell to trigger emotion. In a similar light to the ‘scent organ’ in Aldous Huxley’s Brave New World novel, it works as an olfactory keyboard that stores your favourite wellness scents. It has the ability to choose from an entire palette of scents that changes over time, depending on how you are feeling.

Although still in the early stages of development, the technology offers a personalised olfactory bubble of wellness from a micro-device called eScent® - a kind of portable scent player or ‘iPod’ for scent. Further inspired by UBIK, a science fiction novel by Philip K. Dick, which describes a ‘reality/illusion’ projection sprayed from a can to destabilise a nightmare, this intimate ‘bubble’ signifies a protective ‘skin’ or pendulum that balances wellbeing. Programmed and activated by the user alone, eScent® delivers a non-invasive ‘wardrobe of fragrances’, in a controllable manner depending on mood or time of day. If combined with biometric sensors that measure how you are feeling, clothes and jewellery could enhance mood by dispensing soothing scents to reduce stress and anger, boost energy and increase confidence levels. Similarly, relaxing scents could fight tiredness; analgesic scents could relieve pain, or improve memory.

We have long known that stress is the adverse reaction people have to excessive demands placed on them. With this in mind, I have recently completed a prestigious Knowledge Transfer Fellowship called Smell The Colour Of The Rainbow in the area of smell and scent to reduce stress and improve sleep, through a collaboration with Philips. Funded by the Arts & Humanities Research Council, over the course of eighteen months, I engaged in an active Knowledge Transfer program to explore opportunities resulting from my academic work on eScent® in areas of interest to Philips. I worked with Philips stress and sleep businesses (therapy/mood/SAD lighting) and AVENT (mother/child) on ‘meaningful innovations’ that demonstrated the benefits of scent-on-demand in ‘emotional products’. The project greatly appealed to me, not only because of my erratic mood swings, but as a sufferer of post-natal depression and never being able to sleep the same way again after having children!

On a personal level, the fellowship really gave me the opportunity to embrace my bipolar diagnosis. I worked with some of the UK’s leading smell experts from Cardiff University, along with joint expertise in design, colour and technology. By introducing these elements into the world of health and wellbeing, I used mood-enhancement as the route. Evidence-based essential oils were validated by the latest aromachology research and correlated with colour, to create a personalised ‘therapeutic rainbow’ pendulum, across the range of de-stress > relief > calm > peaceful > relax > super-energise. Clinical evidence on the properties of lavender and sweet orange were critically reviewed and scientific data was extracted in support of the value of essential oils to alleviate stress and aid sleep. My team presented ‘meaningful innovations’ to a wider Philips audience to demonstrate a deep understanding of the therapeutic nature of the oils’ physiological and psychological effects on the body in terms of sleep behaviour and the links between scent, colour and emotional state.

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In November 2011, I presented eScent® as a new Wellness Recovery Action Plan (WRAP) strategy to improve wellbeing at the (Philips sponsored) Quantified Self Europe Conference. It was introduced as a means to complement ‘self-tracking’ patient-driven monitoring tools pioneered by the Quantified Self (QS) movement originating from Silicon Valley in 2007. For example, people with bipolar disorder might find it useful to track sleep patterns or extreme mood swings, to reduce the risk of relapse by identifying early warning body signals (irregular sleep, physiological response of erratic behaviour etc), to sustain daily maintenance plans or to manage medication. By wearing a scent device in addition to QS self-monitoring tools, eScent® would release counteractive scents to relieve tension whenever stress levels exceed a certain threshold. I am not trying to replace mood stabilizers, nor antidepressants, but instead to design a new intimate active ‘scent bubble’ to complement orthodox treatments.

My next step is to introduce a new dimension to fashion by taking the colour/scent work from my fellowship and researching primary (bipolar) emotions which can be expressed at different intensities (depending on personal needs) and mixed with one another to create ‘emotional fashion’. I am excited about the future and the thrill of being able to move my research forward: to discover new connections and new ways of living which I am now commercialising as a (sc)entrepreneur through University spinout companies.

Jenny j.tillotson@csm.arts.ac.uk

Biography and links to her projects:
http://www.arts.ac.uk/tfrg/node/10957
An excellent Cambridge Network news article:
http://tinyurl.com/8r3fmdd
Jenny’s Knowledge Transfer Fellowship project:
http://j.mp/PY5rc3

References in this article:


ATOSITY CONSEQUENCES


I waited a fortnight then requested a copy of my report. Let’s get physical first. On examination [non-existent] it was obvious that full assessment wasn’t on, “due to the client’s too anxious”. Perhaps my osteo’s report was too anxious to be read. But I carried my creased six sheets of A4 and two sheets of thin card, using the bad arm. Reported “unlikely” that my problem would affect my daily life. I’d like the young upstart to see what happens when I drop my soap in the shower!

Mental health? Being diagnosed Bipolar after my first sentence had alerted me, but not enough for the truly creative writing of the report. It seems I whispered timidly, but was irritable. I “stared” – pretty impressive, as he never looked at me. I was seen to be “rocking” in my chair – again pretty impressive ‘cos I was able to sit still during interview’. Apparently I need daily help to take my medication [what?] and never get up before noon [just in time to see myself coming back from voluntary work]. I could go on with the fiction – 20 incorrect observations or suppositions - but I think my CPN’s reaction covers it all. Eyebrows up, jaw down, he said he could only recognise the report as mine ‘cos it had my name on the front.

My assessor’s ‘prognosis’ was based on the “ESA50 questionnaire, the history and examination”. No mention of medical statements. What exactly is this “history”? The examination was cursory or non-existent and (oops) the claimant filled in the ESA. I guess there are quotas to meet. Oh, sorry Mr ex-Minister of Health, they’re called ‘forecasts’. So no physical problem but judged more depressed than I am? I now hear assessors are trained to avoid eye contact; I could’ve been pronounced anything! My own future benefit? Uncertain. I fill in many forms.

It’s outrageous. For example, if you do not rock in your chair, you can be told that you have no mental health problem! Take a companion to your ATOS WCA. Get a copy of your report. Consult Citizens Advice Bureau. Many appeals are being upheld nationally.

Christina Rowland-Jones suggests that, in order to collect as much evidence as possible, people contact Clare Hodgson at the Primary Care Trust by email, so that at least they are made aware of the number of cases still turning up. Email claire.hodgson@cambridgeshire.nhs.uk and please mention Christina.

Aunty d’Presente
PERSONALISED MEDICATION – a Future?

What would you think if your GP referred you to a specialist and the specialist wrote to you and said “just fill out these forms, send some saliva and I will get back to you”. The forms would be about your symptoms and history – these would be fed into a computer to come up with a diagnosis. The saliva would be sent to the Genetics laboratory – this would be analysed to tell you what medicine would be most likely to work particularly for you. The Genetics study would also help to confirm the diagnosis. This might of course be particularly bad news for us psychiatrists as the psychiatrist in this scenario would probably be a computer rather than a person who went to medical school for 6 years! But would it be better for you?

The idea of personalising your medication is already here in some medical specialties. Women with breast cancer have their cancer cells analysed and if a particular marker is found on the cells a specific drug to treat the cancer is used and more likely to be effective. There is a blood test which is occasionally used in schizophrenia. A drug called clozapine is very effective for those with schizophrenia but can also have a dangerous but rare side effect. So it is worth trying to find those people who are most likely to benefit from this treatment. However, the test is not often used as there is still a fair chance of improvement even if the test is negative and so people may still be willing to try the medicine despite the small risk.

It is clear with treatments such as lithium that there is a big variation in how effective it is for people with Bipolar. About 1 in 3 get a very major benefit, but about 1 in 3 get no benefit and the other 1 in 3 get some benefit. Currently your psychiatrist will look at your symptoms, the course of your illness and your family history then make a judgement about how likely lithium is to work for you. But it is a judgement and there is a lot of uncertainty. We think that it is likely that some genetic factors are connected with the response to lithium and if we could find these then you could also be given that information when you are coming to a decision about whether or not to take lithium.

So would you be happy to just get the computer printout and then make a decision? For myself, I am hoping that you will still want to talk to a human (with a medical degree) who has had experience of you and also your illness in other people so that you can come to the best decision. Otherwise I am out of a job in 30 years’ time!

Dr Neil Hunt

MANAGING DEPRESSION – July Talk

Mania can destroy relationships, jobs and finances with spectacular, rapid results. Depression often lasts much longer while still slowly destroying our lives. To discuss depression we were joined by Dr Rajini Ramana, Consultant Psychiatrist, who has made several studies of long-term outcomes.

If someone goes to their doctor with depression and no record of mania so far they will be treated as unipolar (having only lows) rather than bipolar (highs as well). Estimates are that up to 30% of people starting off as unipolar will later become bipolar. In one of Dr Ramana’s studies 8-12% of people with ‘hard to treat’ depression became bipolar in 5 years.

The problem is that if patients are given antidepressants at that stage without a mood stabiliser there is the risk they will switch into mania. Antidepressants are not ruled out for us but we might need a mood stabiliser as well to stop our mood going through the roof. People with unipolar depression are often advised to take antidepressants for a lot shorter time - review after 12 weeks and, if everything is OK, continue for 6-9 months. It can be better to use the types that do not stay in the system too long. Prozac, for example, remains in the system for a longer time than most.

Atypical antipsychotics (e.g. olanzapine, quetiapine) may also help in some cases but there is the risk of weight gain and diabetes. Quetiapine can be effective in a low dose. Lamotrigine, a newer antiepileptic drug can help and will often be used in conjunction with a mood stabiliser. Dr Ramana reminded us that the ‘old’ antipsychotics like chlorpromazine and haloperidol are still there for use and some prefer them. Old treatments like ECT and sleep deprivation are also there as a last resort.

We can help ourselves by maintaining a regular sleep cycle and a routine. Sunshine helps sometimes, supplemented with a light box. Night shifts are not advised, nor is long-haul flight. Exercise is reported as beneficial by many people.

We saw there are several options for treating depression, each with its own benefits and possible disadvantages. There is no need just to suffer in silence.

Phil
MEETINGS – Please note: Latest News on the Relocation of our Support Group Meetings

The Hilltop Day and Carers Centre will move to the Horizon Resource Centre on Coldhams Lane and it is our intention to move our support group meetings there. Building work at the new site is taking longer than originally planned. Our September, October and November meetings will remain at their current location. We will send out email notifications when we can confirm a moving date and any available details of new arrangements. If you hear nothing, do not hesitate to get in touch.

As usual, the latest up-to-date calendar will be maintained on the website. Remember that not all meetings fall exactly on the second or fourth Monday of the month, so do check dates. Email reminders can be sent if requested. Let us know if you’re stuck for transport.

Support Group Meetings at Hilltop, Primrose Street, Cambridge CB4 3EH

We have small groups. Hilltop car park is very near the end of Greens Road and down a little slope. Please use it, rather than the surrounding streets. Come for refreshments at 7.30pm for a 7.45pm start.

The next four meetings are scheduled for Mondays 24 September, 22 October, 26 November and 17 December.

Meetings at St Matthews Parish Hall, St Matthews Road, Cambridge CB1 2LT

We have 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. Come for refreshments and informal chat at 7.30pm for an 8pm start.

Monday 8 October – Medication. CPFT Chief Pharmacist Clare Mundell will bring us the latest news, and give her usual Q&A session. An old friend of ours, Clare is always happy to answer detailed questions.

CONTACT DETAILS

Telephone: 0845 434 9780, up until 6.00pm. This number is for getting information about meetings. It is not a helpline or a number to call for a chat.

Please send any correspondence to us:

c/o Threeways, 14 Home End, Fulbourn, Cambridge CB21 5BS

Website: www.cambridgebipolar.org.uk Group email: cambridge(AT)bipolarukgroups.org.uk

Emails can also be sent to the following. Replace ‘(AT)’ in the addresses with ‘@’ (It’s to reduce spam).

Jackie Duckworth Facilitator/Treasurer jackie(AT)cambridgebipolar.org.uk
Phil Alsop Secretary phil(AT)cambridgebipolar.org.uk
Jon Warden Newsletter Editor jon(AT)cambridgebipolar.org.uk

We are a local group of Bipolar UK, 11 Belgrave Rd, London SW1V 1TU. Tel: 0207 931 6480.
Website: www.bipolaruk.org.uk Email: info(AT)bipolaruk.org.uk Registered Charity Number 293340