BATTLE AGAINST TRANQUILLISERS AGM – 2016
BENZODIAZEPINE 'QUESTION TIME'

PANEL
Introductions
ALISON FIXSEN
Alison is a senior lecturer and disability tutor at the University of Westminster. She is the lead author on a number of peer-reviewed papers, including two on Benzodiazepine withdrawal. One of these articles recounts her personal experience of benzodiazepine withdrawal and recovery. Alison is presently working on a project proposal for a Pilot study developing a benzodiazepine and Z drug support and recovery group and forum for older people, along with Professor Damien Ridge.

SUE MULVENNA
I have spent the last three years working for NHS England as Head of Pharmacy and Controlled Drugs Accountable Officer, and I now cover all of the South West. This role is mainly about improving patient and public safety by supporting the safe and effective use of medicines, and investigating when things go wrong. Before this role I was Head of Medicines Management in Bristol, for the Primary Care Trust (PCT), then the Clinical Commissioning Group (CCG). Previous to that I was Head of Medicines Management for South Gloucestershire PCT; I moved to this role from managing a Community Pharmacy, as I felt I would be able to make more of a difference. I have been working in the Bristol area as a pharmacist for 30 years.

GARY CHEESE
First introduced to Colin in 2012 – becoming addicted to sleeping pills after working nights – got to the stage of spending about £400 a week and taking 70mg a night and taking medication without even realising, Doctors did not have a clue of how to withdrawal – BAT devised a proper programme to cut whatever I felt comfortable with. Ended up by giving tablets to family member who gave the required amount per day because I felt I could trust myself. Initially sent to DHI who directed me to BAT. Don't think I would have got off them without BAT

KATHY BAILEY
I am a Holistic Therapist who works with BAT and DHI to provide Reiki, Relaxation and Meditation to those in need. I was born near Stonehenge and my Dad was a Custodian there, so maybe that is where I inherited my interest in Holistic Therapies. I have spent a lot of time working in Residential and Nursing Homes with people having Dementia and Alzheimer's giving Reiki. I have a love of life after being ill myself with Cancer, so I do understand what pain and suffering can cause to not only ourselves but our families as well. I am also a very good listener.

Question 1
I would like to know more about how you managed your sleep problem without the medication

Gary
it was very difficult and I still suffer from time to time. I don't really know how I coped. I did have a year off work to get over this addiction – my employers were fantastic. I am led to believe my withdrawal was quite quick nevertheless
My main issue with sleep was I was fixated with it to the point that I thought I needed x hours per day to function and I was going back to sleep in the afternoon because I thought I needed that number of hours. Once I had managed to kick that it fell into place – but it was really difficult. I was fixated on sleep. I can't pinpoint how I managed it. It helped that I wasn't working and I didn't have to think 'I need 8 hours sleep because I have to go to work tomorrow' and trying not to sleep in the afternoon. Kathy made CDs which I used to play where I went on a journey which really helped. I used to fall asleep to the CDs and I still go to sleep with the radio on. It was and is still difficult but once you have in your head that I could function on less sleep that was the battle. Quite recently I go to bed and not watch TV which is helping.

Kathy
One of the things I actually say to people is – like Gary will go to bed and watch TV, say a horror film – and its one of the worst things you can do- in my relaxation coursework it said – don't take a heavy / serious book to bed, don't watch TV or if you do, make it something light. Best of all don't have a TV in the bedroom.

Vicky
I'm fascinated by the illegal prescription writing in Bristol which Sue mentioned. Gary mentioned he was buying on the internet. I understand you can buy almost anything from the USA?

Sue
I understand the government have got a department to look at internet access to medicines – people can buy almost anything – even really strong antipsychotic things that they can buy over there (in America) It's interesting that people are going down the old fashioned route of writing fake prescriptions. Probably even more frightening is the NPS – we try not to call them legal highs – from talking to the emergency services it's a massive problem because if they find someone unconscious they don't know what to do. If its heroin they know what the antidotes are but not with NPS, and people have been made terribly ill.
It's a terrible problem in prisons where they're being used in horrible ways. Especially spice which is a synthetic cannabinoid which you would think would calm people down, gets people in a rage and in prison they will give it to new prisoners, and then bet on them fighting.
I know that headshops have now been closed which is good, because as an example we used to get a lot of problems with where there was a shop near a supported living place for people with Asperger's as an example because they didn't really understand the dangers of it – the police used to try all manner of things to shut them down. At the time the legislation came in there was a lot of selling off stock. The internet is very worrying, especially the dark web where you can get all manner of things. It's hard to know how to beat that. When we find out we do feed it back to the government who have quite a good team shutting things down.

Vicky
Una, did you want to say anything about that?

Una
Yes, I wanted to ask if you've come across benzo analogues yet?

Sue
Yes – there's this one beginning with 'E' isn't there?

Una
Etizolam is the most popular one. Again, that is covered by the law that closed down headshops however it has not been publicised that the analogues have not been covered in the same way, and by the same legislation as legal highs. There have been a number of deaths associated with them.

Sue
They're really strong, and they look just like the typical blue pill – and so people were taking them thinking they're that.

Vicky
so where are they being sourced? are they coming from the internet?

Sue
I think they're coming from America.

Vicky
But it's illicit?

Una
It's illicit, and headshops were selling legal highs on one side and benzo analogues on the other, which makes sense – because you can get high and them come down. I just find it really disappointing that in all the publicity about legal highs, benzo analogues were not mentioned, so we've mentioned them in our annual report. I think that the pattern of deaths that happened on 2014 is very similar to how legal highs started.

Sue
… and it's worth mentioning that what is difficult to unpack is the combination of drugs. There's more information coming from the American federal drugs agency is that it's very dangerous to take benzos with opiates as it can cause respiratory depression – and again, I don't think GPs are aware of this. When they add something in, they don't think about the combination.

Pregabalin is another one, and there have been a huge excess of heroin deaths. It was being assumed that pregabalin made heroin stronger and we were being asked could we send a message out to people to say that pregabalin made heroin stronger, and we were thinking they're just going to go 'oh, great' and it's not the message really – it's been difficult to manage that. There's been a lot of work going on in Bristol with AWP psychiatrists, talking to GPs to say don't just keep putting people on Pregabalin. The unfortunate thing about pregabalin is that there's some NICE guidance that came out about neuropathic pain that said at one time that Pregabalin was the thing you should use because it had a licence for it, and all the other meds that GPs use didn't – and it was a big mistake because Pregabalin is very expensive and the drug company had a whale of a time promoting its use. And it makes it very easy for people to get hold of for their own reasons – to pretend that they've got neuropathic pain. It's not difficult. So we've got areas of Bristol where something like 25% of young people are on Pregabalin in places.

Alison Fixsen
Can I just ask - with benzos and z drugs there is a recommended limit – 2-4 weeks or whatever. Is that the same with pregabalin and it just gets ignored?

Sue
No, I don't think so. It gets complicated. It was originally used for epilepsy and now for neuropathic pain – and both of them are long term use.

Gary
A friend of mine has been on them for the best part of 8 years. He's on the maximum dose.

Sue
In years to come we'll probably be sitting round asking how we can get people off pregabalin. When the Z drugs came out – it was like they were the 'new safe thing that wasn't going to be a problem'. And it's always a problem, in the end.

Alison Fixsen
You're obviously used to working with people on pregabalin – can I just ask what the effects are in terms of personality changes and things like that?

Una
Well, it's similar to benzos really – and the coming off is similar. We actually have a client at the moment who's cutting pregabalin before looking at the benzos – he had started cutting the benzos but decided to cut the pregabalin first as he'd been on them a short time – and we're having a look very carefully with him to see what happens. So far he's saying when he makes a cut it's AS difficult but it doesn't last as long. Thats what he's saying so far

Question 2
If you were to come off one or the other first, would you have a preference or would it be personal choice?

Una
We'd always go with personal choice – the whole of our service is based on that, so if someone has a preference …

And what if they don't have a preference?

Una
well then we'd say benzos first. Certainly antidepressants we'd leave till the end – or pregabalin.

Question 3
Could I just ask Alison – you talked about you're research and I wondered if you had any plans or ideas for your next bit of research is going to be looking at?

Alison
Well I need to discuss with everyone else but we've put together a proposal for research into patient benefit – that was the original proposal which took a long time to do. That was working with quite a few people including Heather Ashton and Malcolm Lader – at that point the idea was to work with I think it was healthtalk.org – our Uni has a relationship with the people at Oxford Uni who produce their programmes which are sort of patient experiences online so you can find out what it's like to be a certain kind of person – what it would be like to be on benzos or come off them – so it was for education. It looked like the funding wasn't going to be passed.

We wanted to do something and make it a bit smaller working with the Dunhill trust in how we could support older users. They don't state what older is – it could be over 50, or over 60. This seems to be the area were likely to work in. Possibly in care homes, looking at training but also setting up peer support. we all know it's not just a 6 or 12 week programme – you don't know where you're going to be in 6 or 12 weeks; it just doesn't work like that. It can be very long – years. It has to be a support that's sustainable and some of that may be one lead carer who has a much deeper understanding about benzos able to support people – and the team because people start to doubt individuals. One of the main problems as you know is that it mimics so many other things. It may appear that the person is depressed, has multiple

anxieties – agoraphobia … it can mimic everything. You can think you've got UTIs, end up on multiple drugs and it's so tempting for a prescriber to think they'll add another drug to the cocktail and then the user completely loses their identity s one of the things I am passionate aout is helping people to recover their identity and sense of who they are. When you start to layer drugs like that you don't know what's going to happen. I'd like to help prescribers to understand perhaps a bit of what withdrawal is like. If you haven't done it you'll never know – so you might be able to understand 'oh yes, that might be a symptom of withdrawal. Let's deal with it another way. We'll give them a massage or some reiki – or just talk' It's sometimes just reassurance – someone to say 'it's all right, you will get through it'

Vicki
There's some money coming up through the 'aging better' fund to look at working with older people in a range of setting including residential and care homes. Maybe we could work with you around that.

Question 3
Two questions in one – with all the information around now about benzos and pregabalin etc – is there any real need for them, or is it that were a quick fix society and we need whatever kind of drug, whatever risks go with them?

Sue
I don't know if you saw that programme about the Dr who wanted to get everyone off drugs? It made me angry. I can see where he's coming from but its throwing the baby out with the bathwater. If you just took an individual approach with every person there are things that make a real difference. For example, I didn't get on with fluoxetine but I'm on citalopram now and I've never been more well. I was an anxious child and adult - I went through various antidepressants that didn't work and I have found one that works for me. I'm not keen to come off it any time soon. If any of you have ever been depressed you slightly slip into an alternate reality of thinking 'well, were all going to die alone' because that's the truth isn't it? There's nothing you can do about it – but yet with most people that doesn't feature in their day. You can understand anxiety – it has a cause – but the guy blithely said that antidepressants don't work any better than a placebo but the evidence for antidepressants in mild to moderate depression is really good. Obviously there are places where opioid painkillers are really good, but if you use them for more than a couple of weeks you've got all the benefits you're going to get. I do think there is a place for many drugs that are very useful and I wouldn't want any drug to get completely banned. It's the idea that suddenly NICE guidance says that a certain drug must be used for something and suddenly everyone gets it. Years ago something came out to say GPs weren't prescribing enough antidepressants and then a few years later they were prescribing them too much! It's all looked at as a big thing and not whether an individual needs them. So many people say they're on too many pills and it can't be doing them any good. I used to do a rehabilitation group and ask how many was a safe number 4? 5? 6? and it depends. I know someone who's taking 25 meds a day – he's a diabetic asthmatic and they're keeping him alive. He goes out and plays golf every day. But there may be someone else taking 3 medicines that are doing more harm than good. It depends. The thing that worries me is where GPs are on that scale – all medicines are good or all medicines are rubbish.

Alison
a slightly more idealistic view is that were a sick society in a lot of ways – if you look at our society and compare to something more simple we have a lot more things. I think we can start to examine the way we think about illness and the way we treat it and think about some of the alternatives to the mechanistic view of illness. I work in the complementary therapy dept and none of us ever say 'take people off their medication' because that's dangerous – BUT there is a start and end. I watched some of the programme and it was very black and white but there is a tendency not to ask enough questions – so if we started to explore people's problems we might find another solution more effective in the long term. I sometimes say to my students 'if your car was going wrong and there was a red warning light on would you rip the

warning light off?' so sometimes we want to find out why the light is on. I think its getting better – we have things like counselling – CBT etc.

Vicki
that's what BAT is doing with Coniston on the mental health project – looking at different ways to wellbeing that are not tablet based.

Kathy
Just to say that with doing reiki and meditation is the fact that someone is with people and taking the time to ask how they are. Someone said to me a few weeks ago a gentleman said actually it's so nice for someone to touch me and give me something nice without expecting something in return. Touch is so important – when we're little we run to mum or teacher (you can't do that now) - it's taking the time to give the comfort. I asked someone how they were and they said 'fine thank you' and then they said 'no, I'm not fine' and I said 'just say how you feel'

Vicky
There's a thing going round on social media about the barber in London cutting hair of homeless people who no one talks to and no one touches – it's very moving. There's some interesting stuff about needs like being touched not being met.

Question 4
This question is for the panel as a whole, more to Sue, about customs. I'd love to have BAT advising customs and saying it should be a lot stricter, and joined up.

Sue
Yes, it's a difficult thing – very sad that there either aren't the resources or they don't have the information to join all this up ... as we've mentioned before this juxtaposition of these guys going to all the rouble of writing fake prescriptions, and taking them into pharmacies etc and risk being found by the police, and yet you can just order from the USA! Is it really expensive on the internet?

Well, it's not actually the USA it's coming from – its India, Indonesia – the far east. I used to get calls every 3 weeks from them – if you 'go against' these companies and you buy from a rival or something they will fleece your card. I lost something like £40,000 on my card when I started complaining. They work very closely with people who will rip off your card.

Sue
Was it genuine medication?

You don't know what you're taking – one can out you sky high, one can't. I'm working with BAT now on a prescribed amount and I haven't touched any of the illicit at all.

Sue
I will take it to the regulation agency to try and think about that link up.

There is a guardian article already written about this – not so much Silk Road or the 'dark web' but the fact that you can just google 'where can I buy Benzos from' and you will get 4 or 5 companies. It's like 'whack a mole' trying to shut them down, They will pop up again. It's UK customs that are not really that interested.

Sue
I don't think you're on your own in this, it is a massive problem – we don't even understand the scale of it.

You'd think it would be easy to link up those departments. Surely border control with the probation team.it could take a huge budget. You could order tonight – Zopiclone is easier to get into the country than anything else – and have it within 3 days. Z drugs seem to come faster into the UK because people want them more whereas the 'old fashioned' benzos the market isn't as hungry – but they are on the street.

Sue
The police say that on the street people won't pay more than £1 a pill, which interested me because Pregabalin actually costs more than that. Would you say you paid more than that?

Probably yes – from memory. But as you rightly said you don't know WHAT is in it. I just thought I'd share it.

Sue
I'm so glad you've told us.

Vicki
What's good is that Sue has the link now to feed that back in national level. Thank you

Question 5
Doctors don't seem to be worried about giving Omeprazole to benzo patients but it puts them into withdrawal because it's a Proton Pump Inhibitor – a PPI – I've had experience of a friend of mine and an elderly cousin being in sever withdrawal because they've taken it. I've had it myself but I've been in hospital. It's a common drug that is given to stop the stomach lining being affected if you're having a lot of painkiller – but it gave me very severe side effects of sickness and diarrhoea. I'm an ex-dispenser and I didn't twig that the pill Id had the day before the op – Id taken an omeprazole and was instantly sick when I tried to eat. And when I came home and took myself off them I felt like I'd hit a brick wall – but better afterwards. There's a herbal remedy you can take that does the same but without the side effects. My cousin kept on being told that she could have Lansoprazole or something else.

Sue
It works exactly the same way!

Yes, it does and it goes to show how ignorant the GP was of what it was doing. I'm an executive and so is she, and I visited her that day I had to help her with every single thing – she had cheques to sign and she could barely write. She couldn't cope with anything.

Vicki
Is that something you've heard from other people, Una?

Una
I know that you shouldn't have Omeprazole with benzos – it's contraindicated and it's in the BNF (British National Formulary)

Vicki
So it's widely known apart from in the medical profession! So how do we feed that back in? Will you tell the BMA when you next see them?

Sue
You can use the yellow card reporting scheme – they do take notice of that

You really cannot function - but if no one tells them …

Vicki
We'll make a note of that and see if we can help on an organisational level

Question 6
This is for Una really - I know you've been doing some work in residential rehab and I wondered if you'd seen a change in prescribing and detox practices?

Una
I can't really answer that – what I do know is happening is that particular centre is giving their residents our contact details if they've been taken off benzos there. The feeling we had when we went there was that this particular junior manager had real reasons (whatever they were) for wanting benzo issues to be highlighted and I'm only guessing but I think she may have come up against problems higher up the management tree. So not in practice – although what was discussed was that medications would be done one at a time or even maybe in little phases. For instance they would perhaps be taken off – say if it was heroin – that would happen first and then they would be discharged to BAT where they would learn what it would be like coming off benzos. They would have a bit of input to start them off and then they would go out again. It was quote a well thought out model but I have to say no, it hasn't happened.

Vicki
That's a shame

Question 7
I wonder actually how you DO get on talking to the BMA and the Royal College of Medicine – whether they take that forward and is student doctors are trained in anything you say?

Una
Well, they love everything we say – and they're all very important people – both of the royal colleges, and NICE and public health England etc … there are sub groups that feed into the main BMA group and we're in the Royal College of GPs sub group – were looking at service user information and what I can sey to you at the moment is whenever they publish their minutes they always mention BAT and at the moment they are saying that all the patient information stuff will be informed by BAT. And the other really funny thing that they're saying was that BAT would train Drs on how to speak to patients on benzos so that they didn't upset them so we sent back a whole list of useful things to say and not say. It is good.

Vicki
And that brings us in a nice full circle to Gary's comment that his GP didn't have a clue and that it was actually only when you met Colin – someone who knew what he was talking about …

Gary
He said listen to Colin as regards the cuts and when I'd got to a level then he'd start prescribing.

Question 8
If you were to have a GP in front of you, what piece of gentle advice would you give them?

Vicki
So that will be our final question

Gary
I can only reflect on what the GP said to me – he just said 'cut one every day' and Colin said the amount I was on, if I'd started doing that I'd have had a seizure – so totally rubbish information really

Vicki
So don't give advice that you don't understand? Kathy?

Kathy
Mine would be to listen, and actually when your patient is with you don't be tapping on the computer.

Vicki
That's one of my bugbears – I actually saw a psychiatrist doing that – he never even turned his back to look at the patient. Alison?

Alison
Mine would be to talk to the patient on an equal level – and to respect any changes that they have made in terms of reducing their dose and empower them so that they're the person who makes the decision so that they can be completely honest with the doctor.

Vicki
As Una said it's about the person's choice. Sue – GP in front of you. What are you going to say?

Sue
I suppose I'd say if you're thinking of putting a new drug in make sure you take one out – don't just keep adding them in!

Vicki
They're not smarties! Una?

Una
I suppose the one thing I would say you need to do is reassure the person and acknowledge that what they're saying is what they're feeling. So instead of being defensive and saying 'oh it's not like that at all' – to be able to say 'I don't know, but I can find out for you' but hopefully to have enough training so that they can say 'you will be well in the end' because as we always say to people with training it's the hardest thing you'll ever do but the most worthwhile.