

## QuITT Learning Set – Monday 22 May 2023

### Questions / Answers from the ‘Involving people with lived experience in your QI project’ session.

Claire Atkins (Senior Peer Support Worker from Tees, Esk and Wear Valley NHS Foundation Trust) and Sue Mountain (Expert by Experience from Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust) each shared their journey to quitting smoking whilst experiencing mental health conditions.

They received some questions via Menti, which they did not have the time to answer at the event. Below are the questions and Sue and Claire’s responses to these.

**Q1: Do you think peer support workers should be embedded in smokefree services in all trusts?**

**Sue:**

I believe peer support should be embedded in smokefree services. Especially if they have quit to give their experience.

**Claire:**

Yes, I feel Peer Workers should be in every service in the NHS, as a PSW I am able to connect through my own lived experience to service users on a variety of topics. This can help not only the service user but also the multi-disciplinary team as at times I am able to bridge the gap between the two.

Many service users often confide in me in ways they do not feel comfortable doing with their clinicians, this allows me to foster an honest, open and mutual relationship with the people I work with and as such benefits everyone involved in the care of that individual.

With regards to smoke free services, I feel having that lived experience voice is vital. I openly admit that my inner addict still struggles with the cravings for smoking especially when my mental health is struggling.

Having someone like me on the team allows me to share the struggles I have had and still have around being an ex-smoker, which in turn can allow the team to think of alternative approaches and strategies they may not have considered prior to me sharing my experiences.

**Q2: What about passive smoking? Has your smoking affected your children's life and attitude? Are they smokers?**

**Sue:**

I'm afraid I did smoke with my children I fear everyday what damage I may have done. No smokers. Eldest used to smoke.

**Claire:**

I do not have children of my own, however, I have been in relationships where there have been children and I always chose to smoke outside. That said, the dangers of passive smoking are very real and the impact of that should not be underestimated.

**Q3: How did you manage your peers that smoke still as part of giving up?**

**Sue:**

My peers that smoke I try not to go on at them, but I do mention how fit I feel and how I can manage life without smoking.

**Claire:**

Many of my friends and colleagues still smoke, it usually depends how I am doing within myself and my own mental health as to whether I am able to be around people who are smoking or vaping. I try not to lecture my friends and colleagues; they all know the dangers and health risks of

smoking and many of them make the choice to still smoke and have their own reasons for making that choice.

Smoking/Vaping is an ongoing battle still for me, although I do make a conscious choice not to go back to actual cigarettes and if I feel the need for a “Crutch” I chose to vape.

I had to negotiate with my inner addict, when I am triggered or struggling mentally, I do crave the hand to mouth motion as I think there is something about that giving some stress relief mentally for me. I refuse to go back to actual cigarettes, so when I have that mental need I do allow myself to vape but only for a short period of time until I mentally feel stronger again at which point, I get rid of the vape. I do this so that the next time I feel triggered or like I am struggling I am still able to fall back to a vape and not something else.

**Q4: How do we support patients who are acutely unwell that come into hospital and we are required to take away cigarettes?**

**Sue:**

By supporting them. Reinforce how it is policy and not personal. You are there to help non-smoking in hospital. You can state how it actually effects mental health and that the addiction to nicotine tells you can't cope but as medical staff you will help them manage their lives without cigarettes.

**Claire:**

Personally, for me this is a tough issue to deal with, many people who have been admitted to an acute ward may have lost many of their freedoms and coping mechanisms that they would usually use. Then on top of that they are being asked to give up their only remaining vice, this can be a tough challenge for anyone.

That said, we are a no smoking trust, making sure this is known from the moment of admission. Making sure that cessation services are available as soon as the service user is on the ward, or where possible prior to coming on a ward.

I would suggest that where possible having access to vapes, patches, gum or whatever alternative is preferable to the individual are available straight away and not making the service user wait long periods for these items would be a great place to start.

Moreover, for a longer-term commitment from service users it might be that upon initial admission they are simply too unwell to be approached about quitting. So, waiting for the right time is also something to be considered.

#### **Q5: Is sharing this lived experience with other service users helpful?**

**Sue:**

I believe sharing lived experience help with change and also gives the smoker, as in my case, that it's not just them that suffers if they get cancer but their family and friends. Also, in my case I NEEDED to smoke, I loved smoking or so I thought, but I have managed to get through other cancers and health issues without my crutch.

**Claire:**

Sharing lived experience is valuable for so many reasons, I can honestly say that Peer Support saved my life! When I first discovered Peer support, I was still very unwell with my own mental health. I was not sober at that time and still using maladaptive coping strategies. I found having someone stand in front of me and share their story gave me so much to think about. I remember being at home and reflecting on what I had heard, and I was beginning to wonder how I might achieve that kind of recovery in my own life.

The individual who shared their story with me gave me hope which ultimately turned out to be the spark that lit the flame. I found their story inspirational which in turn gave me the self-belief and eventually self-worth that I had never found from services. Me hearing them share their journey made me believe recovery was possible and without that I genuinely do not know where I would be today.

As a Peer worker now, I often use my own struggles and story to show others that recovery, having a meaningful and purposeful life is possible and I know this because I am literal proof that it can be done. It's not easy but it is possible to learn to live with and manage mental health struggles and lead a fulfilling life.

#### **Q6: What do you feel doesn't help people to quit in hospital?**

**Sue:**

It doesn't help people when they can see others getting let off. Being bored will not help. Try keep them busy even if it's word searches or colouring in.

**Claire:**

I think this will vary from person to person, for me personally when I am acutely unwell, I do crave to smoke. As I mentioned in a previous answer I do negotiate with my inner addict and allow my self to vape if I am struggling.

I think not having access to the items needed such as vapes or patches immediately can cause struggles. If I was acutely unwell, I would struggle with cravings so making sure I had access to any items I needed straight away would be beneficial and if I was made to wait even a short period, I might become more frustrated than I would be if I was offered patches or a vape the moment I was admitted to a ward.

**Q7: What is your best experience of receiving support for stopping smoking?**

**Sue:**

My best experience was when I was in a quit group. I gained friends and we all supported each other.

**Claire:**

The best experience I had was when I initially began to try and quit, my local pharmacist was so helpful, he listened and understood the struggles I had with quitting. He allowed me to try lots of different products until I found what seemed to work best for me. I completed the 12-week course and by the end I was not using vapes or patches and had found I was able to switch from Nicorette gum to just chewing gum. This is process I still use now, so If I find myself using a vape again when I feel mentally ready to get rid of the vape again, I usually switch back to the Nicorette gum until I feel ready to switch back to just gum with no nicotine.

**Q8: What is your top tip for people trying to quit?**

**Sue:**

Mine is to mention their family... the family do not choose to smoke but as a smoker you are forcing your family to worry about you.

**Claire:**

The best tip I can offer is know yourself, it is not for me to tell people the reasons why they need to quit. To quit successfully I had to really want to quit for myself and not because I was being told to.

When at the learning set, I spoke about my inner addict, If I am being honest, I have found my battle with nicotine a harder battle to win than I did with my battle with alcohol and I have not had a drink in 8 years. For me personally there is a strong link to my mental health and smoking, it is a battle I face every day. However, as I began to find myself and my recovery journey, I was able to realise the connection between the two. For me it is very much a hand to mouth motion that gives me some stress relief, so I think an individual knowing themselves well enough to know what they need at that time is critical to anyone successfully quitting.

**Q9: What is the best way to support inpatients to quit?**

**Claire:**

I would say making sure that products are available immediately on admission and not making service users wait for access to vapes or patches or gum.

By having these available immediately, it will set the tone that smoking on the ward is not allowed, that alternatives are offered, available and promoted. If services users are expected to wait for access to smoking alternatives this can cause frustration and irritation which may cause further issues on the ward.

**Q10: Were you offered smoking cessation support when first diagnosed?**

**Sue:**

No, I was not offered cessation when diagnosed.

**Claire:**

No.



**Q11: With your experience of vaping, do you think the current solution of offering vapes is the way to go forward?**

**Sue:**

To me vaping is not a long-term solution. It is safer than smoking but only to be used to withdraw.

**Claire:**

For me personally, I feel using a vape to quit was helpful initially and I am unsure if I would have actually quit without it. What I did, however, learn was that vaping does not allow me to break the habit of hand to mouth stress relief. But yes, vaping although not ideal is better for me than actual cigarettes so I do see the benefit in using these in conjunction with other cessation products.

**Q12: Would you say smoking was the hardest addiction to stop?**

**Sue:**

I would say smoking and drinking on par as it is legal to buy and, in some situations, accepted.

**Claire:**

YES! As I have mentioned I am 8 years sober, although getting my sobriety was difficult, I genuinely have not had even a drop of alcohol in that time and that is something I now do not struggle with and I am proud of. Nicotine on the other hand is a battle I still struggle with especially if I am struggling with my mental health and more so if I have been triggered. I do choose to vape or use gum rather than cigarettes and I have even at times used a nicotine free vape as it fulfils the craving of that hand to mouth stress relief I keep talking about.



**Q13: Do you think you would have given up if it was not for the trauma? If so, what do you think you would have needed?**

**Sue:**

I hope I would have given up. Smoking cessation has come a long way now. I never did quit quitting. I kept trying. Again, reinforcement about it also effecting family.

**Claire:**

I started smoking at a young age (early teens), some of this was possibly because everyone I knew smoked. Moreover, I do feel that I used smoking as a coping mechanism for the trauma and a form of control. Smoking was something I could control when my whole world felt out of control. Smoking gave me a reason to need to leave a space I was no longer comfortable in; it gave me a reason to go for a walk for a few moments on my own and it also gave me a reason to annoy my family (I was 13).

Ultimately smoking became part of me and is something I do feel is very linked to my mental health and my trauma. I found I was personally only able to properly quit after I was sober and after I begun dealing with some of the past trauma. Once I felt mentally stable and I had found a sense of purpose in my life I was able to quit because I chose to want better for myself, and I knew I had better coping mechanisms available to me.

**Q14: Your expert view on challenges faced on admission to acute ward?**

**Sue:**

Never been admitted.

**Claire:**

I feel there are many challenges to being admitted to an acute ward and I also feel it's fair to say that every individual will face different challenges depending on their needs.

Wards can be very chaotic at times; this can impact service users and staff alike; I feel privileged to have been on both sides of that coin. Some of the things I would get frustrated at when I was a patient on a ward, now as a member of staff have a much better understanding of.

Taking the question in relation to the smoking topic, it could be an admission happens overnight, due to staffing levels and stresses of the ward the new admission is told to wait until the day shift staff are on in a few hours to be given a vape or patches for not smoking.

This causes the service user to become agitated and stressed so much so that when they approach staff the next morning they come across as rude. The service user is then unfortunately told the person with the keys to that cupboard is now in a meeting and you will have to wait. When that meeting finishes that same staff member is pulled into another incident. Meanwhile the service user is getting more and more stressed and agitated and starts to vocalise this loudly.

For me this example could happen, I know how stressful wards can be and understand the pressures faced by staff daily. However, for the service user, they feel unheard and are not getting their needs met and often feel the need to vocalise their frustrations which impacts them, other service users and staff. All of which could have been avoided if at

the time of admission, they were asked do you smoke and if the answer was yes they were immediately given products to help with those cravings.

Wards can be a challenging environment, but some challenges can be avoided with the right approaches in place to meet the needs of the service user.

### **Q15: What advice do you have for your younger self?**

**Sue:**

My younger self I would say that you don't have to smoke to fit in, let others come to you because you are interesting, fun, and intelligent.

**Claire:**

I am not sure there is enough space on this page to fully answer this haha.

However, I wish I had learned and realised when I was younger the lessons I learned in my mid to late 30s about positive coping strategies. I honestly, I wish I had met someone like me (a Peer) when I was first sectioned at 16 as then perhaps, I might not have ended up in the trauma cycle that I did for so many years. Perhaps the sense of purpose I have now I could have found earlier in my life.

That said, I am very aware that if I had not of lived through all the trauma and difficult experiences, I have then I would not be me and I rather like who I am now. So, on some level, I think I needed to live through all I did to become me!

**Q16: What do you think would have helped you to not start smoking in the first place?**

**Sue:**

In my era it was so promoted to look sexy, sophisticated, intelligent. If it wasn't promoted (Olivia Newton John) or if my family life had of been better where there was good communication, I may have spoken out about how I was feeling.

**Claire:**

This is tough to answer, I was born in the late 70s, everyone I knew smoked growing up. I think I initially wanted to fit in with my friends and on some level thought it was cool, then as I began to experience trauma in my life it just became a coping mechanism.

So, perhaps if society had been different and those around me had not smoked or if I had not of gone through all the things I did then maybe. Alternatively, it could be that I have an addictive personality. I feel its very hard to say what would have helped me not to start smoking as my life was what it was at that time.