

## **Patient Stories to the Governing Body**

### **September 2018 – Hearing Loss & Audiology Services**

*Using personal experience of hearing loss and audiology services to improve services*

The Chair welcomed Stephen Finn and Lesley Jackson to the meeting and was grateful to them for agreeing to share their experience. He advised that Stephen and Lesley are both residents in East Lancashire and both struggle with hearing loss and invited them to share their story. Lesley provided some background to her hearing loss which became apparent soon after she retired. Following a hearing test, she was given a hearing aid and since then has been upgraded to digital hearing aids, which she wears all the time. Stephen advised that his hearing loss was identified following a hearing test as part of the health and safety requirements when he worked for a Chemical Company. He was referred and initially had one hearing aid, now has bilateral hearing aids. He had been a patient in the Audiology Department over the past nine years and outlined the difficulties he had experienced during that time, particularly relating to appointment details and often having to ring the department to check appointment details. He advised that in June 2018 he rang to make an appointment for a hearing test, to be told he would be put on the waiting list. At the end of August he had not received an appointment and following a further call he received an Page 2 of 11 Minutes Approved by the Chair: 16.10.18 appointment in October. He felt that follow up patient experience is poor and having discussed issues with other patients, a number of them were not aware they could be retested every 3 years. There is also a need to have an understanding of how older peoples lives work, recognising it is difficult for some to get to hospital for an early appointment etc. Lesley pointed out that she was required to have her hearing aids replaced every 3 months, but was not aware of this. She was also not advised that she could collect batteries from a number of sites. She also pointed out that Loop facilities at meetings are also important and it is frustrating if this is not in place. She had been attending a meeting at County Hall for a number of years and a loop system had recently been installed which makes a huge difference to the ability to join in the discussions. Both Lesley and Stephen considered that aftercare is important and the patient pathway needs to improve. They have also recently been involved in the consultation and engagement process for the new audiology contract. Michelle Pilling made reference to the Older People's Forum who receive social prescribing grants, pointing out that all who attend are benefitting from this as they are all part of other organisations and spread the work that is ongoing. She thanked Lesley and Stephen for attending and for highlighting the need for co-production, pointing out that changes can be made when patients provide valuable feedback. To provide an opportunity for Lesley and Stephen to feed their views into the service in terms of redesigning, it was agreed to arrange a meeting with the Trust to discuss how patient experience could be improved. Kathryn Lord agreed to take this forward. Dr Davis advised that he had been involved in the Audiology procurement and the way Lesley and Stephen had contributed had been wonderful and their views had changed the perception. He pointed out it is not possible to deliver everything, but they tried to incorporate a number of the issues raised, recognising that the small things are the important things which make it easier for the service user and thanked them for their participation. It was agreed there is a need to look at the whole system and provide patients with written information about follow ups and repeat hearing tests etc. Dr Robinson thanked both Lesley and Stephen for sharing their story and their frustrations which have been ongoing for some time. Their input into the Audiology Steering Group has been excellent and by making a connection with the Audiology Department and becoming involved with the co-production of the education needs will make a difference in respect of the issues raised. In

conclusion, Mark Youlton confirmed that social prescribing will continue and he thanked Lesley and Stephen for their input.

*Lesley and Stephen have been involved in the audiology procurement which is overseen by an Audiology Steering Group. They have contributed to improving the service specification against which the procurement will be run. Alongside this they have helped us with a patient survey. The results are provided on our engagement pages. We believe that with theirs, and the views and experiences of other patients, our procurement of hearing aid services will be enhanced and the experiences of patients will be vastly improved.*

## November 2018 – the experience of military veterans

### How the voluntary sector can support military veterans

The Chair welcomed Bob Elliott, Liz Hamilton, Andy Greaves and Graham Limb from Veterans in Communities (VIC) who were in attendance to outline the work of their organisation and share the personal experiences of veterans in respect of access to health services. It was felt to be particularly poignant to have this presentation during November being the Armistice 100 years anniversary. Bob Elliott, Operations Manager at Veterans in Communities, thanked Governing Body Members for providing the opportunity for the Team to attend and outline their work. VIC provide a wide range of programmes to support those who have served in any branch of the armed forces, emergency services and their families who are having difficulties returning to civilian life. Ages range up to 60 years and members have all served in different conflicts but their stories are very similar. The issues are not unique but impact on many people and VIC provide support to members before, during and after any therapies that they are accessing. Funding has been received from the CCG over the last five years, together with grants from the Armed Forces Covenant Scheme. There is a lot of good work ongoing which has been recognised by the Ministry of Defense, as the VIC has been chosen to participate in a short film, outlining what is happening in the community for veterans. Over the last five years the VIC has provided support to 249 people, all with different needs, Members viewed a short film which featured Darren who outlined his personal experiences of suffering from PTSD, how it affected his life and the support he has received from VIC. Darren was introduced to art as one of the therapies provided through Combat Stress, which had a positive impact on his PTSD. When he was introduced to VIC he set up an art group for other veterans which has gone from strength to strength. Bob confirmed that Darren is still progressing very well, his confidence has grown significantly, he runs art sessions during the week and his work has been included in art exhibitions. Bob outlined the many activity groups that have been set up by VIC, enabling members to develop a number of skills, recognising that armed forces skills don't transfer to civilian life. Bob had recently attended a Conference in Newcastle and felt it was refreshing to see what VIC started doing in 2012 is being replicated across the country. Bob introduced Andy who outlined his own personal experiences. He had spent four years with the Royal Regiment of Fusiliers and stationed in Afghanistan. Within 18 months of leaving the army Andy suffered severely with anxiety and depression and had difficulty forming relationships. He had few friends and no self-belief. He received therapy through the NHS and was referred to VIC three years ago, where he became involved with the allotment scheme. Over the last two years he has managed to help turn the allotment into a full working allotment and now wants to be a gardener. He has found friends which has helped alleviate the depression and has joined other projects, which has provided social inclusion and team building. He is also an avid walker. He considered that the men and women he met at the Centre made him realise he had a problem, but as a team they can survive and keep going, and the VIC saved his life. He is now meeting new people and has many friends, which has given him self-worth and a much better outlook on life, together with a desire to help others, making his fight a lot easier. He was very grateful to the Centre and the people within it, as he felt he would not be

here if it was not for Veterans in Communities. Bob introduced Graham who had attended a GB meeting five years previously and used a short film to outline his feelings at that time. Today his life has turned around. He had previously attempted suicide and had written a letter explaining why. He received support from the NHS (Fiona Muir) who introduced him to VIC. Over a matter of time, Bob asked him to present the film to the GB of the CCG. He had been a Soldier and a Fire Fighter and since then has done many things with VIC - He started Cognitive Behavioral Therapy (CBT) which helped him through a difficult time and the VIC have supported him throughout this period. More recently Graham had attempted suicide again and was referred for an assessment to start CBT again only to be told he would have to wait 12 weeks. Initially he was advised he would have to wait 6 months, however this reduced to 12 weeks as he was a veteran. Graham handed out a picture which described his feelings at that time. He said that it was through VIC that he got through this difficult period. He became homeless and was introduced to Bravo 22, another charity that provided support and through VIC was introduced to other therapies. Graham considered that CBT was the best therapy he has had and is now progressing well. He thanked everyone at VIC who have supported him and many others at their darkest hour. Bob concluded by saying that at VIC we have those experiencing difficulties and those who have transitioned and are supporting others. By involving everyone, it makes the journey better for everyone, VIC is not about one project, it is about the whole picture.

Discussion followed and Michelle Pilling referred to the social prescription into community therapy and the support provided by Fiona Muir. In trying to move away to more than medicine, it was agreed that anyone who is patient facing needs to understand the benefits that the community can bring. Andy confirmed that for him this was more important than medication, as medication only subdues the issues, but the social aspects helped him to become a member of the community again. Graham also agreed that Fiona was very supportive. Liz confirmed VIC covers the whole of EL, pointing out they are not funded for BwD but would never turn anyone away. The population size for veterans in EL is unknown as there is no specific count and it was considered that a question should be included on the census relating to membership of the armed forces. Bob confirmed that the service is sustained through a Service Level Agreement with the CCG which covers the core cost for EL. The VIC are also part of the Heywood, Middleton and Rochdale (HMR) Integrated Neighbourhood Team linked to Pennine Acute Hospitals NHS Trust. Funding is also received from the Armed Forces Covenant but there is no recurrent funding. Dr Dziobon introduced himself as a GB member and local GP and was fascinated by the stories shared, recognising out that GPs see the after effects of military service. He pointed out that the number of veterans exceeds the number of diabetics and 10% of those who are homeless are ex-servicemen. He highlighted that people are recruited at a young age and come from a family background, developed through military training then return to civvy street, having to negotiate services on their own, which can be difficult. Other than VIC there are little other areas to provide the support they require. Dr Ford highlighted the need to think about service provision and the gaps identified, which apply to all services users requiring MH services, pointing out that the VIC is providing a very useful service. Liz described VIC as the 'custard round the pudding', supporting and enabling those to work to their full potential. In conclusion, the Chair thank Bob and Liz for attending and particularly thanked Andy and Graham for sharing their powerful stories and information would be shared with the PCNs to ensure support services are available in the community.

*Following discussion regarding a business case at the CCG Senior Managers Committee, executives and the Committees in Common (which agrees funding), the CCG has agreed to continue funding the veterans in the community service. The presentation of the patient story provided members with a detailed understanding of the experience of veterans and how this service can complement and support existing health and care services, including GPs to support veterans.*

## January 2019 – Alcoholism and the power of community

### *How a patient discovered the power of community and helping in her recovery*

As a local GP, and the Chair of NHS East Lancashire CCG's Governing Body, I am very keen that we listen to and learn from the experiences of patients. Commissioning (buying) health services for local people, which is what a CCG does, can appear to be quite removed from the day to day realities of most people, and patients. The CCG has been listening to patient stories since our inception in 2013. Each and every one of these stories is powerful and instructive, helping us to understand the experiences of people who live with health problems. Sometimes their experiences of health services that we commission is excellent, and sometimes it is clear we need to do more to improve services.

At our last Governing Body which was at the end of "Dry January" we heard from representatives from Alcoholics Anonymous (AA). Dry January is the national health awareness campaign that encourages people to try to avoid consuming alcohol for the whole of January. We were keen to understand why people turn to drink, and how community organisations like Alcoholics Anonymous can help people with alcohol problems.

We heard from a person who had started drinking excessively and taking drugs. Within a matter of months she had left home, as well as college. She started going to the GP a lot with mental health issues. She felt miserable and unhappy. She couldn't understand why and she was confused and isolated. She tried to commit suicide. There was no pattern to her drinking but it had become the cause of many personal problems for her. She was referred by her GP to a community alcohol team. She was prescribed anti-depressants and referred to hospital, seeing the doctor weekly. She ended up going into rehab. When she left rehab, she started drinking again. When she became a mother, she wanted to gain control of her drinking, but this was unsuccessful. Because she wasn't able to be honest about her drinking and its effects on her life, her GP couldn't help her.

By chance she learned about Alcoholics Anonymous and this completely turned her life around. She followed their 12-step programme, and through the power of group support where she could talk and be honest about her problems, she found a path to recovery. It has now been 17 years since she last consumed alcohol and she accepts that she won't ever be able to drink alcohol again. Because of her transformative experience due to AA, she has become a very active member in AA and continues to go to meetings two or three times a week, sponsoring other people who need help. She said that AA is an amazing organisation of which she is privileged to be part of and to see how other people are able to claw back their lives. She feels she'd be dead without AA. They have helped her to deal with shame and the guilt as well as the collateral damage her drinking caused. On a positive note she is however now happily married with a happy functioning life and works as a local employer.

For me this story was about the power of community groups like Alcoholics Anonymous, and importantly, the power of sharing your story with others who understand what you are going through. Because they have a similar experience, they can give you unconditional positive regard and magically, that seems to help people get to first base and start working hard to recover. She couldn't have honest conversations with her GP but in the company of fellow sufferers who were further on in their journey to recovery she was able to find inspiration, support and build a narrative to help her recover. Her own story was quite a stark and negative one, and I learned that in the company of others at AA she heard and learned more positive and helpful narratives. Mutual support and positive stories or narratives of recovery can really help others on their journey of recovery. I think that is true of alcoholism as much as cancer or asthma. It was also clear that she gained a lot of help and strength through

helping others too. It boosted her self-confidence and self-esteem. One of the best ways of lifting yourself is to give others a hand up too.

It is fair to say that Governing Body members were inspired by this story, and it confirmed to all of us the importance of investing in community, including the voluntary, community and faith sectors. There is power in community, being heard, and helping others. It is certainly more powerful than anything that I could prescribe. It confirmed that our investment in non-medical support such as social prescribing, care navigation, community connectors and services delivered by the voluntary sector is an important aspect of our work.

*GP members of the Governing Body felt that they had learned more about the effectiveness of Alcoholics Anonymous and were keen that other GPs were made aware of the service. In particular due to the reduction of services from Lancashire County Council it was felt that the promotion of Alcoholic Anonymous was vital. The CCG will support Alcoholics Anonymous through the promotion of its services online, to GPs, and through media and social media.*