

## Implementing Peer Support as an Intervention

*Eleri Wood, Renal Nurse Consultant, King's College Hospital*

I have been lucky enough to be involved in the patient peer support service at King's College Hospital, one of the longest running services in the country, since it began over 12 years ago.

We have always seen peer support as a way of helping patients to feel more empowered and more confident, particularly when it comes to making decisions or being involved in their care; so its place in the [Transforming Participation in CKD programme](#) was extremely fitting.

### How it works:

Peer support is available to every single patient in the unit and their significant others, although it is most commonly used in the low clearance setting for decision support.

We tend to keep a pool of around 20 peer supporters on stand-by at any one time. Although the average peer supporter is used relatively infrequently (three or four times a year) we feel it is important to keep a varied range available – young and old, men and women, with experience of a variety of treatment types and from a range of backgrounds – so that patients can have access to someone they can relate to at a time that is right for them. They can choose whether they have a phone-call or face to face meeting. We have found the majority want a face to face as meeting that person and talking through their lived experience is an important part of what they are after.

We only occasionally find people who want more than a one off meeting. In our experience, most patients have made a decision but want the confidence to feel their decision is the right one for them. Having the reassurance of seeing someone who is living on dialysis and talking through their choices with them gives them that support they need.

### Becoming a peer supporter

When we first began running the peer support programme, we commissioned a charity to run the training for supporters, but we were soon comfortable running the training programme ourselves and in fact we now train other units around the country. We have also started 'training the trainers' and disseminating our [training resources](#) nation-wide so that other units are able to train their own peer supporters in-house.

The training is a fairly straightforward four-hour group session to help people understand more about the role of being a peer supporter. They are not expected to be a counsellor or give medical advice. We practice listening skills, we talk about dealing with emotional issues, and dealing with negative experiences that they themselves have had. For example if they have had a bad experience of Peritoneal Dialysis, but they know that many people do find it a good therapy, how do they present that information in a fair way?

We also talk through possible difficult scenarios to give reassurance and discuss sign-posting. It is important that the peer supporters are aware of the other services available at the unit – for example counsellors, social workers and dieticians – so that they can help people know about and access the different services.

Finally, all peer supporters have to sign up as hospital volunteers so they automatically get their DBS background checks, safeguarding and information governance training.

### Peer support and patient activation

Whilst we have not yet officially used the symptom and activation scores from TP-CKD directly within our peer support programme, anecdotally, clinicians do recognise patients who are feeling overwhelmed or disengaged, and refer them for peer support. It would be interesting to see going forward how these referrals correlate with patient's actual activation scores. How will the clinicians' observations compare with what the patient reports?

One of the ways in which we *have* started using Patient Activation Measure and peer support together, is in a pilot research study funded by the British Renal Society looking at the feasibility of offering four weeks of peer support to patients who present late in need of dialysis. This group of patients are often overwhelmed as their kidney disease and the treatment they are receiving is all very new for them.

We have been using the Think Kidneys [Your Health Survey](#) to collect their activation and symptom scores and then offering them a four week dose of peer support before resurveying to look at its effect on their reported outcomes.

### Tips for implementing peer support

- **Remember peer supporters are voluntary.** Some peer supporters have been contributing for years, but others don't get passed the training stage. There was one young man recently who came to the training and then got himself a full time job and wasn't able to continue – great for him but not for us!
- **Be aware of peer supporters own health needs.** Peer supporters can either temporarily or permanently retire due to their own health. We have to remember these are people with significant health issues of their own.
- **Gently, persistently, offer peer support.** One of the main challenges we have come across is under-use of the service.

We have done some published work on this last challenge which showed how crucial it is that clinicians continuously and persistently advertise and promote peer support to patients. Offering a very poorly engaged patient who has a Patient Activation Measure of one or two peer support, and them declining, should not draw a line under the issue. That patient will need to go away and think about it, and may need more encouragement and permission from the clinician that it is the right thing for them. One piece of work showed that some patients felt meeting a peer supporter might suggest that they thought the clinician wasn't doing a good enough job! There are a lot of complexities about when and how, particularly a poorly engaged and overwhelmed patient might feel ready to accept peer support.

For peer support to be successful in patients who have low activation levels, it needs to be gently offered frequently and persistently even if they say no. People need reminding that it is still there and reassurance that it is fine for them to do it when the time is right for them – which could be the fifth time it is offered not the first.

## Peer Supporters – in their own words

### **Shola**

*I had my peer support training back in 2013, so have been a peer supporter on and off for around four years now.*

*For me the motivations behind getting involved were about trying to support another person going through something that I was going through myself, and to help share experiences. When you are going through such a hard challenge in your life, you sometimes don't know where you fit in and can feel isolated. I wanted to help people feel that they belong.*

*Some people don't want to talk to other people about their kidney disease - they feel they might not be understood or they don't want to keep going on about their health to their family and friends. I think having peer supporters around helps people to feel connected. We understand what they're going through, because we are living it as well, and it is something we are going to have to manage for the rest of our lives. Often when you go to clinic the conversation is very much around drugs, whether you are taking the right medication, and about the theoretical aspects of your health, but when you speak to a peer supporter it is much more around how you are doing day to day, how you feel getting up in the morning, or whether you have the network of friends and family around to talk with. Being involved is about us having a voice as renal patients.*

*I think as a patient you should be more involved in your health care. We are living with it so understanding and being willing to engage with the protocol – going to clinic, taking medication, understanding your feelings and how your body is reacting - is all part of looking after yourself.*

*I just want to make people's life a bit better, to address their anxieties, and hopefully give them the encouragement to continue with the journey. Having had renal failure, been on dialysis and now being two years into my transplant, when I talk to people they feel that it gives them hope that they can get through this. It is very rewarding, you get to meet lots of different people and it can feel like a real community – although you do have to have boundaries and be careful not to build up a dependency with your peer.*

*Eleri has done a really good job at setting up the peer support service. We are not left alone and if we have any issues there is a place we can go to discuss them. You are talking to people about your own life and what you have been through and sometimes that can bring up personal issues that you may not have dealt with. There are counsellors available who we can talk to about any emotions that we may be feeling, and we have meetings together as well so we get to meet other peer supporters and have a network of support – that structure is really important.*

## **Agnes**

*After getting kidney disease, I was on dialysis for almost 8 years before getting my transplant. During that time, I learnt to do tasks by myself such as setting up the dialysis machine and needling myself. I asked the clinician if I could be a peer supporter at that time, but I was still very unwell so it was not until after I got my transplant that the hospital called me letting me know there was an opportunity available to take part.*

*I have been doing it since I got my transplant so nearly two years now. I have even gone to conferences and given presentations!*

*My main reason for being a peer supporter was really just to help other patients. When you are sick and you go for dialysis, you don't talk. You want to say things but you don't as there is no-one to talk to about how you feel and whether it is going to be ok. After experiencing this myself I thought, why don't I go and help others, talk to them and make sure they are not depressed or confused?*

*I began by helping to collect data from the patients for the TP-CKD programme around how patients are managing with their health. At first it was a little difficult. It is hard to go and introduce yourself and tell someone who is in pain that it is going to be ok. They might think 'you've got your kidney, I don't want to see you'. I had to introduce the project and [Think Kidneys](#), tell them about how the programme is trying to help them take control and look after themselves; and also help the consultant to really understand what is going on with the patient. Most of the time the consultant doesn't have time to go through everything – they only deal with the urgent things. I would encourage the patients to participate, and told them that the doctor would then know exactly how they are.*

*At the same time I gave them the opportunity to ask me questions – for example, how are you coping since your transplant? It really gives them hope when they see you having gone through the transplant, being well and looking after yourself. It really helps them to cope with their illness.*

*The experience not only helps the other patients, but also the person who is providing it as well. When you go through kidney disease, and even the operation itself, it can be really scary. Someone has lost their life and has given something to you for your own life. It can be really depressing, so going out and speaking to other patients about it helps you as well as them. After my own transplant I was just depressed and stayed in the house. When I started to go to the unit once a week and began talking to people, I saw myself getting better, and found I was managing my own medication better as well.*

*One time, a lady saw me who had a daughter with a kidney transplant. She thought her life was ruined and that she would never get better, but I told her no – you can get through it.*

*It has been such a great thing for me, and for the people I have met – I would encourage anyone thinking about it to get involved.*

Are you interested in introducing peer support in your unit or becoming a peer supporter?

I am very happy to talk people through setting up their own services, or for interested people to come down and observe the training sessions at King's.

We have a number of peer support resources which you can look through, and for more information do get in touch on email at [eleri.wood@nhs.net](mailto:eleri.wood@nhs.net).