Frontiers
in Kidney
Medicine and
Biology

Season 2 Episode 1 – Conversation with Edwina Brown, ISPD President

Guest: Edwina Brown, MD

Peter Kotanko
Welcome to the Renal Research Institutes Frontiers in Kidney Medicine and Biology, where we share knowledge and advances in kidney research with the world,

In this episode, we talk with *Dr. Edwina Brown, Consultant Nephrologist at the Imperial College Renal & Transplant Centre, Hammersmith Hospital, London, and Professor of Renal Medicine, Imperial College London. Dr. Brown is also the* President of the International Society of Peritoneal Dialysis. She is here to talk about her goals as president of the ISPD, incremental PD lowering barriers to entry, and expanding peritoneal dialysis use worldwide.

Edwina, Thanks for joining us today.

Edwina Brown
Thank you for inviting me.

Peter Kotanko
What are your goals as president of the International Society of Peritoneal Dialysis?

Edwina Brown
Well, it is twofold. One, to make society much more inclusive of peritoneal dialysis is done predominantly by nurses, but the membership of the society is predominantly doctors. So, one of my main goals has been to get much more nurse involvement, and I've done that partly by making sure that nurses get promoted to deputy chairs of committees.

With time, that means that they will become chairs of a committee, and they'll get to sit on the council. So, we've already got more nurse members on the council than when I took over. And who knows if our Council, hopefully in the not-too-distant future, will get on the executive and become the president of ISPD. There's no reason why they shouldn't.

However, not all nurses are research-orientated, wanting to be, you know, high-flying professional individuals. A lot of them, particularly in lower-income countries, are much more down to earth doing the practical things and quite honestly cannot afford the cost of being a member of ISPD, which is tied to receiving and being able to access the Society Journal Peritoneal Dialysis

International. So, we are creating an associate membership. We're just finalizing the documents. We have completely decided what will give them reduced rates for membership for accessing newsletters, websites, coming to meetings, etc. So, really creating a club that everybody involved in peritoneal dialysis can join.

So that's been one of my main goals. We’re certainly getting there.

The other goal is to decrease the inequity of peritoneal dialysis in high-income and low-income countries. There are many reasons for that, and we can explore that later in our chat. However, the barriers to peritoneal dialysis are well described predominantly by the KDIGO Promises conference, which was held a couple of years ago and has just been published.

So it's really implementation that's important. And so that's something called the International Home Dialysis Consortium Joint with the ISM, which will focus on increasing access to home dialysis for both PD and home hemo globally.

Peter Kotanko
The inclusiveness and extending access to the content that ISPD provides are fundamentally important. It's just a recognition also of the fundamentally important role that nurses play in our care for PD patients and that your plans are to make PDI, peritoneal dialysis International more accessible, especially to colleagues from low and low- and middle-income countries.

I think that's a really important step forward to ensure that these colleagues are connected to ongoing developments. Where do you think Edwina has the greatest knowledge and research gaps in the field of PD?

Edwina Brown
The biggest gap is how you assess the quality of peritoneal dialysis. The ISPD used its clinical recommendations after a lot of deliberation with a sort of global group, in 2020 It was published. We really tried to get away from a rigid small solute measure of the quality of peritoneal dialysis and to really think about the person's well-being, how they cope with dialysis and how they live their lives.

And that is hard to deliver, hard to assess. It's certainly not related to small solutes, and it's partly dictated by the burden of dialysis and whatever we remove during dialysis. And that principle has been accepted by most countries in the US. There's still the problem of using kt/v as a measure of success of peritoneal dialysis, which results in a high burden of dialysis with unrealistically heavy prescriptions for patients to achieve this magic number.

The other thing that we really need to work out how to do is how do you assess the quality of the unit. So, what I've been talking about is at the individual level, we've also got to think about how units function, how you deliver peritoneal dialysis, and what's the measure of quality. Is it the number of patients?

Is it a ratio of nurses to patients? Is it infection rates? Again, we're not good at doing that, which needs much more focus.

Peter Kotanko
You really call out the assessment of the adequacy of peritoneal dialysis. This is particularly important when we start thinking about the concept of incremental peritoneal dialysis. Right.

What are you thinking about incremental dialysis and specifically also the assessment of these decision points when to change a dialysis prescription?

Edwina Brown

For incremental dialysis. And the same goes for hemodialysis except they are way behind in thinking of PD as really a personalized prescription of dialysis. So, you look at the whole person. They're not starting dialysis and their kidney function disappears the day they start dialysis. So why start them on a huge dose that they don't need that is not only expensive, and deleterious to the healthcare system, but there's also a huge burden for the person.

And I think we need to put ourselves in the shoes of somebody starting on dialysis much more than we do. We are all used to seeing people doing four exchanges a day on the machine every night and doing three times a week hemodialysis. We just accept that as normal. But from the individual viewpoint, you're going from Peter sitting there in a chair leading a normal life, albeit with a GFR of eight or something, and not feeling 100%.

But you're not at death's door and you suddenly go wham into that dark tunnel and must do things that are just frightening. So, I think the concept of incremental is both psychological, and I think that's an important part of it. So, it's a gradual entry into the world of dialysis and reducing the burden of dialysis. So, in terms of PD that’s days off so you’re not doing it seven days a week. You’re using lower volumes and lower exchanges, and then of course, the crunch becomes how do you assess when you need to start increasing it?

I think the first thing is the person needs to know that it is going to be increased. So, it doesn't come as a huge surprise because that's not fair to the individual to start. And you may well just meet resistance if they when you tell them the first time. So, alert them. Then the ISPD recommendations are very clear that the decision to increase dialysis is not based on a single factor.

It's based on how the person is, along with their prior chemistry, any measures of small solute clearance, volume status, nutritional status, etc. So, it's not a quick decision because somebody can tell you they feel fine just because they don't want to increase the amount of dialysis they’re doing. But if you can look and say, I can see that your creatinine is going up, you're losing residual kidney function,

It becomes a conversation. Then it's a conversation about how you're going to increase it. Again, you don't need to go from two exchanges six days a week to four exchanges. You can do it gradually and fit it into the person's lifestyle.

Peter Kotanko

It's a profoundly clinical decision that's supplemented by certain lab parameters, but it's really in your mind, it's the clinical situation of the patient, of the social situation, of the patient. That will inform these decision points. Right?

Edwina Brown
Yes.

Peter Kotanko
You know, it was very interesting. what you said a minute ago, to go from two exchanges in six days to a larger number of exchanges. So, are you saying that incremental dialysis could be something like, I don't know, having a day off from PD?

Edwina Brown
Definitely. Patients take days off anyway, and it's much better to say, okay, of course, you can take a day off, but it's discretionary. You don't have to do it, but you know about it. So, it's factored in. So, both sides know about the day off and you know that none of us want to work seven days a week.

So why do we expect anybody to do dialysis seven days a week?

Peter Kotanko
And I think the point you're making is really to have this sort of honesty and transparency between the patient and the caregiver. And you also indicate something that's very important. I think that it's made clear from the time when PD is initiated that there will be changes along the way so that the patient isn't really surprised by those. Right.

Edwina Brown
Very important.

Peter Kotanko
Do you think Edwina that an incremental dialysis approach lowers the threshold for patients to accept dialysis so it will eventually result in a larger number of patients going on dialysis?

Edwina Brown
Definitely. That's my personal experience. I mean, I run the Advanced Kidney Care Clinic as well as doing peritoneal dialysis. And, you know, when you talk to people, sometimes they put off the thought of doing PD because having to do it every day, because that’s what they read somewhere, or having to be on a machine at night, they don't want to do that either.

So, you know, being able to start them on low exchange CAPD for five nights a week, for example, really increases the number of people who are willing to do PD. It's also fewer boxes of supplies because again, another reason people turn down PD is that they say they don't have space for the supplies. So, it gives them a lower prescription, it’s a lower number of boxes and so easier to store.

And then as you increase the prescription, they've got used to having boxes in their accommodation. They’ve probably tidied it up a little bit and found a little bit more space and it becomes less of an issue.

Peter Kotanko
So, I think these are very, very good points. So, we discussed a little bit of dialysis initiation, this incremental pathway that you strongly believe is a good approach. Now there are also, I mean towards the end of the PD journey, there are also some discussions about detrimental dialysis where the dialysis dose or frequency is reduced what are your thoughts about that?

Edwina Brown
That's a key part. But typically, with all the frailer people when they are starting on dialysis to start having realistic conversations about planning for the end, we run a program for older, more frail people of just two exchanges anything from 5 to 7 days a week, and their fluid status and blood results. We never plan to go to more than two exchanges because we're running an assisted program and we don't measure clearances; we don't measure pet tests.

Edwina Brown
but built into that is a conversation about do you feel better. Do you see any benefit from being on dialysis? On PD? Is it a burden? Does it upset you? Do you have side effects and then we all have conversations about benefits and burdens and whether you want to continue or not? I find that most people in this program continue for three months.

I told them, in the beginning, we'll have this conversation in three months because they feel better. But then you get those who've been on PD for some time. They're coming towards the end and then it's a conversation about things that are not going well now. It’s important to give them information to give them permission so that they can think about stopping dialysis.

I find you get less people wanting to stop PD because they are at home. It becomes part of their life and it's not causing them any problems.

Peter Kotanko
You are practicing this, the decremental approach, in a specific program and you say that it's a good experience with it. What does the pathway from diuretic therapy to palliative therapy without dialysis look like in your institution? I know you have given several talks about this. You’ve published about this, but can you just provide some insights about your approach?

Edwina Brown
I do what I call an annual review when we have a conversation about how things are going and built into that is, I usually come out with a statement like, you know, modern medicine is very good at keeping people going sometimes without a good quality of life. And a lot of people I've seen relatives or friends have long stays in hospitals or residential care and don't want that for themselves.

And then we think about, you know if things are not going well, you have a major event like a stroke. Would you want treatment to continue? Now they often just come up with this in a general statement, like I don't want to put a tube down me. I want to die with dignity and don’t want to have an excessive amount done, etc. And it's really when specific things happen like they’ve had a stroke, they start talking about, you know, you don't have to continue dialysis.

Junior colleagues tell me that when my patients come home after a major event, they find it much easier to have conversations about potentially stopping dialysis seeming so much easier because they've already.

had the initial conversations with me in the clinic. So, they've already thought about it.

Peter Kotanko
We're coming more toward the end of the PD journey. Now let me come back again to that very beginning. I learned from you that when PD is initiated, there seems to be a cohort of patients, a group of patients that swiftly improves, clinically, others that that don't change at all, and others that just improve very slowly and gradually.

Edwina Brown
And I think that shows we're measuring the wrong thing. It's not small solutes. We know we remove larger molecules on PD because of the nature of peritoneal membrane. but we're not measuring them. And we need to start thinking much more about what those are, and we do fingerprints. And we predict who is going to do better. Are these eventually going to become a way of monitoring patients, I don't know.

But it really shows how important it is to talk to your patients and not just come up with a routine prescription dependent on some arbitrary measure.

Peter Kotanko
I think this is a fascinating, fascinating observation you made. Now, when we discussed your goals as a president of the ISPD, you also mentioned that you would want to increase the utilization of PD in low and low and middle-income countries. Edwina, what do you think are the most promising strategies to that end? And I know you have an upcoming conference; I believe in Senegal.

Edwina Brown
That’s right. So, I've been working closely with nephrologists in Senegal where they've got a small PD program trying to identify why it's not growing and what we can do to help it grow. So, most of it is education, identifying people who are keen and enthusiastic, and giving them confidence so that they become the future PD leaders in their country and broader across Africa.

And we're doing this in partnership with industry because we can't do this on our own. And Baxter is already delivering. PD for it. But one of the things we discovered, for example, was that, you know, apparently nobody was ordering the fluid and it was as simple as discovering that it’s all ordered through a central pharmacy, which didn't know anything about PD, and you know nobody realized that this was how it was done.

So having identified this problem the situation has already improved. So sometimes it's just little things like that. We're also linking with Saving Young Lives, industry, and Afron, to create

PD training programs. So, it's education, doctors, and nurses. The whole thing, which we haven't really grasped how to do yet is empowering patients or empowering people.

Because I think that's a key part in expanding PD, and of course, in places like London they have very powerful patient groups who will go to parliament and go to hospitals, politicians, and leaders and say, “We want more home dialysis”. And then that's how you do that. In lower-income countries, there's no tradition of this happening.

The patient groups don't exist. I mean, that's a challenge which we've still got to address.

Peter Kotanko
Edwina, I'm wondering how important you think is local production of PD fluid. I remember the Renal Research Institute was involved in an initiative about 12, 14 years ago in Tanzania to set up a program to produce PD fluid and it failed because of the high-quality control standards, etc. So do you think that local production of PD fluid is fundamentally important or is it also to make sure that if that's not an option, that that really securing transportation, making sure that there are no fees collected along the way, that increase the costs for PD fluid? Would this be the strategy or a mixture of both?

Edwina Brown
It's a mixture, it's the security of delivery of an affordable high-quality PD Fluid is really an important issue. As we know there are only two major manufacturers. There's a third in India which is developing itself but it's still small. But shipping large volumes of fluids around the world is not very green. And in an era when we are really having to stop thinking of the environment, is it going to be possible, as already happens in South Africa, for concentrate and the plastic bags to be sent out and then purified water is added in a local factory?

So that would potentially be greener. There has been a project from the Georgia Institute to produce in low volumes but in multiple places, high-quality fluid. But nothing happened from that project. And speaking to one or two of the people involved, it seems to be the plastic that's the issue. The one thing which we should not be doing is really thinking of ad hoc manufacture of PD fluid which does happen in some countries with quite high infection rates and disastrous results.

And that would be completely the wrong thing to do because it would just give PD a bad name because everybody gets infected or has high rates of infection. So, I think that's the wrong thing to do. So given that it's going to take years for any company to get a factory up and running in a local place, and they're not going to do that until there's a reasonable demand.

I think we're stuck with delivering fluid from the major companies, but perhaps hopefully with more of a mixed economy, with water being added to concentrate into high-quality plastic bags rather, than shipping liters and liters of PD fluid across the world.

Peter Kotanko
Certainly, a very, very complex problem, no doubt about that. So, Edwina, this conversation, which I profoundly enjoy, is coming to an end, but is there something you would want to share with our audience?

Edwina Brown
Just to remember dialysis at home. It empowers the individual. 60% of people will choose dialysis at home. And if you ask doctors, and that's been done at many conferences what they would want themselves, they will choose dialysis at home. However, we don't do this for our patients, and we really need to think about why this mismatch is there and what we are going to do about it.

Peter Kotanko
Thank you so much. I think this was a very important closing statement. I really thank you. Edwina, for carving time out of your very, very busy schedule for this conversation. And I'm looking forward to future interactions with you. Thanks a lot.

Edwina Brown
Thank you for inviting me.

Peter Kotanko
Thank you for joining the Renal Research Institute for this episode of Frontiers in Kidney Medicine and Biology. We invite you to engage with us on our social media channels and look forward to seeing you again soon for the next episode of Frontiers in Kidney Medicine and Biology.