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Inside the IgAN Clinic: Shared Decision-Making Into Practice

Announcer:
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Dr. Barratt:
Hello, I'm Professor Jonathan Barratt. I'm a nephrologist and I'm the Mayer Professor of Renal Medicine at the University of Leicester in the UK. Welcome to our Patient-Clinician Connection on shared decision-making in IgA nephropathy.

IgA nephropathy is a chronic kidney disease, one that affects patients differently depending on disease activity, comorbidities, and life context. Our goal as nephrologists is to go beyond explaining lab results. We must also explore the patient narrative, understand personal priorities, and communicate complex risks and therapies in plain, actionable language to our patients and their families.

Today, we'll illustrate this approach through a series of clinical vignettes exploring how to connect, explain, and collaborate with patients navigating IgA nephropathy and its management.

I'm going to talk about a case that I have seen in clinic. It is a young lady who has recently had a kidney biopsy confirming the diagnosis of IgA nephropathy. She has, at the moment, 1.5 g of proteinuria. She has a GFR of 65 and has just started treatment with a renin-angiotensin system inhibitor, ramipril, and an SGLT2 inhibitor, dapagliflozin.

Her kidney biopsy showed some evidence of disease activity with an M score of 1, an E score of 0, an S score of 1, a T score of 0, and a C score of 0. And when I'm talking to this particular patient, I'm thinking about wanting to give her an accurate description of the diagnosis. I'm thinking about explaining the potential for future risk of kidney impairment. And I'm thinking about the tablets I might want to give, their side effects, the potential benefits of those side effects, and the importance of continuing to stay under nephrological review, to take medications, and take some ownership of having IgA nephropathy in terms of potential beneficial lifestyle changes that we might institute to help preserve her kidney function.

And as the patient is young and female, the other thing I must think about is future family planning and the fact that, actually, we do need to think about how family planning fits into the future plans of this young lady. And whether that's in the near term, the short term, or the medium term.

Dr. Barratt:
So, Bryony, it's lovely to see you again. Before we talk about your lab results, I'd like to understand how this diagnosis makes you feel

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and what worries you most right now.

Bryony:
So, I mean, right now, I'm scared of going into kidney failure. I've read up on the condition and I've seen that it can progress quickly.

Dr. Barratt:
Yeah, and I guess one of the important things is to know where you're looking on the internet, isn't it? Because there are lots of places that you can go looking. And we need to think about some reliable resources that you and your family can review. And I think it is important that we talk through all the features we have in terms of the amount of protein in your urine, your kidney function, how your kidney biopsy looked under the microscope, to see what might happen to you in the future in terms of the kidney function deteriorating.

But I think, first of all, this is something that all my patients are concerned about. It is something that we do need to think about each time we see you. But the important thing to understand is that different people behave differently. Some people's kidney function does get worse over time, but in others, the kidney function can stay stable. And the great news is we have some very good new treatments that are able to control the IgA nephropathy and slow down or even stop any future loss of kidney function.

But in terms of the things other than the kidney side of things, in terms of that and the future of that, what other things do you think IgA nephropathy might impact on for you in your life?

Bryony:
So for me, I mean, I'm 28 years old and I would love to have a family of my own, but obviously that is a concern for me now. So I know that there may potentially be more risks or more kind of care around that. So that's definitely something that I think about with this condition.

And then also, I'm working full-time, so I need kind of a treatment plan that I can manage alongside my full-time job.

Dr. Barratt:
No, and that's completely understandable because we want to make sure that the IgA nephropathy doesn't take over your life. We want you to be able to live your life, to enjoy your life as much as possible, and that we kind of do the heavy lifting from the nephrology side in terms of managing that and making sure that we keep your kidneys and you as healthy as possible.

And as I say, there are a number of things you can do for yourself, which we can work with in terms of diet and exercise and such like. And then, other things we can think about with your medications. But the good news is I think we can work with you. There's no reason why you can't think about having a family. So all of those things are eminently achievable with the right cooperation and partnership between ourselves.

Bryony:
Amazing, that sounds great. Thank you.

Dr. Barratt:
So, Bryony, let's go over what your results mean in everyday terms. And I think it's really important that we do explain to our patients what their results mean, because they need to understand the implications for their health, they need to understand why we're doing the tests we're doing, and patients are genuinely interested in how their kidney function is behaving.

And so, if we think first about proteinuria, when we look at the results that Bryony has, we know that the protein level in the urine is too high. It's over a gram of proteinuria, and that that brings with it a potential risk of progressive loss of kidney function, and it's something we would need to address with Bryony and think about how we might change the treatment to improve that.

In terms of GFR, at 65 mL/min, this is already impaired, suggesting that there has already been quite significant damage to the filters of the kidneys. And that, combined with the proteinuria, tells me that this is a situation where we are going to need to work a little bit harder with the medications to protect the kidneys in an increased manner if we want to think about reducing that lifetime risk of developing kidney failure.

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Blood pressure is very important in terms of helping protect the kidneys against damage. We know that damaged kidneys increase the blood pressure, and we know that high blood pressure damages kidneys, and you can get into this vicious cycle if you're not careful. And so when I am chatting to my patients, in particular Bryony here, I will be asking her to buy a blood pressure machine that she can measure her blood pressure at home. And that we will be able to keep a close eye on her blood pressure, making sure that it is close to our goal as possible, which should be less than 120 over 70 mmHG.

And again, we might need to adjust medications if we're not achieving that. And there are lifestyle modifications that can help increase the likelihood of blood pressure control by being an ideal weight, regular exercise, no smoking or vaping, and modest alcohol consumption.

And then we come on to something a little bit more complicated, which is the kidney biopsy. But the biopsy doesn't just tell us what the disease is, it also tells us how active the disease is and how much damage has already occurred. And we use a classification system called the MEST-C score.

And so when we put all of this together, Bryony, and with looking at your GFR, your proteinuria, your kidney biopsy features, it helps me put together my thoughts about what the likelihood is that your kidneys might get worse in the future if we don't change the way we're looking after you.

Bryony:
With where I'm at, with me having an eGFR of 65, it means that my kidneys are damaged, but they're still stable in this moment?

Dr. Barratt:
Yes, so they are damaged, and that's what we see when we look down the microscope of the kidney biopsy. And that's why the protein in the urine is high. But we have plenty of new treatments that will allow us to control that. And if your kidney function stays at 65, then what I say, generally, is the worst you'll have to do is come and see me a couple of times a year. We'll need to make sure you're taking your tablets and that we make sure we monitor your kidney function and your protein. It won't stop you doing anything. It won't stop you living a completely normal life. And the goal is really to make sure we have a plan in place with you that preserves that kidney function.

Bryony:
Yeah, that sounds very promising.

Dr. Barratt:
So when we think about how we can protect kidneys from further damage, we need to think about all the different things we can do. Some of the things you can do, some of the things we need to do in terms of changing your treatment and thinking about your lifestyle, because the goal here is to make sure that we provide your kidneys with as much protection as we can going forwards.

We have an international guideline that advises kidney doctors about the different treatment options for people with IgA nephropathy. And it's recently been updated. And one of the things that we really want to focus on is getting that protein in your urine as low as possible. And we have a number of ways, as I say, of doing that.

And so at the moment, you're on 2 very good treatments. You're on what we call a RAS inhibitor and you're on an SGLT2 inhibitor. So those are 2 drugs that you're going to be on for the long term because we know that they help protect kidneys continually. And as I say, they also help protect your heart and your blood vessels.

But at the moment, I think we do need to think about giving you an additional treatment to try and bring the protein in the urine down and try and tackle the IgA nephropathy and the deposition of the IgA into those filters of the kidneys. And we've got a few choices. And the newer choices that we have at the moment are drugs like sparesentan and budesonide. These are 2 treatments that have just been approved and available for us to prescribe and have been tested in large numbers of patients in clinical trials.

But I think when we spoke, you mentioned you'd already been on the internet to speak to Dr. Google and you may well have seen lots of stories about different treatments. And which ones did you hear about? And were there any in particular that you either thought you liked the sound of or that you didn't like the sound of?

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Bryony:
I mean, I guess for me, when I've been kind of looking into things, I've seen that quite a few people do end up taking steroids with this. Obviously, I've heard that there can be side effects with the steroids. Can you go through what I'd expect to see in terms of side effects and that kind of thing with steroids, maybe in particular, if that's something that we'd—like a route that we'd go down?

Dr. Barratt:
Yes, so steroids are used to treat lots of different forms of disease, one of which is IgA nephropathy. Different kidney doctors think different things about steroids. Some like to use them; some don't like to use them. I think the major concern is of potential side effects. And the steroid common side effects that you might notice would be increase in appetite, you might gain weight, you may develop a little bit of acne, your mood may change, you may get some insomnia and trembling, and that can have effects on the blood sugar and your bone health. So lots of things here that potentially might be issues that would mean that we possibly might not want to consider steroids because of those many, many side effects.

Bryony:
Yeah, I mean, I'm definitely open to any kind of treatment options. Of course, I put my trust in you, so whatever you kind of think, obviously, I will get the knowledge and stuff and the education around it from you and then I know it's kind of a bit of a collaborative effort in terms of what I can then choose to go forward with.

So, yeah, I'm happy with that.

Dr. Barratt:
Good. And don't forget, this isn't—when we discuss different treatments, it doesn't mean you pick one and you can never have the others. What we're actually talking about is which treatment are you going to start with. And if that treatment doesn't suit you or you have side effects, then we can move on to a different treatment.

Bryony:
Amazing, that sounds great.

Dr. Barratt:
So when we're thinking about new treatments or adding treatments, because you're already taking 2 tablets, don't forget, when we think about adding new treatments, what is important to you? What kind of drives you to want to take these new treatments? What are you worried about with new treatments?

Bryony:
I think for me, with the new treatments, ideally, I would love to keep the condition in remission. But in terms of when I'm taking medications and how I'm taking medications, I would want it to kind of fit around my lifestyle. So like I said before, I am working full-time, so ideally, it would kind of fit around my full-time schedule. Tablets are great for that. And then if there's kind of different options in terms of how to take things, I think it's just something that I would try and have to figure out with like my lifestyle right now.

Dr. Barratt:
And we need to always make sure that we chat to you about whether that fits in with what you're doing and how you are leading your life. And of course, you're already on 2 tablets. What's your thoughts about being on another 2 tablets? That's 4 tablets you might be taking every day, perhaps 2 of those twice a day. Does that fill you with dread, or is that something you think you could fit into your lifestyle?

Bryony:
Yeah. I mean, I think it's something that I could fit in, but ideally, you'd want to be taking medications at a certain time of day so that it's much easier to remember. You can get into a little bit of a routine with it and then you're kind of set, same thing every day. I think I'd find it quite difficult taking some, say, like morning and some maybe in the evening.

Dr. Barratt:
Yeah, and it may change, mightn't it? In a year's time, you might be doing a different job and the pressures may be different. You might be working a lot away from home, for instance. So, I mean, it's something we just need to make sure we discuss regularly, is how the

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treatment plan is fitting around your life. Because we don't want your life to fit around the treatment I'm giving you. We want the treatment I'm giving you to fit around the life that you're leading. And we just, doctors, sometimes just need reminding about that.

Dr. Barratt:
So one of the things I think we do need to talk about is what are we hoping to achieve with the treatments and all the changes that you're making to your life?

I'm going to be looking at the amount of protein in your urine, the GFR level that we measure from the blood, and your blood pressure. And these are all things you're going to have access to as well. And I'm sure you're going to be looking at those and wanting to see what's happening, changing over time, so that you know how well the treatments are working and whether there might be time for a change. And we're going to measure these every 3 to 6 months, and we might measure them sooner if you're not feeling so well. But it is going to be a regular thing going forwards.

And so do you feel comfortable now about understanding the way that I look at your kidneys and how I'm seeing how healthy they are?

Bryony:
Yeah. So I think you've definitely kind of educated me around what I'm looking for in terms of lab results and that kind of thing. And then, also, you've helped in terms of making me aware of maybe lifestyle choices, like you mentioned earlier on, that I can make to help with this condition and my journey with this.

I think, yeah, it's been really good for me to kind of hear what I can do and it just makes it feel like it's a bit more of a collaborative effort between us, which is nice to have that kind of relationship rather than it feeling like you're kind of just telling me, we're going to put you on this treatment, and that's that. It feels like I have a choice in it, and it makes me feel heard, which, thank you for that.

Dr. Barratt:
And I think it is important, isn't it, that you understand what's going on with your own kidneys. You understand the signs that we look for that mean the kidneys are in a bit of trouble and we need to change things, and you understand the signs for when those kidneys are doing well and we've got things under control. And that gives you some sense of control.

Bryony:
Amazing. Thank you.

Dr. Barratt:
Okay. So we've had lots to talk about when we last met, and what I generally like to do when I see someone again, after we've had a very in-depth conversation, is see if you've had any questions from what we talked about or if there's anything I've talked you through that perhaps wasn't as clear when I explained it and that you would like for me to explain again.

Bryony:
I think, at this point, everything that we've gone through, I feel like I've got a much better understanding now of the condition and what to look for, like I said before, in my blood, and things that I can do and control to help. So I think for now I don't really have any questions.

Dr. Barratt:
Great. And I think you undoubtedly know your blood results already, but we did make changes to your treatment last time and the great news is that we're starting to see an effect of those treatments. So the level of protein in your urine has come down very nicely now and is at 0.6 g per day, so that is really a very nice response.

Your blood pressure is perfect. Thank you for keeping a diary; that looks great. And in terms of the exercise that you're doing, that is all very positive. And the treatment combination really does seem to be working for you. And you've not noticed any changes in your health? You've not noticed any side effects?

Bryony:
No, not really. I've been quite lucky, really, that I haven't been experiencing any side effects in particular. There may be slight things, but nothing that's kind of stood out, so nothing that's concerned me or else I would have come to you and asked the questions. I know that I

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obviously can do so.

But yeah, I'm definitely feeling better than I have on diagnosis. I feel much more reassured now. I feel like I have taken a little bit more control over it.

Dr. Barratt:
Great. And how have you found the changes, the fact that you now take tablets regularly, that we have tweaked your diet a little bit and we have got you exercising a little bit more?

Bryony:
I think, in general, I am finding it manageable. It doesn't feel too heavy on me, really, which is good. That's what I was kind of hoping for in terms of like treatment plans, something that felt sustainable.

Dr. Barratt:
Good. And it sounds like you're—because often giving someone of your age, being told about kidney disease, it can be quite shaking, can't it, in terms of thinking what the future holds. But you're feeling very positive about the future. I kind of hear it in your voice and what you've been saying.

Bryony:
Yeah. I think from everything that we've discussed, I do feel much more reassured.

Dr. Barratt:
Each time we meet, you must let me know if things are getting a bit on top of you or we need to rethink how we're looking after you in terms of treatments that we're using. But it's great to hear, and it's great that you've completely embraced the diagnosis, you're taking your medications, you've taken the advice we've given you, and you're really doing the best you can to protect and help your kidneys, which is wonderful.

Bryony:
Thank you so much. Thank you for all the advice and the help that you've given me. And I really appreciate the way that you've kind of explained things and gone through things. I just feel so much more involved. So, yeah, it's nice to have that kind of relationship.

Dr. Barratt:
Fantastic. Thank you.

Dr. Barratt:

So I hope you've enjoyed those series of vignettes, and I hope it's brought through the message that IgA nephropathy can only be managed to the best possible standard if you engage with and you work in partnership with your patients. Patients are eager to learn about their disease. They want to understand about the disease and what they can do to help themselves. And they need to know they can trust their doctor, their doctor will listen to them, listen to their concerns, and that together, you can put together a treatment plan that will give the best chance of kidney protection.

So by using shared decision-making strategies, you can get the best for the patient in a way that is sustainable, and I think that's something that Bryony said, was that she needs a solution that is sustainable for her. She doesn't want to have to do something that she can manage for a month and then it really just messes her life up. We've got to think about how our treatments interact with the patient's entire life. So listen to the patient. When you're talking to the patient, use plain language.

Be open about new treatments. Be aware of what new treatments are coming in in IgA nephropathy. There are new treatments coming

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virtually every 6 months, now. And explain why you think a particular treatment over another is going to be right for that patient. Ask the patient which treatment they would prefer to have based on efficacy and safety. Because if you don't discuss it in the consultation, I guarantee you they will go and look up this on the internet and they may well not get a very balanced view of any particular treatment for IgA nephropathy.

And make sure that you understand the patient's values and priorities. And what is important to one patient may be very different to another patient. And particularly in Bryony's case, we didn't discuss it in great detail, but it's likely that starting a family is going to be a key priority for her in the coming years, and we need to think and address that and proactively discuss it with her when we see her in clinic.

So I think we can do more—although I did focus on proteinuria, GFR, and blood pressure, I think we can do more than just look at those 3 variables when we see that patient in front of us in clinic. We need to ask how the disease is affecting their whole life, not just those 3 parameters, and build our treatment program to support the patient in a completely holistic way, so that they can live the best life they can.

Well, I hope you've enjoyed that and thank you for watching.

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