

## Catching it early: the critical first weeks of rheumatoid arthritis

**Interviewer:** Lucy Vernal (Project Director, Ideas Lab)

**Guest:** Dr Rebecca Stack

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**Intro VO:** Welcome to the Ideas Lab Predictor Podcast from the University of Birmingham. In each edition we hear from an expert in a different field, who gives us insider information on key trends, upcoming events, and what they think the near future holds.

**Lucy:** Today we're with Dr Rebecca Stack who's Research Fellow in Health Research within the **School of Immunity and Infection at Birmingham** (<http://www.birmingham.ac.uk/schools/immunity-infection/index.aspx>) University, but she also works across Sandwell and West Birmingham NHS Trust. Welcome, Rebecca.

Rebecca: Hi.

**Lucy:** So tell us what it means being a Research Psychologist in the field of health and medicine. What do you do?

Rebecca: Well, I originally trained as a psychologist and did a Masters in Health Psychology, a PhD in adherence to medicines, so throughout my research career I've applied the knowledge of psychology to the field of medicine and the field of health and my specific area that I'm really interested in is looking at patient decision making surrounding their use of medicines and their use of health services. So one area which I'm particularly interested in at the moment is why don't people decide to seek help sooner for the emergence of new symptoms, so when people get swollen ankles or chest pains, why do some people tend to wait for quite a long period of time before officially going to seek help? Another area which I'm really interested in is the way that people use their medicines. I mean we're all prescribed medicines and sometimes we don't use them in the way that the doctor prescribes.

**Lucy:** Yeah, I think we've all got a few things sitting at the back of a cupboard or in a drawer somewhere that we never quite got round to taking.

Rebecca: Exactly. Exactly, yeah, so if you think about the last time that you were prescribed medicines, it's a very common thing for people not to take their medicines as prescribed. But for people who are taking medicines over a long period of time, particularly when they're medicines that will really contribute towards their long term survival, it's quite important that doctors and pharmacists and the health service gets an understanding of the way that medicines are being used and if people aren't taking their medicines as prescribed, how we can work with patients to make either their disease management better or to not prescribe medicines which people aren't taking.

**Lucy:** At the moment you're working on something called **DELAY** (<http://www.earlyarthritis.co.uk/profiles.htm>) which is looking at rheumatoid arthritis.

Rebecca: Yes.

**Lucy:** And so what you're saying about why people don't seek help early is really crucial with this particular disease isn't it?

Rebecca: Yes, yes it is. The first three months of symptom onset in rheumatoid arthritis are a crucial window of opportunity. If a treatment is given to that patient within the first three months then the inflammation process can almost be turned off or it can be managed much easier over the long term. If you typically think about rheumatoid arthritis you get an image of people with hands which are very stiff and claw-like. This is what we're trying to prevent so if we administer treatment within the first three months then we can almost turn off this inflammation process and prevent people from becoming quite disabled later on. However, our research has shown that after three months a lot of people are still deciding whether they should even go and see their GP for these symptoms of swelling.

**Lucy:** It doesn't seem that serious. I mean, you know, you can imagine why people think well, my hand hurts a bit or I'm a bit stiff in the morning when I get up but by lunchtime I feel a bit better so they don't do anything.

Rebecca: Exactly. Exactly, yeah, we don't want to bother GPs if it's unnecessary. We don't want to be thought of as a hypochondriac but at the same time when symptoms which are life-threatening or indicative of a chronic illness emerges, it's really important that people go and seek help.

**Lucy:** What your team's doing is ultimately looking for some ideas around how can we encourage people to understand what the symptoms are and get to their GPs within that window. Not only that they get to the GP within three months but they get diagnosed within the three months which in itself is quite a journey isn't it?

Rebecca: Exactly, yes. If you develop symptoms there's a period of time where the onus is on you to go and see your GP. So we call this typically patient delay but once a patient actually arrives at the GP there's a period where the doctor needs to make a decision about whether you have rheumatoid arthritis or a different condition. So this is the diagnosis delay. Then there's a referral delay which is where your doctor will write a letter to the hospital and then the hospital will take some time to actually see you. So we've found that within the UK the longest window of delay is actually patient delay, so this is typically three months that people are waiting and we want to actually be treating people within the first three months so it's really important that people seek help quickly.

**Lucy:** And we all remember the stroke campaign that's been on, those adverts on television which were really arresting and got across their message about seeking help, recognising when someone's having a stroke and what to do about it.

Rebecca: Absolutely, yes.

**Lucy:** So ultimately we might see a big campaign around rheumatoid arthritis?

Rebecca: Yes, that's the aim. We want people to be able to recognise it in friends and family who might be suffering but we also want people to pay much more attention to the changes that happen, and particularly when their hands and feet become swollen to know that this is a real symptom.

**Lucy:** Yeah, because honestly it's not as dramatically life-threatening instantly as a stroke but the point is there's so much more you can do if people can get to their GP quickly.

Rebecca: Exactly, yes, yes.

**Lucy:** And it can affect people of any age can't it?

Rebecca: It can, yes. There are many different types of arthritis and there are arthritises such as osteoarthritis and osteoporosis which are associated with age, so as you get older you're more likely to have those. But with rheumatoid arthritis it can affect any age group – young people might not even think that they have any sort of risk of arthritis – they are at risk from getting it.

**Lucy:** And how many people get rheumatoid arthritis? Or what's the kind of percentage of people that might experience it?

Rebecca: It's about 1% of the population.

**Lucy: OK, so it's not that rare.**

Rebecca: No, it's not rare at all.

**Lucy: I mean we've all got a hundred friends or relatives so probably we'll know somebody who will get it.**

Rebecca: Absolutely, yes.

**Lucy: So if there's somebody out here listening to this podcast thinking hmm, I know someone, a friend or family or maybe myself, and what is it they definitely need to look for and what is it they definitely need to seek help over?**

Rebecca: The symptoms are most apparent in the hands and in the feet, so they tend to affect the small joints and what you're looking for is the joints becoming swollen and feeling very tender when you put pressure on them. And one of the most common symptoms is stiffness in the mornings. So this isn't stiffness after you've been on the bike, it's quite common that after you've had a long period of rest that you feel very stiff.

**Lucy: And is this everywhere on your body or just stiffness in your hands and feet?**

Rebecca: Mainly in the hands and feet, that's where the symptoms are concentrated but it can affect the large joints as well. So if you find it very difficult to get out of bed in the morning because you're stiff and this stiffness lasts for longer than an hour, that's the kind of symptom that we're looking for.

**Lucy: OK. And the point is: go and see your GP, you're not being a pain.**

Rebecca: Exactly, yes.

**Lucy: There is something they can do for you if you are diagnosed and it's really important to get there quickly.**

Rebecca: Yes, to get there quickly.

**Lucy: And so just to look at the other area that you've been working on which is the adherence to medicines aspect, people that have been diagnosed with rheumatoid arthritis or other illnesses for a long time, you're looking at how you can encourage them to carry on taking their medicines when it gets boring and dull and you have to remember and you may not want to carry on taking tablets for a long stretch of time, but obviously those tablets are paid for by the NHS and they might be crucial to that person's wellbeing.**

Rebecca: Yes. As you said, the biggest amount of expenditure within the NHS is providing medicines and the World Health Organisation estimates that about 50% of medicines aren't taken as prescribed. So it means that there's potentially a huge amount of waste but it's not just waste in monetary terms. Not taking medicines can lead to poor disease control, a reduced quality of life and it can also mean that people die sooner from the conditions which otherwise might have been well controlled. So if we can look at why people don't take their medicines properly, particularly when they're taking large numbers of medicines - most often people are prescribed multiple medicines - we can try and tackle their non-adherence and the term 'non-adherence' just refers to people not taking their medicines as prescribed. It's very important to understand the way that people are using their medicines because they do this outside of the health service.

**Lucy: They don't tell the doctors about what they're doing.**

Rebecca: Exactly, yes.

**Lucy: They have no way of knowing that they're either not taking them or they're taking more than they're supposed to take.**

Rebecca: Exactly, yeah. People are managing their medicines on a day to day basis, so they're making decisions about their medicines to fit in with their everyday life and like you said, when people go back to their doctor they don't always tell the doctor about these things because sometimes if you've decided that you're not going to take your medicines because you wanted to go out and have a drink, it doesn't come across very well to the doctor if you think about it. And quite often doctors aren't told about these things and on the other hand it's very important that the doctors know what people are doing with their medicines so that they can help to manage the condition.

**Lucy: So it's about helping the NHS taking a more realistic and practical view of what people are actually doing with their medicines once they've left the GP surgery with that prescription in their hand.**

Rebecca: There needs to be a much more open dialogue between patients and prescribers about the medicines that they're taking.

**Lucy: So two really important areas with potentially great impact on healthcare in this country.**

Rebecca: Yes.

**Lucy: Dr Rebecca Stack, thank you very much.**

Rebecca: Thank you.

**Outro VO:** This podcast and others in the series are available on the Ideas Lab website: [www.ideaslabuk.com](http://www.ideaslabuk.com). On the website, you can find out how to e-mail us with comments, questions or suggestions for future topics for the podcast. There's also information on the free support Ideas Lab has to offer to TV and radio producers, new media producers and journalists. The interviewer for the Ideas Lab Predictor Podcast was Lucy Vernall, and the producer was Andy Tootell.

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