

Outstanding wellbeing questions submitted to WSUK from the WS community (webinar 22nd May)

Access to medication

1. What support is there for Wolfram syndrome patients to get medicines? as pharmacies have a high demand and at several times have not delivered my medicines on time and I had to struggle to get them.

Prof Barrett - So suggest telephone GP and ask about NHS volunteers who will deliver medicines for you

Research

1. At the WS conference last September an expert from Italy was due to speak on his eye/OA research, but couldn't attend. How can we hear about his research?

Prof Barrett - We can discuss inviting him to give a webinar perhaps during the next Wolfram family conference

2. Are there trials on yet for coronavirus itself?

Prof Barrett - Yes there are over 30 active trials of new medicines, repurposed medicines, blood products, and of course vaccines. Over 3,000 patients been enrolled in Birmingham, many tens of thousands nationally.

Symptoms of WS

Taste and smell

1. There's this piece about losing one's taste and smell, which I thought was a wolfram symptom? Is any connection, please?

Prof Barrett - There is no connection between loss of taste and smell in Wolfram, and loss in Covid19. In Covid19, the taste and smell come back, but it can take weeks.

Diabetes

2. How can I better control my sugars? What causes insulin levels to go up and down? Diet is being controlled, but insulin levels are still going up and down.

Prof Barrett - This is a big topic and the starting point is to discuss with your diabetes specialist nurse. There are many factors involved which you could try but needs a one to one discussion.

3. Are there any other alternative treatments available for DM beyond basal and short acting insulins?

Prof Barrett - There are other anti-diabetes treatments, but the evidence for effectiveness is weak. As the body does not make enough insulin in Wolfram syndrome, most people need at least some insulin, and it may be dangerous to stop taking insulin altogether. There are medicines that are taken by mouth, such as metformin; and by injection, such as GLP1 agonists (Victoza and similar). These should only be tried on the advice of your diabetes doctor. They are unlikely to be sufficient to manage the diabetes alone.

4. How much influence does WS have on diabetes?

Prof Barrett - Wolfram syndrome has a lot of influence on diabetes, as it is a part of the condition. Diabetes is likely progressive, needing increasing doses of medicines such as insulin over time.

Sleep/lack of concentration

5. How much influence does WS have on sleep needed? Sleep a lot now.
6. How come when concentrating I get very tired very quickly?

Prof Barrett - We don't know the answers to these questions. We do know that patients with Wolfram syndrome may tire more easily than those without Wolfram syndrome. It is important to rule out common, treatable conditions such as high blood glucose, underactive thyroid gland, low vitamin and iron levels, getting up at night to go to the toilet or for a drink.

Treatments for WS

1. Does a nerve stimulator to help empty the bladder work in WS affected people?

Prof Barrett- This works in some people, but needs to be considered in discussion with a specialist urology doctor. You can ask your GP to refer you.