Health and Welfare webinar Q&A transcript

Oral health and dentistry for all types of EB

with dental specialists from Great Ormond Street Hospital.

Q. Regarding Duraphat, 5,000 toothpaste, I used to get this on prescription, but about 18 months ago I was told that it's no longer available on prescription, so I have to buy it at £9 a tube. They said it's cheaper to buy it through their clinic, than on the internet. So that's the current situation.

A. Duraphat toothpaste needs to be prescribed on a case-by-case basis by a dental professional. We still prescribe it. To the best of our knowledge, it should still be available on prescription in England. Nothing should have changed in that respect. I would probably see if your dentist could write to your GP to ask if they could provide you with a repeat prescription. It's very unusual that your dentist has said that it's not available for prescription locally. But maybe it's something we should look into as well to make sure that's not anything being experienced elsewhere.

Q. Do I need a doctor's referral to get an appointment with you for a personal consultation for the child? We are with the Birmingham team, but I would like to consult with you, is this possible?

A. The best way I would say is that if you're under an EB team, most EB teams have a clinical nurse specialist, and they are phenomenal, absolutely incredible. And they usually pass on any question that you have to your local dental team within that service. And I'd say that's usually the best way of getting that question across to your dental team. That's the quickest way.

As far as I know, the Birmingham Hospital also have a fantastic EB dentist, and we pretty much work the same way. But we are more than happy to be seen here.

Q. Regarding enamel anomalies dental treatment, I already have pre-formed metal crowns but what are GIC and PRR you mentioned on your slide? I've had my crowns for about 50 years. My dentist says they've lasted remarkably well. They are a mixture of what I assume are sort of stainless steel on my molars, and I've got some gold cappings on other teeth. They've lasted very well, but you have to keep brushing and caring for your teeth, going to see the dentist, and so on.

I had a lot of malformed teeth, and it's not a good look when you're growing up and you're a teenager. Eventually I got to a stage when I was in my very early twenties. I had most of the work done, and I would say that transformed my life. It made me a lot more confident. It is worth having the work done.

A. Pre-form metal crowns are probably the best thing, because they're a bit more durable, last long, and require much less maintenance. GIC is the type of material. It's usually the type of material that's used for temporary fillings. So, it is good, and it's a quicker, perhaps an easier procedure to do, but perhaps not as long lasting.

A PRR is a preventive resin restoration, which is a bit like a sealant or a small filling again as a preventative coating on top of the tooth, but they all essentially do the same thing by protecting the tooth and preventing any more breakdown.

I would say, if you have the crowns, they're like the best thing.

Q. I was interested in hearing about the mouth stretching exercises. Is that something that your team advises on or supports. Or is that still the physiotherapy department?

A. A therabite is a very useful device, but any kind of jaw opening, mouth, opening exercises come with quite a few challenges, and are quite tricky, especially for children.

The best person to ask is a physiotherapist or the dentist, or anyone experienced with EB. Really, I think sometimes even the EB nurses in the EB team can help you with that. The therabite is the most common one, and we have developed this Christmas tree thing, which is kind of a screw that helps the children. But to answer your question shortly, it is any health professional that's experienced in EB.

I haven't seen those personally, but they look like they kind of do the same thing. Which is this kind of screw, and it sort of progressively improves the mouth. Opening any of these devices, I think someone who's used them knows, that can be quite strenuous on the jaws. We don't know any of those devices personally, but I would again be guided by someone who is experienced.