



Massoud, explains the consequences of living with the effects of Kawasaki Disease which went undiagnosed for years. As a doctor himself, Massoud points out the opportunities and benefits of increased knowledge and awareness for the acute and long term care of those affected by Kawasaki Disease.



I was diagnosed purely by accident, about seven years ago. A friend of mine, a cardiologist next door, said, "Your father had a heart problem. Just come around and I'll do a whole bunch of tests." And then he diagnosed Kawasaki Disease. He noticed that arteries were large.

Admittedly, I had never had symptoms. Interestingly, I've been through all my life without knowing it. My colleague assembled a whole team of cardiologists, cardiac surgeons, to find what would be the best course of treatment and they started me on warfarin.

As soon as the fourth cardiologist said, well, there is no evidence, I opted out personally to go on aspirin. And about a year and a half after that, I had a heart attack. When I had chest pain, in less than two hours, I was in King's College Hospital and in a cardiac lab and opened. And as soon as they opened up the artery, the pain went. So the damage to my muscle is minimal.

And that's thanks to the cardiac network system that we have in UK. Quite interesting to go from being a doctor, dealing with the day to day activity and seeing patients. Suddenly, you're on the receiving end of acute care and you have very little control.

I'm back on the warfarin. Back on a whole bunch of tablets and also added aspirin. So what they have really done now is a super duper anticoagulation. It is not difficult to take and it has very little side effects. I now know that my disease is a serious disease. It can have serious consequences, and I need to stick to the treatment I have. I'm much more interested about how the rest of those people who have not been lucky, like me, have a fulfilling life and not worry about it. How they go through life, and how they are affected.

There should be early diagnosis. I think that's quite an important thing. Prevention is always better in healthcare than actually treatment. Treatment is never as good. It is much more painful for the child, for the adult, for the family and it's more expensive. As a society we have to deal with early diagnosis.

Now, Kawasaki is one of many other diseases but the effect is long term and it's quite devastating if it is not recognised.

If one can find a way to diagnose early and treat, then they can find a way that to improve the quality of life. We need to know what are the early things we can do to shift the balance

We have created over the last, at least 10 years a cardiac network in the UK. This is amazing. And the fact that I can have a heart attack and cardiac episode in any part of UK and end up in a as an adult in a in a cardiac lab and to be treated so fast is probably something that we have to be proud of as a nation. Now, it should be a marginal effort to extend that to children and it is a marginal effort to recognise this group which require a specific treatment and specific extended skills to be introduced into the system.

So when I say I want a system, I want the system to recognise it and get it skilled up. And to be honest, this is doable. This is not a difficult thing to do. But there is so much effort that has put in by cardiologists, the paediatricians – we just need to bring it to a point that all of this evidence translates to better care. Otherwise, you have a whole bunch of evidence sitting on the shelves – if it cannot translate it to better care – every child, every adult who gets a cardiac episode not treated today – it's actually a missed opportunity. That bit requires speed. We are good at getting systems in place but it takes too long. I'm absolutely sure if we can just build on what we have, we can translate that evidence to better care in a much shorter space of time.

They should be able to – when they are confronted with a patient with Kawasaki Disease, give them a definite management plan of how to manage the disease rather than ambiguity. There are more and more guidelines, there is more and more understanding of it. To be much more actively involved in the management of the patients at that stage.

And then secondly, when the patients come as an acute episode. I expect now our Cardiology is building on the 30 years of knowledge and expertise and manage this disease at marginal effort. So that last mile to accommodate Kawasaki Disease should not be difficult for them to do. It really is not a hard thing for them to do. But if they have not got themselves trained or knowledgeable about it, it is a missed opportunity – it is a missed opportunity for the patient. And for them! As a doctor you want the best for your patient.

To listen to Massoud's podcast on Soundcloud, [click here](#).

