

“Communication with your HTC is key. They don’t want to be dealing with your mum and dad – they want to deal with you and your partner, the person you choose to be with for the rest of your life.”

Darren joined HFA in a webinar to talk about his personal experiences of dealing with life changes when you are young and have a bleeding disorder.

You can watch Darren in the video of the webinar on the HFA YouTube channel - <https://tinyurl.com/WHDvideo-youth-2021>

Darren is 29 years old and has severe haemophilia.

It may have been a shock to his family when he was diagnosed with haemophilia as a baby, but has it ever stopped him? Definitely not, Darren said.

‘I am a fully qualified mechanic and have been working in the heavy diesel industry for more than 10 years now. When I was younger, I worked two jobs.’

TRAVEL

He has travelled widely overseas – all through Vietnam and Thailand, and with his medication.

‘Taking my treatment product overseas had its challenges – it’s massive, but I had the support of my HTC,’ said Darren.

BEING IN CONTROL

‘Communication with your HTC is key. They don’t want to be dealing with your mum and dad – they want to deal with you and your partner, the person you choose to be with for the rest of your life.’

‘You are 100% in control with whatever you choose to do, within reason. I rode a motorbike to work every day along the freeway for about two to three years.

It was not a problem. I snowboarded all through winter as well. It’s about how you support yourself and communicate with your team. Make sure you wear all your safety gear. I snowboarded with my helmet on. When I was a kid, I went water-skiing and Mum and Dad made sure I had my helmet on.’

Who are his biggest supports? Darren counts his girlfriend and parents as key supports in his life. He finds it very important to have positive people in his life – friends and family – who support you to overcome your challenges.

WORKING

Darren gave his tips for managing work.

‘Just be open with your employer – that’s probably the best advice I can give.’ He explained that with haemophilia being so rare, most employers would not understand the impact of haemophilia and may be concerned about you bleeding to death from a paper cut. Educating your workplace is important and dealing with their fears.

TREATMENT AND THE HTC

Darren hasn’t been afraid to take on treatment changes and has taken part in several clinical trials, including extended half-life factors early on. ‘There are some really good things that can come out of it,’ he said.

What was it like for him to transition from the paediatric to the adult HTC?

‘It wasn’t so big and scary for me! I think just be open and be yourself.’

DEALING WITH LIFE CHANGES

QUESTIONS?

Check out Factored In, the HFA youth website, for more info on living life and being young with a bleeding disorder – www.factoredin.org.au

And talk to your team at your Haemophilia Treatment Centre if you have any questions or concerns about managing your bleeding disorder – at work, at home, at play, travelling, in relationships.



One thing Darren recommended was to put the work into recording treatment and bleeds in the MyABDR app. 'If you can logon to Facebook for an hour a day, you can spend 2 minutes putting your diary into your phone,' he said. It's a simple way to communicate with the HTC – and, according to Darren, a great way to save the HTC nurses from chasing you about your treatment diary!

For Darren, having a good treatment plan with your HTC is key with managing the changes in your life. It has helped him take on more challenging work, like working in remote areas and in big major events.

'Just stick to your treatment plan. You will be at predominantly normal levels, and just don't be silly. If you fall over or have an injury, treat it.'

His message to other young people?

'You can live a normal life. Just be cautious. Be very aware of how you live your life.' H

