

# RESILIENCE AND ADAPTING TO CHANGE - CAREER, WORK AND SPORT

**WORLD  
HAEMOPHILIA  
DAY 2021**

for YOUNG  
people



**HFA LIVE ZOOM SESSION**  
**7.30PM EST - THURSDAY 22ND APRIL**  
Resilience & adapting to 'CHANGE'  
CAREER, WORK & SPORT

HFA Zoom and Facebook Live webinar for World Haemophilia Day, 22 April 2021

Facilitator: *Natashia Coco, Haemophilia Foundation Australia*

Speakers:

**Penny McCarthy**, Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, The Alfred, Melbourne

**Hayley Coulson**, Haemophilia Physiotherapist, Queensland Children's Hospital, Brisbane

**Nicoletta Crollini**, Haemophilia Social Worker, Royal Prince Alfred Hospital, Sydney

**Darren**, who has severe haemophilia

Watch the video of the webinar at -  
<https://tinyurl.com/WHDvideo-youth-2021>

Resilience is an important factor in adapting to the many changes that occur during our lives. For young people with bleeding disorders the steps to adulthood involve new responsibilities in many areas of life - tertiary study, working and taking on a career, and managing your treatment, to name just a few. And COVID-19 has made everything more complicated.

In this webinar, speakers explored the challenges for young people, with tips and personal stories.

'It's such an interesting time to be talking about adapting to change,' said Penny McCarthy, haemophilia nurse. 'In the last year I have seen more change in one hit with this COVID epidemic than in all my years of nursing.' She commented that change was part of life at the Haemophilia

Treatment Centre. 'It's a very fluid environment that changes quickly from day to day. A lot of that revolves around the people we look after and making them feel comfortable and addressing their needs - because everyone is different.'

## LIFE TRANSITIONS

One of the big transitions in life for young men and women with bleeding disorders is going from a Haemophilia Treatment Centre (HTC) in a paediatric hospital to an HTC in an adult hospital. This occurs during an exciting time in life - when you are leaving school, maybe getting a serious girlfriend or boyfriend, starting a job or uni - but it can be a bit of a shock to the system, commented Penny. The hospital itself looks much less fun and there is a new team to meet, often a larger team than you are used to, because they will be caring for you from when you are 18 until you are elderly. It can be quite daunting - but it is important to remember that the team is there to support you.

Your relationship with the HTC will also change. You are now the adult in charge of your treatment and care and responsible for making decisions, rather than your parents. During your lifetime with haemophilia, your treatments will necessarily change as new treatments become available. Penny described how this works and how education can help you to manage the process.

Ironically, COVID-19 has made some things easier - for example, the HTC now has access to telehealth so you don't always have to come into the hospital for your appointments.

MyABDR, the app for recording treatments and bleeds, is also a great way to communicate with your HTC. It lets your HTC know when you are having bleeds and how you are treating them and gives an opportunity for a discussion



with the HTC team about other strategies to prevent bleeds – and to support you if you are having trouble dealing with new challenges (like a new baby!).

Penny explained that if you have severe haemophilia or are treating at home, you will need to visit the HTC once a year for a review, but otherwise you can usually communicate with the HTC via phone, email or video calls. The HTC is also happy to see you if you are having surgery or dentistry. They are there to help – just call when you need them.

## EXERCISE

Hayley Coulson, haemophilia physiotherapist, was the next speaker, and gave a lively presentation illustrated with some drawings she had put together specially for the session.

‘There are many positives with regular exercise,’ said Hayley. ‘Social interaction, emotional changes, reducing stress, improving muscle strength and control, which can support your joints and reduce joint pain, and improving flexibility. It can also prevent long-term issues such as heart disease, obesity, high blood pressure and osteoporosis or weaker bones.’

People with bleeding disorders may be unsure about how to start exercising or what to do, so that exercise doesn’t cause bleeds.

‘This is where seeking advice is important,’ said Hayley. ‘Talk to your HTC or your Foundation or look on reliable websites. You can also talk to other people with bleeding disorders – older people or people your age and get their personal experience.’

## INJURIES

What do you need to do if you have an injury?

- Appropriate factor administration if this is part of your treatment plan, as advised by your HTC
- Rest and you can also use ice
- If you have regular joint or muscle bleeds, not walking on the leg is important for recovery
- Monitor the injury carefully. If you can’t walk on the leg, or there is noticeable swelling or limited range of movement in your arm or leg, ask for help – contact your HTC, or the local hospital if you are not close to your HTC, or your regular physio to have a review
- Ignoring the injury and not treating it could impact on your health long-term.

## WHAT KINDS OF SPORTS?

Having a review before you start a sport is always helpful, explained Hayley. This will evaluate:

- Your joint motion
- Your muscle strength
- Your flexibility
- Your ligament stability.

Everyone is different and this will tell you which sports

might be higher risk for you and your body. Contact sports like boxing and rugby should be avoided where possible and discussed with your doctor. Protective clothing and gear are also important. Hayley suggested looking at the BRuCe Activity Calculator for more information and to assess the risk with particular sports - [http://www.brucecalc.net/activity\\_calculator.php](http://www.brucecalc.net/activity_calculator.php)

## WORKING

'It's important when you are deciding on a job that it works with your bleeding disorder,' said Hayley. 'You will be working for quite a long time in your life and having a job that doesn't place a lot of stress on your body will make a difference.'

The relationship you have with your employer can also help. You may benefit from changing the way you do your work and being able to talk to your employer about this will be important. For example, you may like to investigate changing your role from physical work like packing to less physical work, like customer service. Or you may prefer to develop your strength and fitness to manage your work better.

Hayley commented that there are a range of experts who can help you, from your HTC team to exercise physiologists and others.

## MENTAL HEALTH

The third speaker was Nicoletta Crollini, haemophilia social worker, who talked about managing your mental health during the challenges of change and growing to maturity.

'Life isn't a perfect journey and we always need to keep a check on our mental health throughout our lives,' said Nicoletta. 'For young people there can be so many things that you are working through: study, new jobs, relationships, family, body image, health concerns – and even changing your HTC.'

A helpful first step is to identify the people in your life who are your social supports - you feel comfortable discussing what's happening in your life with them, you can be honest and feel they won't judge you. They might be your parents, family, siblings, cousins, your friends and your colleagues.

By talking with your social supports about what's worrying you, you are helping yourself. You also have the opportunity to get advice and help from people you trust

and love. Sometimes they will also share their concerns and you have the opportunity to help them as well.

The team at the HTC are also there to support and guide you on your journey. Other professionals who can help you are your GP, who can link you to other services, like counselling. Nicoletta highlighted that there are also online mental health support services.

### Online mental health support

Questions or concerns? For support you can talk to:

Organisation	Telephone	Website
Beyond Blue	1300 22 4636	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Lifeline	13 11 14	<a href="http://lifeline.org.au">lifeline.org.au</a>
Headspace	1800 650 890	<a href="http://headspace.org.au">headspace.org.au</a>
Kids Helpline	1800 55 1800	<a href="http://kidshelpline.com.au">kidshelpline.com.au</a>

'Life isn't a perfect journey and we always need to keep a check on our mental health throughout our lives,'

## TAKING CONTROL

Another way of managing change is to learn more about what is going to happen, for example, by talking to your employer about your new job or to the TAFE about your new course.

Sometimes changes are unforeseen and can be very unsettling. COVID-19 is a great example of a change we weren't expecting. With these kinds of changes, Nicoletta suggested tapping into the things that help us to get up again when we have been knocked over – our resilience, how have we overcome problems in the past. It might be with the help of friends of family or through taking time to think and reflect, or self-care, with the rituals that help you relax, going for walk or watching trashy TV or playing your favourite video game. And once again, your social supports will be important.

## DARREN'S STORY

Darren then joined the webinar to give his personal experiences of adapting to change.

Having severe haemophilia hasn't stopped Darren from taking on all the challenges of growing to adulthood – working, travelling overseas, having relationships, managing his own treatment and working closely with his HTC.

His advice to other young people?

He thought it was most important to stay in touch with your HTC and stick to your treatment plan.

'You are 100% in control with whatever you choose to do, within reason. You can live a normal life. Just be cautious. Be very aware of how you live your life.'

You can read Darren's story in this issue of *National Haemophilia – Youth News, Adapting to life's changes*.

## Q & A

### Tattoos

#### Q: What about getting tattoos?

Darren has several tattoos but is always careful to choose a safe tattooist. Penny commented that, while HTCs don't condone tattoos, if you are going to get one and you have severe haemophilia, make sure you have it done on the day that you have your prophylaxis.

### Parents and boy stuff

#### Q: How did Darren's parents support him doing all his 'boy things' while he was growing up?

Darren replied that his mother had 'aged very well' considering the rough and tumble when he and his brothers were growing up together! He commented that part of the joys of having boys with haemophilia was that they would do things they weren't supposed to and learn from their own mistakes – for example, kick the footy around and have a swollen foot the next day.

His mother supported him by learning about haemophilia and how to treat him at home, how to ask him appropriate questions, and never wrapped him in cotton wool – always let him try things out, but always with the right safety equipment and an up-to-date treatment plan. If parents hold their children back, it just makes them anxious, Darren explained. They will turn 18 and be too frightened to deal with change.

### Starting a conversation with a new employer

#### Q: How do you start a conversation about having haemophilia with a new employer?

Darren thought there could be a few different ways to talk to a new employer about having haemophilia, depending on the employer and the situation:

- If you are confident about it, you could even mention that you have haemophilia in the interview and explain how it will and won't impact on you and your work
- Darren often says, 'if I didn't tell you, you wouldn't know I have it'
- You may need to go more slowly and give them information and education
- Every employer is different and has different concerns, but many will be thinking about their liability.



### **When is it too late to treat an injury?**

**Q: How long waiting is too long? If I can walk but my knee is still swollen and sore after 6 days, should I call you or is it too late?**

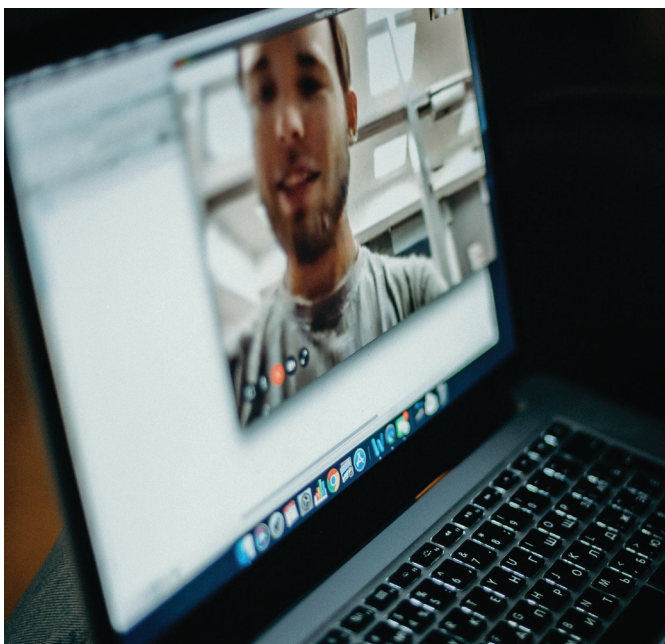
Hayley responded to this question, saying while it is preferable not to wait, it is important to contact your HTC for support and advice rather than ignore a bleed. Even if the injury isn't in the 'acute' phase, when it will respond better to treatment, there are still things that can be done and you will have follow-up advice and guidance from your physio. This is also an opportunity for education about how to manage bleeds – because when you are doing well on treatment and don't have bleeds very often, you forget what to do.

Darren added that in his experience, haemophilia physiotherapists will continue to work with you and always have new things to try, right through rehabilitation, and no matter how long it takes. And he has learned from experience to seek help early, when the injury is more likely to resolve quickly with treatment.

### **Changing treatments**

**Q: Should you contact your HTC to ask about new treatments or wait for them to contact you?**

Penny recommended proactively contacting the HTC to express your interest in changing to a new treatment, particularly now that there are several new treatments. The HTCs have had a lot of questions from their patients and have even had to schedule Zoom group information sessions because the numbers interested are so large. If you contact the HTC, they will already know you are interested.



### **Parents letting go**

**Q: What advice would you give to parents who are having trouble letting go of their children with a bleeding disorder?**

Nicoletta explained that the transition to adult care wasn't black and white and that it is important for parents to feel confident about their child's care, even when they are technically an adult. She suggested taking up opportunities with HTC transition programs to meet the team and see the adult Centre, perhaps attend an appointment or two if everyone is agreeable. It is also important to give young people a good foundation to take responsibility for their own care in their teenage years. Then parents can step away – but also have the relationship with the HTC to touch base if they have concerns, particularly in the first year.

Penny added that the relationship with each person and their family would be individual. She commented that she could understand their concerns as every parent worries, but she thought reaching adulthood and independence with a bleeding disorder was a great milestone and parents should be congratulated for all their hard work in bringing up their child over all the years. Darren suggested rewarding parents – in the first year of transition, take them out to lunch after your review appointment and fill them in on how you are going.

Our thanks to Penny, Hayley, Nicoletta and Darren for taking part in the webinar and sharing their expertise and experience.

### **MORE INFORMATION**

For more information about young people and bleeding disorders, visit the HFA youth website [www.factoredin.org.au](http://www.factoredin.org.au)

If you have any questions about your bleeding disorder or your treatment and care, speak to the team at your Haemophilia Treatment Centre. 📞