

TREATMENT CHANGES

How can patients best prepare themselves for treatment changes?

The last 12 months have seen some exciting new treatment options for people with haemophilia in Australia. Jane pointed out that, while it can be really positive, swapping to a new treatment can also be quite scary.

- **Make sure you have the information you need** – through reading articles and stories, talking to your HTC, talking to your peers.
- **Write your questions down and bring them to your HTC** – there are no silly questions, and if you have more questions after your appointment, you can always talk to your HTC again.
- **Does change cause you anxiety?** Try the things that help you to feel calm and get a good night's sleep before you visit the HTC to change your treatment. Avoid the things that don't help – for example, too much alcohol. Let people around you know that you are feeling anxious. Your HTC can help with an individual plan to support you.

EMBRACING CHANGE

Change is an inevitable part of life. How can you build a life that embraces change?

Nicoletta underlined the importance of having a resilience skillset – your armour and backbone – to manage welcome and unwelcome changes in your life. Some other useful strategies:

- Stepping back and looking at the situation, so you can prepare yourself and make informed choices and decisions
- Take some time to reflect
- Acknowledging that you don't always have control over a situation and looking at what you can control
- Self-care is always key.

SEEKING SUPPORT

When should people seek support if they are worried about their mental health?

Basically, the message is to seek help if you are concerned about your mental health, said Jane. Talk to trusted people in your social network or your health professionals, for example, those at your HTC or your general practitioner or other health care settings where you have a relationship.

This can help you find suitable support and sometimes you may be able to talk through your worries and have help with them.

Online mental health support

Some community services also offer online chat and telephone services when you have concerns and feel you would like some support.

Organisation	Telephone	Website
Beyond Blue	1300 22 4636	beyondblue.org.au
Lifeline	13 11 14	lifeline.org.au
MensLine Australia	1300 789 978	mensline.org.au
Headspace	1800 650 890	headspace.org.au
Kids Helpline	1800 55 1800	kidshelpline.com.au



LENNY'S PERSONAL EXPERIENCES

Lenny has grown up with challenges not only from his haemophilia, but also from other disabilities he acquired through trauma at birth – problems that affect his eyesight and mobility, cause a build-up of fluid on his brain and a palsy, and other learning difficulties. His hearing, however, is acute and he has gravitated towards music as something he loves and now as his career.

This last year has been both difficult and exciting for him. He was working to complete his Bachelor of Arts degree in music and psychology, but COVID-19 restrictions meant that he had to participate on Zoom and with his sight problems, made his group assignments difficult. When he explained his visual difficulties to his fellow students, they were more understanding and the experience of studying improved for him. He has now completed his course – a great achievement!

Another really positive change for him has been switching to a new haemophilia treatment. Because of his vision impairment, he had always relied on his parents to infuse his treatment and had a 'massive needle phobia'. The new treatment is injected sub-cutaneously, under the skin, and is much less complicated. To Lenny's delight and surprise, he is able to manage his treatment himself, which has meant a whole new independent life and future for him.

Read the full version of Lenny's story in this issue of *National Haemophilia*.

Q & A

Q – Lenny, how were you so resilient that you gave the new treatment a go?

Lenny explained that the first thing he did was find out what a 'sub-cutaneous injection' was. Once he learned that he didn't need to find a vein, but could just inject it into the fatty tissue under his skin on his stomach, he was excited because he realised he could inject his treatment himself. Before he has new experiences, he always feels a sense of panic about what it would be like. When he was shown the actual equipment, he was shocked by how small everything was and realised he would need extra strength glasses. He needed to make sure he was doing it right. He had a couple of supervised self-administered injections with the nurses at the HTC, but for the first couple of times on his own, he asked his Dad to supervise him drawing up the solution to make quite sure he had enough.

Q – How did you get over your feelings of anxiety?

One of the most important things for Lenny was the opportunity to research the new treatment online and then ask the nurses at the HTC more questions about how it worked and how to prepare it.

Q – Suggestions on how to cope with recovering from surgery?

In Lenny's experience, being able to sit up and move around after surgery makes rehabilitation more bearable. He had to spend the majority of his time confined to one room but found things to distract himself and occupy his time – watching educational videos and other shows on TV.

Letting others know how you are going is also important, said Jane. You can talk to the HTC social workers and nurses, letting them know if you are having any problems, and they can work with you on how to manage. It's good to have things to watch and read and people to visit you. You can prepare this in advance – a little kit bag of things you had been meaning to do, the book or video you hadn't got around to yet.

Nicoletta also pointed out that it is good to create a routine – waking up at a certain time, mornings for reading, late mornings talking to a relative or watching a show, etc. Create a little bit of structure for yourself. If you are in hospital for a long time, the loss of routine and boredom can be hard and it is helpful to have strategies to overcome it.

Our thanks to Jane, Nicoletta and Lenny for taking part in the webinar and sharing their expert advice, tips and personal experiences. #



Lenny graduating
Photo: Lenny