



**Gavin
Finkelstein**

President,
Haemophilia
Foundation
Australia

From the President

COVID-19 AND LOCKDOWNS

People in different parts of Australia have experienced various states of lockdown and hardships because of the pandemic. I talk to our members around Australia, and also overseas, and while it is harder for some than others, the implications of COVID-19 and, more recently, the Delta variant have been confronting and scary for everyone. In WA we have felt somewhat shielded from the eastern states, but we all know what it's like to have snap lockdowns and restrictions and to have to quickly adjust the way we live and work, and how we communicate and support our loved ones.

People with kids talk of home-schooling nightmares, and I know personally how difficult it is to support older members of my family. I know you may be supporting and caring for someone at the moment and this can become tiring and frustrating, but we need to do the hard yards and keep going. We know living with lifelong conditions like having a bleeding disorder often helps develop resilience and strengths some people might not even know they have until tested, but there will also be times when people need to reach out for support. Please let us know if HFA can help in any way.

We know some people have not been able to keep as well connected with their HTC as before, while others have been able to use telehealth and other services to connect more often. We thank our HTC staff for their work over this very difficult time. It may have been hard for some of our members to explore new treatments for haemophilia that are now available, because they haven't been able to get to their HTC. We urge you to stay connected with your HTC and make plans if you do need information about what new treatments might mean for you.

The HFA office staff still work from home, as the Melbourne office is temporarily closed, and the HFA Council continues to meet virtually. Although meetings via videoconferences are not as good as face-to-face, it has been helpful for some of us not to

have had as much travel. Unfortunately we have been pushed to a virtual national conference this year, but the advantage of this is that people can participate from the comfort of their own home! So please do register to attend the Conference!

HEPATITIS C

An important issue for the HFA Council is to address the consequences of hep C for the bleeding disorders community. The World Hepatitis Day campaign you will read about in this publication is part of this. You might see postcards about hep C at local peer support meetings which are to remind people of the risks and to check their hep C and liver health test results. The *Double Whammy* report highlighted that a cure was a priority for our community. In Australia we have been fortunate to have highly effective hep C treatments available to everyone through the public health system and it is important to take advantage of that and make sure everyone with a bleeding disorder and hep C has treatment and opportunity for cure where this is possible. So we are trying to find people who might not realise they are at risk – or may have wondered, but not got around to following up.

We have also been discussing the ongoing issues with the hepatitis experts - that for some people with cirrhosis or advanced liver disease, keeping an eye on liver health into the future is crucial, even with a cure. Checking your liver test results with your hepatitis specialist after cure to know whether your liver has recovered is another important step, as you may need ongoing follow-up. Sadly, we know that some of our community members have very advanced liver disease from hepatitis C. This is a reminder of the consequences that can arise from hep C and I have shared my personal story to encourage others to please act on their hepatitis C health, if they haven't already.

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Dealing with challenges and change

Sharon Caris

In our June 2021 issue of *National Haemophilia* you may have read about some of the challenges and changes faced by people with bleeding disorders and their carers, and how they have addressed this.

Change can have a big impact on our lives and being able to recognise and adapt to it is a really important tool for our wellbeing.

HFA has adopted the **Embracing our changing world** theme for our upcoming national conference, and there will be sessions on change and coping with change that are practical for everyone.

The COVID-19 pandemic has raised so many issues and concerns for people, especially during lockdowns. Our way of life may have changed because we can't get out and about as much, we may not be able to see family, friends and our other support people as often as before, including our health professionals who have provided support and care.

At our April 2021 webinar on adapting to change for World Haemophilia Day, Nicoletta Crollini (Haemophilia Social Worker at RPAH, NSW) and Jane Portnoy (Haemophilia Social Worker at the

Alfred, Victoria) talked about the importance of resilience, self-care and seeking support. You can also read a report of this webinar in the June edition of *National Haemophilia*.

ADAPTING TO CHANGE WEBINAR

Watch the video and read the report of the Adults adapting to change webinar at <https://tinyurl.com/HFA-adapting-to-change>

Jane noted the importance of seeking help if you are concerned about your mental health; and suggested talking to trusted people in your social network or your health professionals such as at your Haemophilia Treatment Centre (HTC) or your general practitioner or other trusted health professional. Some community services also offer online chat and telephone services when you have concerns and feel you would like some support. There is also online support available for mental health.

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Sharon Caris is Executive Director, Haemophilia Foundation Australia

<p>ONLINE</p> <p>MENTAL HEALTH</p> <p>SUPPORT</p>	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

From the President continued

The Getting Older Report has also identified the need for services and financial support and advocacy around insurance discrimination. This work is ongoing. Don't forget the **Getting Older Info Hub**

where you will find information on a range of issues that arise for those of us who are aging – www.haemophilia.org.au/getting-older.