

ASK US

Q AND A'S WITH ALEX & JANE - ALFRED HOSPITAL HTC TEAM

Changing to a new treatment

In the March 2021 edition of *The Missing Factor*, the "Ask Us" column focused on the Covid-19 vaccine & haemophilia treatment. (To read go to www.hfv.org.au/HFVIC/media/Images/Ask-Us-Autumn-2021.pdf or scan the code below)



Further to this, we want to remind all members that when you read any medical themed articles to always personalise these to your own situation.

Please consult with your treating doctor (including your GP) and the HTC nurses when you question if this is relevant to you.

Living with haemophilia, inherited or acquired or the various bleeding disorders is complex and as we grow older, we may develop other medical conditions over time.

Again, we strongly remind members to have a GP who will work with the HTC in managing your health care.

Remember you are never alone in your health care.

Alex, Jane & The HTC Team
Please send 'Ask Us' questions to info@hfv.org.au

I have been on prophylaxis for many years, and now there is a new option. I know that I really struggle with change sometimes, what can I do to prepare emotionally for change over to a new treatment?

Thanks for the great question, change can be both exciting and unsettling. Stability and routine are often at the basis of our confidence that we can manage. This will help us have a predictable and comfortable pathway through each day, but there is a risk that it may become boring. For those of you living with haemophilia, without being open to the clinical consultation at your HTC, the opportunity to discuss many of the new treatments would be missed. We do know for many people considering change, being prepared and when supplied with the clinical information can make a huge difference to how that change is experienced.

What are the changes that are happening for the bleeding disorders community at the moment?

- New treatments and gene therapy
- Covid protocols, such as wearing masks, using telehealth, sometimes limiting of visitors in hospital, having vaccines
- NDIS and preparation for older age under MyAgedCare

So now it is time to ask how you can succeed when there is change going on in your life.

- If contemplating change causes you to increase your consumption of food and other substances, review your self-care in the form of eating a balanced meal, reducing or ceasing alcohol, other substances such as cigarettes and recreational substances.
- Make sure you are getting enough exercise and enough rest.
- Spend some time doing things that you enjoy, this might be a hobby, sport, visiting with friends, significant others or making time with family
- Information, find out all that you can, have a look at any published material, read what you can, look at trustworthy websites for your information and talk with people who have some knowledge or experience in the area.
- Let your support networks know what is going on, and what support you might need, for example, would you like someone to come with you on the day that you switch over, would you like someone to learn too so that they can support you when you get home?
- Give yourself time, don't expect that you should be okay instantly.
- Check in with yourself and don't be afraid to seek help from your health care team, the varying members of the HTC, your GP, or talk with a counsellor.

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