National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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Let's talk about getting older

HFA NEEDS ASSESSMENT

CONTENTS

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PROBE STUDY

Do you have haemophilia or carry the gene?

Have you completed the **PROBE (Patient Reported Outcomes Burdens and Experiences)** questionnaire?

The survey is available at
https://tinyurl.com/PROBE-Australia

Or ask HFA or your Foundation for a print copy.

Your responses can help to build strong evidence about the impact of haemophilia.

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and this data is crucial for our treatment advocacy.

You are invited to complete the survey if:

- **you are an adult with haemophilia or carry the gene**
- **or you are an adult and DON'T have a bleeding disorder (as a comparison group)**

Consider being involved to help us with this important study!

ANY QUESTIONS?

For more information about PROBE in Australia, visit
www.haemophilia.org.au/research/probe-study

Or contact Suzanne at HFA:
E: socallaghan@haemophilia.org.au
T: 1800 807 173

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

COVID-19

As we approach the mid-year reporting time for HFA, I wonder what our future members will think about the very unusual year of 2020. We finished 2019 with a very exciting national conference and feeling very upbeat. We had new treatment products to look forward to, our community was feeling strong and engaged and we had many plans for community events. As the terrible situation resulting from COVID-19 started to unfold around the world, we were soon to discover we were living in a pandemic that would bring the world to a halt in so many ways. We hope you and your families have stayed well during this time. For Australians with a bleeding disorder there has been an ongoing supply of treatment products and medicines but we know that hasn't been the case for everyone globally, and our thoughts are with National Member Organisations whose members are finding it harder to get treatment and support.

We are grateful for the extra work done by our Haemophilia Treatment Centre staff in extraordinary circumstances to keep connected and to be available to help their patients, whether it's been via telephone or internet, and to manage the difficult situations which have arisen because people needed to attend hospitals for treatment. The National Blood Authority has kept us up to date and assured us the existing plans will meet treatment product needs.

TREATMENT PRODUCT TENDERS

We are still waiting on the outcome of the government tender process for the supply of treatment products. We have many people desperately waiting for a new treatment and we hope we will soon be in a situation in Australia where best practice clotting factor and other treatments is a reality. At the national conference and at our meetings and events we have heard from clinicians and the those who have had the chance to use a new treatment in a clinical trial or compassionate access program just how life changing some of the new options can be. Everyone in our community should have access to an improved treatment which helps them lead a healthier and more fulfilling and productive life. You will read about young Christopher in this publication and share our delight that his life has become so much better.

SUPPORTING HFA

Thanks to the HFA office staff who have been working from home, we have kept a lot of our work going, as you will see from this publication. A great concern is that we have experienced a sudden decline in donation income, possibly partly due to the bushfires and perhaps now because of the difficult time experienced by some of our donors due to the downturn caused by COVID-19. We will need to review our plans significantly going forward to ensure we target the most pressing activities with the funds we have available. Our donation income supports some of our care and services as well as our advocacy and it is critical that we don't slow down our work in this area. If you can help us in any way, please do.

You can donate online at www.haemophilia.org.au/donate or call 03 9885 7800.

WORLD HAEMOPHILIA DAY 2020

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

CELEBRATING 30 YEARS!

2020 saw the 30th anniversary of World Haemophilia Day. The longevity of this celebration is proof of the dedication and tight-knit nature of our community.

The theme of World Haemophilia Day in 2020 was **Get+involved**. We encouraged our community to help increase the awareness of inherited bleeding disorders and of the need to make access to adequate care possible everywhere in the world.

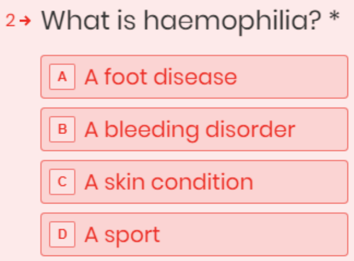
THE VIRTUAL CAMPAIGN

In April 2020 Haemophilia Foundation Australia once again celebrated World Haemophilia Day – but this year in a very different style. HFA developed a virtual pack for families to use in the comfort of their own home. The virtual pack included World Haemophilia Day and Light It Up Red landmark colouring-in sheets, an online quiz and word find. And of course, kids were able to test their friends' knowledge and their own with the online quiz about bleeding disorders!

Visit the HFA World Haemophilia Day page to download the virtual pack - https://tinyurl.com/HFAWHD20

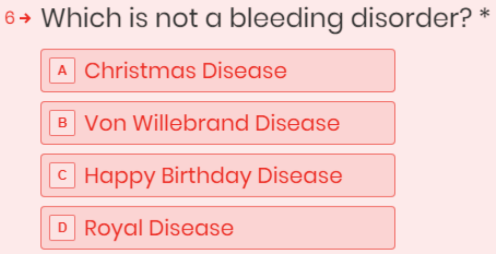
THE ONLINE QUIZ

You can take the online quiz at https://tinyurl.com/ydew8yza



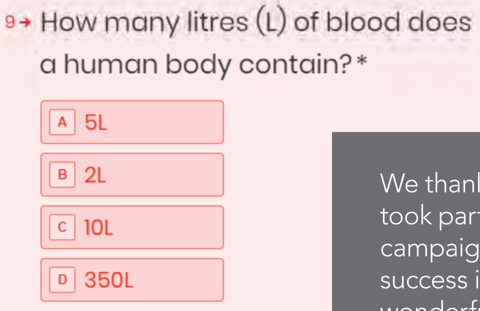
2→ What is haemophilia? *

A A foot disease
B A bleeding disorder
C A skin condition
D A sport



6→ Which is not a bleeding disorder? *

A Christmas Disease
B Von Willebrand Disease
C Happy Birthday Disease
D Royal Disease



9→ How many litres (L) of blood does a human body contain? *

A 5L
B 2L
C 10L
D 350L

We thank everyone who took part in our virtual campaign. What a great success it was, and so wonderful to see people taking part.

LIGHT IT UP RED!

The following landmarks turned red in support of the day and we thank the authorities that organised this.

ACT

Telstra Tower
Shine Dome
The Australian Mint, Deakin

NSW

Sydney Town Hall

QLD

Story Bridge
Victoria Bridge
Reddacliff Place Steam Sculptures
Brisbane City Town Hall
Sandgate Town Hall
King George Square
Munro Martin Parklands
Tropical Dome, Brisbane Botanic Gardens
Gasometer @ Gasworks Plaza
Heritage Façade Light
Town Hall Warwick Clock Face
Mackay City Fountain Precinct
Sir Albert Abbott Admin Building, Mackay
Kurilpa Bridge
Parliament House Brisbane

SA

The new Riverbank lighting feature

TAS

Cardinal Lights

VIC

Melbourne Star Observation Wheel
Geelong intersection Moorabool & Malop St Geelong

WA

Optus Oval
Trafalgar Bridge
The Bell Tower
Elizabeth Quay
Crown House
Yagan Square
Matagarup, Mount Street and Sky Ribbon Bridges
Perth Concert Hall

WORLD HAEMOPHILIA DAY AROUND AUSTRALIA

FACEBOOK LIGHTING UP RED!

What a great showcase of support with people changing their Facebook profile pictures for the day!

Suzanne O'Callaghan is HFA Policy Research and Education Manager

LET'S TALK ABOUT GETTING OLDER

Suzanne O'Callaghan

When we first asked the nurses at Haemophilia Treatment Centres (HTCs) about the emerging issues related to ageing with a bleeding disorder, they said, 'Where do we start?'. And indeed, the Haemophilia Foundation Australia Getting Older needs assessment had a lot of ground to cover!

The *Getting older with a bleeding disorder* needs assessment report has now been completed, the result of many months of intensive work.

WHY A NEEDS ASSESSMENT?

Over the last several decades improvements to treatment and care have created a new phenomenon: for the first time we are seeing a generation of people with bleeding disorders who are living into their senior years. With the newer and emerging therapies, there is hope that they will also be able to enjoy a better quality of life.

This is a welcome change, but it has its challenges. This new older generation is entering unknown territory. They are encountering the issues of ageing faced by the general population and are also the first group to experience the impact of ageing on their bleeding disorder.

'Early ageing' is also a problem for some in our community. Many relatively young people with bleeding disorders experience complications usually associated with growing older, including joint and muscle damage, arthritis, pain and mobility problems. This impacts on many aspects of their life and many have difficulty meeting the eligibility criteria to access support services.

It was important for Haemophilia Foundation Australia (HFA) to understand the needs of older people with bleeding disorders into the future. HFA began work on the needs assessment in late 2018 and during 2019 consulted with the bleeding disorders community, specialist health professionals and other relevant organisations. The Getting Older needs assessment report brings together the findings from that consultation.

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HOW TO ACCESS THE REPORT

The full report has been published in print (black and white) and online (full colour).

There is also a short community report, which is a summary of the findings.

If you would like a print copy of the report, don't hesitate to contact HFA and we will post you a copy:

E: hfaust@haemophilia
T: 1800 807 173

You can download the report from the HFA website – www.haemophilia.org.au

WHAT DID WE DO?

Some of you have met or spoken on the telephone to Preetha Jayaram, who was employed by HFA on a 12-month project to undertake a needs assessment to help HFA understand the needs of older people with a bleeding disorder. Over the 12 months Preetha consulted widely:

- 43 interviews nationally with older people with bleeding disorders, their partners and family, health professionals at HTCs and other organisations with a common interest in chronic health conditions
- 2 community forums, one in the ACT and one in Queensland
- The Getting Older Community Survey, which had 169 respondents from all states and territories.

She transcribed all of the interviews and organised the data from the consultation into themes – a huge job.

We were also able to analyse some age-related data from the PROBE (Patient Reported Outcomes Burdens and Experiences) Australia study and we have included the results in the report.

WHO DID THE GETTING OLDER SURVEY?

169 people completed the Getting Older Community Survey.

89 (53%) returned the **online** survey
80 (47%) returned the **print** survey

133 were **older people with bleeding disorders**
65% were male
34% were female
104 had **haemophilia** or carried the gene
19 had **von Willebrand disease**
15 had a **rare clotting factor deficiency**
7 had **other bleeding disorders**
Some had more than one bleeding disorder.

36 were **partners or family**
19% were male
81% were female

WHERE DID THEY LIVE?

All states and territories were represented.
45% lived in a **capital city**
13.5% lived in a **rural/urban fringe area**
28% lived in a **regional/rural/remote area**

WHAT DID WE LEARN?

'Ageing' and 'getting older'

The first thing that was made clear to us was that 'ageing' wasn't a very helpful word for the community. Older people with bleeding disorders thought that 'ageing' put them in an 'old person' box where they didn't belong, and that it was negative and often discriminatory. Younger people with joint and muscle damage are often referred to as having problems of 'early ageing' but they also pointed out that they were still relatively young and not actually aged in years; they had muscle and joint complications which looked like the problems of ageing.

So, after some discussion with the community about what terminology might work better, we changed the name of the project from the 'Ageing Project' to the 'Getting Older Project. We were careful of the language in the report and, although we did use the word 'ageing' on occasion, this was as a medical term.

Aspirations and goals

HFA's vision is of 'active, independent and fulfilling lives for people in our bleeding disorders community', but what does this mean to older people with bleeding disorders? Understanding their aspirations and goals is essential to achieving this.

When older people with bleeding disorders were asked about their aspirations for the future, most said they wanted to maintain their quality of life, be healthy and remain independent. This involved improving their mobility, reducing stiffness and pain, and being able to participate in family life and enjoy friendships, travel, pursue their interests and to contribute in a useful way to society. Some wanted to continue working as long as they were able to, other were hoping to stop or reduce work. Some were already retired or not working. Being comfortable financially was important.

'To remain fit, healthy and well. Travel. Support my children in caring for their future children, who may have haemophilia. Volunteer work.'

'Maintaining my quality of life as I am noticing my health is getting more challenging year by year.'

'To continue to be active and find a way to reduce stiffness and pain.'

'As I get older I hope to have a comfortable life. Still having quality of life. As I said I am young at heart.'

'The word retire doesn't mean anything to me. I rather not retire and just keep doing things that are worthwhile, whatever that may be.'

Challenges and concerns

What could get in the way of achieving their aspirations and goals? What were they worried about?

The needs assessment covered a wide range of issues and concerns raised by community members and HTCs – you can see more in the full report. We touch on a few below.

There is a culture of stoicism and 'getting on with it' in this older generation. They had grown up in a time before prophylaxis, when there were treatment shortages, and as a result many lived with joint and muscle damage as a result. Many had also been exposed to hepatitis C and some also to HIV through their treatment products in the early days of the epidemics. Health professionals at the HTCs commented on their resilience and determination to overcome challenges.

'The haemophilia community have been so resilient and stoic; they continue that one into their ageing as well. So they manage and push through a lot of things when other people need extra help.'

'Resilience is my strength. It's a marathon and you've got to have resilience.'

However, there is a limit to even the most positive and determined attitude. At a certain point, the combination of their complications with their bleeding disorder with the health conditions of ageing could be too much of a challenge to manage.

'I always had to deal with issues all my life, but I deal with them. If I lose that ability, I feel that's the place I am not really happy about to go to.'

Health concerns were mentioned most often by both the community and health professionals.

Many worried about losing their independence. They spoke about problems with their mobility and dexterity from the joint and muscle damage, arthritis and pain that were the result of bleeding episodes over a lifetime. This could limit their ability to work, make it difficult to travel and prevent them from being as active socially – catching up with family, friends, the foundation activities – all of which was important to their enjoyment of life.

Some talked about the trouble they were having infusing their treatment, with arthritic, shaky hands and scarred veins. Who would look after their bleeding disorder if they developed dementia and moved to a residential aged care facility? Some did not know what aged care services were available or how to access them.

Getting to the HTC for appointments was also becoming more difficult – and there were so many appointments to manage all their health conditions. As they grew older they had more health issues to deal with. This could require liaison with their HTC to manage factor cover for surgery or medical procedures like biopsies or dental work. If they had cardiovascular problems, the HTC would need to work out the best approach to anti-coagulant medications with their cardiovascular specialist.

HTCs were seeing more of their older male and female patients with mild haemophilia and VWD. Bleeding disorders are rare and some talked of the difficulties they had when health professionals outside the HTC would not take their concerns about bleeding complications seriously. Nearly all had a general practitioner (GP) for their general health care, but HTCs were concerned that some were not having regular preventive health checks and could miss out on treating a serious health condition early.

Younger people with the 'early ageing' complications of a bleeding disorder could slip through the eligibility cracks of the National Disability Insurance Scheme and other government safety net support programs.

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'At times it's hard. The only thing that stops me from doing things is my physical being – that being hip replacements and lately I have a heart condition. I am finding with this heart condition, it's more doing shopping. I am finding it little bit more difficult.'

'I can find myself getting a bit shakier now which can make intravenous injections little bit harder.'

'It's difficult to shave, I can't reach my top button. Brushing teeth, cutting up pieces of food, tying up shoelaces are a problem. I buy slip-on shoes. My partner dries and dresses me.'

'As I age I was led to believe that von Willebrands would not be such an issue. I have NOT found this so. My body says otherwise!!!!'

'The radiology team are like, let's do the biopsy now. Then I have to say I have a bleeding disorder, I can't have the biopsy now… okay…then the nurse [from the HTC] calls and plans. My concern with getting older is the invisibility that you get. Older women are really invisible. Older people in general are so dismissed.'

'I use a mobility scooter these days. It's in the back of my car. If I lose the ability to drive, I am going to be relying on other people to take me places.'

WHAT WILL HELP?

Older people with bleeding disorders often develop strategies to work around their physical problems and share them with each other and they had a similar constructive approach to suggesting solutions for the needs assessment. HTCs also took the opportunity to explain the issues they had been managing and discuss their ideas on what else would help.

Patient-centred care

An important underlying principle was to achieve 'patient-centred care'. What will happen along the patient journey as the person with the bleeding disorder grows older? What services and help will they need? What will be the bumps along the way? What can be done to improve their experience – and their health and quality of life? What could help them to stay in the workforce longer?

Some suggestions were:

- Strengthening the role of HTCs in providing and co-ordinating comprehensive care for their older patients, which involves resourcing them adequately to undertake this work
- Innovations in comprehensive care to make access easier, eg telehealth, evening/weekend clinics, HTC outreach to outer suburban or regional areas, HTC liaison with local health care services
- Investigating all suitable transport options available
- Strengthening the relationship between HTCs and GPs
- Ongoing development and proactive use of the Australian Bleeding Disorders Registry (ABDR) and MyABDR, the patient recording app and website
- Education about the special issues of growing older with a bleeding disorder for
    - Older people with bleeding disorders
    - Their partners, family and carers
    - The health and community workers who provide their care
    - Employers
- Access to newer longer-acting and non-intravenous treatments for older people with haemophilia
- Treatments and programs to support being active and maintaining mobility and physical functioning
- Pain management
- Information about and support to access the range of aged care services
- Flexibility in the workplace, an understanding employer, vocational counselling.

'Having to treat less could help. Getting the half-life products might reduce having to treat from every 3 or 4 days, but with the sub-cutaneous product I could treat once a month. Accessing veins will become an issue the older you get, also with my elbow getting worse – and I think about getting dementia or something like that.'

'I think access to therapies to keep strong and mobile. I am talking about my local community support centres, so I don't have to go to the hospital to access my aqua-physio. Having access to parking spaces would help, so we don't have to walk too far.'

'Often a chronic illness such a bleeding disorder needs holistic care. Our current hospital and referral system is such that each specialisation acts as a silo rather than working together. This is fine if a person is treated for a one-off issue. But becomes a problem when an illness creates a myriad of issues that need examination.'

'Lots of things [will help to keep working]. Flexibility of work hours, having an understanding/supportive employer, career advice, support to retrain if required, pain management, physio, counselling, psychosocial support, you name it.'

‘Resilience is my strength. It’s a marathon and you’ve got to have resilience.’

Hepatitis C and HIV

HFA also looked into the specific issues around hepatitis C and HIV in older community members. Nearly all who had been exposed to hepatitis C had been now been cured and were grateful for their successful treatment and the potential improvement to their health and lifespan. Although hepatitis C had a major impact on the working and personal lives of many, they often brushed it over and had tried to take it in their stride.

The needs assessment highlighted that there were still some medical issues with hepatitis C: the need for ongoing liver health monitoring for those with cirrhosis, and the unknown hepatitis C status of some people with mild conditions, including some women who carry the gene. There was also a small number of individuals whose treatment had been unsuccessful or could not have treatment and were living with advanced liver disease.

The consultation underlined the cumulative impact of living with a bleeding disorder on reducing income over a lifetime and increasing health care costs. Having hepatitis C or HIV added to this impact. Although vigorous exploration of government financial safety net options may help some older people with bleeding disorders financially, they will have out-of-pocket health and welfare costs not covered by existing programs. Most have been affected by hepatitis C. In 2004 the Senate Inquiry into Hepatitis C and the Blood Supply made recommendations to extend financial assistance and case management to this group which were never implemented. The report findings noted that providing this would make a considerable difference to managing the care and quality of life of older people with bleeding disorders affected by hepatitis C into the future and supported the need for HFA to pursue these recommendations further.

‘There are the added medical issues [of living with hep C] – the extra layer of appointments and medical management. Getting rid of hep C was a load off psychologically - one less thing to worry about. Also, my risk of liver cancer has dropped dramatically, which was a really happy thing. I have an ultrasound every six months for monitoring, surveillance for cancer. I am lucky to be here. And the treatment for hep C came along in time for me. So, it’s not so bad having an ultrasound every six months, when you are cured.’

‘It’s funny getting older with hep C. It didn’t affect me. I live quite happily. It happened years ago. I get the occasional liver scan. Slight anomalies, the next one will be clear. I didn’t know I had it until the 1990s, by which stage I was married and had children. And suddenly they say you know you have hep C. That kind of hit me with a ton of bricks – when, where? But you get your head around it and go on.’

‘Of course, all that trauma is still there. Most have been treated for hep C and doing well. But 20 to 30 years of their optimal life have been affected. They were not feeling great and only realised after they had [successful] treatment. The early treatments had severe side-effects and caused psychiatric disturbances, for example, one had severe depression and his marriage nearly broke down.’

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Mental health and support

Mental health was identified as another important area. There was much discussion from both community members and HTCs about the need for professional psychosocial care (eg from a psychologist, counsellor, social worker or psychiatrist) and that it should be extended to the person's partner and family as well, when required. However, there was also a big focus on how to support the older person to stay active mentally and socially, to do things that interest them, keep up with family and friends and contribute their skills and experience to the community.

In the Getting Older Community Survey most people said they found it helpful to keep up with other people in the bleeding disorders community. HTCs explained that peer support had a very important role in maintaining resilience. Older community members could share strategies that had worked for them and give each other confidence to take steps to try something different or to advocate for themselves. Friendships could make a big difference. This could be friendships with other people with bleeding disorders or with other people who shared the same interests, and getting older was seen as a time to seek out groups where friendships could be established.

COVID-19 has changed the way we socialise and many of us have tried out digital technologies like Skype and Zoom to keep up with friends and family. Most people who completed the Getting Older Survey said they preferred face-to-face events and only a third were interested in online support. However, after being exposed to these digital platforms recently, their attitudes may have shifted. Although face-to-face events are clearly the first choice as an opportunity to meet and get to know others, digital options for peer support may provide another way for older people with bleeding disorders to connect with each other when they are unable to meet face-to-face because of distance, mobility problems, or other reasons.

'The ones I know are loving the Men's Shed and creating things. One group I know of actually built aids for disabled. I know others who have projects like restoring furniture. Because men love to be doing stuff.'

'It's always better to sit around a table and chat. We have a men's breakfast [in my local haemophilia foundation] and discuss how we manage with certain circumstances. That is something that is practical and relevant to me. People going through the same thing as you is reassuring - you can work it out when you are sitting down together and have a laugh about it.'

'I have never met anyone in Australia who has my bleeding disorder. Hence, my only contact is with people overseas over social media.'

WHAT DID WE LEARN FROM PROBE?

We were able to access age-related data from the PROBE Australia Study in February 2020.

PROBE is a multi-national validated community questionnaire to understand the impact of haemophilia and treatment on quality of life. It compares the experience of men and women with haemophilia or who carry the gene to men and women without a bleeding disorder.

We looked at the results for some key areas, particularly for men and women aged 45 years and over:

- Treatment regimen
- Target joints
- Physical functioning and pain
- Hepatitis C and other health problems
- Work

This was an important way to show the impact of haemophilia. For example, the results demonstrated very clearly how much having haemophilia can increase the experience of pain and problems with mobility or activities of daily living. We were able to compare results in the same age brackets between:

- moderate/severe and mild haemophilia
- men and women
- people with haemophilia and people without a bleeding disorder.

The graphs in figures 1 and 2 show the impact of haemophilia on physical functioning and pain. You can see the full results for severity, age groups and gender in the report.

Figure 1: Physical functioning and pain in the last 12 months - men with haemophilia 45 yrs and over

Total number = 57

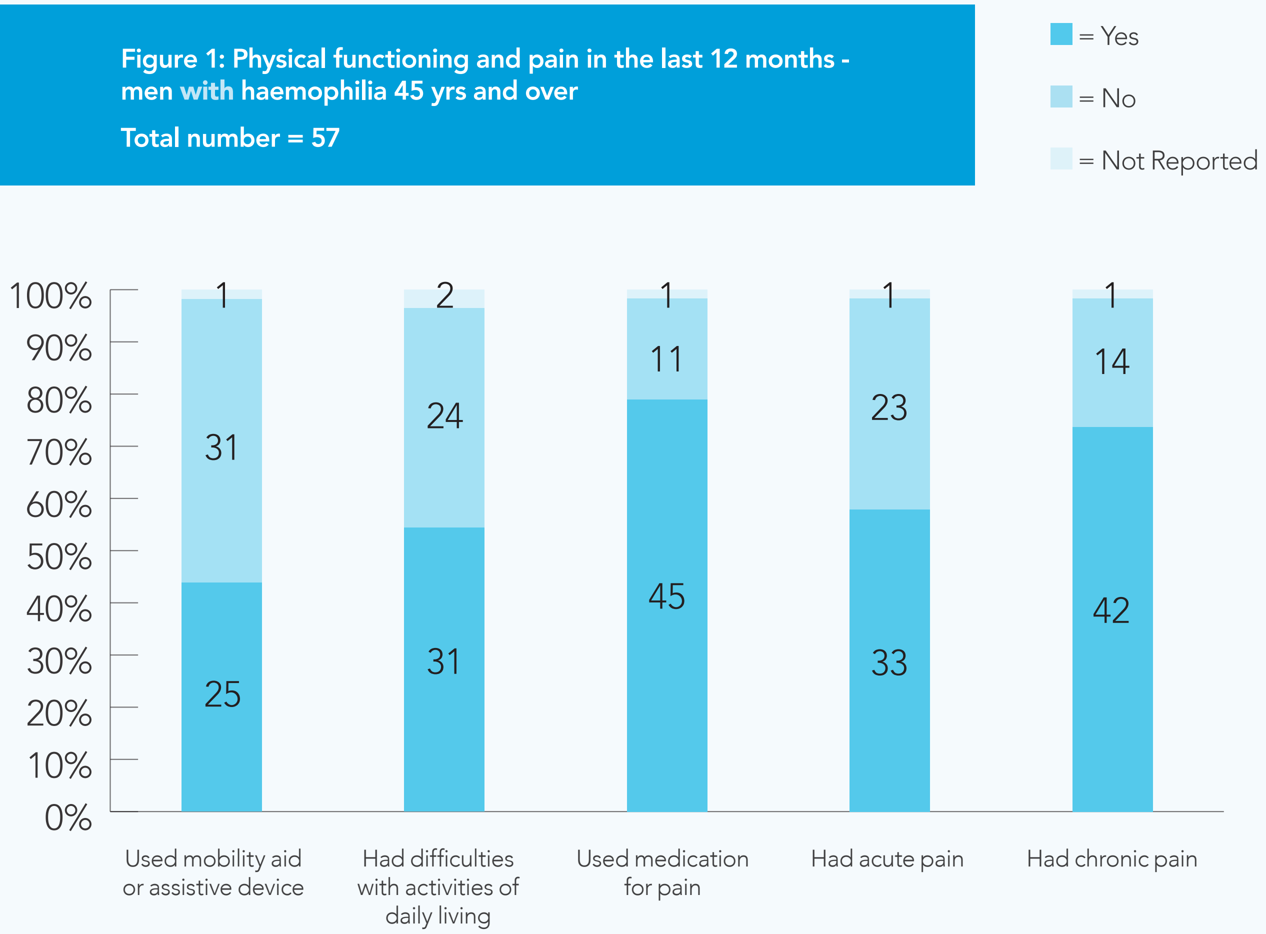
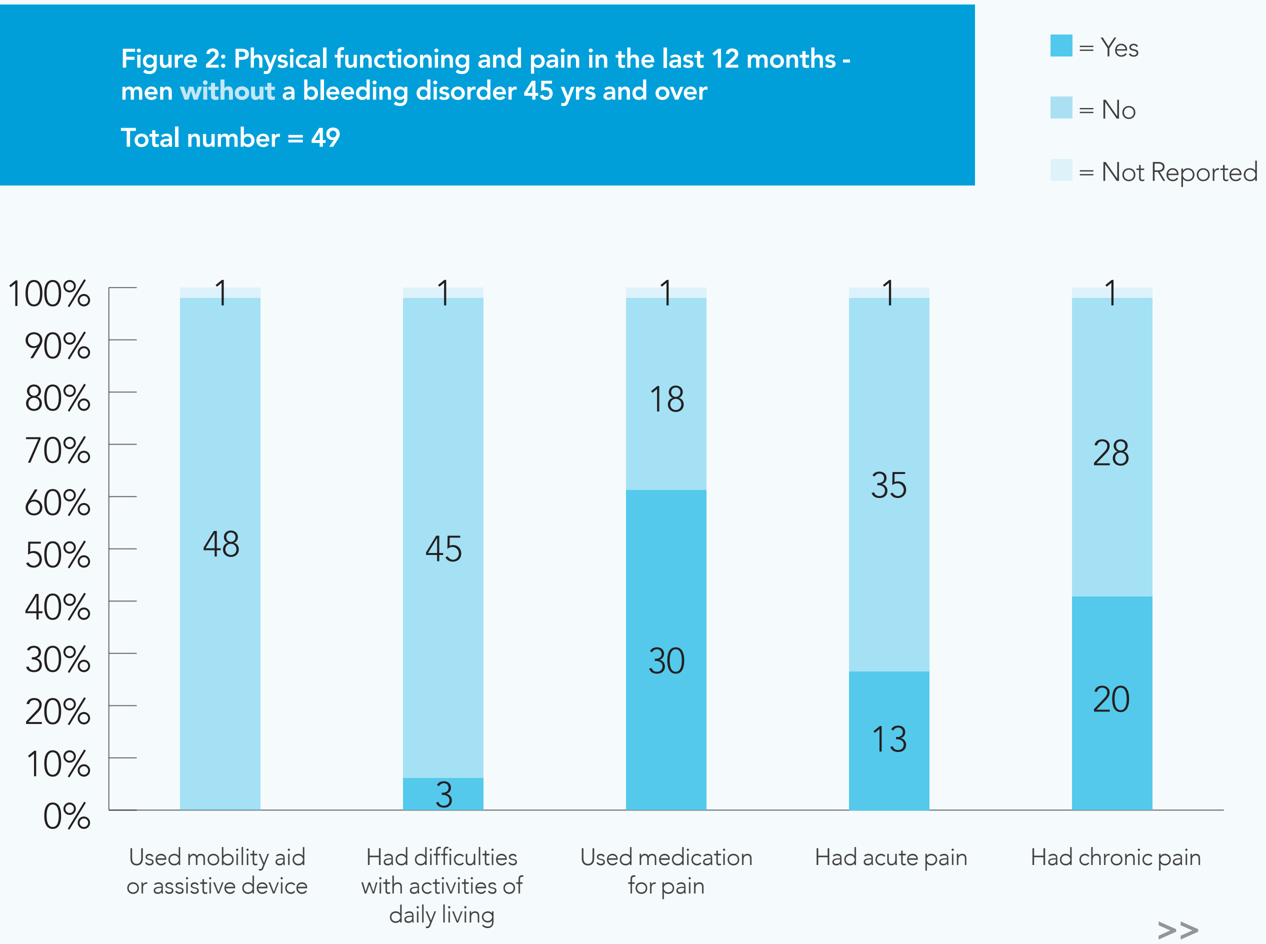


Figure 2: Physical functioning and pain in the last 12 months - men without a bleeding disorder 45 yrs and over

Total number = 49



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GETTING OLDER INFO HUB

Everyone was agreed that there needed to be more information about getting older with a bleeding disorder, but where would you find it? A centralised location was obviously important and a key outcome from the project has been to establish a **Getting Older Information Hub** on the HFA website.

Interestingly, more than 85% of people who completed the Getting Older Community Survey said they used a computer daily and most used it to access information online. Printed education materials were still important to many and HFA will continue to provide some information in print as well as online.

Over the last 6 months the Getting Older Focus Group – a group of older bleeding disorder community members – have been working with HFA on the concept and design for the Info Hub. They worked from the consultation findings and their own experiences to decide the topics and sections include:

- Health and wellbeing
- Services for getting older
- Work and finances
- Support
- Recreation and travel
- Planning for the future
- Connect to others
- For professionals

The Hub is available now and will continue to grow as more information is developed or sourced.

We would be interested to hear your feedback and ideas for more topics. You can find the Getting Older Info Hub on the HFA website – www.haemophilia.org.au/getting-older

NEXT STEPS

Where to next?

The report includes a number of recommendations for HFA to discuss and work through with other stakeholders such as state and territory Foundations, HTCs, other health care services and governments. You will find the recommendations at the front of the full report.

This is a priority area for HFA and we are excited to be embarking on the next stage of our work to achieve our vision of 'active, independent and fulfilling lives' for older people with bleeding disorders.

THANKS

There are many people and organisations who contributed to the report and we would like to thank them all. Please take a moment when you read the report to have a look at the Acknowledgements where they are listed.

A special thanks to the community members who participated in the interviews, the community forums, the Getting Older Community Survey, the PROBE Australia study and the Getting Older focus group; and the health professionals and other agencies who were part of the consultation; and the HFA Getting Older Project Advisory Group, for their guidance of the project.

The Getting Older project was primarily supported by a grant from the Australian Government Department of Health. This project was also supported in part by a grant from Takeda.

Alison Morris is Senior Musculoskeletal Physiotherapist, Perth Children's Hospital and Co-chair of the Australian And New Zealand Physiotherapy Haemophilia Group

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PHYSIOTHERAPY AND BLEEDING DISORDERS DURING COVID-19

Alison Morris and Abi Polus

This information will hopefully assist individuals and families living with bleeding disorders to stay safe and healthy during this period of change.

Please remember that the advice provided here is generic and you should contact your Haemophilia Treatment Centre (HTC) to discuss any specific issues or concerns.

These are unprecedented times. Individuals and families have been adjusting to home isolation, working from home, online schooling and the cancellation of sporting activities, and now to the structured easing of restrictions related to the COVID-19 pandemic.

The way health care services are provided is also changing. Health care workers transitioned, where possible, to video conference consultations to minimise the need to attend the hospital in person, and many are wondering if this will become the new normal?

ACUTE BLEEDS

Firstly, management of acute bleeding episodes remains a priority and treatment pathways are currently unchanged. Presentation at hospital for joint bleeds that cannot be managed at home for factor infusion and other usual management is still occurring. If you are concerned you (or your child) are having a joint or muscle bleed, please follow the routine procedure of calling the HTC for advice or if out of hours presenting to the Emergency Department. Emergency Departments still have strict protocols for triaging potentially COVID-19 positive patients to minimise risk.

Remember, at the first sign of a lower limb joint bleed, aim to stay off the affected leg by using a wheelchair, crutches or a pram and if you are able to, compress the area with a bandage. Follow-up care, including physiotherapy, can be conducted in the HTC or Physiotherapy department as per your hospital's protocol, if needed. Where appropriate it may be conducted via video conference.

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STRICT ADHERENCE TO PROPHYLAXIS ROUTINE

We know that the greatest risk for bleeding is the time spent with low factor levels (especially <3%) and individualised prophylaxis regimes have been designed to avoid this. Missed or delayed doses of factor greatly increase the risk of a bleeding episode. Even though you may be doing less, you may still bleed, or have a minor injury, especially with resumption of activities not undertaken for a while, this may place potential strain on atrophied muscles needed to protect joints. Factor replacement also offers long term protection of your joints from bleeds which can result in tertiary arthritis.

Routines may be disrupted once again. Individuals and families have already shared that maintaining routine has been more difficult as routines have changed. Instead, it may be helpful to set reminders/alarms in phones or place Post It notes on the fridge until new (or old) routines are re-established. For those with myWAPPS set up, you also need to make checking current levels a habit before engaging in any activity.

EXERCISE

Exercise remains an integral part of management for all people with a bleeding disorder.

For those who normally participate in organised sport or regularly attend the gym, it is vital that you maintain your fitness to protect your joints. Those who will be returning to sporting teams need to ensure they reduce the risk of injury when the season recommences. Joints NEED to move to be healthy. Similarly, muscles need to have their usual (or increased) demands put on them or they will atrophy (waste).

You are able to go outdoors to exercise so walk, run, cycle or swim (beach or backyard pool) plus set up some training drills in the backyard or local parks, and now most can train in small groups. For those who engage in activities that involve changes of direction, the FIFA 11+ program (readily available on the internet) is a safe and balanced program of strength, fitness and agility drills that you could incorporate into your routine 2-3 times per week. Just avoid the exercise that involves jumping into a partner!

For those who normally rely on school PE (Physical Education) and incidental exercise, remember that the minimal activity guidelines for children 5 to 17 years involves 60 minutes of moderate to vigorous exercise each day and activities that strengthen your muscles and bones 3 days per week. Those younger than 5 years of age can go for bike rides and play on their scooters. Put on some music and encourage them to dance or consider setting up obstacle courses in the backyard that involve balancing, throwing and catching, jumping etc. If school activity classes are back to a normal routine, that is great. If it is not yet quite back to normal, activity may need to be supplemented.

For adults it is recommended to have at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic physical activity in a week. Get outside and go for a walk or bike ride and do some body weight-resisted exercises: squats, bridges, calf-raises and wall push-ups or small group training are all good options.

Currently, social media platforms have been flooded with ideas to maintain health and fitness while at home and this is likely to continue. Before starting a program, consider whether the exercise is appropriate to you and your fitness level or experience. Do you have limitations or target joints that you need to consider? Start any new exercise program slowly with low repetitions/sets and weight and gradually increase over time. If you are unsure of the suitability of a program, or would like an individualised program or progression of an existing program, do not hesitate to contact your physiotherapists at the HTC and they can arrange a phone call or video consultation.

SEEK SUPPORT

It has been an unprecedented time and will affect both your physical and emotional health. There is still a state of flux and it may still be unsettling. Be kind to yourself and look after your physical and emotional health (which of course are linked!) as best you can. HTCs have various professional experts in these areas and can direct you to the best people to help manage your needs. We are open and functioning and flexible – let us help you!

Since we started writing this article, Australia has done an amazing job of 'flattening the curve' and lockdown restrictions are being loosened. Of interest to many, will be the release of the *Coronavirus (COVID-19) National Principles for the Resumption of Sport and Recreation Activities* (available on the Australian Department of Health website – www.health.gov.au). These principles provide a pathway for the safe return to sport following the COVID-19 pandemic. Grass-roots sports played outside have been given the go-ahead to commence modified training in many states and territories. These modifications currently include smaller groups, no contact and maintenance of social distancing where possible.

If you or your child have the green light to resume training, please remember to build up load gradually to reduce the risk of injury. Unfortunately, fitness and muscle strength do not return as quickly as they are lost! Again, seek advice from your local HTC physiotherapist if you have any specific concerns.

It may still be some time before gyms re-open back to the pre-COVID capacity, with this being touted as one of the last restrictions that will be lifted, so those of you who enjoy your workouts may have to continue with your home set-ups.

Even with the lifting of restrictions, prevention remains the key!

Stay safe.

If you have any questions about your bleeding disorder and exercise or physical activity, contact your Haemophilia Treatment Centre.

Loretta Riley is Advanced Social Worker, Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital

SURVIVING AND THRIVING IN TIMES OF PANDEMICS

Loretta Riley

If I may hazard a guess, 2020 isn't turning out like you imagined.

No-one would have foreseen that we would be physically isolating during our usual activities, keeping a physical distance between ourselves and people we associate with in the workplace, working from home, keeping distance at supermarkets and during any other community activities and staying home as much as possible. That cafes and restaurants would only be able to serve take-away.

Or that outpatient clinic appointments would be transformed into virtual clinics - in the Adult Haemophilia Treatment Centre in Queensland we have been using telehealth (videocalls like Skype or FaceTime) and telephone as much as possible.

Despite the fact that these strategies have been implemented to keep us safe and reduce the levels of transmission of the COVID-19 virus, many people across the world have been experiencing reactions of fear, overwhelm, despair, anxiety and loss at varying levels. These reactions are all normal responses to change and the levels of how you experience them varies from person to person, depending on your individual circumstances and what else is happening in your life.

THE THREAT RESPONSE

When we feel under threat, our amygdalas (which are located in our brain and play an important role in our emotions) are switched on, our brain is in 'protection mode', trying to keep us safe – you might have heard of the flight, fight, freeze response. During the COVID-19 crisis, our brains have been working from this response at some level. Our bodies have been producing cortisol and adrenaline and other hormones as part of this process. These 'stress chemicals' are helpful short-term in our bodies, but over a long time they are not so good for our general health and well-being. When you are in this space, your body is preparing to keep you safe.

You may have noticed:

- Difficulty concentrating and focusing on work or things you need to do
- Difficulty learning new things
- An increased focus on reading and listening for information on the pandemic – what is happening here or around the world
- Feeling fatigued
- Feeling hypervigilant, being acutely aware what is happening around you
- Teariness/more emotional than usual
- Changes in appetite
- Changes in sleep
- Feeling lonely
- Feeling disconnected
- Feeling restless – tapping feet, legs, fidgeting
- Being less tolerant of others and of ourselves
- Being snappy or cranky, edgy or keyed up
- Heart racing, feeling breathless without exertion
- Getting annoyed when something gets in the way of what you are doing
- Finding it hard to wind down or relax

There are many other reactions you may have been experiencing, which are normal responses to this abnormal situation. Very few people living have experienced a worldwide pandemic such as this one and those that were around 100 years ago, when the Spanish influenza epidemic took place, were quite little and so don't have many memories of it. We are now well connected world-wide and daily have been hearing the stories both here in Australia and overseas about the impact of this pandemic, with updates daily on rates of infection and rates of death. We have been physically disconnected from our friends and family. Plans have changed, the way we work has changed. Most importantly, every day there are changes as this situation is 'ever evolving'. It has disrupted our sense of safety and control and our assumptions about the world we live in.

WHAT CAN WE DO ABOUT IT?

We don't need to be passive participants in this environment. We all have skills and strategies that we can turn to which will assist us during this time, and as things keep changing. One thing I have seen over my time as a Social Worker working in the bleeding disorders community is that most people have developed skills in resiliency which can and are being utilised at present. Some of the strategies are helpful and some are less helpful and can lead to increased difficulties if we rely on them. Let's start with the less helpful.

LESS HELPFUL STRATEGIES

Using alcohol and drugs (including misuse of prescription medication) to cope.

The Foundation for Alcohol Research and Education (FARE) reported on a national poll by YOUGov Galaxy in April 2020, that one in five (20%) of households reported buying more alcohol than usual since the COVID-19 outbreak in Australia. In households where more alcohol was purchased than usual:

- 70% reported drinking more alcohol than usual since the COVID-19 outbreak in Australia
- 32% were concerned with the amount of alcohol either they or someone in their household is drinking
- Over a third (34%) said they are now drinking alcohol daily
- 28% reported drinking alcohol to cope with anxiety and stress

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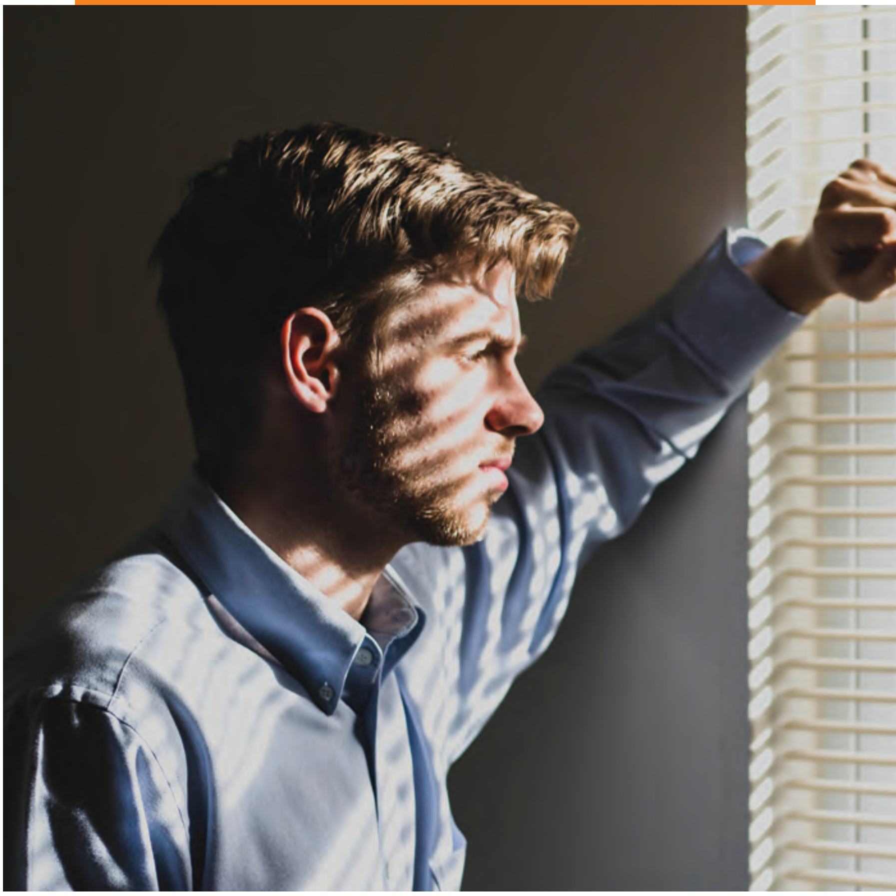
- 28% had been drinking alcohol on their own more often
- 24% had started drinking alcohol and ended up drinking more than they thought they would have
- 20% reported having started drinking alcohol earlier in the day

Alcohol and drugs are not helpful strategies to assist with coping skills. They instead create additional challenges and stressors – including financial concerns, health impacts, relationship difficulties (including increased risk of violence and abuse) and sometimes legal issues, to name a few.

Other less helpful strategies include:

- abuse and violence
- activities which cause harm to yourself
- over-eating/undereating/eating foods that are 'sometimes' foods all the time (eg, bingeing on chocolate daily).

These strategies essentially lead you away from the life that you want to live and have additional consequences that cause harm either to yourself or others and do not improve the things causing you stress.



HELPFUL STRATEGIES

Helpful strategies, most often, are ones that increase DOSE neurotransmitters and hormones, which are Dopamine, Oxytocin, Serotonin and Endorphins. These hormones also counteract the impact of the hormones produced by the fight, flight, freeze response.

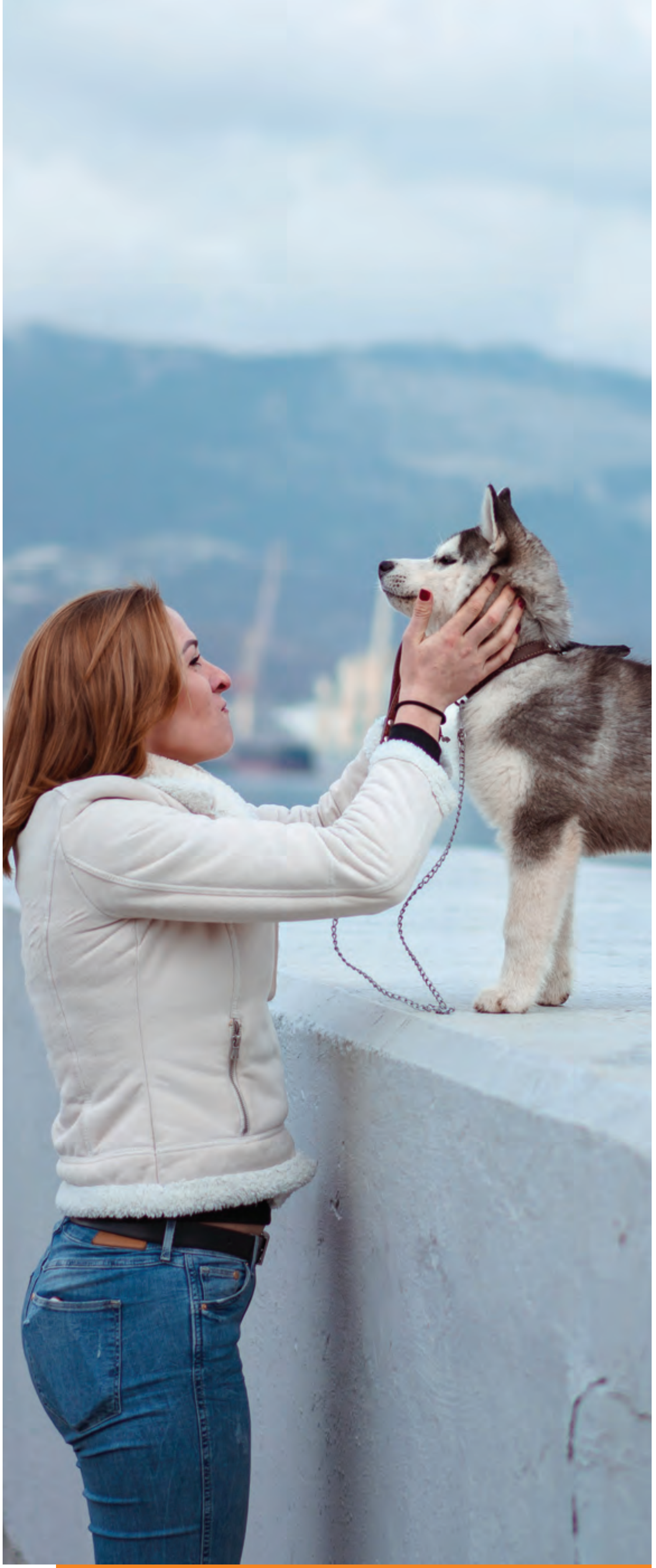
Dopamine – is a 'motivation reward' chemical. The most helpful way to get some dopamine flowing is to write a to-do list, and get the jobs on that list done, ticking them off. You can even jump start (or cheat) by writing down some of the tasks you have already achieved. Any completed task that gives you a sense of achievement and satisfaction will get the dopamine flowing. So, for example you might have a list of jobs – worm-and-flea-treat your pet, vacuum the floors, stack the dishwasher/wash up, fix the broken downpipe, weed the garden. These may be easy for you to achieve. Sometimes, some of the tasks may need to be broken down. Or you may have a never-ending to-do list – get started with some easy-to-achieve tasks. On some days when dopamine levels are particularly low, you might need to start simple and begin with – get out of bed, get dressed, clean teeth, have a shower, eat breakfast, make your bed. All of these achievements will start you off. These all are productive, with the intended consequences being positive.

Oxytocin – you might have heard it called the love or hug drug. The ideal source is a 20 second hug with an appropriate, consenting person. However, in times of physical distancing, this is harder to achieve; and for some people, hugging isn't their thing, but fear not, we can be more creative and still boost our oxytocin.

- Patting and cuddling pets not only gives us an oxytocin boost, but also them. It's a win-win situation!
- Looking at photos of people you love, times that you enjoyed.
- You can even give yourself a hug or similar. What it will look like is arms crossed in front of you - left hand on right shoulder, right hand on left shoulder. Or you can put your hand or hands on your chest over your heart. It is about finding a position that makes you feel comfort and is comfortable for you. For example, giving yourself a hug by the first example may be impossible for you if you have shoulder or elbow issues, but you can place one hand on your chest, giving you a sense of feeling supported and loved.

Serotonin - one of my colleagues describes actions to increase serotonin as things that make you go MMMMmm, or things that bring you pleasure from your senses.

Things you see – might be a picture of your favourite place, the ocean, a garden. It will bring a smile to your face.



Things you hear – music is the most popular – playing your favourite songs, creating and listening to a playlist. It might be the ocean, thunderstorms, rain on the roof, birds singing, wind in the trees.

Things you can smell – coffee, flowers, favourite perfume (or a loved one's favourite perfume that brings back positive memories), cut grass. For me it is rain – (petrichor).

Things you can touch – this one is a bit harder in a pandemic where we are trying to limit touching to reduce spread of a virus. So, massage may be out for many, but feeling the water on your skin in a shower, bubbles in a bubble bath, grass on bare feet, the touch of your favourite shirt, or blanket or even stretching can all assist with serotonin production.

Things you can taste – chocolate, coffee, cheesecake, taste of food, cup of tea. But the trick is taking the time to savour and enjoy it, eating or drinking mindfully, rather than eating on the go or drinking your tea/coffee quickly.

A method/strategy called grounding uses your senses and can help bring down feelings of anxiety, for example. It is sitting or standing quietly and noticing 5 things you can see, 4 things you can hear, 3 things you can touch, 2 things you can smell and 1 thing you can taste. You can mix these around. For example, you might do 5 things you can hear, and 4 things you can see. Just be aware that it might get a bit tricky finding 5 things you can taste (unless you are eating at the time)! This also brings you into focussing on the present moment.

Endorphins – often called the exercise high. Many people feel the boost of endorphins after exercise. So, gyms or running aren't your thing - that's ok, as that is not all exercise is. Find the activity that suits you and that you can do. Your HTC physiotherapist will be a good source of ideas that are appropriate for you. Think outside the traditional especially at this time – dancing in your lounge room, the comedian Miranda likes to gallop, playing with your children, hula hooping. For those less active souls, a good dose of laughter will also trigger endorphins. Laughter yoga reports that voluntary laughter provides similar physical and psychological effects/benefits as spontaneous laughter. You might even find that trying some of the 'laughter exercises' will lead to you laughing spontaneously.

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Gardening - I can't believe I have missed this one out, as it has been my go-to for managing stress and enhancing my mental health for years. Gardening has many benefits for mental well-being, not just in times of pandemics. Being in nature, spending time growing, planting and tending to plants connects us with the present, especially when done mindfully. Gardening is also a form of exercise. Beyond Blue published a document – Beyond Blue to Green - about the mental health benefits of green spaces in 2010. I thoroughly encourage you to read this document if you are interested.

Other helpful strategies

There are also strategies that include **meditation and mindfulness.** The Black Dog Institute encourages having a self-care plan on their COVID-19 factsheet. I would encourage this all the time. Looking after yourself is extremely important and having a 'go-to plan' that you utilise all the time, not just when you are stressed or when the world is experiencing a pandemic, can be very helpful. These can also be useful strategies to add to your toolkit to help with pain!

Many of the posts on social media have been talking about **learning new skills**. As someone who is currently studying, I would say from my perspective (which is also supported by many psychologists and social workers) now may not be the time if you are having difficulty with concentration (for example). However, if you have the space and ability to learn something new, consider using this time for that. I thoroughly encourage everyone to be kind to yourself first and foremost.

CHALLENGES

If you are struggling, it is important to acknowledge it, reach out for help if you need to and give yourself permission to not be perfect or at the same level as you were pre-COVID 19. There is no shame in admitting you are struggling, but the key is in being kind to yourself (treating yourself like you would if you were a good friend) and taking some small steps forward, allowing you to grow through the struggle.Sharing that kindness around will also go a long way. Remember family, friends, colleagues have all been experiencing the coronavirus world in their own way and may be struggling too. Take a breath (maybe two or three) before you react and remember that they may be struggling and need your kindness and understanding.

However, that does not mean that coronavirus is an excuse for all behaviour. Abuse, violence and bullying are never acceptable ways of reacting or responding. Please reach out for help if you are not safe – through the police, a trusted friend, family member, your HTC, for example.

FIND OUT MORE

To end, here are some Australian sites with factsheets, tips and hints to assist you with thriving and surviving during this pandemic, which you can continue to use into the future.

Black Dog Institute - www.blackdoginstitute.org.au/coronavirus-anxiety-resources

Beyond Blue - www.coronavirus.beyondblue.org.au

Reach Out - www.au.reachout.com/articles/how-to-deal-with-uncertainty-during-coronavirus

Lifeline - www.lifeline.org

If you want some free meditations, **Ten Percent Happier** have gathered some of the world's best meditation teachers to share free meditations and podcasts around coronavirus - www.tenpercent.com/coronavirussanityguide

For those who have sadly lost their jobs or hours of work due to the virus, please check out the Centrelink website www.servicesaustralia.gov.au for JobKeeper and JobSeeker information.

Please don't hesitate to reach out to the HTC Social Workers, Psychologists and Counsellors for support. We are here to help and support you.

REFERENCES

Black Dog Institute. Coronavirus: Resources for anxiety & stress. https://www.blackdoginstitute.org.au/coronavirus-anxiety-resources

Beyond Blue. Coronavirus Mental Wellbeing Support Service. https://coronavirus.beyondblue.org.au/

Townsend M, Weerasuriya R. Beyond Blue to Green: The benefits of contact with nature for mental health and well-being. Melbourne: Beyond Blue Limited, 2010. Downloadable from www§.beyondblue.org.au and www.deakin.edu.au.

Grow Your Mind - https://growyourmind.life/

NEWS FROM SOUTH AUSTRALIA

Unfortunately the information evening that had been planned has been delayed by COVID- 19, but we hope when things start moving again and it is safe and appropriate to have community events we will work with the Haemophilia Treatment Centres to hold a community get together.

In the meantime, the teams led by Dr Chee Wee Tan at the Royal Adelaide Hospital and Dr Heather Tapp at the Women and Children’s Hospital are looking after everyone and available to address queries about treatment and care.

ROYAL ADELAIDE HOSPITAL

Royal Adelaide Hospital staff and patients with bleeding disorders were saddened to see Dr Simon McRae leave in January 2020, when he relocated to Tasmania. Simon had been Director of the Royal Adelaide Hospital Haemophilia Treatment Centre (HTC) since 2008 and his untiring work with and on behalf of the bleeding disorders community has been greatly appreciated. He is replaced by Dr Yvonne Brennan, who has worked in HTCs in Sydney, and is now getting to know people in South Australia by phone.

Clinical trials at the Royal Adelaide Hospital are continuing despite staff changes. If you are interested in knowing more, contact the HTC.

WOMEN & CHILDREN’S HOSPITAL

During the COVID-19 restrictions when there was a need to limit contact, a number of patient clinic reviews at the Women's & Children's Hospital were undertaken via videoconferencing. The Women's & Children's Hospital Treatment team would like to thank those families who undertook this with them enthusiastically. The team would appreciate any feedback that would help to improve their service with the addition of videoconferencing to the available options for care into the future. They encourage you to contact any of the team members to provide feedback or if you have any questions.

WHEN LIFE CHANGED WITH INHIBITORS

Christopher's Story

Belinda and Paul are parents of Christopher, aged 7, who has haemophilia and inhibitors.

They talked to HFA about the enormous change a new and effective treatment for inhibitors has made in his life.

Christopher now.

'I don't want to have haemophilia anymore.'

Belinda and Paul heard this time and time again from their son, Christopher.

When he was 10 months old, Christopher had his first bleed in his left elbow. Although he had factor replacement therapy, when he was 18 months old he had a bleed into his elbow that wouldn't stop. His body had developed inhibitors; antibodies which prevented his factor replacement therapy from working.

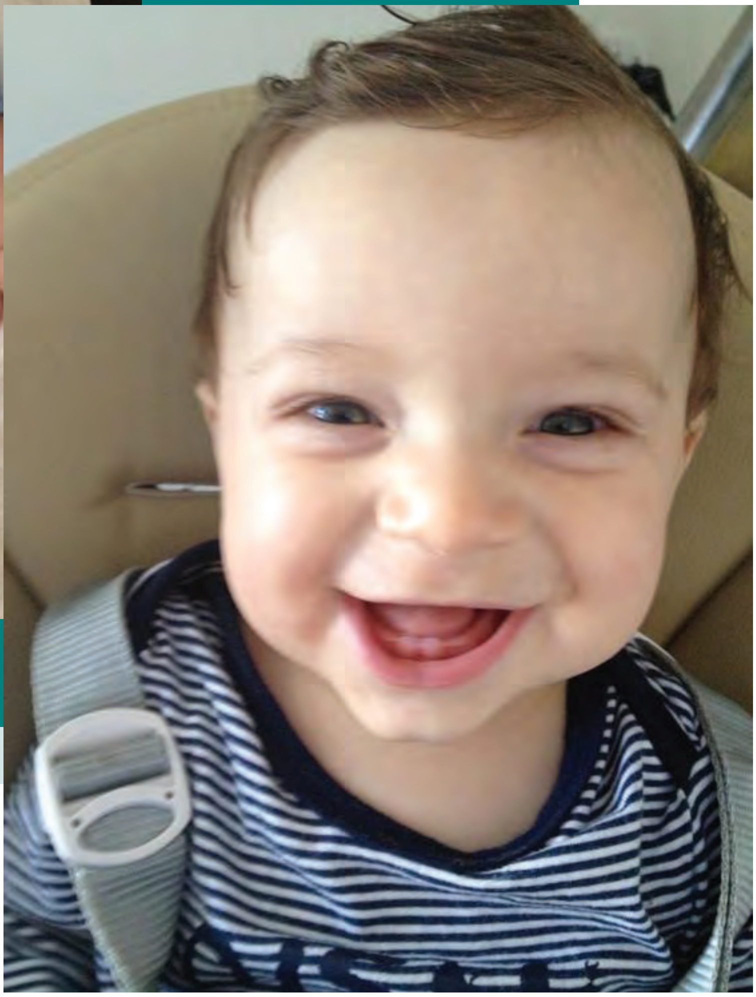
Christopher was not able to do the things most children take for granted - it put his life at risk. Haemophilia tested the family's courage and resilience: it felt to his parents like a very long journey, fraught with fear and anxiety. For Belinda, these times were 'always waiting for something bad to happen'.

By the time Christopher had reached his sixth birthday, Paul and Belinda had grown to fear the childhood milestones we often celebrate. Belinda recalled, 'when he lost his two front teeth, he ended up in hospital for weeks both times because we couldn't stop the bleeding.'

Christopher had suffered significant joint damage in both ankles and one elbow as a result of uncontrolled, spontaneous bleeds. He had to use a wheelchair at school and wear braces to support those joints.

As an active young boy who loved the outdoors, Christopher grew frustrated as his severe haemophilia stopped him from doing many of the things he enjoyed.

A typical day for Christopher involved getting up early, putting numbing cream around the port site in preparation for treatment, which had to be infused into a vein carefully



Christopher as a baby.

and slowly. Once treatment was completed, Belinda put Christopher's splints on before going to school. This whole process could sometimes take up to two hours a day.

At night, Christopher would sleep in the same room as his parents. Belinda explained, 'I could hear him groaning in pain. This is how I would pick up he was bleeding again.'

The opportunity to use a new treatment product late last year made an amazing difference to Christopher's health and wellbeing.

From having a bleed monthly – sometimes even weekly – he now hasn't had a bleed in months. He no longer has to cope with daily intravenous infusions or have hospital stays. Christopher can have physiotherapy on his damaged joints without the fear of causing more bleeds – and without the wheelchair, the leg and elbow splints.

He can now spend his free time being the active boy he always wanted to be, playing with his friends and going camping with his family. This is a welcome change - camping used to be impossible as Christopher's daily infusions had to be carried out in a sterile environment to avoid infections.

For his parents as well as Christopher, the impact has been life-changing. 'We feel as if we've won the lottery. We are able to enjoy life with our son and the normal everyday things,' said Belinda and Paul.

This is a new type of treatment and Christopher's parents are desperately hoping it will continue to work well for Christopher and allow him to grow into a confident, healthy young adult. Christopher doesn't complain about life with haemophilia anymore. He's too busy enjoying all the things he couldn't do before and going to school full-time.

YOUTH NEWS

Successful management of haemophilia is key to playing competition sport, but for Pat it wasn't always that easy.

Patrick Kitschke, from South Australia, is 22 years old and has mild haemophilia. Successful management of his haemophilia has meant that Pat has been able to train for and compete in triathlons. In 2019 he completed a triathlon in Cairns, which he dedicated to raising awareness about haemophilia and fundraising for Haemophilia Foundation Australia.

As a child, Pat didn't want to think about his haemophilia. In his words, he refused to acknowledge he had a *'problem which I didn't want to get sorted out'*. He didn't want to receive treatment, resulting in missed school, and a spontaneous joint bleed which put him *'out for three years'*.

Playing football as a young child, Pat recalls hiding his football-related injuries from his mother to avoid visiting the hospital for treatment.

'I was a terrible patient to the many health practitioners who tried their best to help me when I was little. I not once completed a physiotherapy rehabilitation program correctly. That's where I came in trouble, because I didn't really manage my haemophilia well'.

He can remember waiting more than 24 hours to treat a bleed, increasing the risk of more complications.

Receiving treatment when he was younger was difficult. *'I was terrified of needles, terrified of the people in the hospital, but that's where most of the problems started in my lack of treatment'*. Eventually, he managed to tackle this problem and overcome it. After trialling several treatment options with his haematologist, Pat learnt to do intravenous injections himself, and this is his current treatment.

> *'It has been hard to know when not to go flat out. Knowing when it may actually be time for a rest day, as hard as it may be, actually becomes so beneficial'*

As an adult, it has been particularly important for Pat firstly to acknowledge when he has an injury and then obtain treatment as early as possible to reduce the severity of his injuries and recover as quickly as possible.

Despite being told numerous times to *'stop playing football and take care with cricket'* throughout his junior years, Pat stubbornly continued to play the games he loved. Unfortunately, mistreatment of bleeding and years of playing football has left him with severe arthritis in his knee. Eventually he became fed up with continually being injured, and as a result having to go a week on and a week off from sport. He decided to make a change. Pat has now chosen to participate in a sport where he can manage his body on his own schedule. For Pat this is triathlons: running, swimming and riding.

The most difficult challenge for Pat has been moderating the intensity of his sport. *'It has been hard to know when not to go flat out. Knowing when it may actually be time for a rest day, as hard as it may be, actually becomes so beneficial'*. For Pat access to safe and effective haemophilia treatment has also ensured that his injuries have not progressed to more severe problems as he grows older.

In 2019, with the assistance of his haematologist and a training plan, Pat trained and competed in the Ironman triathlon.

PAT'S STORY

Pat at the Cairns 70.3 Ironman 2019.

'By competing in this event and raising money for HFA, I can bring recognition and say thank you to those people who are there helping little kids like me who never wanted to listen,' explained Pat. *'I also hope to show other people with haemophilia who may not be so active potentially due to fear of injury, that it is indeed possible to get out and about and do things you love'.*

Acknowledging that he has haemophilia and being able to manage it – and, importantly for Pat, **wanting** to manage it - has been instrumental to the successes Pat has made with sport over his lifetime. The key to this, says Pat, is to understand where treatment sits within your life and how important it is to balance your treatment and your lifestyle.

Read Pat's story about preparing for the Cairns 70.3 Ironman in 2019 on Factored In - https://tinyurl.com/FI-ironman

CALENDAR

WFH Virtual Summit
14-19 June 2020
www.wfh.org/virtual-summit

Bleeding Disorders Awareness Week
11-17 October 2020
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

World Haemophilia Day
17 April 2021
www.wfh.org/whd

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BIOMARIN | CSL BEHRING | NOVO NORDISK | PFIZER | ROCHE | SANOFI | TAKEDA

WFH Virtual Summit

The World Federation of Hemophilia (WFH) is committed to bringing the bleeding disorders community together in the name of Treatment for All. This commitment is especially important during the COVID-19 crisis. In June 2020, WFH is bringing the global community together virtually.

The **WFH Virtual Summit** is a series of FREE live and recorded sessions that will take place from 14 to 19 June 2020 and will allow you to connect with the community and increase your knowledge from the comfort of your home or office. All sessions will be recorded and available for viewing later

For more information and to register visit https://www.wfh.org/virtual-summit