

AUTUMN 2023

THE MISSING FACTOR

connect • support • empower

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Choosing or Changing Careers
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HFV is committed to Child Safety. Our Child Safety Statement is available for review on our website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

Opinions expressed in The Missing Factor do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres. The content of this publication is provided for information purposes only. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. No claim is made as to the accuracy or currency of the content at any time. HFV do not accept any liability to any person for the information which is provided.

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HFV supports our diverse community and our magazine reflect topics that impact our community including bleeding disorders, BBVs, mental health and positive health promotion.

Editor: Yarrow Ruane

PRESIDENT'S REPORT

Hi HFV Family,

Welcome to 2023. We kicked off the year with a ten-pin bowling session in Moorabbin, and it was great to reconnect with some families in the South-East. There are lots of HFV events on the horizon including:

- Community Camp on 17-19 March weekend. Get your registrations in before Wednesday 15 March!
- Jells Park Autumn Picnic on Sunday 23 April
- Men's Retreat on 12-14 May weekend
- Social climbing gym day on Saturday 6 May
- Young parents' morning tea on Wednesday 17 May (runs quarterly)
- Ladies pamper day on Sunday 21 May
- Youth camp 23-24 June weekend (first weekend of school holidays)
- And lots more!

Pop the Events Calendar flyer on your fridge and

register for any events that take your fancy. We understand that it can be hard to feel motivated to attend community events post-COVID, but getting together can be great for the soul!

We have included information about all of our upcoming events and do reach out if you have any further questions.

If you have been feeling a bit flat recently, check out Jane's article on page 7. There are so many fantastic goings-on both in the HFV community and your local community too.

We have a bumper careers newsletter issue this month, packed with information to get you into your dream job. Feeling a bit lost in your job at the moment? Have a look on pages 10-15 to see if anything resonates with you.

Don't forget that we are actively looking for HFV committee members at the moment. If you would like to express your interest - or want to come along to a committee

meeting for an insider look - email HFV staff at info@hfv.org.au.

Can't wait to see all your smiling faces at camp. I, for one, will be partaking in a certain bush cooking class on the Saturday - looking forward to a small damper feast!



Leonie Demos

HFV President

POPPA ERL AND ROMAN SHARE A SPECIAL BOND



This article is reprinted with permission from National Haemophilia No 220 December 2022, the journal of Haemophilia Foundation Australia.

Haemophilia treatment has changed over the years. The story of 'Poppa' Erl, grandfather, and grandson Roman, shows just how much. Erl was born in an era where little or no treatment was available and Roman, now 10, has had treatment since he was born. But even for Roman it has been a rocky road. As a small child he developed inhibitors to treatment, which meant his treatment was no longer as effective - and he started to have regular bleeding episodes just like grandfather. Then new haemophilia treatments for inhibitors became available and his life has changed.

Naomi, daughter of Erl and mum to Roman, talked to HFA about their family history and the ups and downs of their journey.

'As a child we had a lovely life growing up. I always really admired my Dad's strength. It was really tough though seeing Dad go through a bleed.'

Erl described his life growing up.

'We come from a different era. A lot of us have experienced similar things, like haemophilia without treatment, so we do have a broader understanding of what haemophilia is all about and how important it is to look after yourself as much as possible - because haemophilia certainly comes back and bites you, if you've grown up when there's no treatment around.'

When Erl was born there were no transfusions available for haemophilia. By the time Erl was growing up whole blood and fresh frozen plasma became available for treatment, which helped people to survive bleeding episodes but did not stop the swelling and the pain.

‘So with a knee bleed, you would have a knee that was the size of a football, as hard as a rock and unbelievably sensitive and painful. I put up with the pain as long as I could day and night at home, and then ended up being taken to hospital and would get some morphine for the pain. But you couldn’t move your leg; you would be out of action for months. It would take many, many weeks before the swelling went down and before the movement returned.

‘It was nothing to be in hospital for three months or six months at a time, waiting for this to settle down and trying to get back on your feet and get your muscle strength back. It would be six months from the beginning of a bleed in the knee before you could take weight or even begin to start walking again.’¹

The gene alteration causing haemophilia is always passed on from a father with haemophilia to his daughters and for Naomi and Erl this created a close relationship.

‘I knew that I was a carrier from a very young age; I guess it’s just always been a part of who I am and haemophilia has just always been there. I certainly always felt a special connection with Dad because of it; I knew it was a rare condition and that made it kind of special in a sense.’

‘My partner David always knew I was carrier and my Dad did have the “talk” with him before we got engaged to make sure that he understood what it meant to have a possible future with haemophilia; of course talking is fine but living through it with your own child is completely different.’

When Naomi and David decided to start a family, they found out the sex of the baby before birth

to prepare the birth plan and knew that they were having a little boy.

Roman was diagnosed with severe haemophilia just after being born. Even though she knew it was a possibility, Naomi still found it difficult to come to terms with the diagnosis. New parents can always be anxious about their baby, but for Naomi, it meant she would have extra worries about Roman’s haemophilia. How would she know if he was having a bleed? Would he be OK? As Roman became mobile they would constantly hover over him trying to prevent accidents that could potentially turn into a bleeding

episode.

Visits to the hospital to treat bleeds were also upsetting for Naomi, especially when she had to watch her little baby having a needle in his vein to infuse the factor - trying to stay brave for Roman, but inside feeling very emotional.

Then when Roman was 2 years old, he developed inhibitors, which are antibodies to treatment so that it doesn’t work as well. He had a port-a-cath device surgically inserted into his chest so he could have regular prophylaxis treatment, which was every single day.



Roman in hospital



Roman recovering from a bleed

‘So often Roman would get spontaneous bleeds, and he would just wake up in pain. It just became our new normal to drop everything, go to the hospital and spend the next week or so dealing with a bleed.’

‘But life does eventually get easier’, explained Naomi.

‘Once they get older, when they are sure on their feet, they can tell you when they are having a bleed. They can verbalise what they are feeling in their body or tell you what happened exactly when they got hurt.’

Ironically, Roman did miss out on plenty of experiences just like his grandfather did when he was a child.

‘When he started school, he spent some time in a wheelchair recovering from bleeds. This was an emotional challenge for Roman - he didn’t want to be different to the other kids and worried the other kids would see his port-a-cath through his school shirt.’

‘He often missed out on friends or family gatherings because of bleeds and was unable to join in with his friends if their birthday parties had trampo-

lines or a jumping castle because they were a risk for him getting a bleed. We even spent a couple of Christmas Eves in hospital and Christmas Days with a bleed. We never went on a holiday because we were worried about being too far from the hospital, him getting an infection in the port-a-cath, getting a bleed, or even just how we would manage to pack all the gear that we need to do his daily treatment.’

‘And then this incredible opportunity came about. There was a new treatment that raises the factor 8 levels 24/7, prevents bleeds even for those with inhibitors AND was to be given subcutaneously [under the skin] every fortnight! We had only dreamed about such a product, but now it is a reality. Roman now just has one small needle every fortnight. The whole process takes 10 minutes.’

‘Roman is now 10 years old. The last few months Roman has started to play sports. He enjoys table tennis and Little Athletics. We still can’t believe how much he can do now and not get a bleed. It is pretty amazing and it is certainly life changing for him. It has really boosted his confidence. He can now participate in the sports and activities that his friends do.’

Erl’s experiences over his lifetime meant he has had a lot to offer Roman, Naomi and David. Living through a childhood with treatment shortages, he knew what having an inhibitor would mean for Roman.

‘Dad is really the only person who truly understands what we are all going through and I think that mutual understanding has helped us both over the years.’

Erl also has a lot to teach Roman about coping with haemophilia and getting the best out

of life.

‘My Dad is doing ok - he has plenty of issues to deal with but he keeps on going. He is pretty incredible. He gets out and about a lot. He loves to go for coffee and cake and is always somewhere enjoying events, wildlife and sunshine.’

‘Roman and Dad share their experiences with photos when they have a bleed, and Dad sends a photo to Roman to show what it looks like when he is at the hospital having treatment. When Roman was younger, he built a “walking stick just like Poppa’s” with clip together blocks. There is a special bond between Poppa and Roman.’

Erl and Roman have lived different childhoods and have different stories to tell about their experience living with haemophilia but now they are both on the same new treatment and they both get to enjoy life with less bleeds.



Roman playing with his sister at the park today

Ask Us: Getting back to hobbies and socialising

By Jane Portnoy

Dear Ask Us,

I haven't been spending much time with other people lately and I have started to feel quite flat. I do enjoy my own company but it feels like I have less friends and activities in my life that I used to, especially compared to pre-COVID. Do you have any advice?

So many people are describing similar experiences. COVID was a big disruptor to social connection. As a community we were asked to spend so much time separate from others.

For some it was a relief and quite enjoyable to have a break from the stress that comes with interacting with others or being part of community groups. However, whilst it might have been good for a while, the big picture was different and as those relationships slowly dropped off, the common experience has been feelings of loneliness and isolation.

We know that these are skills that need to be practiced, much like your muscles need to be exercised. You need to exercise your social skills or else they will shrink up and your confidence will disappear too. When that happens, it can get harder and harder to try new things if they involve interacting with people.

You might be relieved that you don't have to do the 'work' of socialising, however the down sides are that when you don't make connections and haven't got those skills at your fingertips, you can become lonely and isolated. Other people add the "spice" to everyday life. You also miss out on the support of others. Having someone to be there for you and building close friends - these things require you to meet people and start somewhere.

Loneliness is already recognized as a major problem, and puts sufferers at greater risk of many health conditions such as stroke, dementia, depression. (Centre for Disease Prevention and Control, USA, www.cdc.gov).

Finding new activities

Remember your fears are in your head and not obvious to others. Pick one thing and give it a go, don't overdo it if you have been spending lots of time in your own company. It can be overwhelming if you do too much.

- Reach out to an old friend, and catch up over a cuppa, go out for a walk, or whatever it is that you enjoy doing together
- Find an activity that you are interested in (even if only slightly) and go to a class or meeting
- Consider whether there are any pre-covid interests you would like to re-join
- Look at what your local council, local library, TAFE, or University of the Third Age is doing and see if you can attend something
- Think if there is a sport you want to

learn, or participate in (maybe there is a local club or social competition)

- Volunteer - you will be making a difference in your community, and you are bound to meet people.
- Join a gym or fitness class

When you meet someone you'll have to be open to meeting others, ask questions, don't judge, be authentic, let them get to know something about you, and be yourself.

And of course there are those trusted people in your life including the team at your Haemophilia Treatment Centre that you can get support from.

Jane Portnoy is a Social Worker at the Ronald Sawers Haemophilia Centre at Alfred Health. This article was written for "The Missing Factor," 2023.

DEALING WITH GP SHORTAGES



In years gone by, Victorians with bleeding disorders often attended their HTC for a wide variety of health concerns. The community's needs have changed over time, however, with new treatments becoming available and organisations (including HFV!) restructuring. Many people with haemophilia or von Willebrand disease now receive a significant portion of their medical care from General Practitioners (GPs). In fact, GPs play an increasing role in managing many different chronic conditions. GPs provide more than primary care. They also set up chronic disease management plans, provide health advice and refer patients to other medical specialists.

In many ways, GPs are a doorway to the rest of the Australian medical system... So what do you do if there is no GPs near you? HFV members in regional, rural, and remote areas are grappling with this question. There is a severe shortage of GPs across non-metropolitan Australia, which can have a real impact on the health of communities. For people managing chronic conditions like bleeding disorders and arthritis, regular medical care can be an important part of maintaining health, wellbeing, and physical functions. HFV have heard from people facing weeks- or months-long wait times for GPs or taking time off work to travel several towns over to get an appointment.

What steps can I take?

There are no quick fixes to GP shortages, however, there are some actions you can take that might help lessen the negative impacts of GP shortages on your health:



Talk to your GP

Talk to your GP about any difficulties you are having in accessing appointments with them (whether due to finances, life commitments, mobility restrictions, appointment availabilities, etc). Explain your concerns and ask for advice on managing your health within your circumstances.



Telehealth appointments

See whether your GP provides online or telephone appointments. If you do not have a GP, find out whether there are GPs in your region who offer telehealth. There are some restrictions on the type of appointments that can be offered remotely, and to whom. Patients are often required to visit a GP in person first to access telehealth options. Telehealth appointment availabilities may also differ depending on where you live, what GP management plans are available to you, and whether you are Aboriginal or Torres Strait Islander. You may need to contact GP clinics directly to find out about their telehealth options.

HFV may be able to provide assistance if you are unsure how to book and/or attend telehealth appointments, or if you have a technology barrier to attending.



Managing your bleeding disorder

Make sure you are using MyABDR and keeping in contact with the HTC. The team can often provide valuable advice and direct you to relevant resources. Keep the HTC in mind, especially if you are noticing changes related to your bleeding disorder (e.g., increased muscle pain, uptick in bleeds or decreased range of motion).



Health and wellbeing

Take steps to improve your overall health and wellbeing:

- Try to incorporate more exercise and nutritious foods into your routine. Introduce new habits slowly and then build up as you get more confident.
- Make time each week (even if it's while you do the dishes) to reflect on how your body and mind are feeling. "Check in" with yourself to see whether you notice any changes in your mood, physical function, or pain levels.
- If a friend or loved one has their own goals that they are working towards, consider creating a "buddy system" (e.g., track your steps on your smartphone, go to the gym together, share recipes, etc.)

Choosing or Changing Careers

Adapted from:
Choosing or changing your career path
HFA Zoom and Facebook Live webinar,
18 October 2022

I have worked with people with a bleeding disorder who have all sorts of careers. There have been tradies, chippies, plumbers, electricians, truck drivers, lawyers, arborists, physios, nurses, scientists, actors, playwright, swimming teachers, umpires, accountants, bus drivers, farmers, finance workers, IT workers, administrators, mechanics, salesmen, advertisers, hospitality workers, winemakers, teachers, cab drivers, car detailers... The list goes on and on! There are so many jobs that you can do with a bleeding disorder...

-Penny McCarthy (Haemophilia Nurse Consultant, Alfred Hospital)

THE BENEFITS OF WORK

Why do we work in the first place? Well, we need money. We need money to look after ourselves and our families. Money also helps us to feel secure and can be a gateway to accessing things like travelling or buying a house. Although the Australian government can provide some baseline level of financial security, there are also some non-mone-

tary benefits to working. Work can allow you to learn new skills, gain experience, connect with people, and socialise with your community. Having a job and somewhere to go to can be an important aspect of your life. A job can be a way for you to make a positive contribution to society.

Most importantly, working can help you maintain a certain level of mental and

physical health. Routines create good habits and when you have a bleeding disorder, you often need good habits. Taking treatment on correct days, updating your records, attending your doctor's appointments - these things are important. Working can help you get into a healthy routine.

CHOOSING CAREERS WITH A BLEEDING DISORDER

We like to think that anyone can do anything. With the new treatments coming out, young people now are in a much better physical condition than they were in the past. Those young people may be able to do most jobs. There are still some restrictions with the Australian Defence Force and the Police, which the Haemophilia Foundations are working to change. But the most important thing is to focus on what you CAN do. For example, I look after a lovely young man who could not get into the army and really wanted to. He decided to make a compromise and joined the Army Reserves. While that was not



his first choice, it ended up working for him. You have some responsibilities when it comes to deciding on a career path. There are so many people available to you, who have expertise for you to draw upon to set yourself up for success. You have a Haemophilia Foundation and your HTC. If you are thinking about starting a trade, for example, we recommend that you come talk to your HTC about how you can get “work-fit”. Getting work-fit might require you to do specific exercises to get in the best physical shape possi-

ble for the career that you’re interested in. Whether that career is in a trade or an office job, we encourage you to talk to your HTC about it.

Not all jobs suit all people, and we all make decisions about our own limits. These limits can also change over time. For example, we treated a mechanic who found that his joints were damaged from the bleeds he’d had over the years. He decided to transition from being a racing car mechanic into more of an office-based mechanic job. You might be a roof

plumber but find that, after many years of stooping down on the rooves and climbing up and down the ladders, it has started to interfere with your life, and you want to try something else. Getting the HTC team behind you can be great for helping to make those decisions. Often, HTCs or Haemophilia Foundations can hook you up with someone who is already working in the area that you’re interested in.

Penny McCarthy

Ever thought about careers counselling? Craig from Jobs Vic gives us an insider look...



Craig is the Program Manager for the Jobs Victoria Career Counsellors Service, a free career counselling service for people living in Victoria.

Whether you are unemployed, in your first job or in a survival job, what are the steps to get you into your dream job? Career counsellors work to give you the tools and confidence to self-manage that process.

WHAT IS A CAREER COUNSELLOR?

“Career Counsellors provide personalised career guidance to participants who require support to understand, develop, and self-manage their career options. This involves activities such as developing a career plan, identifying skills and strengths, identifying labour market trends,

assisting with resumes and interview coaching. Their role is to help participants understand their career options and provide the tools and confidence they need to pursue them.”

HOW DOES A CAREERS COUNSELLOR LEARN ABOUT YOU AND YOUR GOALS?

We are not a disability service, and we don’t start

with your disability or health condition. Our goal is to look at you holistically as a person and then go from there. We try to understand all your obstacles, challenges, constraints, and frustrations, but also the skills, strengths, experience, and relationships you have. From there, we build out a career plan for you.

Career Counsellors and Service Eligibility

- unsure of their work/career options and pathways
- seeking employment but lack a clear vocational pathway/plan
- unemployed and struggling to secure work due to lack of work experience (e.g. recent graduates)
- underemployed and seeking more secure and/or skilled work
- in need of support to plan a transition to a new occupation/career
- wishing to pursue a professional career involving tertiary education pathways.

The Jobs Victoria Careers Counselling process

- 1 Participant speaks with a member of the intake team who conducts a basic needs assessment. Consent and education/career information is collected and added to profile.
- 2 An appointment is booked for in person, phone or Zoom career counselling.
- 3 Career Counsellor conducts the initial appointment with the participant, of approximately 45 minutes. A career plan is made or career intervention achievement.
- 4 Further appointments based on the participants need are scheduled.
- 5 Resources and summary notes are sent via email to the participant, post session.

Looking to book

Or refer

Call 1800 967 909

Or visit www.ceav.vic.edu.au/jvccs



Identify & Develop Employability Factors



Career Decision-Making

Discovering what kind of work suits you; develop an action plan for making it happen

Skills Enhancement

Identifying the variety of skills and knowledge needed and knowing how to acquire them

Personal Branding (Job Search)

Developing the knowledge, skills, attitudes and resources to be successful in finding work

Ongoing Career Management

Develop ability to effectively manage career changes; maintain a positive mindset and adopt learning as a lifelong activity

The Stages of Career Development

Engage

Reflect on your personal situation and how it relates to your job search. What barriers are you facing? What are your hopes and ambitions? Think about what is meaningful to you in your personal, professional and community life.

Explore

What opportunities could be available to you? What jobs and skills are in high

demand? See if you can find an overlap between your own skills/potential and existing opportunities.

Decide

Identify the career direction you would like to take and think about how to get there. What are your next steps?

Prepare

Develop the knowledge, skills and attitudes you will need to succeed in

your chosen career path. Create an action plan for yourself.

Implement

Take action towards your goals. Put systems in place that will help you have a successful and sustainable career. Think about what factors enable you to be confident in your job. What support systems can you put in place help you succeed in the long run?

Career Services for People Living With a Disability or Health Condition

One in five Australians lives with a disability, making up a large part of the Australian workforce. If you have a disability, there are some important factors to consider on the job. It is important that you have a level of agency in your workplace, and you may require certain accommodations. There are many career-oriented organisations who work with people with a disability or health condition:

- **Dylan Alcott Foundation** - grants and supports for young Australians with a disability embarking on sport, education, or careers.
- **Ability Works** - source tailored job placements for certain groups, including people with a disability and young people.
- **Job Access** - Australian government agency focused on helping jobseekers with a disability and advocating the value of having diverse perspectives in the workplace.
- **Brotherhood of St Laurence** - run dedicated careers programs targeting different groups of people, including people with a disability.
- **Australian Network on Disability** - helps link workplaces with people who need workplace accommodations
- **WCIG** - helps people find meaningful employment in Melbourne and Geelong, including via the NDIS



Q&A - Jobs Victoria Careers Counselling

What is the average wait time for a careers counselling appointment?

About four days. You can check online in case there are cancellations. You can also book two appointments at once to minimise wait times between your first and second appointment.

How many career counselling sessions will I need?

If you just want someone to check your resume, that can usually be done in 45 minutes. If you are wanting someone to really understand you and where you're going, that is will usually take 3-4 sessions. We don't just want you to get you through the door of your next job - we hopefully want to set up a longer-term career plan for you that takes into consideration future changes in your personal life.

What are the eligibility requirements for the services? Is it free?

Yes, it is free! You need to have a Victorian residential postcode and the right to work in Australia. High schoolers are also welcome to come for a chat if they don't have a careers counsellor at school (or would like a second opinion).

Can a careers counsellor help with part-time work? I'm not sure I can manage a full-time job.

We're not just here to get people into fulltime work. It's about work that works for you. It's about matching up the skills you have with your ability to engage with the workforce. It could be gig, survival, part-time, contract - you name it. Our counselling approach is to explore all the opportunities and then filter down to the best fit for you. You can always say "I'm a stay-at-home mum and school drop-offs are important to me. What can I do between the hours of 10 and 2?" We work within your parameters.

How will my data and privacy be managed?

You will be asked to consent to giving your information and having it stored to create the best service for you. For anything to happen with that information, we require informed consent so that you can have confidence in how your data is managed. We are answerable to the state government.

A reminder from Craig:

Many workplaces can accommodate your bleeding disorder or disability but they need to know what you need. You are the expert on your own workplace accommodations and your workplace may need guidance.

Q&A - Talking to Your Employer About Your Bleeding Disorder

If my work needs a medical plan, what's the process?

PM: It often depends what the work is and what they're actually asking for. It's often just a certificate saying that they're "fit for work" and we get the doctor or the physio to check them off. Sometimes they say something like "fit for work but may need some extended leave at certain times". Usually, the HTC will ask what the patient has told their employer and why the plan has been requested.

I don't have a disability but sometimes I have a bleed and might be restricted for a couple of weeks. How do I explain that to my employer?

PM: It's similar to having diabetes, epilepsy, or chronic migraines. You are fine most of the time but out of action every now and then. It's so important to practice communicating clearly with your employer. A medical plan from the HTC can be a good step in setting expectations.

If you have a physical job, you might also need to consider how your choice of hobbies or sport can impact your work. For example, if you're a tradie but get injured playing footie, you might be off work for 6 weeks.

CE: It's not necessarily about whether you have a "disability" but about whether you need those flexible working arrangements. Some jobs can be more flexible than others, and your own demands change over time. It's normal for employers and workers to talk about making adjustments for personal circumstances. It's about having contingencies around when you're not available. Think about finding who you can partner with and how you can structure your tasks. You might need to request things like time off, flexible rostering, a standing desk, etc.

PM: It's the surprises that are hardest for workplaces to navigate. Try to have a plan and stick to it. If you're a good employee the rest of the time, it's reasonable to get time off when you need it.

CE: Also think about whether there are ways you can add value to the team from home. Some tasks are best sorted out in a quiet environment anyway.

PM: Penny McCarthy (Alfred Hospital)
CE: Craig Eastwood (Jobs Victoria Career Counsellors Service)

Webinar Presenters: *Natasha Coco (HFA), Craig Eastwood (Program Manager, Jobs Victoria Career Counsellors Service) and Penny McCarthy (Haemophilia Nurse Consultant, Alfred Hospital)*

Summarised by: *Yarrow Ruane (HFV)*

Thanks to Penny McCarthy and Craig Eastwood for their time.



Disability disclosure chart

What happens if I disclose . . . ?

Time of disclosure	Advantages	Disadvantages	Issues
ON A JOB APPLICATION:	Appears honest. Have peace of mind. Lets employer decide if disability is an issue.	Risk of discrimination. May decrease chance to present skills/explain effects of disability. No comeback.	May have a harder time finding work but usually have a more supportive workplace when you do.
DURING AN INTERVIEW:	Appears honest. Have peace of mind. Chance to explain effects of disability positively in person. Discrimination less likely face-to-face.	May not get job offer. May change focus from your abilities to your disability. You may not handle disability issues in a clear/non-threatening way.	How comfortable are you with discussing your disability? Are you emphasising your disability too much?
AFTER THE INTERVIEW: (When job is offered but before you begin work)	Appears honest. Have peace of mind. If employer changes mind after disclosure and you are sure your disability will not interfere with your ability to perform the job, or job safety, there may be legal comeback.	Employer might feel you should have told him/her before decision was made. Might lead to distrust of you.	Need to look honestly at how disability affects ability to perform tasks of the job. Need to be able to explain how disability will not interfere. This includes job safety.
AFTER YOU START WORK:	Opportunity to prove yourself before disclosure. Allows you to answer workmate's questions. If disclosure affects employment status and your condition will not interfere with your ability to perform the job, or job safety, you may be protected by law against dismissal.	Employer may feel you have falsified application. You may feel nervous and afraid of relapse on the job. Co-workers may not know how to react if you become unwell. You may be treated differently from other staff, eg. given simpler tasks.	The longer you leave the disclosure the harder it becomes. It may be difficult to know who to tell.
NEVER:	Employer cannot react to your disability unless you have a relapse which affects your work performance.	If your disability is discovered and it potentially affects work performance/safety, you run the risk of being fired. May not get the support you need when it is required. Increased stress from fear of being 'found out'.	If you have not had a relapse for a long time, the issue of disclosure becomes less critical.

How to disclose: some ideas

Remember: Always sandwich the 'tricky' information with lots of positive, 'good' information

1. On a job application:

In answer to the question "Do you have any health problems?"

Possible Responses:

(on an application form)

- Not that would affect my ability to do the job.
- I will discuss this at an interview.
- Not applicable (to this job).
- I previously had _____ which I have now recovered from and I do not feel that this will affect my work performance.
- I have a health condition but I feel I will still be able to do the job as required.
- Leave it blank and explain verbally in a job interview if required.
- Do not say 'no' if the answer is 'yes'.

(on an application letter)

If there are long periods of absence from the workforce your resume could be skilled based not employment based so as not to draw attention to it.

2. At the interview:

Possible Response:

I have good insight into my health/condition. I know my early warning signs for illness and have put in place strategies to manage them (if asked to explain, have examples ready).

Note: The responses indicated above for the job applications are also suitable for use in the interview situation.

3. After the job is offered/accepted:

Possible Strategy:

Choose an appropriate time to talk privately with the employer. If in the position for a short time ask for feedback on performance. Let them know regular feedback is important to help gauge your compatibility to the job. If your condition may mean you need regular time off for appointments you may wish to explain why. However, generally all workers have some absence due to appointments.

TIP: Some people who have a bleeding disorder also have a disability, and others don't. Whether or not you have a disability, it is important to think carefully about how and when (if ever) you talk to your employer about your bleeding disorder.

There are no right or wrong choices, but there may be advantages or disadvantages to disclosing health conditions at different stages of job applications.

NEW IN BLEEDING DISORDERS RESEARCH

Treating people with mild haemophilia for dental procedures

ARTICLE: *The important impact of dental care on haemostatic treatment burden in patients with mild haemophilia* by Raso and colleagues (2022)

This study follows a group of 107 males with mild haemophilia (MH) in Belgium and Italy. The researchers analyse the treatments that research participants received for their haemophilia over two years. Nearly half of all participants (44%) received haemostatic therapy (treatment to help clot blood) for a dental procedure. The authors conclude that dental procedures, like tooth extractions and oral surgery, are major reasons that people with MH receive haemostatic therapy. This paper suggests that maintaining good oral health (for example through brushing, flossing, and regular teeth cleanings) can help those with MH to minimise how often they need clotting factor replacement therapies.

Pregnancy and childbirth complications among women with bleeding disorders

ARTICLE: *Pregnancy and childbirth in women with bleeding disorders: A retrospective cohort study* by Young and colleagues (2022)

In this paper, researchers compare the pregnancy outcomes of Utah women with and without bleeding disorders (BDs). The study finds that women with BDs were at an increased risk for several obstetric complications. Serious pregnancy complications were significantly more common among women with previously undiagnosed BDs. The authors highlight that females with BDs are much less likely to be diagnosed in a timely manner compared to males. The paper suggests that early diagnosis and appropriate treatment are crucial for improving the health of women with BDs and reducing their likelihood of experiencing serious pregnancy complications.

Comparing quality of life for people with severe haemophilia A and B

ARTICLE: *No difference in quality of life between persons with severe haemophilia A and B* by Kihlberg and colleagues (2023)

This research surveys 126 individuals with haemophilia (half with haemophilia A and half with B) about their health-related quality of life. The study recruited people from across Denmark, Finland, Norway, and Sweden. Participants completed questionnaires concerning various aspects of their mental and physical wellbeing. Additionally, peoples' joint health was evaluated by qualified health professionals. The authors found that most participants (56-62%) reported some discomfort or pain, while almost half (44-46%) experienced mobility impairments. Very few people described having 'extreme problems' with mental health, discomfort/pain, or usual activities. The findings suggests that people with severe haemophilia A and B share a similar quality of life on average.



Haemophilia Society Newsletter

Blast from the past.. Here's an newsletter excerpt from almost 50 years ago! Lots has changed but some things stay the same.. As ever, we are still on the hunt for committee members!

Office: 11 Mayfield Avenue, Malvern, Victoria, Australia.

President: Mr. Allan Barry,
145 Kerferd Road,
ALBERT PARK 3206

Treasurer: Bruce Mansfield,
49 Silver Street,
CHELTENHAM

Secretary & Editor,
Neville Acklom

1974 No.3

2nd August, 1974.

GENERAL MEETING 16.8.74

As intimated in the previous Newsletter, a General Meeting of members will be held at 8 p.m. on Friday, 16th August, when the speaker will be Mr. W. Pepper, who is an enthusiastic outdoor man and will entertain us with an illustrated talk on his recreations - "Huntin', Fishin' and Shootin'!"

Venue: Mayfield Centre, 11 Mayfield Avenue, Malvern (telephone 20 3221). There is plenty of car-parking space at the rear of the building.

We look forward to a large gathering. Your friends are welcome.

COMMITTEE - NEW MEMBERS?

The Committee is far from being in the doldrums but feels that an injection of new ideas would be stimulating. The Committee comes up for election at the Annual General Meeting on 15th November, and the nomination forms will be circularised with the next Newsletter. Before then the Committee would like ^{you} to think of suitable people to nominate. In particular, they would like to get someone with secretarial experience and with typing facilities available. Who do you know who would fill the bill?

NO MAN IS AN ISLAND.

In varying degrees, all of us are dependent on many others: we rely on other people to produce and merchandise the clothes and food we need, the houses in which we live and every form of service we use. To a large extent this reliance is an act of faith - we don't check that farmers have sown enough wheat to satisfy our hunger but we have confidence that they will. The Red Cross Blood Transfusion Service operates on the same principle but, unfortunately, at times their faith is sorely strained. This is because the supplies of blood do not meet the demand.

Possibly no sector in the community depends upon blood as much as do haemophiliacs, therefore it behoves the society to heed the call of the B.T.S. and to urge non-bleed members to enrol as donors. This will be a service to the community and a service to our own kith and kin.

Mr. Peter Carrollan, the blood donors public relations man, hopes to give enrolments a push at 8 p.m. on Wednesday, 7th August, when he will be giving a talk to young Rotarians at the Ewing Memorial Hall, corner of Burke and Manning Roads, Malvern. His co-speaker will be Mr. Richard Fisher. A blood film will be shown. It should be a most interesting and informative evening. If you need any further low-down telephone Richard at 277 2373.

World Haemophilia Day

April 17 2023 #WHD2023

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.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

This year the international theme is *“Access for All: Prevention of bleeds as the global standard of care”*. The aim is to improve access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders. This means making home-based treatment available as well as prophylaxis treatment to help people with bleeding disorders to have a better quality of life.

Did you know, WFH estimates that over 65% of people living with haemophilia worldwide have not yet been identified and diagnosed.

The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work to improve access to diagnosis, treatment, care and support for people with bleeding disorders in less well-resourced countries with their GAP and Twinning Programs and the Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Haemophilia Foundation Australia is a WFH member organisation and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and various committees that



work to achieve the objectives of WFH. In Australia, our community is fortunate to have access to a range of treatments, care and services. During recent times, some new haemophilia therapies available in Australia have led to fewer or no bleeds and greatly improved the quality of life of those who have been able to use them. We look forward to more novel therapies in the future for everyone.

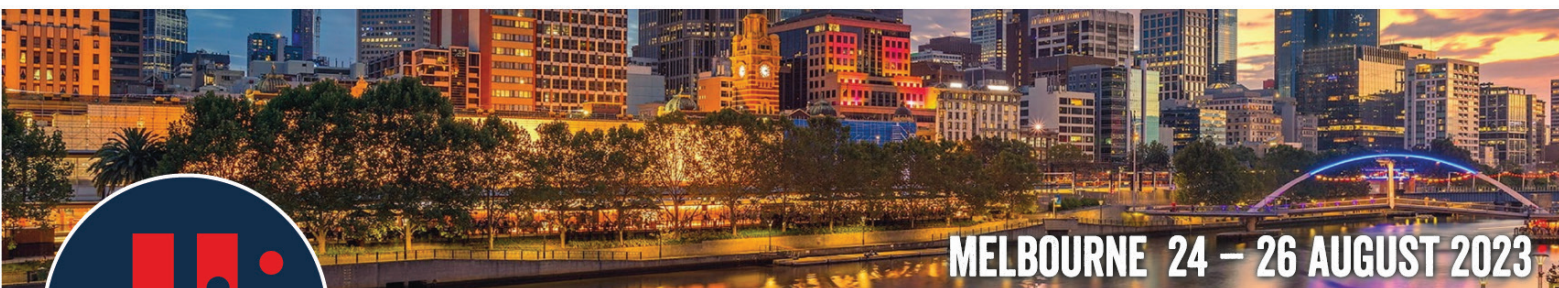
LIGHT IT UP RED

We have many locations and landmarks all over Australia Lighting up Red in support of World Haemophilia Day. In Victoria we have the following locations.

- Ballarat Town Hall
- Bolte Bridge
- Drum Theatre Building, Dandenong
- Geelong Intersection Moorabool/Malop St

For updated locations keep an eye on HFA website www.haemophilia.org.au/WHD and HFA social media platforms.

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MELBOURNE 24 – 26 AUGUST 2023

21ST AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND RARE BLEEDING DISORDERS

2023 Conference

The 21st Australian Conference on haemophilia, VWD & rare bleeding disorders will be held face to face at the Pullman on the Park, Melbourne, 24-26 August 2023.

After a few years communicating and running events virtually and online it will be wonderful to see everyone come together again and at a different time of year to our previous conferences.

HFA conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

The program committee is developing a multidisciplinary program which will interest everyone. Topics will cover:

- new developments in care and treatment
- inhibitors
- new treatments
- gene therapy
- living with a bleeding disorder
- getting older with a bleeding disorder
- women/girls with bleeding disorders
- family planning and genetics
- von Willebrand disease
- rarer bleeding disorders
- managing pain
- bloodborne viruses
- new diagnosis
- youth
- sport and healthy activities
- and.....what's on the horizon?

The program will include presentations from people living with bleeding disorders as experts as well as health professionals and other specialist speakers.

The venue has good access in and around the hotel and on the conference floor, with direct lift access. The hotel is suitable to people who use wheelchairs.

Community Funding

Information regarding HFV community funding avenues will be made available in the coming months.

HFA have also allocated funding to help community members with expenses to attend the Conference.

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Thank you to our sponsors

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For more information, registration link and details visit:
www.haemophilia.org.au/conferences.
Or email hfaust@haemophilia.org.au



Notices & Information

CAMP ACTIVITIES 2023

Camp is almost upon us! Things kick off on **Friday 17 March** - only one week away. Big thanks to all the families who have already registered. We ask that you book ASAP if you have not done so already.

The camp registration deadline is Wednesday 15 March.

Still on the fence about coming to camp?

Check out some of the activities we have planned:

- Yoga
- Campfire
- Stand up paddle boarding
- Canoeing
- Flying fox
- Carnival games
- Caving/tunnelling
- Fashion and design challenge
- Youth leadership activities (including night canoeing)
- Career planning/mentoring session for teens
- Play station for toddlers
- PLUS lots of good conversations!!!

You can book online here:

www.trybooking.com/CEYTU



WOULD YOU LIKE TO JOIN OUR COMMITTEE?

Have ideas about how HFV should be run?
Want to help advocate for other people?

We are accepting expressions of interest (EOI) now for 2022/2023 Committee of Management (COM) positions.

Requirements:

- Lived experience with a bleeding disorder (personally or through family/friends)
- Availability to attend 6-8 evening Zoom meetings per year, typically on Tue/Wed
- Motivated to assist in decision-making, including around sensitive topics

We welcome EOI from a diversity of ages, lived experiences, and perspectives.

Please email your EOI to:
info@hfv.org.au

LIFE MEMBERSHIP NOMINATIONS OPEN

Do you know someone with a longstanding commitment to the Victorian bleeding disorders community?

Send us an email with their details and tell us why you are nominating them:
info@hfv.org.au



13 Keith Street
Hampton East VIC 3188
Phone: 03 9555 7595
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info@hfv.org.au www.hfv.org.au

PATRON: Dr Alison Street AO

EXECUTIVE ASSISTANT

Andrea McColl andrea@hfv.org.au
COMMUNICATIONS COORDINATOR
Yarrow Ruane yarrow@hfv.org.au

COMMITTEE OF MANAGEMENT:

PRESIDENT Leonie Demos
VICE PRESIDENT Dan Korn
TREASURER Bernard Paes
EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:

Ben Inglis
Chris Phong
Zev Fishman

VICTORIAN HAEMOPHILIA
TREATMENT CENTRES



Henry Ekert
Haemophilia Treatment Centre

Royal Children's Hospital, Flemington Road, Parkville
P. (03) 9345 5099 E. he.htc@rch.org.au

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Erin Krake | Clinical Nurse Consultant
Julia Ekert | Administrator/Data Manager
Nicola Hamilton | Physiotherapist

Ronald Sawers
Haemophilia Treatment Centre

The Alfred, 1st Floor, William Buckland Centre
Commercial Road, Melbourne 3004
P. (03) 9076 2178 E. (03) haemophilia@alfred.org.au

Professor Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
Catherine Haley | Physiotherapist
Diana Harte | Psychologist
Debra Belleli | Data Manager

Membership Annual Fees:

\$33.00 Standard family membership
\$16.50 Concession / Allied (Youth Free)
\$55.00 Organisational member
* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.
(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:

Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

MedicAlerts

MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to \$30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Live Well Funding:

All current financial members can apply for Live Well Funding for any item or activity which the applicant anticipates will contribute to a positive health outcome. Priority may be given to funding applications for items or activities related to the management of bleeding disorders and associated health conditions.

Care and Counselling:

This is available through your treatment centre.

Magazine:

MEN'S GROUP

Our current group meet for their Annual Men's Retreat - a much needed weekend away that included massages, relaxation and meditation. In 2022, 11 members attended the retreat, including a Tasmanian! Many promised to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

WOMEN'S GROUP

The group meets once a year over lunch and each alternate year get to enjoy an event with a twist. They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant. If you have an idea for a ladies day, let us know! We are always looking to try new things.

YOUTH GROUP & BLUE SHIRTS

After a successful reunion at 2022 community camp (with lots of new leaders coming on board) the Blue Shirts will be meeting up in September 2022 for an Amazing Race through the Melbourne CBD. HFV have lots of leadership opportunities available for young people looking to have fun and challenge themselves.

GRANDPARENTS GROUP

WE ARE CURRENTLY LOOKING FOR A NEW CONVENOR FOR THIS GROUP. IF YOU ARE INTERESTED PLEASE CONTACT THE HFV OFFICE.

KIDS EVENTS

We have opportunities for kids to connect throughout the year. Recently, several families met for an indoor climbing day. Check out our events schedule for upcoming kid-friendly activities.

Looking for support on your journey to find work?



Our Career Counsellors are here to support people living with a disability find work.

If you have a health impairment or disability that impacts your ability to participate in the workforce, speak to a Career Counsellor today.

A Career Counsellor can help you:

- Understand your career options
- Discover the jobs that best match your abilities, interests and personality
- Identify your transferable skills and strengths
- Assist you with your job applications, including your cover letter and resume
- Empower you to take the lead in your career journey

How can I access career guidance?

Career guidance sessions can occur online, over the phone or in-person, dependent on your preference.

Is there a cost to me?

This service is fully subsidised by Jobs Victoria. Victorians can access it at no cost.



To book call 1800 967 909 or scan the QR code.