

Factor Matters

Haemophilia
Foundation
NSW



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Autumn 2023

Volume 53

Hunter Region Family Fun Day

21st Australian Conference

World Haemophilia Day 2023

Rare Disease Day 2023



About Us

HFNSW is a member driven not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, we provide complimentary services beyond the Treatment Centres such as continuous education, lifetime connections and community events, peer-to-peer counselling, and help with identifying solutions to improve the quality of life for people living with an inherited bleeding disorder.

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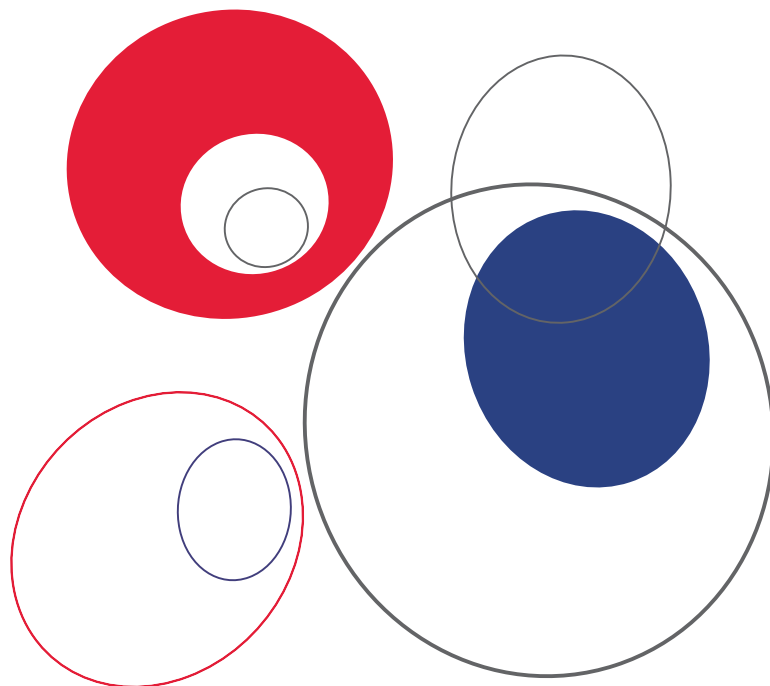
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Coverpage photo:
Cooper Shayne, HFNSW's member
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Dan Credazzi

President,
Haemophilia
Foundation
NSW

A Word from the President

Last month, along with HFA and Dr Liane Khoo, we held an advocacy event in Federal Parliament. Our goal was to keep our Community and Carers at the forefront of Parliament and the Departments they manage. Providing feedback to those who make investment decisions is important, and this event allowed us to do so. Here in Australia, the government continues to provide the latest treatments from around the world. The event was attended by three medical doctors in Parliament, Dr Monique Ryan MP, Dr David Gillespie MP, and Dr Mike Freeland MP. They and their staff appreciated the update on the history and latest treatments from Dr Liane. Sharon Caris described the national HFA while I followed with our story here at HFNSW. Our closing act was Jayden, our lovely son, whose off-the-cuff and heartfelt presentation made the room laugh and cry.

In our last newsletter, we mentioned that we intended to write to the Minister for Sport about giving us a break on camp costs at Narrabeen Sport and Recreation.

Instead, we decided to write the CEO of NSW Sport and Rec first. We wrote to her last month and are still waiting for her response.

Regarding HFNSW real estate, our new office is still in progress by the Sydney Local Health District. We are likely to move in during the middle of the year. The location is conveniently a short walk from the front door of the RPA down on Carillion Ave. Not to worry, we'll have an opening event and invite the Community to the party whenever it's ready.

In April, our annual Awareness campaign will take place, and the RPA will hold a clinical information session about bleeding disorders for all of NSW Health. Additionally, the ANZ Haemophilia conference will take place in Melbourne in August. All the necessary information can be found on the following pages.

*Best wishes,
Dan*



Rare Disease Day 2023

28 February was Rare Disease Day.

It's a day when we join together worldwide to raise awareness about what it is like to live with a rare health condition. While haemophilia is rare, some other bleeding disorders are even rarer. Today we put the spotlight on the range of bleeding disorders and the particular issues for people living with very rare disorders.

Rare Disease Day is also an effort to work globally towards equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease.

Rare is many. Rare is strong. Rare is proud. The 2023 theme of Rare is many. Rare is strong. Rare is proud



reminds us how important it is to come together and connect as a community. This is an opportunity to share personal stories and acknowledge the challenges for our community members who live with a rare disorder.

VERY RARE BLEEDING DISORDERS

Some bleeding disorders are very rare, such as rare clotting factor deficiencies, inherited platelet function disorders and very rare types of VWD. When rare diseases are very rare and numbers are small, this can mean that the development of new and highly effective treatments is slow.

There may even be no treatment that specifically targets that condition.

Many people with rare diseases speak of feeling isolated. Many have never met or heard of another person with their condition. Sharing personal stories is an important way to help people with rare diseases feel connected. It can also help the wider community to understand better what it is like to live with a rare disease.

Sharing personal stories is an important way to help people with rare diseases feel connected. It can also help the wider community to understand better what it is like to live with a rare disease.

You may have seen some other personal stories about living with rare bleeding disorders on our social media platforms in the lead up to Rare Disease Day. Some live with very rare disorders, for example, here is Simoni's story (VWD Type 3):



Growing up with von Willebrand disease

This is a transcript of Simoni's presentation at the 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders. You can watch Simoni's presentation on the Conference portal at <https://haemophilia.delegateconnect.co>.

Hi, I'm Simoni, and I have type 3 von Willebrand disease (VWD), the most severe and rarest form of the disease. Consequently, I have little to no von Willebrand factor and low levels of factor VIII (8). When I was a child, my parents noticed that I bruise easily from daily activities and was often susceptible to minor cuts, which would bleed for a long time. They then proceeded to have me tested, and it was found that I have von Willebrand's at the age of three years old.

MY TREATMENT

Some of my symptoms include a longer bleeding and clotting time for injuries, easy bruising, heavy nosebleeds, recurring joint bleeds and heavy menstrual bleeding, resulting in anaemia and fatigue. At eleven years old, I was started on prophylactic treatment of intravenously administered clotting factor concentrate every alternate day. The support of my haemophilia nurse was and continues to be instrumental in my treatment from the very beginning.

The factor was first administered by help of my nurse, followed by my parents who administered it regularly until I learned to administer it myself recently. My current treatment also involves taking tranexamic acid tablets during bleeding episodes to supplement my regular treatment, which helps slow down the dissolution of blood clots.

MANAGING INJURIES

In early primary school, when I was not on regular treatment, I was highly vulnerable to serious injuries, particularly in sport classes. I did limit my participation in sports to non- or low-impact activities as a measure of caution, which was not a significant problem as I'm not naturally a sporty person.

In my experience, I found it beneficial to let school personnel and close friends know about my bleeding-

disorder and inform them of the specifics of managing a serious bleed or injury so that we could act promptly to minimize the severity of any injury.

An event which highlighted the necessity of this was when I was eight years old whilst playing basketball, my ankle was hit by the ball with high impact. As there was no immediately visible injury, I did not pay much attention until I got home that afternoon, by which time my ankle was severely swollen. After further investigation, we found that I had a ligament injury, which developed into a recurrent issue. If we had taken prompt action then, perhaps the long-term impacts would have been eased.

Prior to beginning prophylactic treatments, I would be treated in a children's hospital and would often have a cannula in my arm for a few days to enable daily treatment. Due to von Willebrand's, I have found that my recovery period from major injuries is quite lengthy. For example, about three to four weeks for an ankle injury, sometimes longer, depending on the severity.

Due to recurring injuries, in particular joints, physiotherapy has become a key part of recovery and helps to build muscle strength to prevent further trauma. Also, nosebleeds can be quite heavy and are difficult to stop, for which I use a nasal spray and administer factor treatment as soon as possible.

As a result of having a bleeding disorder, micro bleeds in joint do result in frequent joint pain and sometimes swelling, which I manage through rest and ice compression along with regular treatment.

MANAGING PERIODS

Upon beginning menstruation, I experienced very heavy periods causing severe anaemia and was required to go on hormonal medication to control it. I remained on medication for approximately two and a half years, after which I was able to move forward without medication.

LIVING WITH VWD

Also, when I know I will be participating in strenuous and high-risk activities, it has been essential to ensure that I have had a dose of my prophylactic factor treatment earlier the same day, not only to mitigate the impact of any serious injury, but also to possibly reduce the time which I might need to recover. As a precaution to be able to manage any injuries or bleeding promptly, I keep a kit with pressure wrap bandages, medications and Band-Aids close by when traveling anywhere. There have been numerous occasions in which my kit has come in handy, and it has been a key part of living with von Willebrand's.

Prophylaxis has proven to be a very effective method of managing my bleeding disorder, enabling me to participate in daily activities with normality. I do still maintain a degree of caution and try to prevent major injuries or be swift in managing any bleeding events. Prophylaxis is now a regular part of my life and is a monumental component of my experience and living with the disease.

Additionally, I am hopeful that a recombinant, long-acting subcutaneous injection will replace intravenous factor in the future, similar to that available for haemophilia treatment, which can be easily and less frequently administered.

Overall, in my experience, living with von Willebrand's does not mean that you should feel restricted or disadvantaged in any way. While it is important to know my limits, learning to manage the disease and symptoms effectively and bringing immediate attention to injuries is even more vital. And with time, I've learned to integrate the symptoms and treatment as a part of daily life.

I think there is a lot of fear and uncertainty that both a person living with the disease and perhaps their friends or family might have. So, I think it's important to cultivate and maintain a support system and try to develop a greater awareness of your condition for those around you.

Thank you.

Source: Factored In (www.haemophilia.org.au), the Haemophilia Foundation Australia youth website

Date accessed: 15/03/2023

International Women's Day



International Women's Day (IWD) – 8 March

– is a time to

reflect on progress made, to call for change and to celebrate acts of courage and determination by ordinary women, who have played an extraordinary role in the history of their countries and communities.

In 2023 IWD is celebrated under the International Women's Day theme, **#EmbraceEquity seeks to help forge worldwide conversation about this important issue and its impact.**



EMPLOYMENT

Getting into the workforce is a pretty exciting adventure. It might be a part-time job while you're still studying or diving head first into a full-time job, You will start earning money, meet new people and gain new skills.

Regardless of your bleeding disorder, it's advisable to prepare for work and begin to think about your future career choices.

CAREER OPTIONS

When you have a bleeding disorder it's a good idea to explore your career options early.

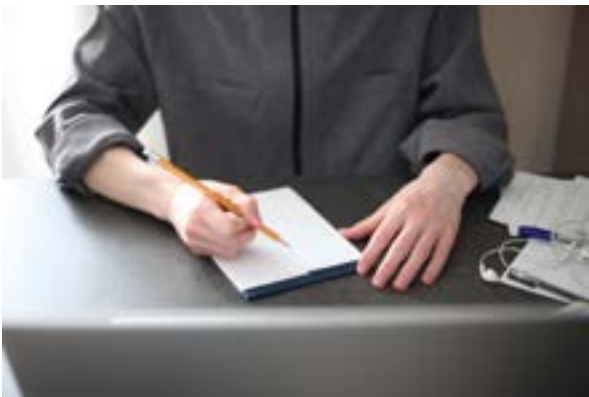
Talk to the career adviser at your school. They can help you explore possible career options and point you in the right direction by suggesting suitable classes to take and assist with the entry forms for University or TAFE.

Talk to your Haemophilia Treatment Centre about your career choices. They will work with you to implement strategies to help you overcome barriers associated with your bleeding disorder to achieve your career ambitions.

Some employers may require a letter of medical clearance from your doctor as part of a medical entry requirement. It is a good idea to check if your chosen career has medical restrictions to avoid future disappointments. For example, the Australian Defence Force (ADF) has very strict medical entry requirements that exclude certain conditions and the police force also has medical requirements for applicants.

You may find having a physically demanding job okay when you are young, but as you age you may need to consider transitioning/pivoting to a less physically demanding role. Often this is able to happen within your workplace, such as going from being a tradie to teaching or managing.

Choosing a career that suits your health needs may be beneficial. For example, if you have a desk job you may be able continue working while recovering from an injury or bleed but as a bricklayer you may require a few weeks off work to recover. Not all physically demanding jobs should be avoided - there are just extra things to think about.



PREPARING FOR WORK

Once you have been successful at getting employment, it's a good idea to have a chat to your Haemophilia Treatment Centre before your first day on the job – they may think of things you haven't. For example...

- Do you need specialised equipment or work wear?
- If there are first aid officers, what do you want them to do in case of an emergency? Do you want them to call anyone else after calling an ambulance, eg your emergency contacts?

- Have you tailored your prophylaxis or treatment regime to ensure the best cover so you can meet the demands of the job?
- Have you thought about how you will respond if other staff ask you questions about your bleeding disorder?
- How far away from a hospital are you if you need immediate treatment?
- If you work at a desk, you could consider getting an OH&S assessment or advice from your physio on the best methods to prevent injury and while sitting for long periods (especially in joints which you might not be able to straighten/extend limbs)
- Consider setting up medical ID on your smart phone, carrying an ABDR patient card in your wallet or having a photo of your card on your phone.

BLEEDS AT WORK - CAUSES

WHAT COULD CAUSE A BLEED AT WORK?

- Uneven ground/poor environmental or ergonomic set-up
- Trips/falls/bumps associated with workplace hazards
- Inadequate physical conditioning for job requirements
- New or sudden increases in physical demands
- Knocking parts of your body on equipment

WHO TO TALK TO ABOUT BLEEDS AT WORK

If you find you are having new or worsening aches or pain, are concerned that you are having bleeds or any other problems, contact your Haemophilia Treatment Centre for advice.

They may need to review your current treatment or prophylaxis plan or provide suggestions about helpful workplace protective equipment or ergonomic set up. Where appropriate, they can also talk to you about your situation and provide supporting documentation for your employer if necessary. They can also give suggestions on plans to manage medical emergencies.

If there is a job you've always wanted to do but you or your parents are worried because of your bleeding disorder, your Treatment Centre can help you tailor your treatment plan to suit your chosen career. personal use and that the vials must not be opened when they are being checked by security officials.

THINGS YOUR EMPLOYER CAN'T DO



YOUR EMPLOYER CANNOT:

- Force you to see their doctor
- Get reports from your doctors unless you give consent.

(There are some exceptions to the above two points, such as for Workers Compensation claims.)

- Sit in on your doctor appointments
- Force you to disclose your medical condition
- Fire you if you disclose your bleeding disorder

There are some situations where you are required to give information about your bleeding disorder, if asked, for example:

- Applying to work in the armed forces or police
- Applying for or continuing a job where your bleeding disorder is likely to have a fundamental impact on your ability to do your work or may pose a risk to occupational health and safety for you or others.

In these cases, employers can lawfully discriminate on the basis of your bleeding disorder.



YOUR RESPONSIBILITIES

YOU HAVE A RESPONSIBILITY TO:

- Inform your employer if your bleeding disorder is going to affect your ability to do your job
- Follow your prescribed treatment plan to reduce your risk of bleeding at work
- Know if a medical certificate is required for missing work (each workplace may have a different policy e.g some require a certificate for missing 1 day, others require a certificate after missing 2 or 3 days).

DISCLOSURE - WHO SHOULD I TELL AT WORK?

When you start a new job or are diagnosed with a bleeding disorder, you may find you have to think about telling others in your workplace. In most cases, whether or not to tell is entirely up to you.

Telling your employer could be a good move and is something to consider for your particular situation. For example, it may help explain any difficulties you are having at work, or why you need time off and may result in changes to your job which will mean you can continue to work as a productive member of a team.

However, before you go ahead and tell, it's important to think about what response you think your employer will have. You could consider getting the help of your doctor, union or the Social Worker or Counsellor or other health professionals at your Haemophilia Treatment Centre to get some pointers.

If your bleeding disorder is not going to impact on your work, you may prefer to take your time and think carefully before you tell your employer or work mates. Remember – once you have told people, you can't take it back and will have little control over who they tell.

If your bleeding disorder is relevant to your work, or medical questions are asked on your employment application, it may be worthwhile to look more closely at what the job entails and consider why the questions are being asked.

It might be that your bleeding disorder is an occupational health and safety risk for the particular job you are applying for. It is important to note that if you don't mention your bleeding disorder when asked on an application form and an accident occurs, you may not be entitled to legal protection.

If you do tell people at your work, you may consider doing a presentation to your work mates explaining what a bleeding disorder is and how it affects you. You could even host a Red Cake Day event!

SOURCES & REVIEWERS

IF YOU NEED MORE INFORMATION OR HAVE QUESTIONS ABOUT EMPLOYMENT, YOU MIGHT FIND IT HELPFUL TO TALK TO:

- Your [Haemophilia Treatment Centre](#)
- Your careers adviser at school/uni/TAFE
- Haemophilia Foundation Australia or your local Haemophilia Foundation

Source: Factored In (www.haemophilia.org.au), the Haemophilia Foundation Australia youth website

Date accessed: 15/03/2023

DISCLOSURE

When do I need to disclose that I have a bleeding disorder?

By law you don't usually have to tell anyone about having a bleeding disorder or carrying the gene.

There are a few situations where you will be required to give this information if asked. These include:

- Applying to join the Australian Defence Force or police force
- Applying for insurance such as Life and Income Protection Insurance
- Applying for superannuation
- Applying for private health insurance
- Applying for travel insurance
- Traveling – you may be asked questions relating to your bleeding disorder by customs and security officers or other government officials
- Applying for or continuing a job where your condition is likely to have a fundamental impact on your ability to do your work or may pose a risk to occupational health and safety.

If you are unsure whether you need to disclose your bleeding disorder it may be helpful to speak with your Haemophilia Treatment Centre (HTC).

If you do choose to tell an employer or service provider, by law they are not able to discriminate on the basis of your condition apart from the exceptions above.

If you need information on discrimination you can contact your state or territory Equal Opportunity or Human Rights Commission, or contact The Australian Human Rights Commission (www.humanrights.gov.au).

You can also contact your Haemophilia Treatment Centre, local Haemophilia Foundation or Haemophilia Foundation Australia.



WORLD HAEMOPHILIA DAY 2023

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 NSW we have the following locations:

- Newcastle City Hall Clock Tower
- Port Macquarie Town Square

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

Join us for a fun-filled day in the Hunter Region!

We are thrilled to announce that we are back with yet another event in the Hunter Region! We'll be hosting a variety of exciting activities for you to enjoy while indulging in delicious food and drinks!



Mark your calendars for

Sunday 30 April 2023,

from 11:30am to 2:30pm,

*at 326 Hillsborough Rd, Warners Bay,
NSW.*



We have reserved a private room, so please make sure to be there at 11:30am so you won't miss any of the fun activities that have been arranged for you.

The Dullboy's Staff will guide you where the room is.

BEST OF ALL, THIS IS A FREE EVENT!

HOWEVER, BOOKING IS ESSENTIAL!

SO PLEASE RSVP BY TUESDAY 25 APRIL THROUGH

WWW.TRYBOOKING.COM/CHCVU

or email coordinator@hfnsw.org.au

IMPORTANT: Please mention Names of all attendees, ages of children, phone and any dietary requirements.

Supported by HFNSW

HAEMOPHILIA FOUNDATION



NEW SOUTH WALES Ugiatus ipidelia conseris et omnit re nusdae re adit quianis ciduntis quisLit



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

In the next few months, details about the funding opportunities available to the HFNSW community will be provided.

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

Thank you to our sponsors

Gold



Silver

CSL Behring



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For more information, registration link and details visit

www.haemophilia.org.au/conferences

or email hfaust@haemophilia.org.au



I think I need therapy. Here are 5 types of psychotherapy to help with almost any mental health problem

John Malouff

Associate Professor, School of Behavioural, Cognitive and Social Sciences, University of New England

You have made a momentous decision: you will seek psychological treatment for your depression, anxiety, substance abuse, or other mental health issue.

Your mind then may turn to the question of what type of treatment would best suit you. To even ask this sophisticated question, you need to realise there are various types of psychological treatment. To make a wise choice, you must understand what each type of therapy provides.



Let's look at several types of psychotherapy (also known as talking therapy) that have the potential to help with almost any mental health problem.

1. Cognitive behaviour therapy

Cognitive behaviour therapy (CBT) is a common type of therapy where the therapist explores the thoughts and behaviours that relate to your therapy goal.

Let's suppose you have been feeling depressed for months. Relevant thoughts might be that no one likes you and that you are worthless. Relevant behaviours might include staying in your home and avoiding contact with others.

The therapist would likely help you challenge the accuracy and usefulness of those thoughts and find replacement thoughts. The therapist might encourage you to do more for fun and to interact more with others.

2. Acceptance and commitment therapy

In acceptance and commitment therapy, you would instead be asked to accept your negative thoughts as yours (regardless of whether they are accurate) and also accept your negative emotions.

The therapist would encourage you to look at your thoughts and emotions as separate from you so you can examine them more objectively. Acceptance might reduce your negative feelings about yourself.

The therapist would explore your values and encourage you to commit to acting according to them. If you value kindness, for instance, the therapist might encourage you to show kindness to others.



3. Psychodynamic therapy

A psychodynamic therapist would help you explore your childhood, searching for traumas and difficulties with your parents.

If you felt unloved by your parents as a child, you would consider whether your parents provide a fair representation of the entire world.

You might consider to what extent you deserve love now as an adult. You might also gain insight into how your early experiences colour your current expectations, and affect your emotions and behaviour.

You might find yourself transferring to the therapist your feelings toward your parents and then realise that others are not your parents and you are no longer an unloved child.

4. Narrative therapy

In narrative therapy, you would explore the stories of your life, particularly the stories that seem to persist.

If you were an outsider in school, reluctant to join in social activities, you may think of yourself as a loner. As an adult, even though you engage fully and successfully in social interactions at work, you may continue to think of yourself as a loner.

In other words, the story you tell yourself remains unchanged despite your social success at work, and you feel depressed about being alone.

In becoming aware of the story of your life, you create distance from the story and you may find ways to change the story (the narrative). In essence, you rewrite the story in a realistic way to develop toward being the person you want to be.

5. Person-centred therapy

In person-centered therapy, sometimes called supportive counselling, the therapist would listen attentively, try hard to understand life as you experience it and try to understand and even feel your emotions.

The therapist would show caring and an interest in helping you, in the expectation that you can find your own way to overcome feeling depressed.

6. A mix of styles to suit you

You can ask potential therapists what type of therapy they provide. Many will say they are eclectic, meaning they try to choose methods to suit each client and specific problem. They may combine methods of different therapy types.

They may also use popular methods such as mindfulness training that do not fit any specific therapy type. Mindfulness training involves focusing on your breathing and being aware of the here and now.

You can request an eclectic therapist to provide a certain type of therapy or certain therapy methods. Once the therapist gets to know you, you can discuss your preferences and decide on the therapy methods to use.





7. How can you decide which one?

You might wonder which type of therapy usually works best. The answer is unclear. Much depends on the specific client, the problem and the therapist.

Most types of therapy work moderately well for treating people with depression. Psychotherapy also appears to be reasonably effective for other types of psychological problems.

CBT has the strongest evidence for treating a broad range of psychological problems (including post-traumatic stress disorder). However, CBT has the most evidence in part because it is heavily studied (for example to treat specific phobias).

Acceptance and commitment therapy is also backed by substantial evidence, as is psychodynamic therapy.

The effects of narrative therapy and person-centred therapy have not been studied so much.

Some people, including those with depression or psychosis, can benefit by receiving psychotherapy and taking medication prescribed by a GP or psychiatrist.

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Theconversation.com

Date accessed: 10/03/2023

Supports available

Please note there are plenty of services available, most do not require you to leave your home. Please reach out for help if you need it!

These services are listed below:

- **Beyond Blue** (For everyone)

1300 224 636
www.beyondblue.org.au

- **HeadSpace** (For young people and parents)

Find local centre online
www.headspace.org.au

- **Kids Helpline** (For kids, young people and parents)

1800 551 800
www.kidshelpline.com.au

- **Lifeline** (For everyone)

13 11 14
www.lifeline.org.au

- **Mental Health Line** (For everyone)

1800 011 511

Contact your Haemophilia Treatment Centre

You can contact your local HTC and connect with the psychosocial worker at the centre to talk through what is happening, and if needed, the psychosocial worker can connect you with long term support.

Talk with your GP

You can also visit your GP who can complete a Mental Health Treatment Plan with you, which is a tailored plan that links you in with specific mental health support services. A Mental Health Treatment Plan will allow you to initially access 6 individual psychological appointments that are subsidised through Medicare. If more sessions are needed you can discuss this with your GP to access more Medicare subsidised psychological appointments. Through a Mental Health Treatment Plan, you will be able to access a range of psychological support specialists such as psychologists, social workers and occupational therapists to assist with your mental health care needs.

HFNSW financial support

If financial challenges are a barrier to you accessing support and dealing with mental health issues, please note that HFNSW is now able to provide support to members. Financial assistance will be offered to HFNSW members dealing with mental health issues through bill rebates for mental health services, including consultation fees. Each year HFNSW members will be able to access up to \$100 of financial support to assist with their mental health care needs.



Colour-in competition is back!

Young Ones Are Invited!

Colour in this page and win prizes such as movie tickets.

Please send by 15 May 2023 to:

Haemophilia Foundation NSW

PO BOX 631, Broadway NSW 2007



MEMBERSHIP FORM 2022-2023

PERSONAL DETAILS

Mr/Mrs/Ms/Other: ----- Name:----- (Required)

(Member details below only required if changed)

Mailing Address: -----

----- Post Code: -----

Ph: (H) ----- (Mobile) -----

Email: -----

Family Details (if completing this as a parent/carer indicate with * for person with bleeding disorder)

Mother's Name: ----- Father's Name: -----

Child's Name: ----- DOB: ----- BD: -----

Child's Name: ----- DOB: ----- BD: -----

Child's Name: ----- DOB: ----- BD: -----

Treatment Centre Attended: -----

PRIVACY

We respect your privacy. Your details will NOT be provided to other organisations or individuals without your permission. Your membership details will assist HFNSW in planning for activities to meet your needs; however, you are not required to provide all details including health information on this form if you do not wish to. Haemophilia Foundation New South Wales (HFNSW) was founded to provide support and education to individuals and families affected by haemophilia, von Willebrand disorder and other related bleeding disorders. HFNSW is a member organisation of Haemophilia Foundation Australia (HFA) which is the national peak advocacy body for the bleeding disorders community.

HFNSW membership automatically entitles you to have access to HFA services and programs, including receiving their quarterly newsletter National Haemophilia. Mark this box if you do **NOT** want your name and address recorded on the HFA database.

ANNUAL MEMBERSHIP \$20 PER APPLICATION (INCLUDES GST) SINGLE OR FAMILY MEMBERSHIP

Membership \$20.00 (Inc. GST) \$ -----

Donation* \$ -----

TOTAL \$ -----

PAYMENT DETAILS

Payment of the membership fees can be made through the following options:

- Cheques/money orders payable to: Haemophilia Foundation NSW Inc.

Mail to: HFNSW, PO Box 631, Broadway NSW 2007

- EFT payment to: Haemophilia Foundation NSW CBA BSB: 062204 Account number: 00902590

WHEN PAYING ONLINE PLEASE USE YOUR FULL NAME IN THE DESCRIPTION FIELD & FORWARD YOUR RECEIPT NUMBER WITH YOUR MEMBERSHIP RENEWAL.

Please retain a copy of this form for tax purposes if desired. A receipt will be posted to you.



HAEMOPHILIA CENTRES

Kids Factor Zone

The Children's Hospital at Westmead

General: (02) 9845 0000

Robyn Shoemark (Nurse)-- quote Pager no. 7052

robyn.shoemark@health.nsw.gov.au

Ady Woods (Nurse)-- quote Pager no. 6273

adrienne.woods@health.nsw.gov.au

Social Work Department:

Schn-chw-socialwork@health.nsw.gov.au

Sydney Children's Hospital Randwick

Haematology

C2 North, Sydney Children's Hospital

High St. Randwick NSW 2031

General: (02) 9382 1111

Grainne Dunne (Nurse)

Direct: (02) 9382 1240

Grainne.Dunne@health.nsw.gov.au

Royal Prince Alfred Hospital

Haemophilia Treatment Centre

RPA, Missenden Road

Camperdown NSW 2050

Stephen Matthews (Nurse)

stephen.matthews1@health.nsw.gov.au

Phone: (02) 9515 7013

Newcastle - Adult Services

Calvary Mater

Haematology Department

Corner of Edith & Platt Streets

Waratah, NSW 2298

General: (02) 4921 1211

Dale Rodney (Nurse)

Dale.Rodney@calvarymater.org.au

Bryony Cooke (Social Worker)

Bryony.Cooke@calvarymater.org.au

(02) 4014 4811

Newcastle - Paediatric Services

John Hunter Children's Hospital

Lookout Rd

New Lambton Heights NSW 2305

General: (02) 4921 3000

Jaime Chase CNS

0448 511 539

jaime.chase@hnehealth.nsw.gov.au

Cathy Morrison (Social Worker)

cathy.morrison@health.nsw.gov.au

HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

HFNSW Annual Family Camp: HFNSW offers free of charge family camp for people with bleeding disorders and their families

NSW Community & Educational events: HFNSW offers fun community and educational events for members and their families/carers across NSW for different purposes including raising awareness, building community, and updating, training and educating.

Newsletter: HFNSW provides quarterly newsletters that offer information and details of events, personal stories, education, treatment information, etc.

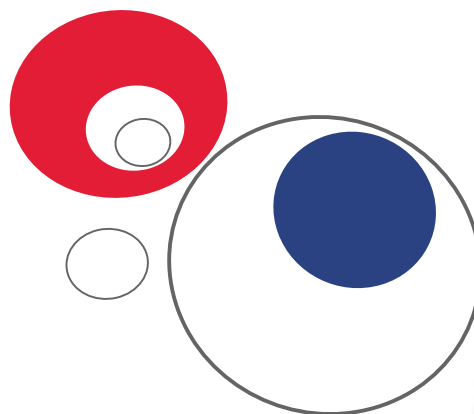
Financial Assistance: HFNSW offers MedicAlert subsidies, shoes rebates, Mental Health Consultation rebates, travel assistance, education & training, grants.

Information and Support: HFNSW provides information and support in the form of:

- Education and assistance to members with bleeding disorders and those who also have HIV
- Tutors and entertainment to members who might require extended hospitalisation
- Information and social activities for members and their families
- Rural visits to areas of NSW where there are no specialists

HFNSW COMMITTEE...

Being a member driven organisation, the committee is always interested in hearing from its members, community, friends and family. If you want to have a say in how the Foundation delivers its service and shapes its future, please contact the office at coordinator@hfnsw.org.au



**APRIL 17
2023**

**WORLD
HEMOPHILIA DAY**



Your Continued Support Matters!



MELBOURNE 24 – 26 AUGUST 2023

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

Registration link and details available at www.haemophilia.org.au/conferences

