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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. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control.

Editor: Julia Broadbent



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PRESIDENT'S REPORT

CONNECT EMPOWER

AND WHY IT'S SO IMPORTANT

As we come to the festive season and life gets busy enjoying company of family and friends it is also time to reflect on events at HFV.

As always a busy time for committee and staff as we try to connect with our community.

A great lunch in Shepparton as we joined with some of our rural members. Great to see everyone and enjoy a beautiful meal together. Families travelled from Echuca and surrounding areas and good to be reminded of the extra challenges facing rural families.

Speaking rural again thanks to the Field family and support team for all your hard work for HAW. Thanks to Bending Bank for supporting the community awareness raising as well as fundraising towards many fantastic projects at HFA. For all others in our community doing an activity and event for HAW I thank you on behalf of all at HFV for your efforts and time.

Next year will be a very busy time in October so let's prepare now. Melbourne will be hosting the National Conference. Very exciting indeed and we hope many of our members will be attending as we look forward to learning more about sessions and speakers.

If a conference isn't enough to look forward to, we also have the Red Ball in the following week. The fundraising committee are doing a fabulous job and we encourage everyone to support them in their efforts in any way you can. Put your family, friends and work mates on notice that the Ball is coming and book a table or two. Think about what you can do with your connections to gather prizes and sponsors for the night. Start saving your coins for your ticket and maybe a new frock or suit? It will be an amazing opportunity to raise well needed funds and raise community awareness of our issues so please be a part of October 2017 as you won't want to miss out.

Youth camp is coming up. HFV is very excited to offer spaces to young men from SA thanks to donation by CMV. Many thanks to Kate and Andrea for making this happen. A great chance to integrate with our mates over the border and hope this

can grow in the future.

While supporting our young men HFV are also working in partnership with both HTC's to improve transition for our families. Although the focus group couldn't proceed due to lack of numbers we are still keen to hear from you. What works, what doesn't, give us your ideas to work together for improvement. Love to speak to you.

A new initiative for HFV in partnership with Straight Arrows led to a retreat for men in our community with the additional health challenges of HIV. We are excited to support this initiative and I encourage you to read all about it in the newsletter. This important initative was financially supported by Straight Arrows, HFV and HFA.

Enjoy the new look magazine!! Well done to Julia for your inspiring effortless work. Many thanks to both Andrea and Julia for all you do. Above and beyond over and over throughout the years. I thank you both personally for your support as well as from the committee and our community. Thank you also to fellow



committee members. Your dedication and energy makes the work we do fun and engaging.

Thanks to all our volunteers during the year for all your hard work. Peer leaders do a very important role in ensuring events happen and are always considered and welcoming to all. From Zev for men's retreat, Marie and Jackie for grandparents and a special thanks to Julie Boal. After 12 years of managing ladies day out she is taking a well deserved break. Thanks for you thoughtfulness and efforts in diversity of activities and locations with lots of fun and tears over the years. Heartfelt thanks from all at HFV and hope someone is interested in stepping into your role organising the ladies lunch which is a very important event on our calendar to connect support and empower as women sharing a special bond that you have helped to foster.

So our AGM and Christmas wind up is upon us take time to relax and enjoy yourself. If we don't see you at upcoming events we wish you a very happy and safe Christmas with family and loved ones. 2017 will he a bumper year for our community and we would love to have you actively involved with HFV. Everyone has something to offer and your thoughts and opinions are critical to our core business. Our motto is simple. Connect, support, empower. With your new year resolution ask yourself how can you connect, empower and support others impacted by bleeding disorders as all at HFV ask the same of our role to you, our community.

Looking forward to a busy and exciting 2017

Stay safe. Stay well and make sure you stay in touch.

Leonie Demos HFV President

oh, the places you'll go!

Visiting the Alfred may not have been your first thought, but if you are a young man or woman with a bleeding disorder and you live in Victoria it is likely that you will have to include this hospital in your list of places that you have to visit.

There are many changes at this stage of life, and of course we all handle change in our own way. Some people see it as welcome and exciting. For others it's uncomfortable. Sometimes change comes with challenges that are predictable, other times they are unexpected. These changes relating to your health care are often at the same time as lots of other changes.

Becoming an adult is an exciting time. There is more freedom and fun however there are also some new responsibilities. There are new skills to learn and things to work through. These include dealing with driving, bills, finances, accommodation, work, university, voting, and also managing your health. This shift of responsibility from parents to you is part of your journey to independence.

Parents can find these changes really tough too. They have to make all these adjustments with you, and they also have to start getting used to letting you take on some of these responsibilities.

Changing your haemophilia treatment centre brings its own concerns. There is new staff that you will have to rely on including doctors, nurses, social workers, psychologists, and physiotherapists. You will even have to go to a new hospital. There are also some great new opportunities for professional help.

So how can we try and make this an easier process?

We think we are tuned-in to your needs. But how can we really be?

There are many variables, everyone has a unique personality and experiences and it takes us a while to get to know you and your family or support crew.

What is Transition?

Here are a few definitions that I have found useful in coming to understand how to transition

- 1. "Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems." (Blum et al. 1992)
- 2. "In the context of haemophilia, transition also refers to the continual process of learning about haemophilia and how to manage the many aspects of care. Transition is more complex for families living with haemophilia. Each stage of development involves extra learning for the parents and the child, and the comprehensive care team as well." ("13 Transitions Toward Independence" Wu, Purves, Breakey, Creighton Collaboration between British Columbia Children's Hospital, Vancouver, Nurse Coordinator, and The Hospital for Sick Children, Toronto, Ontario)
- 3. "A multi-faceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from child to adult centred care" (Chong 2011 HFA conference)

How does The Alfred deal with transition from RCH?

One of my jobs as a Social Worker in our team is to help you in transitioning your health care to The Alfred. I regard this as one of the most important parts of my job. It can have a huge impact on the relationship that you and your family make with us.

As you probably know your adoles-

cent brain (15-25 year olds) is at its peak for learning, but still under construction for some of the other functions such as impulse control, and decision making. As part of taking on responsibility, people often make mistakes. It is often through making mistakes that learning and creativity is able to blossom. Hence it is a time for us to seize the opportunity, and support you and other young men and women, but also provide a safety net and supports to enable you to take on responsibility. It is also essential for growing up, that young people realise that they are accountable and that they do have to own their actions.

We encourage all people transiting to the Alfred to be involved with Haemophilia Associations. There are a number of ways that this can happen, attending the camps or other events. These occasions have been carefully planned with the involvement of this centre and the haemophilia foundations. We see the benefits of attending these events over and over again.

The Alfred 2016-2017 Transition

Tuesday 14th September, we invited all the future patients of the Ronald Sawers Haemophilia Centre, and their families to come along to an evening to meet the team. There were about 14 patients invited.

Our goals were to:

- Give these young man and women a chance to meet their future treating
- Make the Alfred less unfamiliar/ mysterious/alienating
- Give these new patients a chance to have a look around and to ask any questions
- Improve the transition experience from the RCH to the Alfred because evidence based research tells us that transition is a time when health care engagement reduces
- Reduce anxiety about changing Haemophilia and bleeding disorder treatment centre and hospital

The Program on the night

We started with a tour of some parts of the hospital that patients are likely to visit when they come in with a bleed or for a clinic visit. After this we introduced our team and there was an opportunity to ask

questions. There were great questions, here are a few:

How do clinic appointments work?

We will send out a letter with an appointment. If this is not suitable we encourage you to let us know, and we will do our best to change it. Sometimes it may be really important for us to see you, but we realize that you have a busy life, and other commitments, so we always try and work with you. Our Clinic times are every Monday morning and every alternate Tuesday afternoon.

Why we have certain people in the team?

Our team is made up of doctors, a registrar, clinical nurse consultants, social workers, physiotherapist, and psychologist. We also have close ties with the dentist and the dental registrar, pain doctors, rheumatologists. These people

are all skilled and knowledgeable in their own field and understand bleeding disorders and how this impacts on what they do. The impact of bleeding disorders on a person's life can vary a great deal, but it can have emotional and physical

Do you have to attend the dentist at the Alfred?

Most people are happy to attend their own dentist. The dentist at the Alfred, due to workload constraints can only see people with severe haemophilia on a regular basis.

We have found that dental procedures such as extractions are generally easier and safer if done here at the Alfred. Our dentist will accept referrals from outside Dentists for removal of wisdom teeth and other tooth extractions for all people with bleeding disorders.

When do you come to the clinic and when do you go to Emergency

During business hours (8:30-5 Monday to Friday) there are nurses available to speak with. If you have any questions it is best if you can call. Sometimes it is best if you come to the clinic, but generally if you are going to need an admission or some tests it will be bet-

ter if you go directly to the Emergency Department. The nurses can direct you as to where you should go.

What do you do if you are on a trial that is based at the Royal Children's Hospital?

Each trial is individual, and will have its own setup, however the doctors will work out what is the best way to proceed to ensure that everything works best for you. They may be able to transfer your care and your registration to the Alfred, or they may work out it is best if you continue with the trial at the Children's but transfer your care.



A few attendees commented that they had learnt something new about their condition.

After the formalities were finished we had pizza, sushi, drinks and an opportunity to talk together. In this more informal setup we found the chance to open up discussion and an opportunity for patients and their families and the professionals to get to know each other.

The team here at the Alfred really enjoyed meeting our future patients and families and finding all about the interesting things about them, and their plans for the future. We don't often get the opportunity to meet on an informal basis outside of the clinic.

We felt that our pre-transition evening was successful, this was confirmed through survey response. Everyone who responded found the session reduced their anxiety about transition. We asked participants to complete a one page survey, to examine how we were meeting the goals that we had set. Our team feel it critical to future planning and in working on a broader transition model. Analysis of our service gives us information. Much research has been undertaken into the impact of poor transition. The consequences are significant and costly for consumers, their families, and for health service providers. The costs include, but are not limited to, quality of life, engagement, satisfaction, pain, and monetary costs.

Many other patients were not able to join us, but we have been able to use this opportunity to contact them, and start the process of introducing our service and getting to know them.

The next step in this transition process

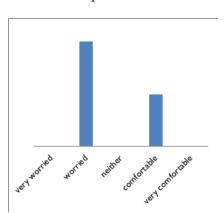
The two teams from The Royal Children's Hospital and The Alfred had a formal clinical handover meeting. We used the ABDR to look at a summary of each person's medical information.

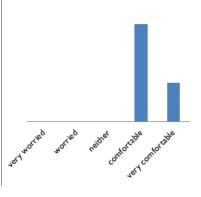
In December and February we will hold transition clinics to formally meet and review all our new patients. At these clinics we look forward to meeting our new patients. We are hoping to continue getting to know these young men and women and their families. In this way we are aiming to maximise their good health. We are also keen to reduce the negative impact of poor transition. We know that young people are generally motivated and it is important to harness this eagerness to improve their health. Usually engagement with a Haemophilia Treatment Centre is both an indication of and a pathway towards best possible health.

Survey results

Before this session how did you feel about changing to the Ronald Sawers Haemophilia Centre?

After tonight how do you feel about changing to the Ronald Sawers Haemophilia Centre?





By Jane Portnoy

Jane is a Social Worker at Ronald Sawers Haemophilia Centre at The Alfred, in Melbourna Australia

* This article will also feature in HFA's National Haemophilia Publication.

ANXIETY & DEPRESSION

Men in rural and remote areas

Isolation and difficulty accessing services are some of the challenges faced by men living in rural and remote communities.

For those making a living from the land, there is some evidence to suggest that the farm environment is hazardous to mental health, with farmers experiencing high rates of stress and depression. In Australia, male farmers die by suicide at rates significantly higher than the general population and non-farming rural males.

We encourage people living in rural and remote areas to explore all the information and resources on this website. You'll learn more about the signs and symptoms of depression and anxiety and the actions you can take to look after yourself, your mates and your family.

If you, or others you know, are experiencing depression or anxiety there are effective treatments available, and the sooner you take action the better – either for yourself or by referring someone else to the right resources.

This website is a fantastic resource, and you can always talk to your doctor or someone at the beyondblue Support Service if you need further information.

Your own local social network is also a great support, particularly when times get tough, so talking (on the phone if your nearest friend or neighbour is too far away) and sharing experiences across the community will assist in building resilience.

It's important to remember that depression and anxiety are common conditions, not weaknesses, and with the right treatment, most people recover.

beyondblue Support Service Support. Advice.
Action

1300 22 4636



Managing STRESS at WORK

Workplace stress is a major risk factor for anxiety and depression. Most jobs have some degree of stress, and this is often beyond our control – we can't always set our own workloads and deadlines, or change the workplace culture. However, there are some strategies everyone can adopt to manage and reduce their own stress levels, as well as finding a positive work-life balance.

Part of taking care of your mental health is also about looking at your overall wellbeing. A balanced diet, exercising regularly, getting enough sleep and avoiding harmful levels of alcohol and other drugs all contribute to mental wellness.

What do we mean by 'work stress'?

Everyone knows what stress feels like and we've probably all experienced it in a range of settings – at home, school or work, or while getting outside our comfort zone. But when we talk about work or job-related stress, we're referring to situations where there's a mismatch between the requirements of your job, and your capabilities or available resources. As a result, you're put under an unsustainable level of pressure.

A range of factors can contribute to job stress, including:

- working long hours or overtime, working through breaks or taking work home
- time pressure, working too hard or too fast, or unrealistic targets
- work that's monotonous and dull, or which doesn't use your range of skills or previous training
- roles where you have low levels of control or inadequate support from supervisors and/or co-workers
- job insecurity
- a lack of role clarity or poor communication
- conflict with colleagues or managers
- bullying

• discrimination – whether based on gender, ethnicity, race or sexuality.

Signs of work stress

Stress is a normal response to the demands of work. It can be beneficial in short bursts, helping you stay alert and perform at your best. However, prolonged or excessive job stress can be damaging to your mental health. Stress can be a trigger for someone with depression and/or anxiety, and may cause an existing condition to worsen. And it's not just your health that can suffer – as well as affecting your relationships and life outside work, stress can increase your risk of injury, fatigue and burnout.

Physical signs of stress include:

- chest pain or a pounding heart
- fatigue
- reduced interest in sex
- nausea, diarrhoea or constipation
- getting colds more often
- muscle tension, pains and headaches
- episodes of fast, shallow breathing and excessive sweating
- loss or change of appetite
- sleeping problems.

Non-physical signs include:

- feeling overwhelmed or frustrated
- feeling guilty or unhappy
- being irritable
- losing confidence and being indecisive
- thinking negatively
- having racing thoughts
- memory problems
- excessive worrying.

Finding a balance that works for you

With busy schedules, it's easy to become overwhelmed with work and not find time for anything else. The trick is achieving a balance that promotes your overall health and the success of your career or business – often easier said than done.

We've put together some tips to help you manage your stress levels and look after yourself.

If you're feeling stressed or anxious, try and postpone major life changes such as moving house or changing jobs.

Finding someone to talk to can help – either a close friend, a family member, counsellor or psychologist.

Learn to relax. Make sure you set aside time for the things you enjoy, such as exercising, meditating, reading, gardening or listening to music.

Take your annual leave each year and make sure you have a proper break from work.

Get out of the workplace during lunch – even if it's just for a 10 minute walk. You'll feel refreshed and more productive in the afternoon.

Try scheduling meetings during core work hours, not your personal time. Restrict your overtime hours and speak to your manager if demands are unreasonable.

If you frequently work late, try leaving on time at least a couple of times a week. Check out these helpful tips. Avoid checking your email or answering work calls out of hours. If you notice any changes in your thoughts, feelings or behaviour, see your GP or health professional. The earlier you seek support, you sooner you can recover.

Heads ûp

Heads Up is all about giving individuals and businesses the tools to create more mentally healthy workplaces.

www.headsup.org.au



In September a unique group of men attended a weekend away, organised by Matthew Powell, a most passionate advocate for people living with Haemophilia and HIV. HFV was privileged to be part of this both important and truly significant initiative.

Matthew is a peer worker with Straight Arrows and approached HFV with his plan to engage with all Victorians living with haemophilia and HIV (contracted through treatment with contaminated blood products in the 80's) and bring them together. With financial support from Straight Arrows, HFA's Damien Courtney Memorial Endowment Fund and HFV, Matthew was able to achieve his goal.

We know this is just the start for this newly formed, long overdue, valuable peer group and look forward to being part of any future initiatives. Anthony has kindly shared his experience from the weekend below.

Hi, my name is Anthony, and I live with severe Haemophilia and HIV. Recently, I was very fortunate to spend a luxurious long weekend in the country with 5 other men who live with haemophilia and HIV. The event was organised by Matt Powell, the peer support worker from Straight Arrows, and supported by the Haemophilia Foundation Victoria. I'd like to express my sincere thanks to those two organisations for very generously providing us with an opportunity to relax together, share experiences and get to know each other.

A number of months earlier, we established contact through a private facebook group, so that we could plan the retreat and sort out the practicalities. We gathered at the gorgeous Lochniver Farm Retreat not far from Maryborough. The hospitality was wonderful, with a special lady called Sharon spoiling us with delicious, healthy meals and rejuvenating massages. All we needed to worry about was eating, sleeping, enjoying the beautiful countryside (from the window because the weather was atrocious!) and keeping warm by the comforting log fire. Oh, and watching the doggies win the Grand Final, which we did with great pleasure.

It was amazing how quickly the group got talking about all the ins and outs

of bleeding disorders and viruses. We couldn't help but compare bleeds, hospitalisations and "medical care gone wrong" stories in a hilarious one-upmanship kind of way. But the conversation ranged widely, covering disclosure, especially to girl-friends and mates, work and career challenges, sporting pursuits and misadventures, and relationships with parents and siblings. Everyone could relate to the burden of keeping their HIV status concealed, and the social stigma of HIV. Several of us are now married with children and we shared ideas about how and when to disclose to our children.

It was a profound experience for me to meet and get to know these wonderful guys. For me, hearing their stories, and seeing how they have negotiated and coped with these big challenges was absolutely priceless and enthralling. It's not easy to explain the emotions I felt upon meeting them - they have experienced and overcome challenges so parallel to my own. For much of my life I have been very private about my illnesses, especially the viruses. Yes, my close family and friends know, and they are wonderfully supportive, but there is nothing like comparing notes with others who have been there. I mean exactly there.

Once again, a warm thank you to

Matt Powell, Straight Arrows and Haemophilia Foundation Victoria. I look forward to future get-togethers with the guys, even if it's off our own bat. I'll be keen to share and hear from them their take on the thrills and spills of the next stages of life. A life we never expected to last so long, and all the more sweet for it.

Anthony



HFV Magazine | Summer 2016

CONNECTING with our community

On Sunday the 25th September Leonie Demos and Fiona McDonnell from our committee and Andrea McColl headed north to spend the day in Shepparton to meet up with some of our members at our HFV regional visit. What's the reason for our regional visit? It's simply to connect, support and empower.

The venue for our lunch was perfect. The Connection was set amongst bushland a little way out of town and gave us a real sense of being out of the hustle and bustle of city life.

Our venue hosts were particularly attentive, having experienced haemophilia through a cousin of theirs. A small world! Once we arrived we met with five families who had come from all directions. Some from Echuca others from other regional towns but all within an hours drive of Shepparton. The food was magnificent but more importantly was the opportunity for us as a foundation to connect with our members, for our members to connect with each other and equally importantly for us as a foundation to understand the challenges and issues faced by regional families in our community.

connect

Our main objectives for the day were to:

- connect families with each other
- connect families with HFV
- create a sense of community
- offer an opportunity to meet new
- provide a forum to talk about issues and challenges

help develop a regional network in North Eastern Victoria

One of the main benefits for our staff and commit-

tee who attend, apart from the opportunity to meet with our members, is that we can then takes these challenges or issues that have been identified back to our committee and see how we can address these issues as an organisation. It is often only speaking to people face to face that we gain a full understanding of what the issues are for those in our community living regionally with a significant health condition.

Following the lunch we are now delighted to announce that Jamie Horkings is our new Regional Peer Support Leader for North Eastern Victoria. (Last year Jamie joined a number of other HFV members to participate in Peer Support training provided by HFV). If you live in this area and would like to catch up with Jamie or other people affected by bleeding disorders please contact Jamie through the HFV office on 03 9555 7595.

Often it is simple things that we take

for granted that can be a real barrier for regionally based people.



The more we talk and connect

with each other, the bigger the voice we have so please come and join us

at future regional visits and if you do have concerns regarding your or a loved ones' bleeding disorder please just give us a call as we may not be aware of the challenges you are facing and/or we can try and put you in touch with others who have been there..





Giving FACTOR to Children at Home

Prophylaxis with factor concentrates has been, without doubt, a great advance in the management of severe haemophilia and is well established in developed countries such as Australia. However starting regular factor infusions in infants and young children brings many challenges; finding veins is often difficult and upsetting for all involved and the thought of home treatment is a daunting prospect for most parents.

Infusaports (or 'ports') are temporary devices that are surgically implanted to allow easy access to a central vein. Ports have a reservoir that is inserted under the skin, usually on the chest. The reservoir connects to tubing (a catheter) that is tunnelled under the skin and feeds into a large vein in the neck. A special needle is inserted through the skin and into the port reservoir and the injected factor travels along the catheter and into the bloodstream.

By establishing reliable vein access, ports make home treatment feasible in small children. But while ports bring considerable benefits, they are not without risk. Infection is the most common complication and parents are provided with comprehensive education so they learn how to administer factor safely and with a technique that minimises the risk of infection. Parents make a decision with the staff at their Haemophilia Centre if and when a port is appropriate for their child. And for children who have a port, the next step is to transition to peripheral veins once the veins further develop. The Haemophilia Centre at The Royal Children's Hospital Melbourne wanted to develop a formal port education package. As the first step in the process we carried out a study to explore the experiences and education needs of parents who had learnt to use a port to administer factor to their child.

SO WHAT IS IT LIKE FOR FAMILIES LEARNING TO USE THEIR CHILD'S PORT?

Firstly, most parents were learning to use the port at a time when they were still dealing with the distress of the diagnosis of haemophilia in their child as well as beginning to experience bleeds, trips to the emergency department and treatment. So a very difficult time!

There were four main themes that emerged from the study focus groups:

1. DEALING WITH FEAR AND ANXIETY

Most parents told us they were very anxious when accessing their child's port for the first time. They described 'shaking', 'sweating' and feeling 'nervous'. Many felt very emotional about putting a needle into their child and fearful of hurting them. There was enormous anticipation leading up to the first time they accessed their child's port but once it was over there was great relief and the feeling that in fact it wasn't so bad and much easier than expected.

2. A SUPPORTIVE LEARNING EN-VIRONMENT

Many parents described the relationship with and the support received from the person teaching port access as one of the most important aspects during their learning. It was important that the teacher could foster confi-



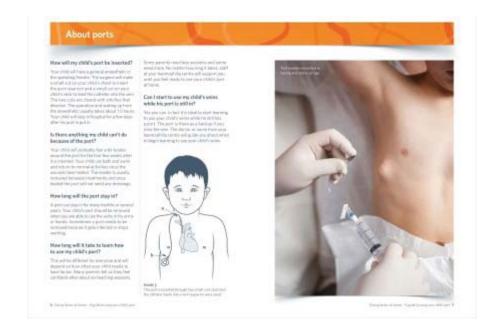
dence in parents during this difficult time and that both parent and child felt comfortable with and had trust in their teacher. Respecting the needs and wishes of the child was significant, as by 'making my child feel comfortable you [the parent] are automatically in a different place'.

3. ESTABLISHING A RITUAL

Interestingly, many parents described the importance of having a routine or ritual around how the port was accessed. This helped both parent and child to feel comfortable and confident about the procedure. Children responded well to having some control and the ritual also assisted parents in their learning process. Parents described practices such as their child always sitting in the same place and position, always inserting the needle on the count of three and always setting out equipment in the same way.

4. EMPOWERMENT AND LIBERATION

Parents described taking over their child's treatment as empowering. After a life dominated by the uncertainty of bleeding episodes and urgent visits to the Emergency Department for treatment parents could now take control; 'feeling in control after feeling so out of control ... I think that's the biggest stand out about ports'. Ports were seen as a 'blessing', allowing most children



to participate in all kinds of activities including sports and school camp.

WHAT INFORMATION DID PARENTS WANT IN AN INFOR-MATION PACKAGE?

Parents asked that a teaching package incorporate photos, checklists and 'step by step' instructions. They also expressed the desire to hear the voices and experiences of other families and so we included stories, anecdotes and tips from other parents. In addition, consistency of teaching was identified as very important and so a checklist and information directed to nurse teachers was included as a mechanism to address this issue,

especially for when several nurses are involved in the teaching process. The education package was developed with the help of parents who were experts in their child's port access as well as those who were learning for the first time.

The study helped us to have a greater understanding of what it is like for parents learning to give factor to their child via a port and to develop an education package that we hope will address parents' needs. The ability to give treatment at home was liberating for families but also meant less connection to the hospital and other families. Parents told us the enormous value they found in sharing

their experiences and stories. This highlights the importance and great work of our Haemophilia Foundations in providing strong support and opportunity for children, families and adults with bleeding disorders to connect with each other.

MORE INFORMATION

If you have any questions about your child and ports, please contact your Haemophilia Treatment Centre.

ACKNOWLEDGEMENTS

A special thank you to the families who generously gave their time to share their experiences of learning how to use their child's port, to write their stories, to be photographed and to review and pilot the port guide. Development and publication of the port guide was supported by a Bayer Haemophilia Caregiver Award. Thank you also to the Educational Resource Centre at the Royal Children's Hospital, Melbourne for their expert photography and design.

JANINE FURMEDGE

Janine Furmedge is the Haemophilia Nurse Coordinator at the Royal Children's Hospital, Melbourne



18th Australian & New Zealand Conference ON HAEMOPHILIA & RARE BLEEDING DISORDERS

Melbourne • 12-14 October 2017

Preparing for a health or medical appointment

Summary

- It may help to write down a list of your symptoms so you can tell your general practitioner (GP) or other healthcare professional during your visit.
- You may like to write down your medical history and lifestyle activities so you can talk about these with your GP or other healthcare professional.
- Prepare a list of questions you want your GP or other healthcare professional to answer. These might be about your illness or condition, treatment options or tests you need.
- If you are unsure how to talk about your health issue, it can help to practise what you want to say.
- Prepare the things you need to take to your appointment, such as your Medicare card, scans or test results.

Some people find it hard to talk about their health problems with their general practitioner (GP), nurse or other healthcare professional. They may become nervous and flustered, get distracted or forget to mention symptoms. By preparing for your visit and writing down things like your symptoms, medical history and a list of questions, you'll remember what you want to talk about with your healthcare professional, including all the questions you want to ask.

How to prepare for a healthcare visit

Whether you are preparing for a visit to doctors and other healthcare professionals in a community health centre, private clinic or hospital, there are some things that you can do to get the most out of your visit.

Think about your medical history

Think about your medical history and write down:

- the list of topics you want to talk about
- any concerns or things that you think are unusual about your health
- any recent medical appointments, admissions to hospital, treatments or visits to other doctors or healthcare professionals
- a list of the medication you're taking, how much you take, how often, and if there have been any recent changes (or bring all your medications with you, in their original packaging if possible)
- a list of any over-the-counter medication, vitamins or herbal supplements you take
- any allergies you have
- any related tests or scans you have had, for example, an x-ray (and bring these with you if you have them)
- your family health history.

Record your symptoms

If you have any symptoms, write down:

- when they started
- what time of the day they happen and how long they last
- how often they happen
- anything you've done that makes them better or worse
- if they stop you from doing anything.

Write down information about your lifestyle, such as:

- your diet
- your physical activity
- how much alcohol you drink
- whether you smoke (and how much)
- sleeping patterns and any sleeping aids you may use
- life events or situations that may be causing you stress.

To give your GP or other healthcare professional an overview of your healthcare, make a note of any other treatments you're having, such as physiotherapy, counselling, acupuncture or naturopathy.

Any special needs you have

If you need an interpreter or have other special needs, such as needing wheelchair access, let the receptionist know when you book your appointment.

Ask questions and discuss your health

It may help to make a list of any questions you have and put the most important questions at the top. A list will help you to remember the questions you want to ask your GP or other healthcare professional, particularly if you are feeling stressed about your diagnosis.

Once you are with your GP or other healthcare professional, be ready to have an open, honest discussion. Open communication is a two-way process. Remember, everything you talk about with your GP or other healthcare professional is private and confidential.

It is important to talk with your GP or other healthcare professional about any health-related issues such as drug or alcohol use and any risky behaviour you may do.

Some people feel uncomfortable asking their GP or other healthcare professional to explain things they don't understand. If this is the case, you may want to ask a family member or friend to come with you to the consultation for support, to take notes and help you to remember things, or to ask questions on your behalf.

Practise what you want to say

If you have to talk about something that makes you feel uncomfortable, it can help to practise the things you want to say and the questions you want to ask.

Practising what you want to say may help you to feel less nervous or embarrassed. It may also comfort you to know that your GP or other health professional has been trained to talk about sensitive issues.

What to take to your appointment

Put together a checklist of things you might need to bring for your visit, including:

- your Medicare card
- your pension card or healthcare card, if you have one
- details about your private health insurance, if you have it
- your medical records and test results, unless they have been sent ahead
- the names and contact details of other healthcare providers you see
- a notebook and pen
- your notes, including questions to ask
- a list of your medication or the medication itself
- a letter of referral from another doctor, if you have one
- your glasses and hearing aid, if you use them
- something to eat or drink if you are likely to have to wait for a long time
- a book or some other form of entertainment to pass the time while you wait.

Where to get help

- Your GP
- Your healthcare professional

betterhealth.vic.gov.au

This page has been produced in consultation with and approved by:

Ladies 2016 Day 2016

For this year's Ladies Day Out Event we ventured down to Peninsula Hot Springs where we relaxed in the warm, sometimes hot, (and for one brave soul, very cold), therapeutic pools. It was a perfect day for it with a cool breeze making the water feel all that much nicer. As always we had a lovely time catching up, meeting new friends, and talking, lots of talking. We had our own private, incredibly amazing, Arabian Marquee we could retire to and enjoy a beautiful lunch and just chill out. It was a great way to refresh and take a little "time out" from the daily stresses of life.

This year marks the 12th year of our Ladies Day Out peer support events and so, as I feel that I've pretty much exhausted my "idea inspirations", I have decided to retire my mad googling and let someone else take the group on with a fresh vision and purpose, and perhaps an entirely new direction.

I'd just like to give you all a little reminder of all the fun we've had, kicking off with a very low key Lunch at Albert Park way back in 2005 following up later the same year with massages at Brighton Day Spa. The next year we all headed off to tour the beautiful Como House with a little yoga in the gardens. Next we headed to Elwood for some African Drumming lessons, pizza and "3min Angel" massages. A Chocolate Tour of the city was next, who doesn't like chocolate! A classy

High Tea at the Woodman's Estate winery in Moorooduc was very appropriate for a "Ladies" Day Out. In 2010 not only did the Saints have a drawn Grand Final to throw my plans into disarray but we all had a go at throwing clay onto a pottery wheel and sculpting the weirdest collection of fish ever seen to man at Northcote Pottery, before chowing down on a wonderful Lebanese lunch. The Colonial Tramcar Restaurant was a much more dignified affair although some may have left a little tipsier than others. No one wanted to be tipsy the following year as we cruised the bay enjoying High Tea on the High Seas. The next year we all discovered just how unfit and not very flexible we were as we tackled a Circus Skills workshop with the Women's Circus in Footscray. A relaxing Thai massage and Cuban food in Prahran then made amends for the pain of the previous year. I always knew I wasn't a dancer but this became painfully more obvious as we all frocked up and made our mark on the Bollywood Scene with Dance Baladi before enjoying a great Greek lunch at the Aegean. Which brings us back to this year and the Peninsula Hot Springs and Moroccan lunch. So you can see we've explored some interesting relaxation options and eaten our way across many different nations but most of all we've enjoyed wonderful company and great support.

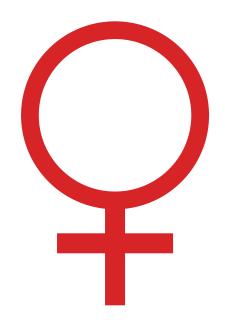
I would like to take the opportunity to thank all at HFV, the committees over this time as well as the staff, Julia, Andrea and Pamela. Mostly thanks to all the ladies who've come to any of the Day's Out. The friendship and support you all show for each other is amazing and an incredible resource for our Haemophilia family.

I've had a wonderful time organising these events and hope whoever is next in line will get the same enjoyment. If you think you can help or have any ideas on what you'd like from a Women's Support group please get in touch with HFV.

PS...I've put together a little pictorial walk down memory lane. Hope you enjoy.

All the best,

Julie Boal





ADVANCED CARE PLANNING... what is it \$ why is it important?



Advance care planning - overview

Key messages

- Advance care planning allows a person to express their preferences to inform future medical treatment if they become unable to participate.
- An advance care plan can be verbal or written.
- Advance care planning puts the person at the centre of care.
- Advance care planning has been shown to improve the quality of care people receive at the end of their lives.

Advance care planning allows people to clearly express their values and preferences to inform clinical decision-making when they are unable to directly participate.

An advance care plan is also known by other names:

- · advance care directive
- living will
- · advance directive
- · statement of choices.

In Victoria health services must give due consideration to an advance care plan, no matter how it is documented.

What form does the planning take?

Advance care planning can be verbal or written. Ideally the plan is a combination of both in order to strengthen its influence on clinical decision-making. Advance care plans can result in:

- expression of personal values, preferences for treatment and care
- · appointment of a substitute decision maker.

Conversation and communication

Advance care planning is an approach to communication in which a person can discuss goals, values and choices about their preferred outcomes of care.

It puts the person at the centre of care, involving them, their family (if appropriate) and the clinicians responsible for their care.

In advance care planning discussion with family members, clinicians and/or significant others, the person can convey their preferences for future care. Decisions should be confirmed in writing.

Who is advance care planning for?

Priority groups that would benefit from help in articulating their wishes for future treatment and care include:

- aged or older people who are frail
- people of any age with chronic progressive and life-limiting conditions
- · people approaching end of life
- · people with multiple co-morbidities and/or at risk of conditions such as stroke or heart failure
- people with early cognitive impairment
- people who are isolated or vulnerable.

Benefits of advance care planning

Advance care planning has been shown to improve quality of care at the end of life and increase the likelihood of a person's wishes being known and respected, for example:

- · clients and families report greater satisfaction with the end of life care provided
- surviving family members report reduced levels of anxiety, depression and post-traumatic stress.

Advance care planning has benefits for the health practitioner and the broader health service system. These include:

- supporting better client outcomes
- assisting clinicians to provide person centred care.

What advance care planning is not

Advance care planning highlights several separate but related treatment issues. As a result, its role and purpose can be confused with other decision making, legal and communication concerns. Advance care planning is not:

- a substitute for good informed consent about current treatment options (although discussing the values and potential health outcomes of these may help decisions to be made)
- a tool for distributing fair and equitable healthcare resources across the wider community
- a replacement for clinical face to face
- · communication and engagement.

For further information on Advance Care Planning please go to www2.health.vic.gov.au

Advance Care Planning
Department of Health & Human Services Victoria
+61 3 9096 1350 acp@dhhs.vic.gov.au





health.vic

Victoria's hub for health services & business

Achieving the Extraordinary *for three decades*

What an extraordinary achievement! Over three decades of work supporting HFV and our community.

In September, a number of HFV members and staff joined with the Roberts family in thanking Ann Roberts for her tremendous commitment to HFV for almost three decades.

only for the personal support she received from Ann at camps when her children were young but also for the great body of work she had overseen at HFV in her roles as President, Vice President, Treasurer and Committee member.

We hope Ann looks back on her time with HFV as fondly as we do and recognises the important role fascinating (and at times exhausting) journeys to all corners of the globe through her involvement with the World Federation Hemophilia.

We would also like to acknowledge the support of the whole Roberts family. Anyone who takes on a volunteer role within an organisation requires the support of their family as the role often takes them away



Ann was presented with memory book that included many photos from over the years from Family Camps, Christmas Picnics and HFV events including the twinning program with the Philippines that Ann was instrumental in establishing. Leonie Demos thanked Ann not

she has played at HFV in ensuring we are this strong body within the bleeding disorders community that can continue to empower, support and connect our members.

Looking back through the archives it is wonderful to see the close friend-

ships and tight bonds that Ann's family formed over the years with other HFV families who had shared their journey.

Ann's commitment to improving the lives of others with haemophilia led her on some from their family - and this was true for Ann so we would also like to recognise and thank Danny for his support of Ann and HFV.

We very much admire sense of community that is innately present in Ann and Danny and remind Ann there will always be a place for her at the HFV table.

Thanks Ann - you are very special to our community.





Haemophilia Awareness Week 2016 Red Cake Day



Celebrating Awareness Week in Neerim South

Thank you to the Field Family for all their efforts in running their annual 'Paint the Town Red' Haemophilia Awareness Week event.

This event is so generously supported by many members of their local community residents and businesses in Neerim South. Home made cup cakes are donated, as are sausages from the local butcher, bread from Tip Top...to name but a few.

Our thanks go out to all our supporters!



HFV FAMILY CHRISTMAS PICNIC & AGM

Scienceworks was the perfect venue for our annual picnic and AGM this year and offered a great opportunity to **connect**, **support** and **empower**! Our committee and staff were joined by over 70 members, including 3 new families each with toddlers with haemophilia that we connected with through the RCH.

Leonie Demos thanked the committee, staff, sub committees and all our stakeholders for their support throughout the year and took the opportunity to highlight many of our successful member programs and initiatives including our youth camp, family camp, mens retreats, grandparents and friends lunch, ladies day out and fundraising projects past and present.

As staff and committee we celebrated our achievements from this year and are looking forward to an exciting member focused year ahead working together with our community.



HEP C Treatment Update

Suzanne O'Callaghan, HFA

HFA has been monitoring access to the new hepatitis C treatments for people with bleeding disorders around Australia. We have been pleased to see that most people have started treatment or have an appointment to discuss treatment. Some have now completed treatment and are going through the process of waiting the 12 weeks to hear whether the treatment has cured their hepatitis C.

WHAT'S STOPPING YOU FROM TREATMENT?

However, we are aware of some barriers stopping people from accessing the new treatments and are looking at ways to overcome this:

- Distance from testing and treatment centres
- Not convinced that the treatment will work for them or have few side-effects
- Financial problems
- · Other priorities at this time

If you or someone you know have a problem that is stopping you from accessing hepatitis C treatment, we strongly encourage you to talk to your Haemophilia Treatment Centre or your local Foundation or HFA to see what solutions can be found.

DO YOU KNOW YOUR HEP C STATUS?

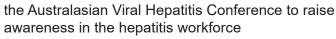
Another concern for HFA is that some men and women with mild bleeding disorders may not know that they were at risk of hepatitis C if they ever had a clotting factor treatment before 1993.

Screening of the blood supply and HCV viral inactivation manufacturing processes for clotting factor concentrates were not introduced until the early 1990s, so anyone in Australia who had a clotting factor treatment for their bleeding disorder before 1993 needs to be tested for hepatitis C.

Over the last several years Haemophilia Treatment Centres have been checking the hepatitis C status of their patients in this group as they come in for a review. Men and women with mild disorders, including women who carry the gene and have only had an occasional need for factor treatment, may go for years without needing treatment and are often not in contact with their local Haemophilia Treatment Centre to have their hepatitis C status reviewed.

What is HFA doing about this?

- Social media campaigns to raise awareness in the bleeding disorders community
- Poster at



NOhep

- Working with the Australian Haemophilia Centre Directors' Organisation to alert general practitioners about this issue in case they have patients with mild bleeding disorders
- Working with Hepatitis Australia on a national campaign to reach the wider community of people with hepatitis C who have not yet accessed treatment.



CHANGE YOUR FUTURE

Having these new treatments available on the PBS is a great opportunity to have a future without hepatitis C for the bleeding disorders community. Some people have been worried that if they have treatment and it is not successful, they will not have other options. The aim of the hepatitis clinicians is to cure hepatitis C in all Australians – so please be reassured that if someone is unlucky enough not to be cured with the first round of treatment, other treatment options will be considered and there are more in the pipeline.

The Australian Government is committed to eliminating hepatitis C in Australia by 2026. Let's see if we can achieve this much earlier in the bleeding disorders community!

If you have recently been on the new treatments we'd love to hear from you - maybe we could share your story with our community. If so, please call the office the HFV office on 03 9555 7595. Thank you.

Royal Children's Hospital

2017 HAEMOPHILIA TEACHER'S SEMINAR

Please let your child's school or kinder know about this seminar.

Booking forms (to be completed by schools/kinders/ childcare centres). • are available on our website www.hfv.org.au

9am to 12.30pm

Friday 10th February 2017

Royal (hildren's Hospital, Ella Latham Theatre.

Entry via 1st flr HELP (entre

50 Flemington Road PARKVILLE

TEACHERS.

You are invited to attend the 14th Haemophilia Teacher's Seminar presented by the Haemophilia Treatment (entre Team at the R(H. Supported by Haemophilia Foundation Victoria.

* NEW DATE...Ioth FEBRUARY

COMMENTS FROM TEACHERS WHO HAVE PREVIOUSLY ATTENDED

- Haemophilia is not something to be scared of!
- I feel assurance that promoting physical activities is the right thing to do
- Listen to the child, he knows his own body
- I now have the confidence to know what to do
- Not to treat kids with haemophilia any differently
- I now know what I need to have in place as my role as his teacher
- The boys were incredible and their stories really highlighted everything spoken about
- I am now comfortable with myself and the idea that I will have to assist our little boy
- I feel much better about dealing with my student in a "non over anxious way"

SPEAKERS:

Dr Chris Barnes
Director Haemophilia Centre
Janine Furmedge
Haemophilia Clinical Nurse
Nicola Hamilton
Physiotherapist

Special Guest Speakers:

• A primary and secondary
school child with Haemophilia



diary dates

DEC

9-11 Blood Brothers Youth Camp

FEB

10 RCH Teachers Seminar

24-26 Mens Retreat

MARCH

19 Grandparents and Friends Lunch (TBC)

APRIL

17 World Haemophilia Day

28-30 Family Camp

TBC Grandparents & Friends Lunch

OCT

12-14 Haemophilia Conference Melbourne

20 Haemophilia Red Charity Ball



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 Julia Ekert | Office Data & Product Manager Nicola Hamilton | Physiotherapist Wade Wright | Social Worker

RONALD SAWERS HAEMOPHILIA CENTRE

The Alfred

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

Dr Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social
Worker
Abi Polus | Physiotherapist
Diana Harte | Psychologist

HFV MEMBER SERVICES & PEER SUPPORT

Membership Annual Fees: Standard family membership \$33.00 Concession member \$16.50 Allied Member \$16.50 Organisational member \$55.00

* 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.

Other Subsidies:

- SOS Talismans are available for purchase for \$15.00 from the office.
- 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:

Care and Counselling:

This is available through your treatment centre.

Magazine:

Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au

The HFV Office:

The office is usually open from 8.30 am to 4.30 pm Monday to Thursday. If you plan to come to the office, we suggest you ring ahead to check if the office is staffed.

We are located at 13 Keith Street, Hampton East, Victoria, 3188.

Phone: (03) 9555 7595 Fax: (03) 9555 7375

Website: www.hfv.org.au Email: info@hfv.org.au

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 2016 twelve members attended the retreat, including a number of first timers, all promising 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 usually get to enjoy an event with a twist. Our most recent event our ladies spent a day at the Peninsula Hot Springs and enjoyed a beautiful meal together.

They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant...to name but a few.

YOUTH GROUP

The Youth Group aim to meet up a few times a year usually based around an activity like laser skirmish or bowling and then head out for lunch.

We also have our actively involved Youth Leaders who are present at our family camp. They attend specific youth leadership training led by our formally trained youth leaders – an initiative developed by the leaders themselves.

GRANDPARENTS GROUP

The Grandparents and Friends lunch is a great opportunity to connect with all the grandparents and share the company, stories and experiences so please come along and enjoy the day. Lunch is provided by HFV and the company is always good!

The initial impact of haemophilia can be a traumatic and stressful time in our lives and interaction with other grandparents can be a reassuring and rewarding experience.

BOYS GROUP

Our Boys Toys Day Out is a wonderful opportunity for our boys to get together with other boys with haemophilia or related bleeding disorders and to spend the day with their dad or another significant male in their lives...grandfathers, uncles or family friend.

Previously our Boys Toys events have included fishing trips, Go-Karting, Laser Tag and Tree Top Adventures.

Haemophilia Foundation Victoria

Presents

The Haemophilia **Red** Charity Ball



Friday 20th October 2017

The Peninsula Room, Central Pier 161 Harbour Esplanade, Docklands

Dress code — a touch of rec

The HFV Fundraising Committee invite you, your family, friends and colleagues to consider attending The Haemophilia Red Ball which will be held 20 October 2017.

This event is designed to raise much needed funds that will directly support valuable HFV member programs and to raise awareness of haemophilia and other related bleeding disorders. This will be a fantastic opportunity to promote awareness of the difficulties faced by our members, build stronger relationships with our community's funders and to raise funds to support our member community.

We have been fortunate enough to secure a high end venue at Central Pier 161, Harbour Esplanade, Docklands. The evening will include dinner, drinks and entertainment. A silent auction will be held on the night and we hope to have an extensive range of high end auction items available. The event will be targeted mainly at corporate sponsors in order to maximise funds raised. We would, however, hope to see a good number of our community represented at this event. It will be a wonderful way to celebrate Haemophilia Awareness Week 2017 in style. The ticket cost has not been finalised as yet however it is likely that the cost may prohibit some of our members from attending. If you are unable to attend there are still several ways in which members can support this fund raising event:

- volunteer to assist in the planning of the event
- volunteer to assist at the event
- assist in selling tickets to the event
- speak to your local businesses and contacts about items which could be donated to sell at the silent auction
- investigate any opportunities to sell corporate tables to the event

Further details on how to purchase tickets will be available in early 2017. If you have any inquiries about this event please contact the HFV office on 9555 7595.

Thank you for your support!

