



Julia Minty is a Committee Member of Haemophilia Foundation Australian Capital Territory and carries the gene for haemophilia

WOMEN AND PEER SUPPORT

PEER SUPPORT FOR WOMEN IN A LOCAL CONTEXT

How are local Foundations exploring peer support for women? What can we learn from their experiences?

The importance of peer support for women affected by bleeding disorders was a key finding in HFA's consultation for The Female Factors Project. Often feeling isolated and as though they are the only ones with their experiences, women have found connecting and sharing stories to be immensely valuable and empowering.

The local Foundation activities to connect and support women are a concrete way of making a difference for women. HFA also makes a point of including personal stories from Australian women with the evidence-based information in all The Female Factors education materials.

This report from Haemophilia Foundation Australian Capital Territory (HFACT) is the third in a series about local peer support for women from Australian State and Territory Foundations.





HFA spoke with Julia Minty from HFACT about the Foundation's peer support activities for women.

STARTING UP

How do you go from thinking a peer support group for women is a good idea to making it happen? Julia Minty was part of the push to set up the women's group in the ACT and recalled how it came about.

'Our Women's Wisdom group is our key activity supporting women,' said Julia. 'We started it in April 2008. It's already more than 10 years old, which is hard to believe! There was a sense that there was an unmet need in that area. I think a few of us thought, why don't we try getting women together on a semi-regular basis. It can be women with a bleeding disorder, carers, partners, friends of people with bleeding disorders – we took a very inclusive approach. I can't remember the exact details of the first event, but it was clearly successful because it has continued pretty consistently since then.'

Being personally affected by a bleeding disorder (her father has haemophilia as do her three sons), Julia was keen to help establish and benefit from the group, but could also see the bigger picture for the community. 'I've been connected with the community all my life,' commented Julia. 'My family has always been involved with the HFACT Committee in one way or another. So I was part of the conversation with other women about starting a support network for women. My husband and I wanted to start a family and I knew the group would be beneficial to us, but I could also see it would benefit others in the community. My whole family was on board, my sister, and my mother who was on the phone with us inviting women in our community to come along and participate.'

WOMEN'S GROUP MEETINGS

The HFACT Women's Wisdom group has been very successful.

'The group meets about three to four times a year. We get a pretty good turnout, considering we are a fairly small community: 10 to 15 women, sometimes more,' reflected Julia. 'There are the women who come all the time, but there are also new people from time to time, which is always welcome. You feel like you are giving them some sense of connection, someone to talk to.'

'We have a range of activities. Some of the events we have done have been afternoon teas that someone will host, or we will go to a café. One of the most successful events recently was a women-only drinks on a weeknight after work. It was only intended to be an hour drop-in on your way home, but as it turned out, 15 or more women came, it went for 2 hours, some new women came and joined the Foundation, we exchanged phone numbers and email addresses, and discussed a whole range of interesting topics. For example, one woman with a bleeding disorder was pregnant with her first child, so there were experiences to share and ways to assist each other.'

'We also have other opportunities for women to connect, for example, at community camps, and the annual midwinter dinner. Sometimes there will be a special session at the HFACT community camp where women will meet separately to chat, but often women will just feel more confident about catching up with each other in general camp activities. You can really see the network fostered through the Women's Wisdom forum at work in these broader events because you can see the connections the women have built with each other and there is a natural ease and friendliness straight away.'

STRATEGIES TO MAINTAIN ENGAGEMENT

'We are pretty flexible in our thinking about the kinds of activities or events the Women's Wisdom forum holds, and like to try different things out.'

'However, one thing we noticed was that when there was no particular focus for a gathering, interest would start slipping. We have found it is good to have a key point of discussion or key speaker to give a focus to the meeting and that tends to attract members to come along.'

'On one occasion we met at the [former] counsellor's house for afternoon tea and had invited a music therapist as a guest speaker. She played her harp and talked about her experiences as a therapist in medical settings, and that was thought-provoking and different. Often this kind of approach can work as an ice-breaker, something to start the discussion, so that people relax and open up.'

'On another occasion we went to one of the women's house for afternoon tea and had the genetic counsellor



from The Canberra Hospital speak to us. It was well attended and quite a few young women came along to that because of the subject matter.

'The group waxes and wanes and sometimes we have had to contact women directly to invite them to attend. Women appreciate that personal touch, the extra step to make them feel included, especially in an area like haemophilia, which can be a bit male-dominated. We do promote the events in the newsletter, but you need to follow up with personal contact to keep people involved and keep the group alive.

'The HFACT counsellor is very active in enabling women to get in touch with each other, bringing new members into the forum and facilitating the exchange of contact details. Bringing people into the fold can be a challenge - making them feel part of the group and letting them know that there are people there they can talk to and who will listen to them.'

IMPACT OF PEER SUPPORT

Bleeding disorders are rare and treatments and services are specialised, which can be very daunting for women negotiating the health system for the first time for themselves and their family. Peer support can be invaluable.

Julia described her experience of using the women's network to provide peer support to women with bleeding disorders in the ACT.

'My sister Rebecca and I have personally set up one-on-one catch-ups with other women who were having particular issues and we were able to draw on our own experiences to share in our conversations with them. One example was with a woman who was new to Canberra and was trying to start a family but was having difficulties finding out what networks and services were available. We were able to put her in contact with the genetic counsellor; share our experiences of testing during pregnancy and post-birth. She found this very useful and then felt comfortable to join the after-work women's drinks to talk to the other women.

'Another example I have personally is of a mother wanting to know how she could put together

information packs and emergency plans to assist her child with haemophilia starting at childcare and then at school. She wanted to know how you go about this process – it can be quite challenging when you first let your child go out into the world and have other people take over their care. We talked with her about how we managed this and what we did. We ourselves have been on the receiving end of this kind of advice in the past: years ago when our children were starting childcare, we also went through the Women's Wisdom network and spoke to a woman who had already gone through this important step with her son. She explained the process to us and shared the proformas she had developed for emergency plans and so on, and we then developed our own. This transfer of knowledge is incredibly important.

EDUCATION MATERIALS

Education materials like **The Female Factors** booklets are an important tool to use with peer support. These kind of resources have been posted out with the HFACT newsletter, but are also valuable information to take to one-to-one meetings with new people. 'The HFACT counsellor is well aware of the range of new resources and is proactive about making them available to community members and the hospital, which means they are there for people to access them when needed,' said Julia.

MAKING IT ATTRACTIVE

One of the most important lessons HFACT has learned from the Women's Wisdom forum is to make sure an information night or a peer support meeting is tied into a good social experience. 'The most successful events have been a good social catch-up but have also had a particular focus – a topic of interest or something else that draws people in. Once the women are there, the networks begin to get established and then the benefits really start to flow.'

Julia's final reflections on establishing a women's peer support group? 'To get a group off the ground, you need a fairly committed and sustained push and to have some attractive events. The groups will ebb and flow, but just keep pushing them along – there are real benefits for the women in your community'. ■