

## Youth – challenges, taboos and myths

Jane Portnoy

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Chair ~ Robyn Shoemark

Growing up ~ Dale

Mother and son journey through teenage years  
~ Heidi & Sam

Resilience

How to deal with cyber bullying and communication

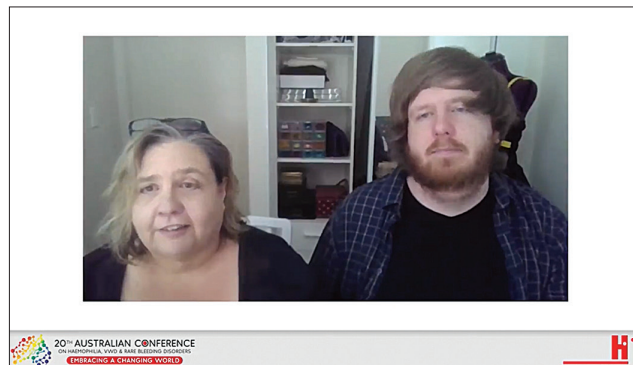
Looking after your mental health  
~ Monique Craft, Beautiful Minds

The patient voice was a strong feature of this virtual conference, and the session on youth was a great example.

Dale and then Sam and his mum Heidi spoke with a frankness, and wisdom which is true for many who have lived with haemophilia. Their presentations and the fabulous questioning from the chair Robyn Shoemark addressed many of the challenges that we see over and over again. How to allow a young person to develop and try new things, how can parents sit back and treat their child as a child first when they are worried about all the things that might happen.

I was in awe of Dale's parents who allowed him to go along and give rugby a try. The decision not to play rugby belonged to Dale and allowed him to learn how to make his own choices. Dale has tested the limits, and tried many things, he has also been a fabulous advocate for himself, and spoke up when he wanted to participate.

Heide and Sam's stories were honest, and so helpful. Thinking ahead in career planning was Sam's strategy, and it has set him up in a career of teaching that will not be limited by any physical challenges.



Heidi and Sam sharing their story and tips

### TIPS FOR GROWING UP

A few of the tips from Dale, Heidi and Sam:

*'Don't let anyone limit your choices. Try something at least once, and if it doesn't work out, at least you can say you tried. You only live once, and you'd rather not have regrets.'*

*'Don't wrap your kids in cotton wool, and don't let others do it either. Children need to thrive and try things in their lives.'*

*'Make treatment a normal part of everyday routine.'*

*'They supported me. I worked it out for myself.'*

The message from all was that kids will find a way, so parental support is worth a great deal. They will also then feel able to tell you about when it doesn't go well.

### TIPS FOR MENTAL WELLBEING

After setting the scene so well with the accounts from young men with haemophilia and their parents, we heard from Monique from Beautiful Minds. Her presentation was very interesting and had helpful suggestions with practical tips for young people and their families, accompanied by demonstrations.

Dealing with 'overwhelm' or the build-up of anxiety was the first issue she tackled – in particular for families 'to create harmony in the home'. I have described a few of her strategies as they were great suggestions.

### The Body Thump

Stand up.  
Put both your arms out in front of you, one with a fist and the other with the palm out flat.  
With a gentle fist, start gently patting the opposite hand (which is out flat).  
Then move up the arm and across the chest.  
Then switch hands and repeat on the opposite side.  
Following this with two fists gently tap down the sides of the torso, and then on the chest.  
Monique mentioned that making a gorilla sound helps to make this exercise even more effective.

### Breathing

Monique suggested a variety of breathing exercises, including the straw technique:  
Pretend you are breathing through a straw  
Inhale through your nose  
Exhale through your mouth, with your lips pinched like they're holding a straw  
Gradually slow down the breathing, closing the eyes.  
This allows the body to relax through the breathing, to get more oxygen and allows us to feel more in control.

### The STOP strategy

**S**top  
**T**ake long slow breaths out  
**O**bserve your surroundings  
**P**roceed  
Which allows the brain to move on through anxiety and then allow us to proceed.

### 54321 activity

5 things you can *see*  
4 things you can *feel*  
3 things you can *hear*  
2 things you can *smell*  
1 thing you can *taste*

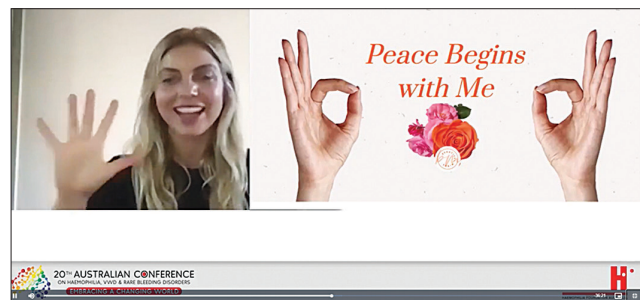
### The Ice Technique

This technique is used by celebrities and public speakers.

Grab some ice and hold it. This

1. Lowers your temperature
2. Stops the adrenaline
3. It is the only thing that you can feel

Going through any of these exercises helps you take your mind off whatever is creating your 'overwhelm' or anxiety, and allows your mind to slow down, and have a break and then get back to the things you want to be doing.



### CYBERBULLYING

Monique also spoke about cyberbullying, with some very useful tips.

1. Select the guests to your virtual home carefully (ie, choose who you interact with in your social media world and don't be afraid to disconnect people who are disrespectful to you and your friends)
2. The power is in no response
3. Take screen shots (as you will need to have the details and the evidence)
4. Report it
5. Block, block and block

All in all, the youth session was a really thought-provoking look at some of the challenges for young people and their families and to hear tips and advice from young people themselves as well as parents and expert professionals.

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