



Being a teenager with a bleeding disorder

Jaime Chase

Adolescence is a time of great growth, development and also a time of great insecurity. As a young person you are trying to find your way in the world and where you fit - especially with your friends. Adolescence is often filled with trials, mistakes and lots of learning experiences and this is ok – when we make mistakes we learn, become more knowledgeable and understand more about our life and where we stand in the world.

Having a bleeding disorder when you are developing as a young person adds another layer or complexity to experiences that are already sometimes difficult, anxiety-provoking or important to you and your sense of self.

As you continue to grow as a person you will start to move away from your parent or caregiver and start to assume some independence around choices for you and your body. This is where a close and supportive relationship with a key person and your Haemophilia Treatment Centre (HTC) will help as you continue to grow and develop into an adult.

KNOW YOUR BLEEDING DISORDER

As a young person, it's important that you have a clear understanding of your bleeding disorder and what it means to you. Your family and your HTC can work together with you to learn over time – including your bleeding disorder's 'proper' name, cause, what it will mean for you, inheritance and treatment.

As you become older, it's time to begin taking charge of your bleeding disorder care - make your own appointments, move towards giving your own treatments and monitoring injuries. Every young person needs a key person in their friendship group who knows they have a bleeding disorder. Think about who of your friends know you have a bleeding disorder- especially as you start to be more independent and spend more time away from family and caregivers.

Do you have your HTC's contact numbers on your own phone? Do you know who to call and when? Do you know when to carry treatments with you in case of trauma? Do you know how to store them? These are all questions as a young person you need to be confident in answering. If you don't know the answers, chat to your HTC and your parents/ caregivers about them.

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COMMON EXPERIENCES

There are a lot of questions around experiences that you may have as a young person that have an extra layer when you have a bleeding disorder. Some of these are addressed below. If you ever find yourself wondering what to do in some of these examples, it's a great idea to chat with your HTC about the issues before they happen. Then you are prepared and know what steps you may need to take - just in case.

Alcohol - As you grow into an adult you may start to experiment with drinking alcohol. Alcohol is known for its ability to lower inhibitions and take risks that you might not normally take. It is always a great idea to have a friend who is aware of your bleeding disorder in case of an injury/trauma situation - just in case you are unable to speak up for yourself. Great ways to keep safe are wearing a medic alert, ensuring the lock screen on your phone is set to say you have a bleeding disorder, ICE information completed on your phone and carrying your ABDR card.

Drugs - If you do decide to experiment with drugs, be it vaping, smoking, marijuana use or other, be aware about what is safe for you. You need to have a safety net plan just like when you have alcohol, and you need to have a clear understanding of the effects of the drugs you are taking.

Piercings - Piercings include those to your ears, nose and other areas such as the nipple, face areas and genitals. Before you have a piercing, talk to your HTC and have a treatment plan in place pre-procedure. This will reduce your risk of the procedure not being successful or the proceduralist not proceeding due to increased bleeding.

Tattoos - Discuss tattooing with your HTC before the procedure as tattoos may not be as successful with increased bleeding. A treatment plan pre- and post-procedure will ensure the best quality tattoo is achieved.

Periods - A young woman with a bleeding disorder is quite often at risk of developing heavy menstrual bleeding or heavy periods. This may be debilitating for her. If your periods are longer than 8 days, you change sanitary protection every 1 to 2 hours and often pass clots it may be worth discussing with your HTC. There are plenty of options to help manage heavy periods and your HTC is a good place to start the conversation.

Taking risks - Being a young person is a time of great experimentation and finding out your limits. Having a bleeding disorder means that you do have to take extra precautions and perhaps plan your adventures/experiences accordingly. Being aware of your limitations and what to do in case of an emergency are all things where you need to have a clear understanding and a plan. Talk to your HTC and trouble shoot issues for you, know what to do in case of an emergency and who to contact. Going to concerts, festivals and overnight trips with friends all may need some extra thought. Plan ahead so you have an awesome time!

Sex - Having sex for the first time can make young people very anxious, even more so if they have a bleeding disorder and worry what effect that might have. Your HTC will talk openly and honestly with you about these issues and what you might be anxious about. You can put a plan in place in case of issues and know who to call (believe it or not your HTC has heard it all before and can manage anything that comes up, promise).

Feeling different - No one likes to be different when they are navigating their way through adolescence. If you have a bleeding disorder, sometimes you can feel different, especially when you have to plan a little bit more than your friends. If you are struggling with how you are feeling, there are a number of people who can help. Your HTC may have a social worker or psychologist for you to see or be able to refer you to one for further support.





Alternatively your GP can create a mental health plan for accessing support. Needing to talk about how you feel about having a bleeding disorder is OK. Lots of young people feel the need for this extra support and find it helpful - and accessing help is an important way to take care of your wellbeing and develop a positive mindset.

Adolescence and growing into young adulthood is an amazing time of self-development and self-discovery. Having a bleeding disorder does not mean that you can't try different experiences - it's just that some may need some more planning and troubleshooting.

Having a good relationship with your HTC and a thorough knowledge of your bleeding disorder is important as you move to the next exciting stage of growing up into a young adult. You and your HTC can make sure that the experiences you have are planned for as much as possible so you don't need to feel like you are missing out during your journey to become an adult.

Find out more

Factored In (www.factoredin.org.au) is an HFA online resource with hot-topic information and stories for and by young Australians with bleeding disorders, both in their teen years and moving into young adulthood. There are also Q&A, answering questions submitted by young people, and you can submit your own questions if there are things you would like to know that aren't already covered.

Where to get help

- **Kids Helpline** (www.kidshelp.com.au) - call 1800 55 1800. Telephone and online counselling for ages 5-25
- **Lifeline** (www.lifeline.org.au) - call 13 11 14
- Call **Parentline** (www.parentline.org.au/parentline-in-other-states) in your state or territory for counselling and support for parents and carers
- **eheadspace** (headspace.org.au/online-and-phone-support) to chat online
- **SANE Australia** (www.sane.org) – for people living with a mental illness and their carers – call 1800 18 7263
- **ReachOut.com** (au.reachout.com) – a youth mental health service. Visit the website for info or use the online forum
- **Raising Healthy Minds app** (raisingchildren.net.au/guides/raising-healthy-minds) is a free app with evidence-based information to help parents or carers with the wellbeing of their child
- **Beyond Blue** (www.beyondblue.org.au) – call 1300 22 4636 or chat online with a trained mental health professional
- **Head to Health** (www.headtohealth.gov.au) - for advice, assessment and referral into local mental health services - call 1800 595 212 from 8:30am to 5pm on weekdays (public holidays excluded)

Source: HealthDirect. Kids and mental health - www.healthdirect.gov.au/kids-mental-health

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