

Starting school with a bleeding disorder

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Starting childcare, kindergarten or school – or high school - can be both an exciting and daunting transition for children and their families.

When a child has a rare bleeding disorder such as haemophilia, there is additional anxiety for both parents/guardians and educators. Parents may worry about entrusting the care of their child to others. Most educators will not have experience with bleeding disorders and are often worried about what this might mean for the inevitable falls and scrapes in the playground and be unsure about including children in activities and sports.

HOW TO EDUCATE SCHOOLS?

Providing information for schools and childcare is a key role of the Haemophilia Treatment Centre (HTC) with the goal to support parents, allay the fears of educators and for children to have a safe, active and full school life.

Depending on the size of the school, key contacts may include teachers, first aid officers and a school nurse.

Some of the key messages provided to schools include:

- Most students with haemophilia can lead healthy and active lives and participate fully in the school community
 - Appropriate activities and sports are encouraged to promote physical and mental health
 - A student with haemophilia will NOT bleed profusely from a simple fall in the playground or a minor cut or injury
 - Standard first aid is the same as for any other student
 - A knock to the head or major injury requires prompt medical attention which may require factor replacement
 - In the instance of an injury, contact the parent or guardian immediately.
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Most childcare centres and schools will request a **medical 'action plan'** for children with a medical condition. Your HTC can provide an action plan with key information about your child's bleeding disorder, how to recognise a bleed, appropriate first aid and when to call the parent/guardian or an ambulance in the rare case of a significant injury (emergency management).

STARTING HIGH SCHOOL

Starting high school is such an exciting time for young people and their families - but it may be filled with a bit of apprehension too! The school is likely to feel and be a lot bigger than their primary school and it can be easy to feel a bit lost and nervous when they begin.

Orientation days are a fantastic way to feel more comfortable in the environment. Another way to ease transition is for parents and guardians to chat openly and honestly about what high school might look like and what ways you can troubleshoot any issues.

Tips and tricks for high school

- Tell your HTC your young person is transitioning to high school. The sooner they know, the more time they have to help with transition.
- Find your contact! Help your young person connect and feel comfortable with their year advisor, First

Aid Officers and/ or Wellbeing Officer. This is the staff member who will be your and your young person's contact for school issues, further support and firsthand knowledge of bleeding disorders.

- Some young people may need access to the bathroom during school time due to heavy periods. Discuss this with the school and check if your HTC may need to provide support or advice.
- Make sure your young person keeps sanitary items readily available for school in case of flooding. A key contact at school is very useful for this issue.
- Make sure your Emergency plan is up to date and completed by your HTC as required.
- Your HTC will offer school education sessions, either pre-recorded, virtually or in person.
- Plan ahead - work with the school and your young person regarding camps, excursions and sporting events so everyone is prepared.
- Talk to your young person about wearing a MedicAlert® ID bracelet or necklace or something similar. Make sure the emergency screen on their mobile says they have a bleeding disorder and that they carry their ABDR patient card in their wallet or have a photo of their ABDR card on their phone.

LOCAL SCHOOL RESOURCES

Each state and territory has its own way of managing health conditions in schools.

Speak to your local Haemophilia Treatment Centre or your local Foundation about resources and education for schools on haemophilia that is suitable for your child. They may have a school pack that they will tailor for your child. Some may be able to work with you to provide an education session for the teachers and/or students in the school, or to develop an individualised plan in collaboration with you and the school. They may also offer other types of education, such as an annual seminar for teachers.

This is an example of an **HTC information page for teachers**. There are short videos of children with haemophilia answering common questions from teachers - <https://tinyurl.com/RCH-HTC-teacher>

For information on sport and exercise for young people with haemophilia, visit the online video set and toolkit **On the move with haemophilia**. This is aimed at parents, teachers and coaches, and is available on the HFA website - <https://tinyurl.com/HFA-OTMWH>.

What did the schools say?

Typical feedback from educators after a haemophilia information session:

'I was really nervous about having a child with haemophilia in my class. Today has put me at ease.'

'I feel better prepared to look after and enjoy the company of the child in my care.'

'Key message that I learnt today: that a child with haemophilia will not bleed to death if they fall over in the playground. There is no need to panic if the child is hurt.'



ENCOURAGING INDEPENDENCE

High school is a time where young people start to move away from their parents and caregivers and start to exert independence. Sometimes this is a difficult time for the parents/caregivers, especially in the context of a bleeding disorder. While some young people crave freedom and independence, others may need that extra push to become confident and self-motivated. Wherever your young person sits on this spectrum, there are ways everyone can help young people thrive. Skills you can help your young person practice are:

- **Being independent at home** - learning to cook, being responsible for cleaning areas of the home, doing their own laundry
- **Managing their time** - becoming responsible for their own work and study and learning how to create, maintain and stick to a timetable is very helpful for high school life
- **Increasing confidence** - learning to deal with new situations, meeting new people
- **Being responsible** - looking out for their friends and themselves
- **Taking responsibility for their bleeding disorder** - making their own appointments, attending part or all of their clinic appointments by themselves
- **Having a sound knowledge of their bleeding disorder** and what this means to them
- **Being responsible for their own treatment**, as applicable.

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Other ways to encourage independence are to create clear boundaries which may evolve as your young person gets older. These include:

- **Going out with friends** - where are they going and how late can they be. They need a person in their group who knows about their bleeding disorder. Discuss who it will be and how they will help in case of an incident/accident
- **Contacting when they are out** - when and how they should check in
- **Using social media devices** - what platforms are okay and any device-free times.

IT IS OKAY TO LET GO!

As a parent or guardian you want your young person to grow into a confident, capable, knowledgeable adult. Your HTC wants this too! When you begin to progressively let go and allow your young person to become more independent with life with a bleeding disorder, you learn to trust them and they learn to trust themselves.

High school will be a bit of trial and error on both sides of you and your young person. With a bit of trial and error and help from your HTC, your young person will learn to trust themselves and the decisions they will make both about their lives and their bleeding disorder.

High school is an amazing time of growth for a young person. With the steady guidance of parents, caregivers with the support of the HTC, they can learn, grow and go on to great things.

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