

Telling your daughter's school and carers



Telling your daughter's school and carers - key points

- If your daughter has a bleeding disorder, you will need to let her school know and help them put together an 'action plan' in case of an emergency
- Make sure the information in the action plan is kept up-to-date and that you are confident the school knows what to do
- You may want to talk to your daughter about the pros and cons of telling friends at school
- If your daughter experiences bullying or other problems because of her health condition, speak with her school about it

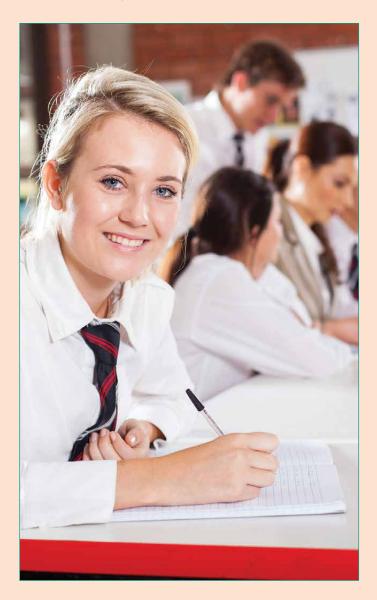
- Anyone caring for your daughter, such as babysitters, will need to know what to do in case of an emergency. It may also be important to explain why she has bruises.
- Some parents have an emergency plan with contact numbers that they leave with babysitters or carers
- Your Haemophilia Treatment Centre (HTC) can help with information for the emergency/ action plan and with educating your daughter's school.



Telling others about bleeding disorders

Telling school

If you are the parent of a girl who carries the gene, and who has a bleeding tendency, you will need to let the school know. This is so they can develop a personal or 'action' plan in case of an emergency. In some schools they may need to prepare a more detailed student health support plan. Make sure you keep this information up-to-date, and that you're confident the school knows what to do in case of an injury or emergency. Your Haemophilia Treatment Centre (HTC) can help you develop a plan and can provide information to give to your daughter's school. The medical information you give to the school, including a copy of her ABDR patient card if she has one, should remain confidential. If you're worried about this, ask the school what they will do to protect your daughter's privacy.



School teachers, family and friends now know the best thing to do is to stay calm, commence standard first aid treatment, as you would for any other child in regards to a nose bleed or a cut and that for more urgent matters call an ambulance and give them her treatment details.

If you have a daughter who carries the gene you might want to talk with her about the pros and cons of telling school friends. On the one hand she may find it helpful to have one or two friends who know what's going on for her. On the other hand friendships can change rapidly in school so she may want to take her time deciding whether to tell and who to tell. Privacy can also be an issue as news can travel fast in the school environment. Very occasionally kids with health conditions can be the target of bullying. If this happens to your daughter consider contacting the school to discuss how this can be addressed.

I have a standard letter I give to any new care giver, be it the school or a new parent who asks my child to have a sleepover. It explains in simple terms what haemophilia is, what to do, and finally that it's OK – that I am comfortable with people knowing.

Telling early childhood services

If it's possible your daughter has a bleeding tendency it's important that you inform her Pre-School or other Early Learning or Care Service provider. Well-informed staff will recognise when they need to take action if there is an injury or emergency. With the help of the HTC, you can develop a management plan so your daughter is properly looked after until you're able to step in. If your daughter bruises easily it may be helpful to talk openly about this – parents of children with bleeding disorders who have bad bruises have occasionally been suspected of child abuse. Accurate information from the outset can avoid this situation.

I can honestly say that not one person has shied away or that my child has been excluded from parties, sleepovers or sport because I ensure that people are at ease. If you are open and explain it in simple common terms people simply say 'oh OK, no problem – I get it'.

Telling babysitters

People taking responsibility for your daughter would need to know what to do in an emergency if she has a bleeding tendency. Let them know but reassure them they do not need to treat her any differently, unless there is an injury. If she bruises easily you can explain this, so they know this is normal for her. Some parents have an emergency plan with steps to take and numbers to call and leave this in an accessible place, such as on the fridge or next to the telephone.

The other parent did not raise a sweat and it was not awkward. We had the conversation and they were happy to know what to do. I have had various conversations with her school teachers, dancing instructors, sports teachers, family and friends to explain the condition. From the outside she does not look 'different' to any other child, however, when you mention bleeding disorder, their faces change.

People, given the right information about our condition, are no longer nervous.

Ask your HTC to help you with the emergency plan. They will have samples you can use and can make it specific to your daughter.

Telling sports teams or coaches

Regular exercise is recommended for us all. If you or your daughter has a bleeding tendency you may wish to let the coach or trainer know what to do in case of injury. The haemophilia nurse or physiotherapist at your Haemophilia Treatment Centre can tell you if there are any additional precautions you or your daughter should take and what you need to let others know about.

For more information about sport or exercise, visit the HFA website: (www.haemophilia.org.au) and the *Factored In* website: (www.factoredin.org.au).