



Parenting a teenager with a rare bleeding disorder

How is parenting different if your child has a rare bleeding disorder? Elizabeth's daughter Grace has Glanzmann thrombasthenia, a rare hereditary platelet function disorder. Elizabeth spoke to HFA about the strategies her family has developed to manage the risks for a teenage daughter who has unusual bleeding problems.*

Grace has Glanzmann thrombasthenia. *'She has platelets but they don't function properly, so she has a treatment plan of "don't get hurt"!*' explained Elizabeth. While risk management is very important, Grace has a medical treatment plan for her bleeds with a variety of treatment products and a specific treatment plan for her periods that has been worked out with her gynaecologist.

THE CHALLENGES OF RISKS

Grace's diagnosis as a baby was very unexpected and Elizabeth and her husband have developed strategies to manage Grace's bleeding risks over time as she has grown up. Initially it was very challenging: *'we were first time parents and it felt like it was one long learning curve.'*

Now that Grace is a teenager, both she and her parents have a wealth of childhood experiences to draw on and her parents feel it is important to support her in developing independence and taking responsibility for herself – but also to enjoy her life.

'Grace just goes about life and has fun and always assesses her risk for injury.'

'Grace is our only daughter. She is a typical teenager. She loves life, she loves fishing and camping and loves being outdoors.'

'So she can go for a run and be careful about it, but she is not going to play footy or even basketball or netball. She goes and finds things that she can do. When she wants to try new things, we try to make it happen.'

'But Grace makes all her own decisions now. She covers academic and I cover bleeding until she feels comfortable taking over that. I help her with her appointments and I remind her if I feel some of her decisions about what she's doing is a risk for her health, but she understands what she can do. She has just learned it along the way.'

MANAGING SCHOOL

What is a 'contact sport' for Grace? With a new year starting, Elizabeth thought about what the letter to Grace's new teacher should say and decided to be very direct:

'I said, Grace will let you know if she is able to participate in what you may or may not consider contact sports. But you need to know that when she is sitting out, she needs to be safe too because she always gets hit in the face with a ball, whatever sport she is playing.'

It has been important to work with the school to align what everyone thinks is acceptable. For Grace, this approach has resulted in some strategies that work well for her – to streamline her treatment so she doesn't feel like she is missing out on her classes or feeling like *'the odd kid who is sitting there with an icepack'*.

For example:

- A red flag on her file and emergency plans and strategies in place
- An ice pack in the staff freezer with her name on it
- Quiet places she can go to ice or treat her bleed or injury
- A first aid kit in Grace's bag and a first aid kit for her in the office.

A SUPPORTIVE FRIENDSHIP NETWORK

Accidental injury when children are growing up is inevitable. But having a bleeding disorder can be challenging at school, where there can be children who think it is fun to hurt other children. With Grace they could see a result straight away:

'If they push her over and she skins her knee, she bleeds like a sieve and has an egg.'

'She has amazing friends now who rally around her. When she fell over and she couldn't really walk, they got an ice pack for her and went and got a teacher.'

Being careful extends to playing sport and socialising as well.

'When she does sports or when she goes out with her friends, she has to be out with more than 2 friends in case she falls over and hurts herself.'

MANAGING AT HOME

At home there is a balance.

'What's important is finding what works for you in a routine and inside and outside the house.'

'We're relaxed about some things and strict on others. And we have rules – like she needs to be safe about what she's doing.'

'I do notice that we do things differently. She is only allowed to cook when we are at home in case she gets a burn or cuts herself by accident. She loves to cook and she is a good little chef.'

Keeping fun in her life has also been important.

'If you have a bad day and you have something fun to do, you can just go and do it.'

'Grace always wanted a pond and she now has one. So she can go out there every day and feed her fish and play with her fish, because they love coming up to eat off her hand.'

OPEN COMMUNICATION

With a bleeding disorder open communication is crucial. Some bleeding episodes can have very serious consequences and recovery can take weeks longer if the bleed is not treated quickly.

'When she does have a bleed she really needs to tell me so we can fix it. We nearly missed a head injury because she was trying to protect her friend – and lied and said "I fell over because I walked into a pole" but really she had fallen over and hit her head on cement when her friend was angry and pushed her.'

They have also been fortunate to have a good family friend whom Grace trusts.

'If your child is having a bad day and they just don't want to talk to you, it's important they have someone that both you and they are comfortable with.'

'Grace is a teenager – I think she always talks to me, but she might not. But she has a friend of mine that she adores and my friend absolutely adores her. And if there's anything she can't tell me or her dad, she can tell her.'

'But Grace is such a good kid. Most days the worst thing she does is roll her eyes at me. When you're a parent and you complain that your daughter rolled her eyes at you, you're pretty lucky!'

Ultimately for Grace and her parents it's about living life and finding the positives – 'the things to look forward to.'

'We just feel normal. It's one of those things in life. And for Grace, it's just being careful.'

**Elizabeth and Grace are not their real names*

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