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Sharing experiences with haemophilia

"Moving Out"

Baxter

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> No matter what you do, stand your ground because there's always someone to back you up. If you want help you only have to ask.

Moving out

You are becoming independent. Leaving school. Leaving home perhaps. Going to college or university. Starting a new job. But you have haemophilia. Should that stop you? Absolutely not!

Nevertheless, it's important to remember that it will be very difficult to be independent if you don't know some of the basic facts about your haemophilia. How else can you take control of your life?

So before you read any further, take a look at the following checklist. These are things you need to know, and why you need to know them.

Do you know	Why you need to know
...what kind of haemophilia you have - A or B?	The kind of factor you inject, and how often you inject it, depends on what type of haemophilia you have.
...how severe your haemophilia is?	Haemophilia is classified by how 'severe' it is, which means how much factor you produce yourself. The more severe your haemophilia, the less factor you produce and the more you need to inject.
...how you can tell if you have a bleed in a joint?	If you've been using factor every week since you were diagnosed you may seldom have felt a bleed. But you need to know what to look out for, just in case.
...why you should avoid bleeds?	It might be tempting to occasionally 'forget' your factor. But before you do, find out what long-term damage you may do to your joints if you bleed.
...when to ask for help?	Being independent is fine but everyone needs help sometimes. You need to know when to cope alone...and when to call for help.

Know all the answers?

Then read on.

Not quite sure? Well now is the time to find out. Talk to your parents, the people at your Haemophilia Centre or the Haemophilia Society (the phone number is at the back of this book) and explain what you need to find out. Then when you know the answers, pick up this book again and read on.

Taking 'total control'

Being independent is about taking control of yourself and your life. So the next thing to consider is your infusions.

You've probably been doing your own infusions for some time. But just quickly check - are you totally in control?

- Do you prepare everything yourself?
- Do you know how much to inject for your regular infusions?
- And can you work out how much extra you need if you have a bleed?
- Do you know what to do if a bleed is not settling down after treatment?

When you know all these things you're ready to take 'total control'.

The choice is yours

Once you take 'total control' you can set out on the road to independence.

So what does being independent really mean? In essence, being independent means making your own choices and living with the results, good and bad. No one to blame if things go wrong; but all the credit when things go right!

So how do you make sure things go right? No one can be sure that all their choices will work out for the best, but you can increase your chances of getting the result you want. How? Well try to make each major decision an informed choice. Before you set off on a particular path find out as much as you can about the likely results of what you decide.

Here are a just few examples of the choices you can make for yourself and some of the issues involved:

Choosing your sport - some sports will give you more chance of having a bleed than others. Contact sports like rugby, for example, may not be worth the aggravation they will inevitably cause. For others, like football, it will now be up to you to balance the risks you run against how much you really want to play. Read up about all the sports available to you before you make your choice. Some excellent booklets are available including another in this 'Sharing experiences with haemophilia' series called 'Sport & Exercise'.

> "Not playing rugby can be an advantage. I spent time hanging around with girls rather than lads, and believe me that can be an advantage!"

Choosing your career - first of all find out which careers are closed to people with haemophilia. These include, for example, the armed services, police and airline pilots. No point in setting your heart on a career that you cannot pursue. Beyond these careers, however, prophylaxis has opened a lot of doors that were previously closed.

Choosing where to travel - there is a whole world out there to explore. Just remember that before you set off you need to be sure you can get regular supplies of your factor. The health system in many countries is not as sophisticated as you are used to in the UK. Your Haemophilia Centre and the Haemophilia Society will be able to give you advice.

Want to change the world?

So, now you are in control and you're making your own choices. Do you suddenly feel like you want to change everything, to do things your parents or your teachers wouldn't approve of? Dye your hair blue? Wear shoes your mother would hate? Stay out until the early hours? Everyone does it, don't they?

For you there is an even bigger temptation. Once you take control of your regular injections of factor you could stop taking them. That's your choice.

> "I felt that I wasn't a normal teenager because of the injections. I thought I could be normal without the injections."

Taking factor regularly - three times a week for haemophilia A or twice a week for haemophilia B - is called 'prophylaxis'. If you stop taking your factor regularly and just use it when you have a bleed this is then called 'on demand' treatment.

If you have severe haemophilia you will have been taking prophylaxis for many years. Your regular injections of factor will have protected your joints over the years, preventing damage from regular bleeds.

Therefore, before you change to 'on demand' treatment, just make sure you are aware of the risks you are taking. Not just the pain from a swollen, bleeding joint or muscle. Arthritis and long term joint damage can make everyday life painful, sports impossible, disrupt your studies or your employment and could force you to alter your chosen career.

> "I was a rebel when I was thirteen. if I'd known then what I know now about haemophilia, I wouldn't have fought with my parents about my injections. I've got to live with the consequences - I've got arthritis in my ankle."

So here's a bit of straight talking. Face facts. You may want to be exactly like your friends. Do what they do, go where they go. And you can be - almost - but only if you take your regular injections of factor.

Still want to stop your injections? Well, it's up to you. Whatever your choice, remember you can always change your mind...Your Centre staff will always listen to you and help you.

Leaving home

Leaving home can be a real test of your independence; your chance to prove that you really can cope on your own.

The parents of some young men with haemophilia can find it quite a wrench when their son leaves home. When you were young so much of their time was devoted to your care. No wonder they may have real difficulty letting go.

> "It seems as if your mother loves you more because she cares for you and takes you to hospital."

If your parents are reluctant to let go, you have a choice of two ways to leave home, the rough and the smooth.

The rough way to leave home - you could just up and leave. Turn your back on the problems your parents may have and simply go. But is this what you want? Things might never be the same again and, while you might want complete independence now, there will be plenty of times when you'll need your parents' friendship and help.

The smooth way to leave home - on the other hand you could try demonstrating how well you will cope on your own. Reassure your parents that you've got your head screwed on and know the pitfalls of looking after yourself and how to cope with them. Share your plans with them. They will still probably be sad to see you go of course, but equally happy and welcoming when you return.

A bit of practical advice

So, if your new independence takes you away from home, here are a few practical things it will now be your responsibility to consider:

Identify yourself - away from your family and old friends you need to be doubly sure you carry some identification with you. Get your green card up to date with your current address, treatment centre details and details of your general practitioner (GP). You need these details with you at all times so carry your green card or you could get a MedicAlert bracelet or necklace from:

MedicAlert Foundation
1 Bridge Warf
156 Caledonian Road
London N1 9UU

www.medicalert.org.uk

Alert your Haemophilia Centre, or find a new one - if you are simply moving to a new home near your current Haemophilia Centre, let them know your new address so they can send you your appointments. If you plan to study or work further from home, your current centre will be able to give you the address of another, closer centre where you can register.

Find a new GP - like everyone else you will have occasional medical problems that are totally unrelated to your haemophilia. GPs have a good all-round knowledge of these kinds of problems so when you move find yourself a good local GP. You simply go to the surgery of your choice and ask to be registered. But remember, many GPs have never treated someone with haemophilia so even they may need you to take a little time to explain about your treatment.

> "The school doctor asked every year 'Is he getting better?'. He didn't understand."

And a dentist - but don't forget to tell them about your haemophilia. You can do so with confidence as both dentists and doctors will respect your wish for confidentiality.

Keep contact numbers safe - particularly if you are living alone keep the contact numbers of your doctor and Haemophilia Centre in a safe place so you can find them easily if you need help.

To tell...or not to tell

New job, new college, new university all bring with them new friends and workmates, employers and tutors. So who do you tell? It is now up to you to decide.

Before you make up your mind, think about some of the issues:

Finding out - if you don't tell people fairly soon after you first meet you need to consider how they will react if they find out later. Will they feel their trust has been betrayed?

Will they take the time needed to understand that nowadays, by using your factor prophylactically, your haemophilia places very few limitations on your lifestyle?

Storing your factor - if you have a bleed you need to get to your factor, so where can you store it safely at college or work? If you tell your tutor or employer, could they make a safe storage place available?

> "At college I keep my factor at reception. If I need it I ask reception for it and then treat myself at college."

If you have a bleed - how will your employer, tutor or new friends react if you have a bleed? If you warn them in advance they may be understanding. On the other hand they may over-react and be over-protective.

> "People panic if I cut myself. I have to calm them down."

Taking time to explain - if you do decide to tell people at work or college, remember they may have little or no understanding of haemophilia; they may be scared if you bleed, they may even think haemophilia is catching! You will need to be patient and take time to explain and deal with their concerns.

> "I don't like haemophilia B being called a disease. It isn't catching!"

Time off - if you have a bleed and need time off work or college, how will your employer or tutor react if they don't understand why? Even when people know about your haemophilia they may not understand its treatment.

> "At work they think it's just an excuse to go home if I say I need an injection."

In the end you probably need to ask yourself just one question 'Will telling this person make my life easier or more difficult?'. Only you can decide but if, on balance, you think life would be easier then why keep your haemophilia a secret?

A bit about sex

One of the big benefits of a new college or a new job is you will make new friends, both male and female. Your chances of finding a partner will probably never be better than they are now! You're meeting people you weren't at school with. They don't remember you when you had a face full of spots or when your only line in chat was about your favourite football team.

When it comes to telling friends about your haemophilia the issues are the same as in 'To tell...or not to tell'. But what do you tell your partners about your haemophilia? It rather depends upon how serious your relationship is becoming. When a relationship becomes more than 'just friends' there are two new issues you need to consider.

Safe sex - The first concerns safe sex. If your relationship is a physical one, practicing safe sex - using a condom - is important for every young man (straight or gay) and you are no exception.

Starting a family - The second issue arises if your relationship with a girlfriend becomes more serious. Is she the one? Can you see yourself settling down with her and starting a family? It may still seem a long way into the future but make sure you know now how haemophilia is inherited and how it may or may not be passed on to your children. You need to be able to discuss this with your partner when the time is right.

Staff at your Haemophilia Centre will be able to help you and your partner with information and counselling on starting a family. They will ask if you would like to speak to a geneticist - a doctor with specialist knowledge on how genetic disorders like haemophilia can be passed on and the likelihood of haemophilia affecting future generations. In the meantime, ask for the next book in this series 'Sharing experiences with haemophilia' called 'Planning a family'.

Looking forward

So, whatever you hope independence will bring - a new job, a new career, a new home, or a new relationship - look forward to your future with confidence. Remember, coping with haemophilia all your life has already made you very strong.

> "Having haemophilia has made me mature quicker. I was rebellious for a while but I've come through that."

As you become independent, no one will be telling you exactly what you should do or exactly what choices you should make. Just remember, look at the issues, find out as much information as you can, and when you feel you are ready, make your choices.

From now on, it's up to you!