



## INFORMATION FACT SHEET

### VON WILLEBRAND'S: GENERAL INFORMATION

#### What is von Willebrand's?

Von Willebrand's is a blood clotting condition, which is usually inherited. It was first described about 70 years ago and is named after the person who first reported it.

Erik A. von Willebrand was a Finnish haematologist who lived in the early part of the last century. On graduating in medicine from the University of Helsinki, he moved to the Aland Islands. There he studied the local community, concentrating on a familial bleeding disorder called 'Alandic Haemorrhagic disease'. This is what we now know as 'von Willebrand's'.

The medical term for the condition is 'von Willebrand's disease'. However, as the word 'disease' can carry some stigma, we call the condition 'von Willebrand's' (vW) throughout this factsheet.

Von Willebrand's Factor is one of the proteins in the blood that helps to make blood clot. In vW either there is a shortage of von Willebrand factor, or there is something wrong with its structure so that it does not work properly. Because of these problems, it takes longer for the blood to clot and for bleeding episodes to stop.

#### Types of von Willebrand's

vW is divided into 'types' according to whether someone has a low amount of von Willebrand factor or has a type of von Willebrand factor that does not work properly, or both. Knowing the type of vW helps the doctor decide what kind of treatment will be best for each individual.

##### Type 1

This is the mildest and most common form of vW. Someone with type 1 has low levels of von Willebrand factor but the von Willebrand factor that is there does function normally. Three in every four people with vW have type 1.

##### Type 2

In this type, the von Willebrand factor produced does not work efficiently. Type 2 vW is divided in four subtypes: 2a, 2b, 2m and 2n.

- Type 2A is the most common type. People affected have von Willebrand factor which does not work properly. This type of vW is classed as moderate.
- Type 2B is classed as moderate to severe and can be characterised by thrombocytopenia (low platelet count).
- Type 2M can cause mild to moderate bleeding episodes. It can be difficult to diagnose and is very like type 1 vW.
- Type 2N causes reduced levels of factor VIII because the vWf cannot bind factor VIII properly. It is likened to haemophilia A and only correct investigations will distinguish between the two. Bleeding is classed as mild to moderate.

These subtypes are treated in different ways, so it is important to know the exact type.

### Type 3

This type is classified as severe and is the rarest form of the condition, affecting one to five in a million people in the UK. Someone with type 3 usually lacks von Willebrand factor altogether and has low amounts of clotting factor VIII. A person with type 3 vW will experience regular bleeding problems which may be severe. These could include frequent nosebleeds or bleeds into joints and muscles. Women and girls may suffer heavy periods that require treatment to limit bleeding. People with severe vW will need treatment before and after any type of surgical or dental procedure.

Once you have been diagnosed as having one of these three types, the severity and type of your condition will not change, although the symptoms you experience may change throughout your life.

### **Who does it affect?**

vW affects approximately 1% of the population of the UK. Most people are diagnosed with a mild form of vW. For many people, it is so mild that it is not diagnosed at all unless they have excessive bleeding after surgery or a major accident. The severe form of vW is uncommon.

### **How is von Willebrand's inherited?**

Von Willebrand's is mostly a genetic condition. This means it is passed down through the genes from parent to child. The abnormal gene in vW is on one of the regular chromosomes, not on one of the sex chromosomes (like haemophilia). So, unlike haemophilia which usually affects only males, vW affects males and females in equal numbers. (See chart on page 3)

In what's called the classical inheritance pattern, the vW gene is usually dominant. This means that a parent who has vW has a one in two (50%) chance of passing a vW gene on to each of his or her children. Types 1 and 2 are usually inherited in this way.

Many people carrying this gene are asymptomatic which means that although they will not have bleeding symptoms, they can still pass the condition on to their children, who could have more severe symptoms than their parents.

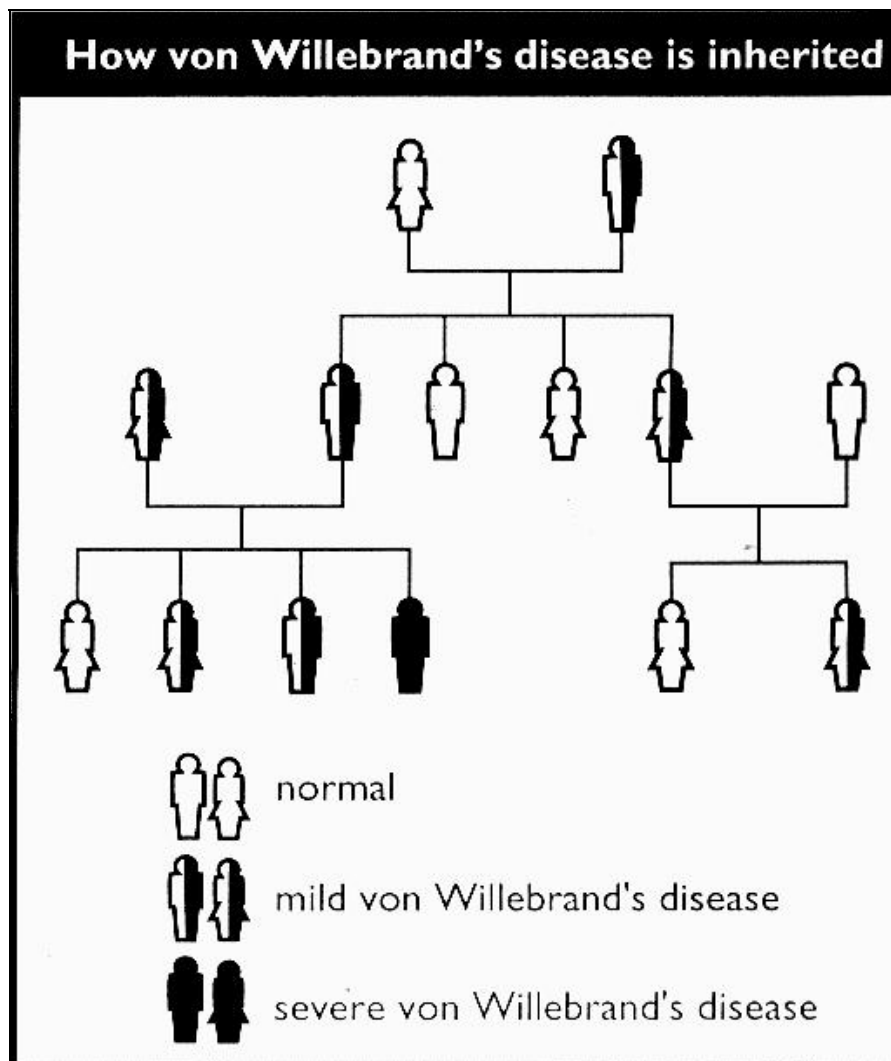
In the less common inheritance pattern, two parents, each with vW but without symptoms may together have children who are severely affected by vW. This form of inheritance is called 'recessive'. Type 3 von Willebrand's is usually inherited in a recessive pattern.

Different members of the family can be affected more or less severely than others. This means that some family members may be unaware that they carry the abnormal gene, and the doctor may wish to test other family members, even if they have never had any abnormal bleeding problem. For some people who have no symptoms their bleeding disorder is only identified when another family member is diagnosed.

### **Is von Willebrand's only an inherited condition?**

No. There isn't always a family history. Some children have vW because there was a mutation, or change in the gene, during pregnancy. When this happens that person's chances of passing the condition onto his or her children are the same as those of a parent who has inherited the condition, whether or not they have bleeding symptoms themselves.

vW can also be acquired rather than inherited, but this is very rare. This means that a person is not born with the condition but develops it later in life. For example, someone with serious immune system problems, such as rheumatoid arthritis, systemic lupus erythematosus, types of kidney failure, or certain cancers, might develop acquired vW. This problem is usually caused by antibodies which someone produces against their own clotting factors: the antibodies can destroy von Willebrand factor or factor VIII preventing them from working.



### **What are the symptoms of the condition?**

*Symptoms of vW differ for men and women. Women and girls wanting advice on this condition should get a copy of 'A guide for women living with von Willebrand's' available from the Haemophilia Society. See page 12 for details.*

Some people with a defective von Willebrand gene may not have problems of symptoms, while others may have bleeding problems after tooth extraction or surgery.

Some of the following symptoms may be experienced:

- frequent nosebleeds, which may be severe
- easy bruising
- excessive bleeding in the mouth (from tongue and gums)
- Bleeding into joints and muscles (in severe cases – type 3 vW)

In most cases bleeding usually occurs only after an injury although people with severe vW may bleed spontaneously with no apparent cause.

### **Tests for diagnosing von Willebrand's**

If your doctor thinks you may have vW, he or she should refer you to a haematologist – a doctor who specialises in the diagnosis and treatment of bleeding disorders.

The diagnosis is made by a careful consideration of your personal and family history of bleeding along with blood tests on yourself, and often blood tests on other members of your family.

The haematologist will want to find out two main things:

- whether or not you have vW and
- whether you have type 1, 2 or 3 vW.

Some of the following blood tests will be done.

#### *Factor VIII clotting activity*

This measures the amount of factor VIII clotting activity.

#### *Von Willebrand factor antigen*

This measures the amount of von Willebrand factor in your blood.

#### *Ristocetin co-factor activity and/or collagen binding activity*

This measures how well the von Willebrand factor works.

#### *Von Willebrand factor multimers*

This measures how the von Willebrand factor molecule breaks down into individual protein complexes.

#### *Platelet aggregation tests*

This measures how platelets work.

#### *Bleeding time*

This measures how long it takes for bleeding to stop when a small cut is made in the skin. This test is not usually carried out on children.

Tests may need to be repeated, because the levels of clotting factors can vary over time. This is particularly the case in mild vW, where clotting factors in the blood may fluctuate, sometimes giving a normal result and sometimes showing an abnormal result. It could take several days or weeks before all the test results are available. Unfortunately, this often results in increased stress or worry.

Von Willebrand's can also be difficult to diagnose in mild cases where the results can be very near to and almost within the normal range. A diagnosis of vW is also harder to make:

- if you are under a great deal of stress
- if you have been crying just before the test
- if you have just had surgery
- if you have had a recent blood transfusion
- if you exercised strenuously just before the test
- in a new-born baby.

The above cause the body to release hormones which may increase the levels of von Willebrand factor in the blood, leading to what are called 'false normal' laboratory tests. This is why tests may need to be repeated several times before an accurate diagnosis can be made.

Once a firm diagnosis is reached, you can work with your haematologist and haemophilia centre on a management and treatment plan. It also means that appropriate action to prevent excessive bleeding, can be taken before dental extractions or other operations.

An accurate diagnosis is essential. Without a proper diagnosis, people with a bleeding disorder might face a potentially dangerous outcome from an accident or surgery.

#### **Different types of vW: just how 'mild' is 'mild'?**

On pages 1 and 2 we described the three types of vW: types 1, 2 and 3. A major part of testing and diagnosis is to find out exactly what type of vW you have so that appropriate treatment can be prescribed.

A lot of people find that even though they are diagnosed as type 1 – classified as 'mild' – they still have constant bleeds and other symptoms. The word 'mild' may disguise a lot of pain, discomfort and distress. Even very mild bleeding disorders may disrupt the lives of some individuals. People with so-called 'mild' vW may still find the condition seriously affects their quality of life. If this is the case for you, then do make sure you get all the information, treatment and support that you want and need. On the other hand, it may cause you very little trouble.

#### **Is there a cure?**

There is no cure for vW, but it **can** be treated effectively.

#### **The impact of diagnosis: learning how to cope**

It can be worrying to be investigated for a blood disorder, and all sorts of fears may run through your mind. So if you, or your child, or another member of your family has been diagnosed with von Willebrand's it can, at first, be a frightening and confusing experience.

The process of coming to terms with the diagnosis, like any chronic condition, is different for each person. Talk with others – friends, parents or carers, counsellors, health care professionals and other individuals with vW.

Ask questions about anything that concerns you, and keep on asking questions until you are satisfied with the answers. It's really important to get proper explanations in language you understand.

Don't be afraid to discuss fully with the haemophilia centre staff any anxieties that you might have which prevent you from leading a normal life.

Coming to terms with having an inherited condition will raise many questions in your mind and may stir up all sorts of emotions. You may feel angry or scared about the condition and how it will affect you or your child in the future. Talking to others with the condition can help. (See page 13 for information on the Haemophilia Society's Support Network.)

The support of the haemophilia centre staff will be especially valuable when you are just learning about the condition, and help you to work out how you are going to manage it. Always be prepared to be assertive and make your needs and concerns clear when talking to health care professionals.

The impact on parents whose child is diagnosed with the condition can also be difficult. Some parents feel angry that their child has been diagnosed with vW. This is a normal reaction. Parents with a newly-diagnosed child may feel guilty that they passed on the gene to their baby, although this is clearly no-one's fault. Having a child diagnosed with a chronic condition can be very stressful. At first you may have all sorts of fears, but over time parents gradually learn how to cope.

Generally speaking, reality is usually not half as bad as the things we imagine. The following are some of the emotions you may be feeling.

#### *Shock*

Finding out that you, or your child, have vW may leave you feeling stunned for a time.

#### *Denial*

You may try to deny that you, or your child, have the condition – hoping that it will go away. You may feel embarrassed or uncomfortable to tell your relatives and friends that you, or your child, have a bleeding condition.

#### *Anger*

You could feel anger at many things, but especially with the thought: 'Why me?' or 'Why my child?'

#### *Fear*

Hearing the diagnosis – 'vW' actually named – can be scary. This is especially true if you have not heard about it before or if you have a family member who has had a rough time with the condition.

More and more is being found out about this condition and your haemophilia centre staff should be able to give you information and support.

## How is von Willebrand's treated?

### Treatment at a haemophilia centre

People diagnosed with vW should receive on-going care from their haemophilia centre. There are two types of centres for the treatment of haemophilia.

1. Haemophilia centres provide care, information and support for people with a bleeding disorder.
2. Comprehensive care centres are available in some areas: they offer a wide range of services for people with bleeding disorders such as genetic testing and counselling, treatment plans and reviews. People with vW should be registered with and regularly reviewed by a comprehensive care centre.

Please contact the Haemophilia Society if you would like details of your nearest haemophilia centre or haemophilia comprehensive care centre.

Wherever you choose to go, it is important to find a doctor who specialises in treating vW. If a health care provider is not aware of treatment options, you or your child could be deprived of a procedure or treatment that could change or improve your life.

Various treatment options are available for the different types of vW. Discuss the best treatment approach with your doctor and ask as many questions as you need to about your options, and the risks and benefits of each treatment suggested.

The important thing is that your treatment team treats you as an individual, and gives you treatment and support tailored to your needs.

### Treatment options

The treatment prescribed depends on the type of vW you have and the severity of your bleeds. In this section, we take a brief look at the different treatments available.

Individuals with a mild form of the condition may only need medication when having surgery or dental extractions.

For minor bleeding problems, such as bruising, treatment may not be necessary. A nosebleed may stop by pinching the nostrils together for 10–15 minutes and repeating this procedure if necessary. Some bleeds in the mouth or tongue may be treated with medicine, such as tranexamic acid tablets or liquid. For some women with mild type 1 vW, treatment with oral contraceptives might be the only therapy needed. We look at tranexamic acid and DDAVP in more detail on page 8.

More serious bleeding problems may need to be treated with infusions of blood products injected into a vein. For all types of vW treatment may be necessary before any type of surgery, including dental extractions.

### *Blood-borne viruses*

Replacement factor made from human blood has been known in the past to carry blood-borne viruses, including HIV and the hepatitis C virus.

These blood-borne viruses affected most people with bleeding disorders who received clotting factor concentrates from any source before 1986, when effective heat treatment was first introduced in the UK (1987 in Scotland). Before then, most concentrates were contaminated with

hepatitis C, because blood clotting factors came from pooled blood received from many different donors.

All blood products used to treat vW are heat treated. Donors are screened, and plasma is sourced in the USA. This means that donated blood and blood products are the safest they have ever been from blood-borne viruses. For more information about the safety of blood products used to treat vW, talk to your haematologist or contact the Haemophilia Society.

### **What types of treatment are available?**

The following are some of the most commonly used treatments.

#### *Desmopressin*

Desmopressin or DDAVP is a synthetic hormone and not a blood product. Desmopressin is one of the most frequently used treatments for the milder types of vW.

#### How it works, and who it is suitable for?

Desmopressin works by causing von Willebrand factor to be released from its storage sites in the lining of the blood vessels. This produces a temporary rise in the amount of von Willebrand factor and factor VIII in the bloodstream.

This treatment is used mainly for people who have type 1 vW as it works at increasing the level of von Willebrand factor.

People with type 2 von Willebrand's have abnormal von Willebrand factor, so releasing an increased amount of this factor into the bloodstream may not correct bleeding. Many haematologists are cautious about treating people with type 2B vW with desmopressin because the drug may over-stimulate the platelets, causing them to clump together excessively. This may lower the blood platelet count, and may make the bleeding worse. People who have type 3 do not have any stores of von Willebrand factor, so the drug does not work for them.

#### How desmopressin is used?

Desmopressin is usually given by intravenous infusion by haemophilia centre staff.

The haemophilia centre may give you a test dose of the treatment to decide on the appropriate dosage and evaluate whether it will work for you.

A high-strength nasal spray form of desmopressin is also available, and is a convenient way to take the drug for some people.

#### Are there any side-effects?

For some, the drug has a water-retaining effect. Other side-effects may include facial flushing, facial warmth and less commonly, headaches. Some doctors are cautious about infusing desmopressin in older people or those with heart problems.

#### *Tranexamic acid*

Tranexamic acid helps to stabilise the clot. It slows down the body's natural process of breaking down a clot: this helps to stop bleeding and promotes the healing process. It is often administered in tablet form, but can be given in syrup form or intravenously. On its own, it is used to treat minor bleeding episodes, such as nose bleeds, but it can be used in combination with other medications such as DDAVP or clotting factor concentrates. The syrup form is recommended for children as they find it easier to take.

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### *Clotting factor concentrates*

For effective treatment of vW, the clotting factor used is derived from human plasma, because only human plasma contains the vW factor. This concentrate is effective in treating most people with severe vW. Recombinant factor VIII, which is a genetically engineered product, does not contain vW factor and therefore cannot be used in the treatment of vW. No recombinant vW factor concentrate is available yet.

### **Home treatment**

Self-injections are sometimes recommended in severe cases. Home treatment involves infusions of von Willebrand factor and factor VIII (for those who need it) at home rather than in a hospital or medical setting. Your treatment team will teach you how to infuse yourself, or how to infuse your child or another member of your family.

Giving a child an injection into a vein can be difficult, so using a device called a Port-a-Cath can help. This uses a tube and valve placed under the skin and is an easier way for some parents to give their child an infusion. Port-a-Caths are available where there is a medical reason for using them, such as weak veins.

Port-a-Caths are also sometimes used for adults who have difficulty finding and injecting into a vein.

### **Importance of medical advice when using other medicines**

People with vW **must not take aspirin** in any form because it makes bleeding worse. Always read the label of any medicine package carefully and do not use the drug if it contains aspirin. If in doubt, ask a pharmacist.

Some medicines, such as warfarin, affect the clotting factors and are therefore not suitable for people with vW. Other drugs, such as non-steroidal anti-inflammatory medicines, may need to be avoided. Do consult your vW specialist for advice if you need to use any other medication or herbal remedies.

### **Immunisations against hepatitis**

If you have a type of vW that requires treatment with clotting factor concentrates, it is advisable to find out whether you have been infected with hepatitis A or B. If you are negative, you should be immunised against these viruses. Your haemophilia centre can advise you.

### **Planning ahead for surgery**

Any invasive procedure, such as a tooth extraction or major surgery, can cause bleeding for people with vW. This means it is vital that you tell your doctor, surgeon or dentist that you have this condition well before any invasive surgery or procedure. Treatment can then be planned ahead and discussed with medical, nursing and dental teams who must liaise with the haematologist who manages your vW. This means that you can be given either intravenous desmopressin or clotting factor, if necessary, before the procedure begins, allowing your condition to be managed safely.

### **Emergency treatment**

Emergencies can happen: car accidents, falls, broken bones and so on. There will be occasions, after such an accident or when travelling, when you may need to seek treatment in a hospital accident and emergency department, or get assistance from people who are not familiar with vW.

Patients may need a blood transfusion for life-threatening haemorrhages after surgery or trauma. As a precaution, always carry information about your condition and the treatment you have been prescribed. Your haemophilia centre can provide you with a green card which gives details of your condition and treatment, or you can wear a medic alert tag.

### **Who should I tell?**

It is entirely your choice whether or not to reveal information about your bleeding disorder. However, you may decide to tell a trusted colleague or friend in case you need help in an emergency. Parents will need to tell the school about their child's condition so that the staff will know what to do if there is an accident or emergency. Teachers and other staff at the school may want information about the condition so that they understand how to respond. It would be useful to give them a copy of this factsheet, and perhaps suggest a visit from your haemophilia doctor or nurse to the school.

Finally, it is important to be able to explain your condition and its treatment clearly so that others can help you in an emergency.

### **Treatment while travelling**

Distant communities and small islands may not have the facilities to cope with a bleeding emergency. Many hospitals do not stock clotting factor concentrates and some do not stock desmopressin. Discuss your holiday and travel plans in advance with your haemophilia centre, particularly if you need to take a supply of treatment with you whenever you travel.

It may be advisable to go somewhere within easy reach of a city with a medical centre. *The Global Treatment Centre Directory*, a guide for travellers which lists hospitals around the world which have a specialist in bleeding disorders, is available on the Internet. Please contact the Haemophilia Society for more details.

### **Importance of physical activity**

Physical activity is very good for your physical and emotional health and well-being. People with vW should exercise regularly to keep their joints and muscles strong and to keep healthy. Swimming, walking, cycling, hiking, golf and tennis are just some of the recommended activities to maintain general fitness and muscle tone.

There are certain activities which should be avoided as they carry a high level of risk such as rugby, karate, skiing and other contact sports. Your doctor may want you to think carefully about the activities you want to do. Staff at the haemophilia centre can advise you on physical activities.

### **Issues for parents**

People who have a child with a genetic condition often blame themselves or feel guilty. But you can only be guilty of something you have control over, and you have no control over your genetic make-up.

Children with vW can take part in all classroom activities and their motivation level and achievement rate will be the same as any other child's. Students with vW should be treated as any other student. Being seen as 'different' or 'special' can be harmful to a child's emotional and social well-being. It is only in cases of severe vW that bleeding episodes may mean your child has to miss some school and may need extra help in catching up with their school work. Treatments can be very frightening for a young child, and it is important for parents to be there to reassure them and let them know that everything will be alright.

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### Finally ...

To maintain a healthy lifestyle, learn as much as you can about your condition and understand the impact it has on your life. Find medical professionals with whom you feel comfortable and who listen to your concerns and needs. Working with your medical team and making decisions together will give you a greater sense of control and choice in managing your life and treating your condition.

Try not to let vW undermine your child's or your ability to live life to the full.

Remember vW is treatable and is most common in its mildest form. The majority of people with vW can live a full, normal and fulfilling life.

### Further Information

For further information on von Willebrand's contact:

The Haemophilia Society

Chesterfield House

385 Euston Road

London NW1 3AU

Tel: 020 7380 0600

Freephone: 0800 018 6068

Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk) Web site: [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

The Volunteer Telephone Support Network:

Need a listening ear? Talk in confidence to someone with similar experiences.

Freephone: 0800 018 6068

World Federation of Hemophilia (WFH)

1425 Rene Le Vesque Boulevard West

Suite 1010, Montreal

Quebec, Canada H3G 1T7

Email: [wfh@wfh.org](mailto:wfh@wfh.org) Website: [www.wfh.org](http://www.wfh.org)

### Reading List

#### Publications

Those publications marked with a (w) can be downloaded from our website.

- *A Guide for People Living with von Willebrand Disorder*  
Produced by the Haemophilia Foundation Australia, 1998
- *Meeting von Willebrand Disorder for the First Time – A Guide for Parents*  
Produced by the Haemophilia Foundation Australia, 1998
- *Understanding von Willebrand Disorder – A Guide for Teachers*  
Produced by the Haemophilia Foundation Australia, 1998
- *A Guide for Women living with von Willebrand's (W)*  
Produced by the Haemophilia Society, 2001
- *A Guide for Women and Girls with Bleeding Disorders*  
By Jill Williams, produced by the National Hemophilia Foundation, 1998
- *A Patient's Guide to von Willebrand's Disease*  
Produced by Centeon, 1996
- *Everyday a Milestone (video)*  
Produced by the Haemophilia Society, 1998

- *National Service Specification for Haemophilia and related Conditions (2001)*  
The aim of this specification is to inform those with responsibility for commissioning haemophilia services of the recommended standards of care that should be made available to all patients with inherited bleeding disorders.  
The specification was developed by the National Haemophilia Alliance, a partnership between patients with inherited bleeding disorders and professionals involved in the delivery of haemophilia care.

#### Articles

- *Von Willebrand Disorder*  
By Alex Susman-Shaw, article in *Nursing Standard*, April 1999
- *There's Life in the Sick Dog Yet!*  
By Catherine Slater for the Bulletin, Issue 1, 1998
- *Living with von Willebrand's Disease*  
By Nigel Shepherd for Bulletin 1995
- *Living with von Willebrand's Disease. A Tale of Three Generations*  
By the Baker Family for Bulletin 1995
- *Questions and Answers for Patients and Parents with von Willebrand's Disease*  
By Dr Paula Bolton-Maggs, 1995

#### **Hepatitis C (HCV) Booklets – produced by the Haemophilia Society**

- *Being There: A guide for parents of young people with hepatitis (1999)*
- *Living Life to the Full: A guide for young people (14 and older) on learning to live with hepatitis C (1999)*
- *Alive and Kicking: A guide for young adults on living well with hepatitis C (1999)*
- *Meeting the Challenge: A guide for adults with hepatitis C (w) (2001)*

#### **Other Fact sheets Available from the Haemophilia Society: All available on our website**

Benefits	Employment & Haemophilia
Haemophilia Gene Carrier 1- Carrier testing & counselling for possible carriers	
Haemophilia Gene Carrier 2 – Screening tests & other procedures	
Travel Insurance	Hepatitis C – Series of fact sheets
Haemophilia and HIV	Orthopaedics

#### **A full publications list is available from the Society**

#### **Sources of support**

Here are some sources of support, which you may want to call on from time to time.

You can *phone* our freephone helpline for support, advice and information on 0800 018 6068 between 9am and 5pm, Monday to Friday.

*Volunteer Telephone Support Network* - The Haemophilia Society has set up a telephone support network of volunteers, who are available to speak to other people affected by a bleeding disorder. The volunteers in the support network represent a broad range, from parents of affected children to adults who are affected. You may want to talk to someone who has already dealt with a particular problem to get some new ideas or to talk through your own ideas. You

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may want to share a worry or something that has gone well. It may be that you want to talk about general stresses.

Get in touch with our services team who will try and match you with a volunteer, or you can e-mail us at [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk) or phone us on 0800 018 6068.

### **From your haemophilia centre**

You should expect an explanation of the diagnosis, and its implications. This should also include the opportunity to talk to a nurse or a social worker, and to receive counselling and support if you need it. You can ask to be put in touch with someone else with von Willebrand's so you can compare notes and get support.

### **From a counsellor**

#### *Free services*

- Ask at your haemophilia centre for a counselling referral. There may be a counsellor attached to the centre; alternatively, staff at the centre may be able to access a counsellor in a different part of the hospital service.
- Ask your GP for a counselling referral. Some GPs have a counsellor as part of their group practice team.
- Contact Youth Access, which can give you details of young people's projects, information and advice, and counselling services in your area. The telephone number is 020 8772 9900.
- Many social workers and nurses are also trained counsellors.

#### *Fee-paying services*

The British Association for Counselling can supply a list of accredited counsellors in your area. The phone number is 01788 578328.

### **From other professionals**

Try the school nurses, teachers and tutors, nurses, doctors, social workers and other professionals involved in your care.

### **From family and friends**

Don't forget your parents and carers, other family members, friends and partner. They can all be vital sources of support.

The Haemophilia Society has a range of books on haemophilia specifically for children. If you would like a full list of our publications or to order a publication from those listed above, contact Tom on 0208 7380 0600 or email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk). You can visit our website at [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

We are grateful for the help and advice given in the production of this fact sheet. In particular we would like to thank Brady Baxter, Haemophilia Nurse Specialist, Great Ormond Street Hospital for providing advice on this fact sheet. We would also like to thank our corporate and trust sponsors.

**This fact sheet can be reproduced in a larger print. Please contact the Haemophilia Society for details.**

*The fact sheet can only give basic general information drawing on medical opinion and evidence available at the time of writing. Different people may give you different advice on certain issues and there may be some variations in the way care is managed in different hospitals and in different areas. It is important that you contact your own doctor(s) and nurses(s) for further information and advice on your own individual circumstances.*

*Revised June 2003*

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