



THE
HAEMOPHILIA
SOCIETY



**Dental care for adults with
a bleeding disorder**

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Introduction

In this booklet you will find information on looking after your teeth, mouth and gums, dental care and types of dental treatment if you have a bleeding disorder.

Good dental care is essential for everyone. Taking good care of your teeth, mouth and gums (oral hygiene) is important to reduce the risk of dental problems. Although many people feel anxious about seeing the dentist, regular visits will ensure that any problems can be identified and treated early, preventing more complex problems later on.

If you have a bleeding disorder, looking after your teeth, mouth and gums is especially important. Poor dental health can lead to gum disease, which can cause bleeding problems and tooth loss that could otherwise have been avoided.

Preventing dental problems is an essential part of oral care. Neglecting oral health leads to pain and swelling. Emergency visits are difficult to access so **DO NOT** wait until you are in pain to see your dentist. A successful preventative routine will reduce the need for treatment and should reduce the number of emergency visits.



Finding a local dentist

All dental practices have guidance to follow when treating someone with a bleeding disorder and for those with less severe bleeding, most procedures can be carried out in a dentist's surgery. If you are not already registered with a dentist, it's easy to find one that is convenient for you to visit.

- If you live in **England**, you can find a dentist by visiting the NHS Choices website at www.nhs.uk/Service-Search/Dentists/LocationSearch/3
- If you live in **Scotland**, visit www.mygov.scot/register-with-dentist/
- If you live in **Wales**, visit www.wales.nhs.uk/ourservices/findannhsdentist
- If you live in **Northern Ireland**, visit <http://servicefinder.hscni.net/> and use the 'Search for a service' facility.

If you need dental treatment in an emergency and you don't have a dentist, find one by calling NHS 111. Don't contact your GP, as they will not be able to offer emergency or out-of-hours dental care. Contact your haemophilia centre for further advice if necessary.

When looking for a dentist, contact the dental surgeries that are convenient to you directly to find out if they are accepting new patients and if so, register with the surgery. It's important to remember not all dental practices provide NHS dental care, so make certain to ask if you are unsure.

You may face difficulty in accessing primary dental care due to the lack of understanding by your dentist of your bleeding disorder. Some local dentists may refuse to undertake any major dental work because of your bleeding disorder. If this is the case for you, your haemophilia centre may have access to a dentist on site or be able to give you details of local dentists who specialise in treating patients with bleeding disorders. Do ask your haemophilia centre for advice.

The Haemophilia Society advice is that you see your dentist at least twice a year to help prevent dental problems.

Care provided by your local NHS dentist

For people with haemophilia, severe von Willebrand Disease and any other severe bleeding disorder, most major dental work such as extractions or surgery is carried out in hospital as a matter of precaution.

This allows your haemophilia centre medical team to give you any necessary treatment and to monitor your factor levels if necessary. But for routine extractions, if you can self-administer concentrate your haemophilia centre can often give you a treatment plan so that you can visit your community dentist.

If you have a mild bleeding disorder it is fine for you to attend your own dentist for routine care such as check-ups and fillings. For more invasive treatment such as tooth extractions, gum surgery or some deeper injections (nerve blocks) you and your dentist must contact your haemophilia centre for advice.

Your NHS dentist will provide treatment that is clinically necessary to help you protect and maintain good oral health. This means they will provide any treatment you need to keep your mouth, teeth and gums healthy and pain free. Talk to your dentist to find out what treatment options are available to you.

Dental implants (replacing missing teeth) are not routinely available on the NHS unless there is a medical need. The cost for a single tooth dental implant varies, and can range from £1,500 to £5,000.

If you normally pay for NHS dental treatment, the amount you pay will depend on what treatment you need. Ask your dentist to explain the current NHS dental charges and your treatment plan. See page x for information about who may be eligible for free dental care.

‘Oral bleeding is most commonly a consequence of dental disease and not a consequence of an inherited bleeding disorder.’

Dr Lochana Nanayakkara, Consultant in Restorative Dentistry

Find out more

For more information about NHS dental treatment, visit:

www.nhs.uk/common-health-questions/dental-health/which-dental-treatments-are-available-on-the-nhs/

Remember, you may need pre and post treatment with clotting factor concentrate, desmopressin (DDAVP) and/or tranexamic acid for certain dental procedures. It is important that your haemophilia centre is aware of all invasive dental treatment you have.

Avoid aspirin and NSAIDS (anti-inflammatory medicines like ibuprofen as they can increase bleeding.



Visiting your local dentist

Before your appointment

When booking your appointment, make sure that you tell the dental surgery that you have a bleeding disorder. It is important to give your dentist your haemophilia centre contact details in case they need to contact your haemophilia doctor or nurse to discuss treatment you may need. Ask your haemophilia team/dentist to give you a letter to take to your local dentist (see example below).



Hospital address / contact details

Dear colleague,

Re: Primary dental care for patients with inherited bleeding disorders

Thank you for registering....[patient name]...for primary dental care

Although he/she has an inherited bleeding disorder (.....) routine check-ups and hygiene work will be safe to perform at your practice. We are fully supportive of trying to deliver primary care for our patients as locally as possible.

Any concerns or questions should be referred to the Haemophilia Centre (email as above) for a reply within 48-hours.

Any interventional procedures should be referred to Dr
(name and contact details of dental consultant).

This hospital provides / does not provide emergency out of hours advice for acute dental procedures. Patients with inherited bleeding disorders needing access to emergency dental service should also contact our on-call haemophilia registrar via the hospital switchboard to ensure appropriate factor replacement and follow-up.

Yours sincerely,

During your appointment

On your first visit to a new dentist, you will be asked about your medical history, your general health and whether you smoke.

At your check-up, your dentist should:

- carry out a full examination of your mouth, teeth and gums
- ask about any problems you have experienced with your mouth, teeth or gums
- ask about your teeth-cleaning habits and give advice on the most appropriate ways for you to keep your mouth, teeth and gums healthy
- ask about and give advice on your diet, smoking and drinking
- discuss with you when your next visit should be
- identify if you need any further treatment, and if so, explain the risks and costs of any treatment.

If you need further treatment

Any further treatment that your dentist feels is clinically necessary in order to keep your mouth, teeth and gums healthy is all available if you have an NHS dentist. If your NHS dentist says that you need a particular treatment, you should not be asked to pay for it privately, but NHS dental treatment still has a cost. Medical conditions do not exempt patients from payment for dental treatment.

You don't have to pay for dental treatment if:

- you are under 18, or under 19 and in full-time education
- you are pregnant or have had a baby in the last 12 months
- you or your wife/husband are on low-income benefits, e.g. income support or pension credit guarantee credit.

You may be eligible for free or discounted treatment if you qualify for the NHS low-income scheme.

Find out more

For more information about paying for dental treatment, visit:

www.nhs.uk/common-health-questions/dental-health/who-is-entitled-to-free-nhs-dental-treatment-in-england/

Your dentist should give you a written treatment plan that sets out the treatment you need and the costs of that treatment. Remember, even if your treatment involves a number of visits, you will only pay one charge for each complete course of NHS treatment. And if your NHS treatment fails within 12 months, your dentist should repair or redo most treatment free of charge, unless you were advised that the treatment was unlikely to be long term.

Questions to ask if you need further dental treatment

- Who will be carrying out the procedure?
- How many times have they carried out this procedure?
- How much will my treatment cost?
- If there are complications and I need more treatment, will there be extra costs?
- Is the work guaranteed for a certain length of time?
- Who can I contact for advice after treatment?
- When do I have to pay?
- What happens if I am unhappy with the results?
- Who pays for any work that is done to correct any problems?

Oral hygiene and prevention

It's never too late to start taking better care of your teeth and gums. Good dental care can prevent problems and the need for treatment in the future.

Managing dental disease may require the use of clotting factor concentrates, so prevention is really important. The commonest problems are gum disease (periodontal), tooth decay (cavities), and tooth sensitivity.

Brushing

- Brush your teeth at least twice a day for two to three minutes; ideally, brush them after every meal. Use fluoride toothpaste to prevent tooth decay and holes in your teeth.
- **Spit, don't rinse.** Fluoride is an important ingredient in toothpaste as it helps oral health by strengthening the tooth enamel making it more resistant to tooth decay. If you need to spit and rinse, rub your teeth with a tiny amount of toothpaste afterwards to help protect them.
- Change your toothbrush every two to three months or sooner if the bristles are worn.
- Use a medium bristled toothbrush and don't brush too hard as this can cause the gums to bleed and eventually recede (especially around canine teeth and premolars).
- Develop a good brushing technique to remove plaque (bacteria that forms on teeth) and food particles from the inner, outer and biting surface of the teeth. Brushing your tongue will also help to freshen breath and remove bacteria.
- Electric toothbrush or manual? There is no evidence to suggest one is better than the other – if you brush and floss your teeth properly then a manual toothbrush works just as well. Whichever you use, you must brush your teeth at least twice a day.
- Avoid sharing toothbrushes to stop the spread of infections.

Healthy gums don't bleed

If you have bleeding gums, it may not be caused by your bleeding disorder.

It could be due to your oral hygiene, which can be easily managed.

Good oral health means you are less likely to need invasive dental treatment.

Flossing

- Ideally, you should floss every day as this keeps your gums and teeth healthy.
- Healthy gums do not bleed during flossing, even in people with a bleeding disorder, but you may find that your gums bleed or are sore for the first few days that you floss. This should stop once the plaque is broken up and your oral hygiene has improved.
- Try not to be too aggressive when you floss as you risk harming your gums.
- You should contact your haemophilia centre if gums bleed for longer than 20 minutes or bleeding stops and starts again.
- If you don't know how to floss or you find it difficult, your dentist can give you guidance.



Mouthwash

- Don't use mouthwash at the same time as brushing your teeth as it washes away the fluoride in your toothpaste. It is best to use a mouthwash at a different time.
- Fluoride mouthwashes are good for tooth decay.
- Chlorhexidine mouthwash (e.g. Corsodyl) helps with gum problems such as bleeding gums, gingivitis, irritated gums and mouth ulcers. It also helps with healing after dental surgery or treatment. Chlorhexidine mouthwash can cause brown stains on teeth so speak to your dentist before using it. Chlorhexidine can have side effects, but not everybody gets them. If you get irritation of the mouth, soreness or swelling of the inside of the cheeks then tell your dentist or haemophilia team.

Avoid sugary drinks and snacks

- Avoid eating sugary foods or drinking sugary drinks and fruit juices between meals as this can cause dental cavities.
- Processed foods can also have high amounts of sugar in them. Check the list of ingredients before you buy them – sugars may also be listed as carbohydrates.
- 'No added sugar' doesn't necessarily mean that the product is sugar free: it's simply that no extra sugar has been added.
- If you snack between meals choose healthier options such as cheese, raw vegetables, breadsticks, bananas and nuts.
- Drink still water, milk or diluted sugar-free fruit drinks.

Dental hygienist

- To prevent gum disease, visit your hygienist at least twice a year, as your teeth need to be routinely cleaned.
- A scale and polish is usually pain free, so it's important to let your hygienist know if you feel discomfort.
- Removing plaque can cause bleeding gums, so it may be necessary to use a treatment such as an antibacterial mouthwash.

Dental appliances

Braces

If you need braces a treatment plan should be agreed with your haemophilia centre medical team before it begins. When fitting your braces your orthodontist (specialist dentist) will take special care to avoid damage to your gums. Plaque can get trapped on your gums and teeth when wearing braces, causing inflammation and gum bleeding. Good oral hygiene with careful brushing and flossing is important while wearing braces. Clean each tooth individually, taking your time to ensure you have removed all the plaque. Visit your orthodontist regularly for adjustments to your braces and to check for cavities and signs of gum disease.

Dentures

If you have missing teeth you can be fitted with dentures. It's important that your dentures fit properly so you don't bite your gums and cause bleeding. You should remove your dentures for cleaning after eating. Use a soft-bristled brush, then rinse them in water before putting them back in your mouth. Clean your dentures every night, soaking them in a denture-cleaning solution to remove stains and bacteria.

Preventing dental emergencies

- Always wear a mouth guard when playing sport – ask your dentist to make one for you.
- Mouth guards can also be used protect your teeth from trauma caused by clenching and grinding.



Other causes of dental problems

Pregnancy

You can experience more bleeding from gums during pregnancy regardless of whether you have a bleeding disorder. Gingivitis (mild form of gum disease) during pregnancy can cause swollen, red, tender gums that bleed when you brush or floss. So, it's important to see a dentist during your pregnancy and for the first year afterwards. Dental treatment is free during this period (see page 6).

Xerostomia

Xerostomia (dry mouth) can be a side effect of medicines you are taking, certain diseases and infections, and certain medical treatments. It's also common in older people, particularly in women who have poor general health. Having a dry mouth means you are at more risk of dental decay, periodontal disease (gum disease), oral infections (particularly thrush) and intolerance of dentures. Xerostomia may cause you to have bad breath, especially during the night.

Receding gums

Receding gums can be prevented: the best way to avoid, prevent, and delay significant tissue loss is to know the cause. It can be caused by using a toothbrush with stiff bristles, which can also wear down the enamel on your teeth causing sensitivity. Gum disease (periodontal disease) means your gums become infected and come away from the surface of the tooth, causing deep gum pockets around your tooth and gum recession.

Smoking can cause severe gum recession and your gum tissue to lose vital blood supplies, allowing for infections and tissue loss. Giving up smoking will mean your gum tissue will have better circulation and less irritation, which will help keep your gums tighter around the roots.

Tongue and lip piercings can cause gum tissue to shift out of place, exposing the tooth because of repetitive rubbing against soft tissues and gradual damage to the tissue. But the biggest cause of receding gums is lack of dental care, delayed cleaning, untreated cavities and persistent gum problems.

HIV

If you have HIV you are more likely to have sores and infections in your mouth or on your tongue. If you have a low CD4 count, you may also be at higher risk of dry mouth, gum disease, mouth ulcers, thrush, abnormal cell growth, and fungal and viral infections. Speak to your dentist if your sores haven't healed within 7-10 days or you have an unusual change in your mouth.

You must tell your dentist your HIV status so that they can check for HIV-related gum problems and ensure that any medicines they use don't interact with your HIV medicines. Also tell your HIV specialist if your HIV treatment is causing you to have a dry mouth. Get your teeth professionally cleaned by a hygienist more often than twice a year if you are prone to plaque build-up.

Hepatitis C

If you have hepatitis C you may have lower levels of platelets or clotting factors other than factor VIII or IX due to liver damage, which can lead to easier bleeding. Treatment for hepatitis C can lower your immunity to infection so can cause mouth sores. Your dentist can advise you on your diet, vitamin supplements (e.g. vitamin B12) and mouthwashes that may help.

If you have HIV and/or hepatitis C you should:

- Tell your dentist and dental hygienist that you have HIV or hepatitis to ensure you receive appropriate dental care. Your confidentiality will be respected.
- Rinse your mouth twice daily with an antiseptic mouthwash.
- See your dentist regularly as they will have a good understanding of living with these viruses and can reassure you about any concerns you may have.
- Contact your haemophilia centre for haemophilia treatment recommendations and platelet levels (if indicated) before invasive procedures.

Types of dental treatment

Prevention advice

Your dentist will give you advice on how to prevent dental disease at your routine dental appointment. This might include advice on diet, showing you how to clean your teeth and how to stop smoking.

Hygiene treatment

Routine hygiene treatment is unlikely to cause any bleeding problems. But if your gum condition is poor and you need a local anaesthetic before your dentist cleans under the gums you might need to be referred to the hospital.

Removable dentures

Making and fitting dentures to replace missing teeth can safely be done by your local dentist.

Repairing teeth

Repairs might involve fillings, crowns or bridges to replace missing teeth. Your local dentist can do some of these treatments but it will depend on the type of local anaesthetic injection you need.

Removal of teeth and surgery

Tooth removal or surgery usually needs to be carried out in a dental hospital or hospital dental department so that you can have treatment beforehand to limit bleeding afterwards. This would be arranged by your dental and haemophilia teams. Avoid rinsing and spitting for up to 24 hours after having a tooth out to avoid dislodging the clot. Tranexamic acid can be used if bleeding persists.

Local anaesthesia and injection

Some injections can cause bleeding. They should therefore be done in a dental department or hospital. Others can be safely done by a local dentist.

How to complain about poor dental care

In most cases, if you are unhappy with the care or treatment you have received, it's best to speak directly to your haemophilia centre. Your haemophilia centre should be able to help you to work through any issues you are encountering accessing good dental care or treatment.

You may also want to speak directly to the dental practice concerned to tell them that you are unhappy with the care or treatment you have had when visiting the dentist.

Dental practices have their own formal complaints procedures, and many issues can be resolved in this way without being taken any further.



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With special thanks to Dr Lochana Nanayakkara, Consultant in Restorative Dentistry at the Royal London Hospital, for her help with this booklet.

Lochana is the Clinical Lead for the North London Adult Haemophilia Network Dental Service. She is also the Vice-Chair of the Dental Committee of the World Federation of Hemophilia.

The Haemophilia Society makes every effort to make sure that its services provide up-to-date, unbiased and accurate information about bleeding disorders.

We hope that this information will add to the medical advice you have received and help you to take part in decisions related to your treatment and care. Please do continue to talk to your doctor or specialist nurse if you are worried about any medical issues.

Your Society: getting in touch

The Haemophilia Society
52b Borough High Street
London SE1 1XN
Phone: 020 7939 0780
Email: info@haemophilia.org.uk
Web: haemophilia.org.uk



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