Managed Clinical Network – Special Care Dentistry South East Wales

Protocol for dental care of patients with Inherited Bleeding Disorders

October 2016

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1. Introduction

People with inherited bleeding disorders present a particular risk with regards to dental treatment. It is imperative these patients are treated safely and appropriately to avoid unnecessary risk of bleeding, but also to minimize the use of clotting factor concentrate in situations where alternative methods of treatment can be effective.
There are a number of conditions which may present to the dental surgeon, the most common being an uncharacterised bleeding tendency, where no laboratory abnormality is detected in the face of a clear history of bleeding. Of the inherited coagulation deficiencies Haemophilia A and B and Von Willebrand's disease account for 95-97% of those (Vassilopoulos and Palcanis 2007). Delivery of optimum outcomes requires partnership working between the patient, dental teams and haematologists. Dental care should focus on evidence-based preventive plans and quality treatment to ensure patients experience minimal treatment needs. This must be aided by wilful participation in any preventative dental plan by the patient. Patients must be made aware of how to prevent oral health problems in order to reduce the need for invasive dental treatment

2. Aim

The purpose of this protocol is to detail the care pathways which exist for the safe treatment
of patients with inherited and acquired bleeding disorders undergoing dental care, and provide guidance on how dental treatment should be carried out in this patient group.
The protocol:

- Aims to support the delivery of safe, high quality, patient-centred care which encourages a system of robust and transparent quality assurance and the appropriate use of resources in a cost effective and evidence based manner
- Supports a service design which encourages the use of a variety of service providers
- Provides an indication for a range of clinically justified management modalities, which are available to assist patients requiring dental treatment
- Follows 'Delivering Better Oral Health Toolkit' 3rd edition (2014) for evidence based oral health prevention
- Adopts the principles of the World Health organisation Surgical Safety Checklist
- Adheres to the Special Care Dentistry Communication Plan (Appendix D)

3. Scope

- All dentists and dental care professionals (DCPs) in South East Wales.
- For haematology team members including Consultants, medical and nursing staff
- All General Medical Practitioners (GMP's) in South East Wales

4. Dental Care Pathway for Patients with Inherited Bleeding Disorders

4.1 Service Objectives

The majority of dental treatment for adult patients with inherited bleeding disorders should be delivered wherever possible and safe to do so within the General Dental Services (GDS) (see table 2).
The salaried Community Dental Service (CDS) and / or Hospital Dental Service (HDS) can offer care to patients who because of their condition would not be suitable for treatment in the General Dental Service.
Paediatric patients would usually be seen in the CDS or HDS with some requiring treatment under General Anaesthesia (GA) in the hospital setting (see Section 4.7.1).
Dental treatment is provided with close liaison with the patient's haematologist, under a shared care arrangement. Adult patients within the CDS / HDS should be managed by a dentist from the Adult Special Care Dentistry team, whilst paediatric patients by a member of a Paediatric dental team.

When a patient is diagnosed with an IBD, the Haematologist should ensure that the patient is given oral health promotion/advice. For children this would include appropriate

referral to the Community or Hospital Dental Service, and for adults ensuring that the General Dental Practitioner is made aware of their IBD and the care pathway

4.2 Referrals

Where referral to a CDS or HDS clinic are required, the referring service should provide as much information as possible to care for the patient in an appropriate and timely manner.

4.2.1 Non-urgent secondary referrals are accepted for patients with one or more of the following parameters:
- Have a General Medical Practitioner (GMP) in Wales
- Have a Postcode in Wales
- Are under the care of a haematologist within Wales for a bleeding disorder
- Are unsuitable for treatment in the GDS, because of their disorder
- Require a shared care approach in order they can be safely managed

4.2.2 Referrals are not accepted for:
- Any patient who can access care from a General Dental Practitioner
- Any patient requiring non-operative treatment only (i.e. denture construction)

4.2.3 Urgent referrals

In cases where patients may need to be assessed urgently (i.e. with pain and or infection), referrals should be made directly through the dental emergency service and followed up with a faxed or password protected e-mail referral. The referrals administrator at the dental emergency service will contact the relevant senior clinician to arrange an urgent appointment.

4.3 Inherited Bleeding Disorders

4.3.1 Haemophilia A and B

Haemophilia is an X-linked disorder affecting approximately 1 in 10,000 people (World Federation of Hemophilia - www.wfh.org). Haemophilia A is a deficiency of factor VIII which is the most common haemophilia affecting 90% of sufferers.
Haemophilia B (Christmas disease) is a deficiency of factor IX. Both diseases result in a prolonged bleeding time.
The diseases are classified into the following categories:

Table 1: Classification of Haemophilia

Plasma Factor Levels	Degree of Haemophilia	Characteristics
<1 iu/dl	Severe	Frequent spontaneous bleeds. APTT significantly prolonged
2 - 5 iu/dl	Moderate	Few spontaneous bleeds. Bleeding after minor trauma. APTT significantly prolonged
6 - 40 iu/dl	Mild	Bleed only after trauma or surgery APTT may be normal or prolonged according to the plasma concentration and sensitivity of the laboratory assay

(Adapted from Berry et al 1996 and Brewer and Correa 2006)

Factor levels of >40iu/dl are unlikely to be associated with a bleeding tendency, with a level of >50iu/dl being the lower end of the normal range.

The treatment of haemophilia involves replacement of the deficient clotting factor by intravenous infusion to either control or prevent bleeding. The current replacement involves recombinant factor concentrates. Prior to this plasma derived factor concentrates led to further complications in this patient group with exposure to human immunodeficiency virus (HIV) and hepatitis C virus (HCV). Concern also has been expressed regarding exposure to variant Creutzfeld-Jacob disease (vCJD) (Brewer and Correa 2006).

4.3.1.1 Inhibitors to Factor VIII or Factor IX

Allogenic antibodies to infused factor VIII develop in up to a third of patients with severe haemophilia A, around 9% of patients with mild to moderate haemophilia and less than 3% of patients with haemophilia B. (The Haemophilia Society www.haemophilia.org.uk). These antibodies have been termed inhibitors since they inhibit the action of infused factor, tendering such treatments ineffective.
A patient with an inhibitor must be managed with alternative agents which bypass the need for the relevant factor e.g. recombinant VIIa or FEIBA. Immune tolerance regimes aim to eradicate the antibody, thus allowing the correct factor to be used again. A patient with an inhibitor who requires dental surgery is at increased risk of bleeding, since the bypassing agents are not as effective as sole use of the relevant factor. It is important in all patients with inherited bleeding disorders that prevention is optimised, dental treatment is minimised and management regimes in place to reduce the impact of their oral health on their medical condition, but it is absolutely essential in the case of patients with inhibitors to clotting factors.

4.3.2 von Willebrand's disease

von Willebrand's disease (VWD) is the most common bleeding disorder affecting up to 1% of the world's population (Lillicrap and James 2009). The central feature of the disease is an abnormality in von Willebrand factor, either quantitative (type 1 – partial quantitative, type 3 complete absence) or functional (qualitative – type 2) (Lillicrap 2008).

The symptoms of the disease are:
- Easy bruising
- Prolonged bleeding from lacerations
- Epistaxes
- Bleeding from gums
- Menorrhagia
- Post-dental procedure bleeding
- Post-surgical bleeding
- Excessive post-partum bleeding
- Muscle haematomas (type 3 VWD)
- Haemarthrosis (type 3 VWD)

(Lillicrap and James 2009)
Treatment of VWD can be divided into two types: adjunctive therapies that aim to provide indirect haemostatic benefit; and treatments that increase the plasma levels of von Willebrand factor and factor VIII. (Lillicrap and James 2009)
The main adjunctive therapy in use is tranexamic acid, which can be used for its local and systemic affects. To increase levels of von Willebrand factor and factor VIII either desmopressin (DDAVP), after a successful therapeutic trial, or intermediate purity plasma-derived factor VIII concentrates (which contain von Willebrand factor, the carrier molecule for factor VIII) can be used.

4.4 Providing dental care to patients with known bleeding disorders

Dental treatment can be provided under a number of regimes, co-ordinated with the patient's consultant. The aim of treatment is to ensure it is provided safely and in the best interests of the patient. One of the basic tenets of dental treatment is a prevention regime; aiming to reduce the prevalence of dental disease in patients and hence dental intervention (Anderson et al 2013; Rafique et al 2013).

4.4.1 Prevention planning

All patients with inherited bleeding disorders should have a comprehensive prevention plan. All interventions and recommendations should be based on evidence-based prevention advice as detailed in Delivering Better Oral Health: An evidence-based toolkit for prevention, 3rd edition (Department of Health 2014).
Prevention advice and intervention is provided by dentists and DCPs.

4.4.2 Treatment provided

The dental service for patients with inherited bleeding disorders provides any treatments necessary to make the patient dentally fit, including fillings, periodontal therapy, fixed and removable prosthodontics, orthodontics and extractions. Root canal treatment will

be offered to suitable patients where the prognosis of the tooth is deemed favourable, in order to avoid extractions.

4.5 Treatment planning in patients with known bleeding disorders

Due to advances in research and new dental techniques the majority of interventions can now be safely carried out without recourse to factor replacement or other cover. Table 2
illustrates the treatments that do and do not require cover. Further detailed information can be found in the subsequent sections.

Table 2: Managing dental procedures in patients with inherited bleeding disorders

Procedures that do not require factor cover +/- tranexamic acid	Procedures that require factor cover	Procedures that require factor cover with prolonged post-operative monitoring
Examination Radiographs Local anaesthesia: Buccal infiltrations (upper and lower arch) Intra-papillary injections Intraligamentary injections Non-surgical periodontal therapy Restorative treatment Endodontic treatment Orthodontic and prosthodontic treatment	Simple extractions (1 - 3)	Planned surgical or multiple extractions (≥ 4 teeth) Biopsies Local anaesthesia: Inferior dental block Lingual infiltrations Any patient with factor inhibitors are treated as requiring prolonged postoperative monitoring for any extraction unless informed otherwise by the patient's consultant.

4.5.1 General principles

Dental treatment should be carried out with care in patients with inherited bleeding disorders to prevent accidental damage to the oral mucosa. Local haemostatic measures should be taken to address any localised bleeding which includes the use of suturing wounds, the use of oxidised cellulose packing (e.g. surgicel) and postoperative anti-fibrinolytic agents.
Tranexamic acid has been shown to significantly decrease the amount of factor replacement necessary to undertake surgical procedures (Brewer and Correa 2006). It

binds to plasminogen and inhibits subsequent lysis of fibrin. Orally administered tranexamic acid does not appear in saliva at detectable levels (Sindet – Peterson 1987), but it can be used topically as a mouthwash to inhibit fibrinolysis for hours, increasing the stability of the clot. In order to benefit from systemic effects in patients with inherited bleeding disorders a 'rinse and swallow' technique is advocated (Scully et al 2002).

4.5.2 Periodontal treatment

It is thought unlikely that periodontal treatment such as a scale and polish will result in significant bleeding even in patients with factor inhibitors (Brewer 2008). However, in practice some patients will experience unacceptable bleeding, which can be minimised by the use of tranexamic acid tablets, taken 24 hours prior to the periodontal treatment. Blood loss can also be controlled by direct pressure and the use of post-operative tranexamic acid mouthwash, which has been found to be as effective in reducing haemorrhage after scaling as factor replacement (Lee et al 2005).
In patients with severe periodontal disease it may be necessary to undertake the treatment over a number of visits. Initially, supra-gingival scaling, intensive oral hygiene instruction and advice regarding use of chlorhexidine gluconate mouthwash, followed by sub-gingival scaling once inflammation has reduced. (Brewer and Correa 2006).
Many patients with severe haemophilia will be receiving regular haematological prophylactic replacement and their prophylaxis can be tailored so that it is given prior to any treatment. If bleeding occurs then the haemophilia centre will advise on future episodes of periodontal treatment.

4.5.3 Local anaesthesia

The majority of dental treatment is routinely carried out under local anaesthesia, a bleeding disorder is no indication for deviation from this practice.

4.5.3.1 Buccal infiltrations

Buccal infiltrations can be used safely in patients with inherited bleeding disorders without recourse to factor replacement. Local anaesthetic solutions containing a vasoconstrictor would be preferential due to the local effects on haemostasis (Brewer and Correa 2006). Standard infiltrations using lignocaine 2% with adrenaline 1:80,000 can be used to anaesthetise all upper teeth and lower anterior and premolar teeth. The buccal bone around the lower posterior teeth is denser and does not allow infiltration so readily but this can be
surmounted by using articaine 4% with adrenaline 1:100,000. This amide local anaesthetic can be used to successfully anaesthetise lower posterior teeth using the standard infiltration technique (Brewer 2008).

4.5.3.2 Intra-papillary and intraligamentary injections

Can be used to supplement buccal infiltrations to achieve palatal or lingual anaesthesia for upper or lower teeth. With intraligamentary injections there is a slight risk of bleeding into the periodontal ligament. (Brewer 2008).

4.5.3.3 Inferior dental blocks and lingual infiltrations

Inferior dental blocks which are the routine mode of anaesthesia for lower molar teeth should only be administered after raising the clotting factor levels. With this technique there is a risk of bleeding into the muscles and hence haematoma formation in the

retromolar or pterygoid space which may result in airway compromise. (Brewer and Correa 2006) Similarly lingual infiltrations can result in significant airway compromise due to bleeds from the lingual vessels.
As discussed above both techniques can be avoided by use of buccal infiltrations with either lignocaine and adrenaline, or articaine and adrenaline, plus supplemental techniques.
Should an inferior dental block be deemed necessary due to the nature of treatment being undertaken eg multiple molar extractions in patients who are having factor replacement therapy then a standard technique should be used with an aspirating syringe to avoid administration close to vessels.

4.5.4 Restorative treatment

Routine and advanced restorative treatment can be carried out in patients with inherited bleeding disorders, including those with inhibitors providing the local anaesthetic guidelines above are adhered to (Brewer 2008). Care should be taken to protect the oral mucosa and any bleeding resulting from the use to matrix bands or wooden wedges can be controlled using local measures. (Brewer and Correa 2006).

4.5.5 Endodontic treatment

Endodontic therapy is considered low risk in patients with inherited bleeding disorders. Routine endodontic techniques should be undertaken including the use of rubber dam. It is important to ascertain the working length of the canal and to keep instrumentation within the canal space to prevent bleeding in the periapical tissues.
Bleeding from pulp tissue can be controlled by thorough removal of any remaining tissue and use of sodium hypochlorite as an irrigant. Calcium hydroxide paste as a medicament may be used to control bleeding. Continuous bleeding at the apical foramen may cause problems if the final root canal filling is placed early but this can be managed by the methods above. (Brewer 2008).

4.5.6 Orthodontic and prosthodontic treatment

Removable and fixed appliances can be used without concern providing due respect is given to mucosal integrity and ongoing gingival and periodontal health. (Brewer and Correa 2006)

4.5.7 Extractions and surgical procedures

Extractions and surgical procedures must always be planned with the patient's haematology consultant, as they would require cover in all but very mild cases of inherited bleeding disorders. In general terms teeth should be removed either singly or in small numbers to ensure haemostasis can be achieved, particularly the first extraction/s. The following procedure should be carried out for extractions:
• Extractions should be conducted as atraumatically as possible with minimal impact on the gingival tissues.
• Following extraction the socket should be packed with oxidised cellulose e.g. surgicel and sutured if the margins of the socket do not oppose well.
• Patients should be advised to bite onto a pack post-extraction which has been dampened with tranexamic acid solution. The clinics where haematology patients are seen stock a 10% tranexamic acid solution (5ml) for use on dental packs in the surgery setting only. For further information on tranexamic acid please see section 4.6.6.

• Appropriate post-operative monitoring should be arranged in liaison with the patient's haematology consultant.
• Standard post-operative instructions should be given to patients with particular reference to contact details should they experience postoperative bleeds or complications. The standard instructions should be altered to ensure the information is relevant for patients with inherited bleeding disorders, particularly the removal of ibuprofen as a suitable post-operative pain reliever.

4.5.7.1 Post-extraction complications

With careful planning, post-extraction and post-procedure haemorrhage should be unlikely. Should any bleeding occur the following should be undertaken:
• If the bleeding is significant and/or prolonged and there is concern for the patient's health they should be referred directly to:
o Paediatric patients (<16) – should attend Paediatric Assessment
o Adult patients (>16) – should attend an Emergency Oral and Maxillofacial Clinic or Accident and Emergency
• In these cases the Haematology or Paediatric Consultant or specialist nurse must be contacted immediately

• Otherwise and if able:
• Inspect the wound to try to identify any bleeding points
● Use local anaesthesia to provide pain relief and local vasoconstriction
• Any mucosal tears should be sutured
• Bleeding from within the socket should be managed by irrigation and repacking
• The patient should be instructed to sit up and bite firmly on a pack dampened with tranexamic acid mouthwash solution
• An analgesic may be prescribed
• Once all local measures have been carried out the patient should be referred directly to the haematologist.

4.6 Procedure for arranging dental care in patients with known bleeding disorders

The overview of the care pathway for patients with inherited bleeding disorders can be found in Appendices A for Cardiff and Vale University Health Board including those patients based within Aneurin Bevan University Health Board and Cwm Taf Health Board.

Information leaflets for patients regarding the link between dental health and their haematological condition; and information leaflets for dentists on treatment of these patients can be found in Appendices D-G.

4.6.1 Assessment appointment

Routine Cases

A thorough medical, dental and social assessment will be made at the initial appointment. It is important that the patient's social circumstances are not forgotten as this it likely to impact on the arrangements for post-operative monitoring if necessary. The treatment need will be discussed with the patient and any options for treatment

before a treatment plan is finalised. Following the assessment a report and treatment plan will be sent to the patient's Haematology consultant this will detail the treatment needed by the patient and the suggested sequence of treatment. Any treatment items which may require factor cover and or tranexamic acid tablets/mouthwash will be indicated by the dentist.
The Haematology consultant will forward a surgical management plan for the individual patient prior to any intervention appointments. The plan details the arrangements for each individual appointment or treatment item if needed or general management strategy.
The plan will also include details of who to contact in the event of post-operative complications.

Urgent Cases
Urgent cases will require close liaison in management between the local Oral and Maxillofacial Surgery and Haematology teams. These patients are likely to attend through a dental emergency clinic, the haematology clinic or Accident and Emergency. A thorough dental assessment should be undertaken, including radiological examination where required, to ascertain the immediate dental need. Liaison with the local haematological clinic / staff on call should be undertaken swiftly to arrange any appropriate haematological cover required to allow the dental procedure to be completed safely.

4.6.2 Subsequent appointments
The treatment plan should be scheduled to address treatment needs in a systematic manner. In the absence of pain the treatment plan should begin with intensive prevention advice and intervention, moving on to restoration of carious teeth. It is imperative that teeth should be restored before embarking on extractions as the number of visits and exposure to factor cover should be kept to a minimum. In some circumstances it may be unavoidable to undertake extractions before all other treatment has been completed but this should be avoided whenever possible.

4.6.3 Appointments where no factor cover is required
Ideally appointments will be offered for dental treatment close to the patient's home. In some circumstances this may not be possible and is dependent on clinician availability. Patients will be offered standard post-operative care advice and instructed on who to contact should they experience any problems. In almost all instances this will be the hospital department.

4.6.4 Appointments where factor cover is required
Appointments should be scheduled for mid-morning, this will allow patients sufficient time to attend the hospital for factor cover and get to the dental appointment. It also allows adequate time to monitor patients post-operatively during working hours.
Ideally appointments will be undertaken at a clinic close to the Haematology Department; this will be dependent on clinician availability.
Patients will be instructed on who to contact in the event of any problems; this would normally be the hospital department.

4.6.5 Post-operative monitoring

The arrangements for post-operative monitoring will be directed by the patient's haematology consultant. In some cases it may be appropriate for patient to be released home to be monitored by an appropriate person, they may remain at the dental clinic, or be monitored in the hospital setting.

4.6.6 Tranexamic acid

Tranexamic acid as either a mouthwash or tablets should be prescribed for the patient by the patient's consultant or Hospital service. The prescription will indicate a suitable dose according to the patient's condition and body mass and whether (if mouthwash) the solution is for oral rinsing only or for use in a rinse and swallow technique.
Tranexamic acid for use as a mouthwash is an unlicensed preparation which can only be obtained by special order. The solution has a short shelf life (North West Medicines Information Centre 2007) and therefore should be obtained and supplied to the patient close to the appointment time.
Tranexamic solution (5ml at 10%) is available, in clinics where haematology patients are seen, for local application to dental packs following extractions.

4.6.7 Completion of episode of care

At the end of the treatment course patients will be advised on the recommended recall interval in line with National Institute of Health and Clinical Excellence guidelines (National Institute of Health and Clinical Excellence 2004). Patients will be informed on who to contact in case of dental problems or an urgent dental need.

4.6.8 Discharging patients to the General Dental Service (GDS)

Ideally patients with stable oral health should be referred from the CDS or HDS to the GDS on completion of their course of treatment. Patients in this category would be managed in a shared care model by accessing a regular dentist for routine check-ups and being treated on referral by the Hospital Dental Service for interventions, particularly where factor replacement therapy or post-treatment monitoring is required.

4.6.9 Feedback to Haematology Consultants after treatment episodes

Should any patient experience problems during treatment or post-intervention this should be fed back to the Consultant haematologist by the most appropriate means (telephone conversation, e-mail and/or letter) and documented clearly in the clinical records.
Any adverse incident should be reported via the normal reporting and management of incidents arrangements.

4.7 Special considerations

4.7.1 Paediatric patients

Although the normal modality for treatment for patients would be local anaesthesia, and there is no justification for general anaesthesia in adult patients for the reason of their inherited bleeding disorder, it is accepted that general anaesthesia or conscious sedation may well be justified in paediatric patients. It may be considered particularly when a large number of treatment items require completion or when the patient is

unable to sufficiently cooperate with the treatment to achieve oral health. All other options for treatment will be considered before resorting to general anaesthesia.
The majority of paediatric patients with inherited bleeding disorders will remain under the care of the Hospital / Community Dental Service, unless it is agreed with the parents and the general dental practitioner that they can be cared for primarily in the general dental service with their family.

4.7.2 Patients requiring prolonged post-operative monitoring

It may be felt that some patients, particularly those with factor inhibitors or severe disease may benefit from a period of prolonged monitoring which would render them unsuitable for treatment in the primary care setting. In these cases adult patients may be treated in the hospital setting with the benefit of an inpatient bed. Patients can be treated under local anaesthesia in the theatre setting utilising the Oral and Maxillofacial Surgery / Special Care Dentistry lists before ward based monitoring. Child patients may be treated on the Paediatric Comprehensive Care list as outlined above in section 4.7.1.

4.7.3 Referrals to other services.

It may be necessary to refer patients to other services to complete their episode of care. The patient's consultant will be informed of any onward referrals.

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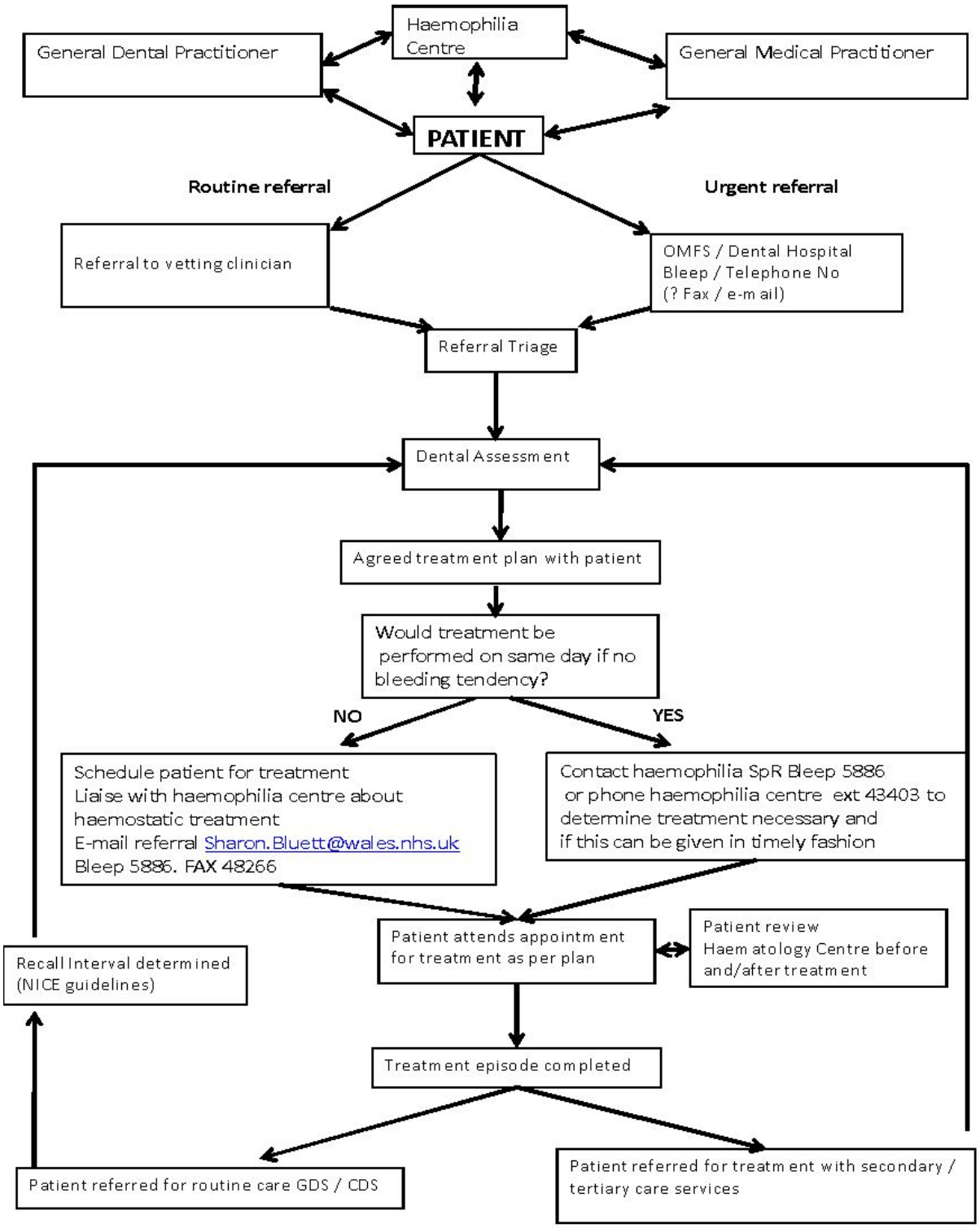
Appendix A – ABHB, C&VUHB & CTHB Care Pathway



Appendix B – Patient Information Leaflet

Arthur Bloom Haemophilia Centre,
University Hospital of Wales,
Heath Park,
Cardiff.
CF14 4XW.

Inherited Bleeding Disorders (IBDs)

Looking after your teeth and gums

Who is this leaflet for?

You may have a bleeding disorder such as haemophilia, von Willebrand's disease or a platelet disorder or be a relative or carer for someone with these conditions.

Why are your teeth and gums important?

It is important for people with bleeding or clotting disorders to take good care of their teeth and gums. This can reduce problems like toothache, mouth infections or extractions. It can also reduce the need for medical treatments, such as transfusion of clotting factors or blood products.

How do I prevent dental problems?

You can prevent dental problems by:

- Brushing your teeth, at least twice daily.
- Reducing the frequency and amount of sugar in your diet.
- Avoiding smoking.
- Having regular check-ups with a dentist, at least twice a year.

Attending the dentist

You must tell your dentist about your medical condition. If you are not sure, just check with your Haemophilia Centre.
Remember to update your dentist if your medical condition changes.

It is completely safe to attend your general dental practice for regular check-ups and most types of dental treatment. Your dentist **must** contact your Haemophilia Centre for advice before some types of dental treatment, because of the higher risk of bleeding complications, such as:

- Tooth extractions.
- Nerve blocks.
- Gum surgery.

- Dental implants.

Frequently asked questions

Can I use my local dentist?

Yes, you can use your local dentist for most of your dental care. Many of us like getting a full range of dental care in a convenient location. Your local dentist may be able to do many aspects of treatment, but this depends on the severity of your condition and the type of dental treatment you need. For some procedures, you may need to come to the Dental Hospital.

If you or your dentist need more advice, please contact the Haemophilia Centre on 02920-743403.

Should I brush my teeth if my gums bleed?

Bleeding gums are a sign of gum disease. Commonly, people notice this when brushing their teeth. Sometimes people avoid brushing, due to the bleeding. In fact, this makes the problem worse. Teeth can become loose and eventually be lost.
We recommend using a soft/medium toothbrush with a small head and a pea-sized amount of toothpaste containing fluoride, at least twice a day. Electric toothbrushes are also very effective.

What if my gums continue to bleed, despite brushing regularly?

If your gums continue to bleed, seek advice from your dentist, who will recommend other methods of cleaning your teeth and tooth brushing.

Your bleeding disorder may mean your gums bleed a little more easily and for a little longer, until the gums heal. Your dentist or dental hygienist may recommend professional cleaning. Patients are often advised to take tranexamic acid tablets or mouthwash before and after professional teeth cleaning.

What is Tranexamic acid?

Tranexamic acid prevents blood clots from breaking down and helps to stop bleeding.

What happens if I need a tooth extracted?

This must always be co-ordinated by your Haemophilia Centre. They will arrange this with your dentist or a specialist dental centre. The Haemophilia

Centre will advise you about the need for factor replacement therapy, based on the severity of your bleeding disorder.
Tranexamic acid tablets or mouthwash are normally prescribed before and after the extraction. The dentist will stitch the wound and use a special surgical pack, to stop any bleeding.

I cannot find a dentist locally. What should I do?
Phone your Haemophilia Centre on 02920-743403.
You will be given a number to contact, depending on where you live. You will be assigned to a dental team in the Hospital Dental Service or the Community Dental Service.

My dentist seems to be unsure of treating me because of my condition. What should I do?
Please show your dentist this leaflet, and the 'information for dentists' letter.

What should I do if I have a dental emergency?
Phone your own dentist for advice first or contact NHS Direct on 08454647.
If you are not registered or cannot contact an emergency dentist, phone the Haemophilia Centre on 02920-743403.

For more information, please visit the website www.wfh.org for oral care for people with haemophilia or a hereditary bleeding disorder.

Appendix C – Dentist Information Leaflet

Arthur Bloom Haemophilia Centre,
University Hospital of Wales,
Heath Park,
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Inherited Bleeding Disorders (IBDs)

Dear Dentist,
All patients with inherited bleeding disorders should be seen for regular dental checks in general dental practice.
Most patients can safely receive most of their dental care, including invasive procedures, in general dental practice. This includes patients with moderate (1-5% clotting factor) or severe haemophilia (< 1% clotting factor) because they are usually able to self-administer treatment to correct their blood clotting system.
The Haemophilia Centre can advise on how to correct haemostasis for any invasive procedure or whether the patient needs to be referred to the Dental Hospital for a specific treatment on a case-by-case basis. Treatment might include the use of tranexamic acid or self-administering coagulation factor concentrate or desmopressin.

General tips
The following procedures are safe for patients with mild haemophilia:

- Fillings; avoiding nerve blocks and lingual infiltrations and careful use of suction/aspirators.
- Supragingival scaling; but it needs to be staged and covered with tranexamic acid, if oral hygiene is poor.
- Root canal treatment, with careful rubber dam placement and working within the anatomical apex.
- Dental impressions, with careful tray placement and gentle soft tissue handling.
- Radiographs; careful positioning in the floor of the mouth and retromolar regions.

Areas of concern
Please consult the Haemophila Centre prior to the following procedures for advice on haemostatic treatment. These procedures pose a significant risk of bleeding complications for all patients with bleeding disorder but can often be safely performed with appropriate haemostatic cover:

- Nerve blocks
- Dental extractions
- Sub-gingival root debridement
- Dental implant placement
- Minor oral surgical procedures

Local Anaesthesia
Buccal infiltrations, with aspirating syringes, are safe to use for patients with bleeding disorders. Lingual infiltrations and inferior dental (ID) blocks can potentially cause deep bleeding, which may compromise the airway unless the patient has had appropriate haemostatic cover.

Alternative techniques to anaesthetise lower molar teeth include buccal infiltration injections with 4% articaine and intra-ligamentary anaesthesia.
If an ID block is necessary, patients with **less than 30% clotting factor** levels will require factor replacement therapy, before administering the injection.

Pain relief
NSAIDs and aspirin can aggravate bleeding but may be used on a case by case basis if haemostasis has been corrected. **Do not** prescribe without receiving advice from the Haemophilia Centre.
Paracetamol or codeine-based products are more appropriate to use.

Concurrent illness
Patients with other conditions, such as liver dysfunction, must be referred to a specialist dental centre, as there is increased risk of bleeding complications.

If you have any queries or concerns, please contact:
Arthur Bloom Haemophilia treatment centre on 02920-743403 (Monday-Friday 9am-5pm)
Specialist dental centre: Special Care and Sedation Unit, Cardiff University Dental Hospital on 02920-746356 (Monday-Friday 9am-5pm).
Oral Surgery Unit, Cardiff University Dental Hospital on 02920-742416 (Monday-Friday 9am-5pm).
Community Dental Service: Cardiff and Vale HB: 02920-190175; Pontypridd: 01685-351000; Cwm Taf HB: 01443-680166; Powys HB: 01267-229692, Aneurin-Bevan HB: 01633-623728/9.

For more information, please visit the website www.wfh.org for oral care for people with haemophilia or a hereditary bleeding disorder.

References:
1. Brewer A., Correa M.E. (2006) Guidelines for the dental treatment of patients with inherited bleeding disorders. World Federation of Haemophilia Monograph No. 40.
2. Lee A., Boyle C., Savidge G., Fiske J. (2005) Effectiveness in controlling haemorrhage after dental scaling in people with haemophilia by using tranexamic acid mouthwash. BDJ; 198: 33-38.
3. Scully C., Dios P.D., Giangrande P. (2008) Oral care for people with hemophilia or a hereditary bleeding tendency. World Federation of Haemophilia Monograph No. 27.

Appendix D – Special Care Dentistry Communication Plan

SPECIAL CARE DENTISTRY
Communication Plan

January 2015

The Special Care Dentistry in Wales Implementation Plan (November 2011) confirms a requirement to provide 'regional and relevant local information for patients and clinicians' together with 'interim and substantial guidance regarding network and speciality development'. It is good practice for the SCD Advisory Group to have a Communication Plan

Communication Standards

Working with all relevant local stakeholders, Managed Clinical Networks (MCNs) in consultation with Health Boards will comply with Standard 18 of the Standards for Health Services in Wales and ensure effective, accessible, appropriate and timely communication and information sharing:

- internally and externally;
- with patients, service users, carers and staff using a range of media and formats;
- about patients, service users and their carers;
- on the full range and locations of services they provide; and
- address language and communication needs

MCNs will need to identify their key stakeholders and service users to ensure communications are clear and appropriate for their target audience

Key stakeholders

Key stakeholders include internal and external colleagues, as well as the public. They will include:

SCD patients and carers
Welsh Government
Local Health Boards
Public Health Wales
Consultants and Specialists in Special Care Dentistry
Community Dental Services
Consultants and Specialists from other Dental specialities
Dental Practitioners and their teams
Local Authorities
Third Sector

Communication Mechanisms

HBs and MCNs to establish develop and agree effective methods of communication with key stakeholders. A variety of communication methods should be considered and may include websites, newsletters, e-bulletins, network meetings, social media and other mechanisms to share key messages, stimulate discussion and allow effective 2 way communication

There must be Individual responsibility and accountability for maintaining the local NHS Website.

Key messages to communicate

The SCD Advisory Group will want to see a level of consistency across the MCNs while allowing for appropriate local flexibility. The key components will include :-

The range and location of services, opening hours, access, facilities and contact details

Dental helplines and what to do in the event of urgent dental need

In line with principles of prudent healthcare, information will be included for patients, service users and carers on their role in maintaining their oral health and preventing oral disease and helping them to make healthy choices

Patient experience and feedback should be sought in line with principles of the National Service User Experience Group. This should be taken into account when developing and delivering services, and should be used appropriately to improve services. Use of patient experience and feedback should be communicated.

A reference to the CDS Annual Quality Statement in line with health board process for AQS publication

Role of the SCD Advisory Group

The SCD Advisory Group will take a lead role in ensuring that the Communication Plan:

- Addresses the issues outlined in the SCD Implementation Plan November 2011;
- Focuses on the needs of SCD patients and carers;
- Ensures access to relevant and up to date information is available to all stakeholders;