

**Emergency and out of hours care for patients  
with bleeding disorders –  
Standards of care for assessment and treatment.**

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## **Background**

In the UK, care for patients with haemophilia and related bleeding disorders is coordinated via a network of designated Haemophilia Centres (HC) or Haemophilia Comprehensive Care Centres (HCCC). All HCs and HCCCs are involved with the provision of emergency care. Registered patients have open and direct access to the haemophilia centre during the normal working day. However, arrangements for the provision of care in the evenings, at night and at weekends varies between centres. A recent survey of current practice identified that at present there is no uniform model for the provision of emergency care (*UKHCDO survey – results presented at 2008 AGM, Nottingham*).

The experience of patients attempting to access emergency care is also variable. Many patients report poor experiences when dealt with in the Emergency setting (*Pan Thames Haemophilia Consortium – Review of Configuration of Haemophilia Services, 2008*). Often appropriate advice from the local HC or regional HCCC is not sought and appropriate follow-up arrangements are not made (*E Franklin, Abstract World Federation of Haemophilia meeting, 2008*). This can result in significant morbidity and occasional mortality. Involvement of medical staff with the appropriate knowledge and expertise in the care of patients with bleeding disorders in these circumstances is essential.

For patients with bleeding disorders who are already hospitalised – there is also an issue with the delivery of out of hours care. There is an increasing move to the provision of cross cover arrangements in hospitals and the development of “Hospital at Night” teams to deliver care within the range of speciality areas. It is important that the pathways of

care for both the assessment and delivery of treatment of hospitalised patients with bleeding problems are robust.

This document aims to provide a framework for the establishment of standards for emergency and out of hours care which should be applied within existing regional haemophilia networks and subject to local audit.

## **Existing Standards**

Standards for emergency care of patients with bleeding disorders have been recommended in the “National Service Specification for Haemophilia and Related Conditions” (full document available at: [www.haemophiliaalliance.org.uk](http://www.haemophiliaalliance.org.uk)):

### ***7.2 On-call arrangements***

Patients with haemophilia are often not treated appropriately when they present out of hours to an accident and emergency department. Effective treatment is more likely to be administered promptly and efficiently if the following measures are adopted:

- On call arrangements for haemophilia should be clearly identified to junior hospital medical staff and triage nurses
- There should be a consultant haematologist on-call at all times with responsibility for patients with haemophilia; appropriate mechanisms should be in place for meeting the training needs of such consultants
- Junior medical staff responsible for the care of haemophilia out of hours should receive formal education about haemophilia and its treatment
- A protocol for the management of patients with haemophilia out of hours should be available to junior medical staff
- There must be laboratory back-up for the emergency care of patients with haemophilia and related disorders
- Patients should be given clear information as to who they should contact in the event of an emergency

- The exact way in which on-call arrangements are delivered to the above standards will need to be interpreted at local level following an assessment of staff levels and facilities; this may involve the establishment of shared on-call arrangements between Haemophilia Centres and Comprehensive Care Centres
- Local ambulance controls should be instructed to direct patients with haemophilia and related conditions to the nearest Haemophilia Centre, as long as the clinical situation allows

This document seeks to expand and define these measures in more detail – both to aid the planning and provision of emergency care and provide a framework of minimum standards for audit and service improvement.

## **Standard 1**

- **Patient / Parent education and information**

**All patients (or parents) should have clear written information about the type of problems which should prompt access for emergency assessment**

- All patients should be issued with the new “haemorrhagic states card”. In addition written information should be provided appropriate to the age and nature of the bleeding disorder (examples of information sheets for parents/carers of children with bleeding disorders are attached in *Appendix 1*).
- Specific information for mild/moderate patients should emphasise the importance of seeking attention following trauma. Patients/parents with non-severe bleeding disorders often under-estimate the potential bleeding following moderate trauma which may lead to a delay in accessing appropriate treatment.
- Specific written information concerning head trauma and symptoms of bleeding which may be unfamiliar (such as melaena) should be given to all patients/parents.
- Following trauma, patients who are on home therapy should self-administer treatment prior to coming to hospital.

- Specific consideration should be given to patients who do not speak English as their first language to ensure appropriate and understandable information is provided.
- Medic alert identification and information should be recommended to patients with severe bleeding disorders.

## **Standard 2**

- **24 hour open access**

**All patients with bleeding disorders should have open and direct access to emergency advice and assessment on a 24 hour basis.**

- The principle of direct access is very important.
- Prompt assessment and treatment of bleeding problems is associated with a better outcome – delays in treatment often lead to the need for more prolonged therapy for many bleeding episodes and adverse outcomes.



### **Standard 3**

- **Initial telephone contact**

**All patients should have a clearly written telephone number to use to make initial contact with the out of hours service**

- Early telephone contact ensures that telephone advice only can be given if required. Any telephone advice should be clearly documented.
- If urgent assessment is required the patient can be told directly where to attend according to local arrangements or the clinical situation.
- The HC should be informed about all out of hours telephone contact to ensure appropriate follow up arrangements are made.

## Standard 4

- **Ambulance services and transport**

**Patients with bleeding disorders who require emergency care should be transported to a hospital with a HC or HCCC.**

- Unnecessary delays to the assessment and treatment of bleeding problems sometimes occur if the patient is brought to an emergency department in a hospital without a HC. In addition treatment products are not readily available leading to further delays in patient management.
- The aim of emergency transportation should be to ensure the patient is brought to the most appropriate place according to the clinical circumstances. Even when the acute problem is not directly related to bleeding – it is important that the underlying bleeding disorder is managed appropriately for emergency surgery etc.
- In general all patients with bleeding disorders, on production of a haemorrhagic states card, should be taken to the hospital where their HC is located. ***If this is not possible the ambulance crew should alert ambulance control who should communicate the destination of the patient to the HC emergency contact number.*** This will facilitate early discussion with the destination emergency department and the transfer of the patient or dispatch of treatment products as appropriate.

- Clear arrangements with local ambulance services should be put in place to ensure good channels of communication between patients/parents, ambulance crew and the haemophilia service.

## Standard 5

- **Prompt assessment and treatment**

### **Prompt assessment and treatment should be provided in a designated clinical area**

- Patients should have access to an appropriate clinical area for out of hours assessment. The location may vary according to local arrangements. Children should have access to a dedicated paediatric area. If the Emergency Department (A&E) is used – there should be a mechanism to ensure delays do not result from the triage process.
- On arrival in the assessment area the *maximum time to assessment should not exceed 15 minutes*. If treatment is required the *maximum time to delivery of treatment should not exceed 30 minutes*.
- Local guidelines should emphasises the importance of adequate treatment after trauma – particularly in non-severe bleeding disorders – where the degree of bleeding provoked by trauma is often under-estimated (by patient, parents or health care professionals).

## **Standard 6**

- **Pathway of care for out of hours assessment and treatment**

**A written pathway of care for out of hours assessment, treatment and follow up should be constructed by every HC or HCCC.**

- Each HC or HCCC should construct a pathway of care for emergency situations. A suggested template is attached in *Appendix 2*. Such an algorithm should be adapted according to local arrangements. The pathway should also include audit, risk assessment and a mechanism for review of critical incidents / near misses within a clinical governance framework.
- The pathway should include a robust mechanism for notification to the HC of all out of hours attendances.
- There should be a clear mechanism for arranging appropriate follow up and early assessment of acute bleeds by a physiotherapist with specialised haemophilia knowledge (within 24 hours of initial presentation).

## **Standard 7**

- **Training of staff involved in out of hours assessment and treatment**

**All staff involved in out of hours assessment and treatment of patients with bleeding disorders should receive appropriate training.**

- Training should be provided by HC staff.
- Evidence of appropriate training of emergency department staff and familiarity with the local care pathway should be in place.
- Training should include:
  1. the importance of careful venous access
  2. the avoidance of intramuscular injections and drugs which exacerbate bleeding
  3. immobilisation of bleeding joints
  4. the reconstitution and administration of treatment products

## **Standard 8**

- **Emergency access to medical records and treatment products.**

**Medical records, treatment information and treatment products should be readily available in emergency situations.**

- Information required to ensure the appropriate treatment of patients with bleeding disorders should be readily available. As hospitals develop electronic patient records there is an opportunity to ensure rapid electronic information is available.
- Minimum clinical information should include:
  1. Diagnosis
  2. Severity (baseline clotting factor levels)
  3. Inhibitor status
  4. First line treatment product
  5. Previous response to treatment (particularly DDAVP)
  6. Previous adverse events
  7. Public health “at-risk of vCJD” status – previous UK plasma recipient
  8. HIV/HCV status
- All clinical episodes should be clearly documented.

- Treatment products should be stored in an accessible site to ensure ready availability in urgent situations - so there are no unnecessary delays in administration of treatment. The range of products available should be determined locally. There should be a robust method for the recording of all treatment administered to patients.
  
- Wastage of products should be minimised.



## **Standard 9**

- **Emergency access to expert haematological advice**

**Advice in the management of emergency clinical situations should be available from a Consultant Haematologist or Nurse Specialist with haemostasis expertise**

- Robust arrangements for the provision of on call expert advice should be in place within each haemophilia network.
- Local arrangements may vary but should include 24 hour access to either a doctor or nurse specialist with appropriate training and experience.
- All HCs should have access to a regional CCC for emergency advice.

## **Standard 10**

- **Laboratory monitoring in emergency and out of hours situations**

### **Laboratory testing for emergency diagnosis of bleeding disorders and treatment monitoring should be available in all haemophilia networks**

- Appropriate laboratory support for the clinical service is essential. HC laboratories should be equipped to provide emergency coagulation factor assays.
- CCC laboratories should be equipped to provide specialised haemostatic tests (investigation of coagulation factor inhibitors, rare coagulation factor deficiencies and platelet disorders).

## **Standard 11**

- **Planned out of hours activities**

**Out of hours care of hospitalised patients should be carried out by appropriately trained staff.**

- Patients with bleeding disorders who are hospitalised for treatment of bleeding episodes or following surgery should be managed according to an agreed local treatment plan in order to prevent delayed bleeding.
- Prescribed treatment should be administered by staff with appropriate training. HC staff should provide such training.
- The importance of administration of treatment at the prescribed time should be emphasised.
- There should also be arrangements for planned out-patient treatments to be administered in an appropriate setting such as a designated ward.

## **Standard 12**

- **Audit**

**The standards of care outlined in this document should be subjected to regular audit**

- The demonstration of compliance with these standards of care for emergency and out of hours practice should be part of the external audit of CCCs and HCs.
- Audit should also involve the experience of patients and parents.

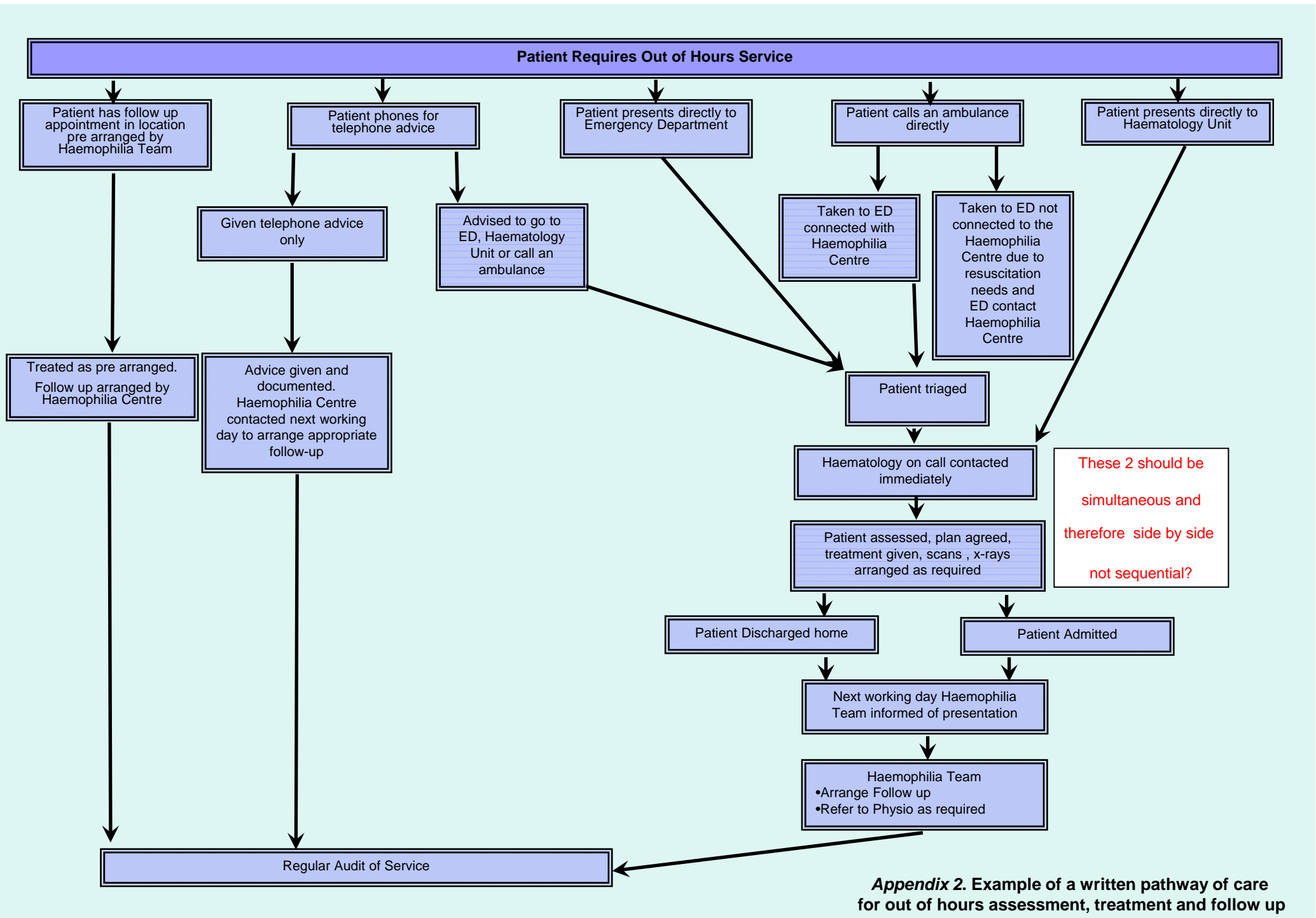
## **Appendix 1 – Examples of written information for parents/carers of children with bleeding disorders – edit as required for local use**

### **Advice for the parents and carers of children with severe bleeding disorders**

- Your child has a severe bleeding tendency which could lead to you needing to seek medical help and advice at times when your Haemophilia Centre is not open.
- Some potential problems will be recognisable to you, for example, a joint bleed if you have a son with haemophilia or an injury that has happened to them. However occasionally unusual symptoms can occur which you need to be aware of.
- If your child experiences any of the following you must discuss it with the doctor on call for your Haemophilia Centre even if you are planning to take your child to a more local Accident and Emergency department:
  - A head injury
  - A swollen, painful joint or muscle which limits your child's ability to move around
  - Blood in their urine or poo (this may not look like fresh blood, but more like tar)
  - Coughing up or vomiting blood
  - A nosebleed or bleeding from the mouth
  - A severe or sudden headache
  - Unexplained drowsiness
  - Severe back pain, especially if they cannot straighten their leg because of pain.
  - Pain in their tummy,
  - In babies and children who are not yet talking, refusal to eat, irritability or drowsiness can indicate a bleeding episode.
- Keep the contact phone numbers for your Haemophilia Centre and the hospital switch board number available at all times. This information will be on the haemorrhagic states card that has been given to you, along with information about your child's medical condition.
- If they are on home treatment it is often appropriate to treat them before taking them to hospital and this can be discussed with the doctor you speak to.
- **Even if you need to attend another hospital to get emergency care it is vital that you let your Haemophilia Centre staff know where you are taking your child. By informing the Haemophilia Centre staff, you will speed up the care you receive in another hospital because the centre staff can give advice to the doctors you see, who may never have seen a child with a bleeding disorder before.**

## **Advice for the parents and carers of children with mild or moderate bleeding disorders**

- Your child has a mild or moderate bleeding tendency (insert details) which could lead to you needing to seek medical help and advice at times when your Haemophilia Centre is not open
- Your child may have relatively few problems as a result of their bleeding disorder on a day to day basis but it is very important that you can recognise signs of potential bleeding and that you know how to seek medical help.
- If your child is significantly injured, the injury may not result in obvious external bleeding but can have life-threatening results if not treated appropriately.
- If your child experiences any of the following you must discuss it with the doctor on call for your Haemophilia Centre even if you are planning to take your child to a more local Accident and Emergency department:
  - A head injury
  - A swollen, painful joint or muscle which limits your child's ability to move around
  - Blood in their urine or poo (this may not look like fresh blood, but more like tar)
  - Coughing up or vomiting blood
  - A nosebleed or bleeding from the mouth
  - A severe or sudden headache
  - Unexplained drowsiness
  - Severe back pain, especially if they cannot straighten their leg because of pain.
  - Pain in their tummy,
  - In babies and children who are not yet talking, refusal to eat, irritability or drowsiness can indicate a bleeding episode.
- Keep the contact phone numbers for your haemophilia centre and the hospital switch board number available at all times. This information will be on the haemorrhagic states card that has been given to you, along with information about your child's medical condition
- **Even if you need to attend another hospital to get emergency care it is vital that you let your haemophilia centre staff know where you are taking your child. By informing the haemophilia centre staff, you will speed up the care you receive in another hospital because the centre staff can give advice to the doctors you see, who may never have seen a child with a bleeding disorder before.**



**Appendix 2. Example of a written pathway of care for out of hours assessment, treatment and follow up**