Living with Haemophilia:

IN THE CLASSROOM

A teachers' guide

The information provided is not a substitute for professional and/or medical advice. Please consult a healthcare professional for further advice

This brochure is intended for teachers of pupils with haemophilia and has been developed and funded by Takeda UK Ltd

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Haemophilia is a rare inherited condition that results in **blood** taking longer to **clot.**[1]

It means that everyday knocks and bumps can cause hidden internal bleeds.[2,3]

Because it is unusual, several misconceptions and myths surround it. For those living with the condition, such rumours can make life difficult. Affected children may worry unnecessarily, or lose confidence and self-esteem.[4–6] Teachers play a vital role in reassuring affected children – encouraging them to participate and thrive both in school and later life.[3]

In reality, almost all children and students with haemophilia enjoy school life just like anyone else. They join in everyday activities, go on school trips and excursions and play non-contact sports.[3,7]

Armed with a little knowledge, it's easy to safely monitor haemophilia – and straightforward to manage, should a minor injury occur.[3]

Teachers in the UK aren't expected to administer medication or injections to children with haemophilia in school.[8] This may be done by the child's parents or guardians, the student themselves (if older) or a medical professional from a local haemophilia centre.

If you're a teacher who has a pupil with haemophilia (or any other inherited clotting disorder) in the classroom, this brief guide should help you better understand the condition.

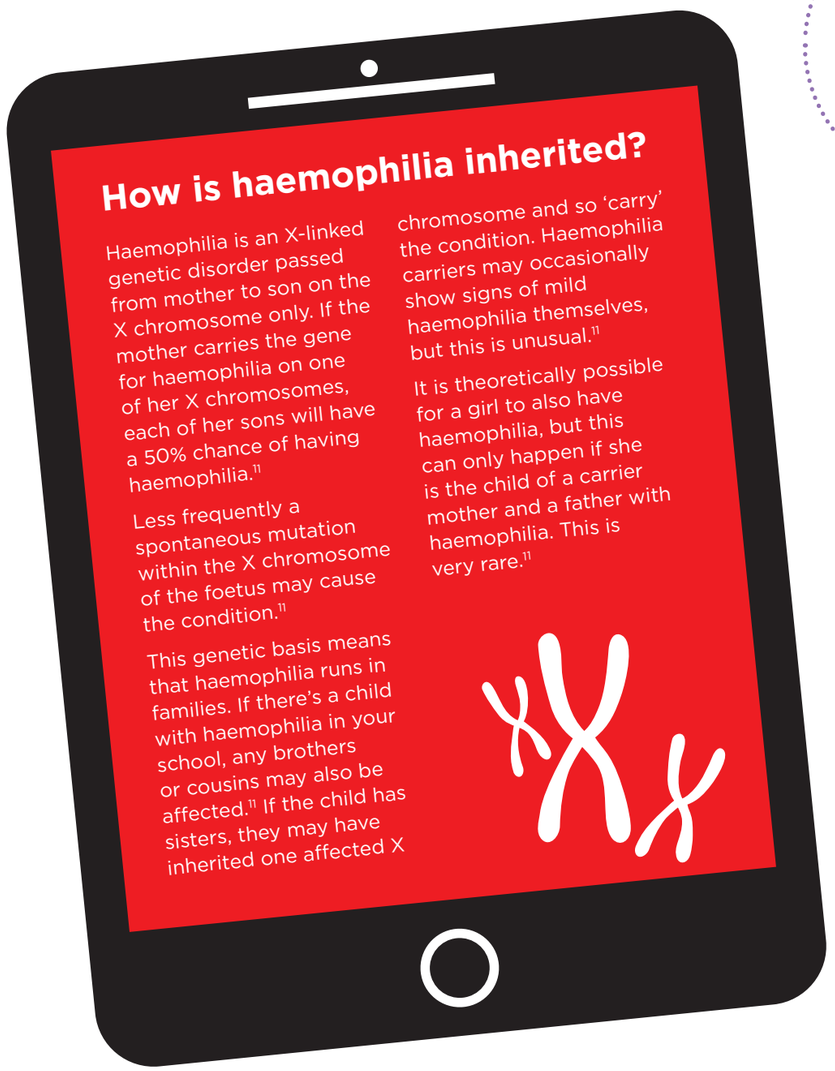
Contents

What is haemophilia?

Haemophilia is an inherited genetic disorder where important proteins, called clotting factors, are missing or reduced.[1] This means:

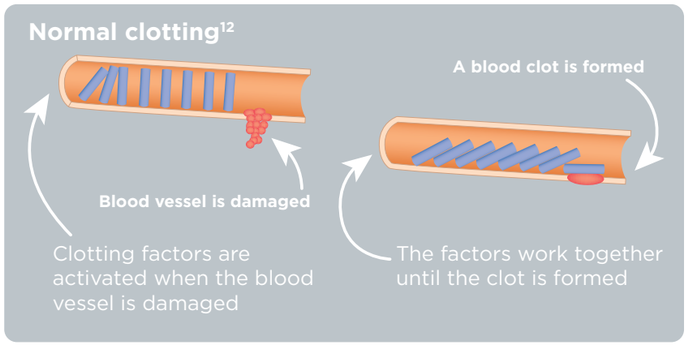
- Blood takes longer to clot after sustaining injuries[1]
- Knocks and bumps can also cause internal bleeding under the skin or into joints[1,9]
- In the event of a bang to the head, bleeding can occur into the skull, placing pressure on the brain[1]

Fortunately, haemophilia is rare, affecting around 10,500 people in the UK.[10] Worldwide estimates suggest one boy in every 5,000 will be born with haemophilia A and one boy in every 30,000 will be born with haemophilia B.[9,11]



How does haemophilia affect clotting?

When we sustain an injury, normally the body produces several proteins called clotting factors ranging from Factor I (one) to Factor XIII (thirteen). This happens in a sequence to coagulate, or clot, the blood. In people with haemophilia however, this process doesn't happen correctly so the blood takes longer to clot. This may lead to blood loss, which can be life-threatening.[12]



Figures showing how a blood vessel is damaged and how a blood clot is formed

Aside from haemophilia there are a few other rare, inherited clotting disorders which cause bruising and bleeding from mucous membranes, such as the inside of the mouth. Often these conditions will only come to light if, for example, a tooth is extracted and the bleeding appears prolonged.[9]

of people with haemophilia have **Haemophilia A**.[10] This means there is a deficiency or absence of clotting Factor VIII (eight).[10]

of people with haemophilia have **Haemophilia B**.[10] This means there is a deficiency or absence of Factor IX (nine).[10]

What are the symptoms of haemophilia?

It all depends on how severe the condition is – mild, moderate or severe and clotting factor levels.[2]

Mild or moderate haemophilia

People with mild haemophilia may not really have many problems. In fact, many are totally unaware that they have haemophilia at all.[2]

For those with moderate symptoms, spontaneous bleeding is rare. In both mild and moderate cases, even though the blood clots more slowly than normal, the condition is only likely to cause concern after serious injury or during major surgery.[11,13]

Severe haemophilia

In people with severe haemophilia, it's slightly different. Less than 1% of the clotting factors are present.[9] The clotting mechanism is so compromised that they can bleed even when there's no obvious sign of injury.[2] The main problem is NOT from open cuts, but from *internal bleeding we can't see.*[2]

Everyday knocks and bumps damage small blood vessels in all of us.[14] Normally, our bleeding stops and the damage is repaired – often before we even know it's started.[14]

But for someone with haemophilia, once bleeding starts, it goes on for longer.[9] Trivial injuries can lead to bleeding into the muscles and joints, causing them to become inflamed, swollen and painful.[9]

In people with haemophilia, an incident like this is called 'a bleed'.[1,9] It requires treatment with an injection of the clotting factor that is missing or deficient. This is known as an *intravenous (IV) infusion.*

Antibodies and inhibitors

Some people with haemophilia develop inhibitors, which are antibodies that stop their clotting factor replacement treatment from working effectively and can make bleeds more difficult to control.[9,11,15] These people are treated with a bypassing agent that 'bypasses' the inhibitor or an engineered antibody to help the blood to clot.[9,11,15]

Approximately 1/3 of people with severe haemophilia A develop inhibitors at some point in their life.[16] People with mild or moderate haemophilia A are less likely to develop an inhibitor than those with severe symptoms.[16]

Inhibitors are far less likely to develop in people with haemophilia B, and then mostly in people with severe symptoms.[9]

Treatment for haemophilia

Preventative treatment: Prophylaxis

Because repeated bleeds can also lead to long-term damage, particularly to the joints, many people with haemophilia A and B (without inhibitors) now receive regular infusions of factor.[11] In general, this happens between two and three times a week, individualised to the child and often at specific times, such as mornings before school, to prevent bleeds occurring in the first place.[9] Alternatively, some people with severe haemophilia A may receive injections under the skin with an engineered antibody every week or longer to restore Factor VIII function.[15] These types of treatment, called prophylaxis, are usually effective in preventing bleeding, including that which occurs for no obvious reason (these are called spontaneous bleeds).[15]

As needed treatment: On demand

When haemophilia is mild or moderate, it may only be necessary to administer clotting factor treatment as and when a bleeding incident occurs.[9] This 'as needed' infusion regime to treat specific bleed instances is called 'on-demand' treatment. Children with severe haemophilia may also require on-demand treatment, e.g. following an injury.[3]

How children get their injections

When treatment is administered regularly (prophylaxis), it will be injected in one of two ways depending on the type of treatment: either under the skin of the abdomen, arms or thighs (called subcutaneous – for engineered antibody), or directly into the bloodstream (IV – for clotting factor treatments). It may be given by a parent/carer or medical professional and sometimes by the child themself.[15,17] There are two main methods for injecting into the blood stream:

1

Peripheral Venous (or IV) access

- Factor is infused directly into a peripheral vein, usually in the hand or arm, via a single, disposable butterfly needle with a tube connected to it[18,19]
- Alternatively, where repeated infusions are needed over a few days, a small plastic tube (cannula) with a cap for access is inserted in the vein and left taped in place. Once the treatment cycle is complete, the cannula is easily removed[18]
- If needed, to increase blood flow and provide better long-term access to a vein, a surgeon may link a vein and an artery in the forearm or upper arm. This is called an arteriovenous fistula or AV[18]

2

Central venous access

- Here, factor is infused directly into one of the major central veins, usually in the chest, via a central catheter or a port[18]

Central catheters

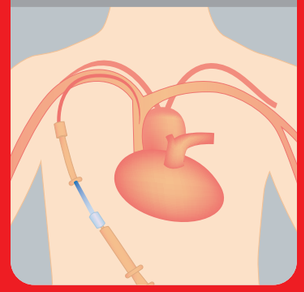
- A catheter is a flexible tube threaded into a main vein by a doctor in the operating theatre or x-ray department[18]
- One end stays in the vein, the other comes out through the skin, usually on the chest wall[18]
- Factor is given through an injection cap on the outer end of the catheter[18]

Ports

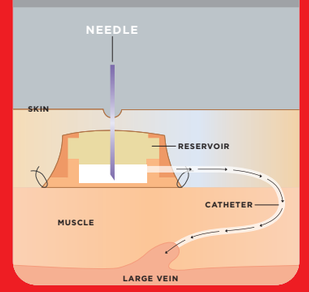
- A port is a small device, inserted under the skin, usually on the chest. It is inserted by a doctor in the operating theatre or in a special area of the x-ray department[19]
- A self-healing membrane (septum) and a special needle allow multiple factor injections to be administered via the port[19]
- A port can stay under the skin for a long time – for months or years, if needed[19]

To reduce the risk of infection, the area around a catheter or port must be kept clean.

Central catheter[20]



Port[20]



Common drugs used to treat haemophilia (without inhibitors)

Preventative medication

- An engineered version of clotting Factor VIII for haemophilia A[21]
- An engineered antibody designed to restore Factor VIII function in severe haemophilia A[15]
- An engineered version of clotting Factor IX for haemophilia B[21]
- A plasma-derived version of clotting Factor VIII for haemophilia A[22]
- A plasma-derived version of clotting Factor IX for haemophilia B[23]

On-demand medication

- Desmopressin, a synthetic hormone that stimulates the production of clotting Factor VIII in mild/moderate haemophilia A[21]
- An engineered version of clotting Factor VIII for haemophilia A[21]
- An engineered version of clotting Factor IX for haemophilia B[21]
- A plasma-derived version of clotting Factor VIII for haemophilia A[22]
- A plasma-derived version of clotting Factor IX for haemophilia B[23]

How might haemophilia affect schooling?

Because of the effectiveness of modern treatment, haemophilia should not have a serious impact on the child's education. Affected pupils need to know they can trust their teachers or school nurse and confide in them.[24]

Making arrangements

Talk with parents, guardians or medical advisors to understand any special arrangements the school may need to accommodate the child's needs.[8] For example:

- **Regular access to school premises by parents/carers to administer medication during the day[8]**
- **Secure storage of any drugs and equipment held on school premises (including refrigeration of drugs if needed)[8]**
- **Safe disposal of sharps and medical waste[8]**
- **Medical history/ documentation in the event of an emergency at school[8]**
- **Contact details for parents/ carers**

Attendance

Children with haemophilia are no different from any others in looking for excuses to get out of lessons and activities they don't like. If they think they can get away with a fictitious bleed, they may well try it.[3]

That said, although it is just as important for children with haemophilia, as it is for any other, to attend as regularly as possible, there may be times when they have to miss school while they recover after a bleed. In very rare circumstances they may require some type of aid such as a wheelchair or crutches.[3]

So be aware of this and have the necessary arrangements in place before the event. You will naturally want to do all you can to help a child who has been absent to catch up on missed work and get back into their normal school routine.[3]

School excursions, visits and trips

It's important to encourage a child to concentrate on all the things they can do rather than the odd one or two they can't.[3]

With a little forward planning and discussion with specialist haemophilia services, there is no reason why children with haemophilia can't enjoy the full curriculum including all extra-curricular activities. When school trips are scheduled, think ahead about:[3]

- **Administering regular medication – can the pupil self-administer medication? Could their parent/carer accompany the child on the trip?**
- **Accessibility (if an issue)**
- **Refrigeration of drugs (if needed)**
- **Availability of medical records**
- **Details of the nearest haemophilia centre and doctor or specialist haemophilia nurse**

In addition, for trips abroad, also consider:[3]

- **Travel/medical insurance arrangements**
- **A GP medical declaration letter for customs and any medical provisions**
- **Details of local treatment facilities**

Sports

In general, most school-based activities can be enjoyed by a child with haemophilia.[3] The only obvious exceptions would be contact sports such as rugby and boxing, due to the risk of head and neck trauma. Some consultants also advise avoiding football due to the risk of ankle injury.[3] Playing team sports helps build confidence, and swimming is excellent for low impact exercise.[3]

In particular, talk to parents/ carers about participation in any sports or events that may involve physical contact. Parents/carers may choose to give prophylaxis on PE or sports days.

Playgroup/Nursery, Infant and Primary School

It is important children join in all play activities with their classmates, especially at this age. Typical play rarely presents a problem aside from the occasional bruise.[3] Cuts and grazes are generally easy to deal with (see page 14 [What to look out for – general cuts, grazes and bruises]).[3] In class, let children use scissors and other sharp instruments just as their other classmates do – all children need to learn how to work safely.

Primary school sport isn't usually as competitive or rough as later years. Unless a child has a particular problem like a 'target joint' (one which is particularly prone to bleeds), they should join in.[3] As always, consult parents and carers as needed for advice.

The only time treatment may be required during school hours is if they get an injury that keeps bleeding steadily e.g. an accidental bite to the tongue or an injury to the head, joints or genitalia (see page 15 [What to look out for – head injuries]).[3]

Secondary School

As children get older, they get more competitive. The sports they enjoy tend to get rougher, and the range of sports and other activities they want to join in gets wider.[3] But that's not a problem.

Sport and exercise in school is good: it strengthens the joints and builds up the muscles which then protect them, making bleeds less likely.[3] Provided the correct equipment or protective clothing is used, most sports are fine for children with haemophilia.[3] In the event that any particular sport does cause a problem, it is not usually too difficult to find an equally satisfying but safer alternative.

It's tricky to lay down hard and fast rules about which sports aren't suitable for people with haemophilia. Opinions vary, and the relative risks and benefits will vary from child to child.

It's probably better to avoid 'violent' contact sports, such as boxing, wrestling, rugby, contact martial arts, etc., but there's virtually no sport that hasn't been played and enjoyed by people with haemophilia. If you're in any doubt, talk to the child's parents/carers.

What should you look out for?

Many incidents that you might expect to cause problems can easily be dealt with by simple first aid. Others cannot.

There are some injuries that cause a bleed. Guidelines for recognising a bleed are shown on page 16. Whilst older children with haemophilia will be able to explain any discomfort they feel, younger children may not. Always be aware of nursery, playgroup, infant or primary school children with haemophilia who may be crying or seem distressed for no apparent reason; they may be in pain from a bleed and need your reassurance and help.[3]

Incidences of bullying are rare, but can occur in any school. Fortunately, today's zero-tolerance approach means almost all instances are swiftly identified and dealt with before they become problems. The nature of haemophilia can make some children feel self-conscious, so talk regularly with the child to address any concerns or worries they may be experiencing.[25]
If threatened or taunted, ensure that the child knows not to respond physically, but to talk to a teacher or another trusted adult.

General cuts, grazes and bruises

Minor cuts, grazes and bruises that are an everyday part of childhood don't normally cause any significant problems for a child with haemophilia. Normal first aid will be adequate.[3]

People with haemophilia don't bleed faster than anyone else. For those on adequate prophylaxis treatment, nose bleeds, cuts and grazes will generally slow and stop with standard, basic first aid measures.[3]

As with dealing with any form of open bleeding, or blood spillage, use normal precautions (e.g. wearing gloves, cleaning up with dilute bleach solution and paper towels, safe disposal in a sealed polythene bag).[8]

Cover cuts and grazes with a plaster and/or bandage and apply direct pressure for a few minutes. If a cut is deep and may require stitching, cover it and contact your local haemophilia centre for treatment as well as parents/carers.

Bruises are only a problem if they are particularly painful. This may indicate a deeper underlying bleed. Bruises resulting from a head injury or injuries to the genitalia may have serious consequences and should be referred for treatment immediately.[3]

Never use non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen unless advised to do so by the haemophilia centre.[12] These medicines can interfere with blood clotting.[1] If pain relief is needed, paracetamol may be used at the age-appropriate dose if there are no allergies.[3]

Nose bleeds

With the child sitting upright, apply firm pressure to the lower part of the nose, just above the affected nostril for 10-15 minutes, or an ice pack in a towel on the bridge of the nose for a maximum of 5 minutes, or both.[3] If the bleeding fails to stop, contact the parents/carers and consider A&E transfer as per school protocol.

Bleeding from the tongue, or in the mouth

Any bleeding within the mouth is harder to deal with because any clots that form tend to be either dislodged by the tongue or food or washed away by saliva.[3] Sucking an ice cube may work, but usually bleeding inside the mouth will need treatment at the haemophilia centre.

Joint bleeds

Older children should be able to tell you themselves if they are having a bleed.[3] Younger ones may indicate that there is a problem by appearing upset or by 'protecting' a limb by limping or not using it.[3] The most common sites for joint bleeds are the shoulder, elbow, wrist, hip, knee and ankle.[3]

Joint or muscle bleeds should be treated by the parent or haemophilia centre as quickly as possible.

Some of the signs of bleeding into joints or muscles[3]

- Pain or a tingling
- Swelling of the affected joint or muscle
- Redness
- Heat over the affected joint or muscle
- Loss or impairment of movement

Treat any bleed around the face, neck, or throat as an emergency and immediately involve the parents/carers and consider A&E transfer as per school protocol.[3]

Abdominal injuries

Any impact to the abdomen should be monitored closely – it is difficult to detect internal trauma and bleeding.[3]
Parents and carers should be notified immediately.
Staff should watch for any worrying symptoms that may require medical intervention.

Some of the signs of an abdominal bleed[3]

- Black, bloody or tar-like bowel movements
- Blood in urine
- Pain
- Vomiting of blood (black or red)

Head injuries

Any head injury may potentially be serious: if bleeding occurs within the skull, it will place dangerous pressure on the brain.[3] Even if you feel the 'injury' really is trivial, you should still keep a close eye on the child for the rest of the day. Inform parents/carers so that you, or they, don't miss vital warning signs of something serious. If in doubt, get help from the haemophilia centre.

Minor head injuries

Children often bang their heads. If they aren't overly distressed and aren't in pain, the bump is unlikely to have caused a bleed and probably does not need treating.[3,26] Nevertheless, **watch the child carefully and if in doubt, get help.[3]**

If the head bump was hard enough to cause bruising or swelling, it should always be treated by the parents/carers or the haemophilia centre.[3,26]

Serious head injuries

Serious trauma is usually the result of a hard blow to the head.[3] An injury which knocks any child unconscious is always very serious, but especially so for those with haemophilia.[3] Be aware it may well not be immediately obvious that the head has actually received a blow – for instance in a collision or fall where the child seems okay.

The following symptoms may indicate a medical emergency and require an ambulance:[2,26]

- A severe headache
- A stiff neck
- Being sick (vomiting)
- Sleepiness or loss of consciousness
- A change in mental state, such as confusion
- Difficulty speaking, such as slurred speech
- Changes in vision, such as double vision
- Loss of co-ordination and balance
- Fits or convulsions
- Paralysis of some or all of the facial muscles

If you see any of these signs, however the injury was caused, the child needs treatment as soon as possible by your nearest hospital or haemophilia centre.

Recognising a bleed

At Playgroup/Nursery, Infant and Primary School

If the child is miserable and/or crying for no apparent reason, check for the signs of a bleed.[3]

At Secondary School

As they grow, most children with haemophilia will recognise the signs themselves to know if they are having a bleed.[3] However, they may not always wish to bring problems to your attention. Be aware of uncharacteristic quietness or hampered mobility and check for the same signs as in younger children.[3] If in doubt, contact the child's parents/carers or haemophilia centre.

Children with haemophilia should be treated just like any other child. Just be a little extra vigilant so you can learn to recognise bleeds.

What are some of the signs of bleeds?

Muscle and joint bleeds[3]

- The area may feel tight, warm or swollen
- The limb is often painful, stiff or difficult to extend
- The limbs may be unequal in appearance

Bumps to the head[3]

- If a child has bruised their head, contact the parents/carers or seek help from the haemophilia centre

Mouth, gastrointestinal (GI) and urinary tract bleeds[3]

- Visible bleeding from mouth to tongue
- Bloody or black tar-like motions
- Blood in urine

What to do[3]

- Call the child's parent and/or guardian
- Call the child's haemophilia centre for advice
- If there is swelling or discomfort, apply an ice pack in an appropriate protective cover to the affected area. A bag of frozen vegetables or ice cubes wrapped in a towel make an effective substitute

Teacher FAQs: Practicalities in class

Will I be asked to administer haemophilia treatment (e.g. injections)?

No. If a child has haemophilia, and they are not yet managing their own medication, day-to-day treatment may be provided by parents/carers or medical professionals who will come in to school.[3]

Will I need to have any special training or knowledge?

No, but you should understand the essentials about the condition as outlined in this guide.[3]

Does the condition pose any special risk to others in school?

None whatsoever. If an injury ever causes a wound that bleeds, use exactly the same first aid techniques and precautions as you would normally.[3] If children are managing injections themselves, they will know the procedure to dispose of their sharps safely.

How can I best help a child with haemophilia?

That's easy: be there for them. Get to know the child well, earn their trust and make the time to talk with them regularly.[3] The better your rapport with the child and the family, the more support, reassurance and insight you will be able to provide.[3] Make every effort to encourage children to participate in and enjoy every aspect of life both inside and outside school.[3] Be aware of what to watch out for regarding possible bleeds, how to contact parents/carers or the haemophilia centre for advice, and how to use your basic classroom first aid.

Haemophilia terms:
Glossary

Butterfly needle
Small needle, shaped like a butterfly, with attached tubing used for peripheral venous access[18]

Carrier
A woman who has the gene that causes haemophilia on one of her X chromosomes. Women rarely suffer with the condition as their other X chromosome is normal so they still produce either Factor VIII or Factor IX, just at lower amounts than those who don't carry the gene[11]

Central Venous Access Device (CVAD)
Medical device surgically inserted into the body to deliver different types of medication, or to take blood samples from a vein[27]

Clotting factor
Medicines used to prevent or treat bleeds in persons with haemophilia[21,30]

These are also called coagulation factors and are proteins that circulate in the blood to help control bleeding[21,30]

Infusing
Administering solution into a vein[28]

Inhibitors
Antibodies produced as an immune response that inhibit clotting factor activity[9]

On-demand
Treatment of a bleed as and when required[21]

Peripheral veins
Veins away from the central part of the body, usually in the hands, arms, feet, legs or scalp. Administration of drugs into these veins is a technique called peripheral venous access[29]

Peripheral venous access
The ability to administer solutions into peripheral veins[29]

Port
Small device inserted under the skin by a doctor in the operating theatre. It is used to give fluids or drugs, or to withdraw blood from a vein (see also CVAD)[18]

Prophylaxis
A treatment regimen to prevent symptoms of a disease developing. Prophylaxis in haemophilia involves regular injections of clotting factor to prevent bleeding, or an engineered antibody to restore Factor VIII function[15,21]

Sharps
Needles, syringes with needles attached, scalpels and lancets that need to be discarded after use as biomedical waste[18]

Sharps container
Leak proof, rigid, puncture-resistant container with a re-sealable lid used to safely store and transport used sharps[18]

Subcutaneous
Administered under the skin[30]

Notes

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