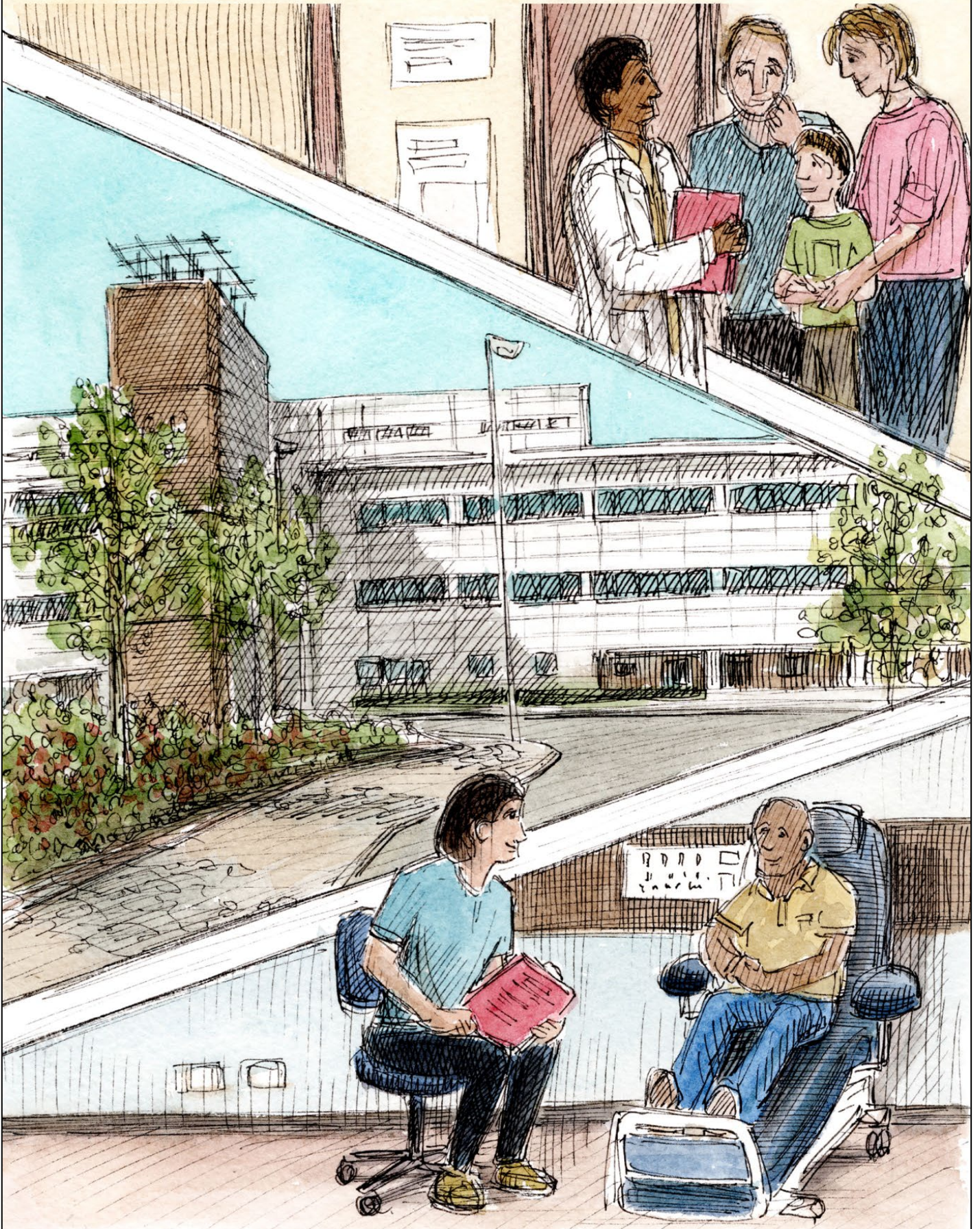


The Edinburgh Haemophilia Centre



Commonly Used Abbreviations within this Information Leaflet

EUHANET	European Haemophilia Network
GDPR	General Data Protection Regulation
LPCH	Lloyds Pharmacy Clinical Homecare
MDSAS	Medical Data Solutions and Services
NHD	National Haemophilia Database
NSS	National Services Scotland
OPD	Out Patient Department followed by a number e.g. 1
RHSCYP	Royal Hospital for Children and Young People
RIE	Royal Infirmary of Edinburgh
WFH	World Federation of Haemophilia
Bleeding Disorder Card	A card that summaries diagnosis and emergency contact in case of an emergency to be handed to A&E/Paramedic
Haemtrack	Electronic treatment record system for those on Home Treatment

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Centre Contact Details

Our Opening Hours

Monday - Friday 08:30 to 16:30

Haemophilia Centre Reception 0131 242 1270

Please phone the Haemophilia Centre Reception for routine enquiries, non-urgent clinical issues, medication / treatment issues and to rearrange appointments. Your call will be directed to the appropriate member of the team or, if unavailable, you will be called back. If you are leaving a message, please remember to include your name, date of birth and phone number.

Our Address

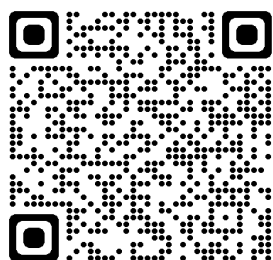
Haemophilia, Thrombosis and Immunology Centre
Out Patient Department 1 (OPD1)
Royal Infirmary of Edinburgh
51 Little France Crescent
Old Dalkeith Road
Edinburgh
EH16 4SA

Our Email address

RIE.haemophilia@nhs.scot

(Please do not use for emergency contact or to share unnecessary personal information).

NHS Lothian website



www.nhsllothian.scot

Emergency Contact Numbers

Adult

Out of Hours (Ask for On-Call Haematology Registrar)	0131 536 1000
Haemophilia Centre (08:30-16:30, Mon - Fri)	0131 242 1270

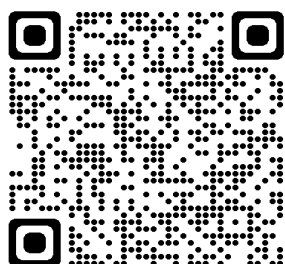
Children & Young People

Lochranza Emergency Triage Phone (answered 24/7)	0131 312 1731
Lochranza Daycare (09:00-17:00, Mon - Fri)	0131 312 1335

Depending on the nature of your call, you/your child may be asked to attend the Haemophilia Centre/Lochranza Daycare in office hours, or you may be directed to A&E.

If attending A&E, please bring you/your child's bleeding disorder card with you and show it to A&E staff on arrival.

Further information about the Royal Hospital for Children and Young People can be found on www.children.nhslothian.scot



Useful Telephone Numbers

Adult

Ward 206 (Inpatient Base)

0131 242 2061

Visiting Times:

10:00-12:00, 13:00-17:00 & 18:00-20:00

Children & Young People

Ward Lochranza (Inpatient Base)

0131 312 1334

Visiting Times:

10:00-12:00, 13:00-17:00 & 18:00-20:00

Benign Haematology Nurse Specialist

07814 765 560

Home Delivery

Lloyds Pharmacy Clinical Homecare
lpch.hphteam@nhs.net

0345 263 6135

Haemtrack (technical issues)

MDSAS
support@mdsas.com

0161 850 5075

Getting Here

Car or Van



The closest car park to our centre is Car Park 2B. You can enter the building by Out Patients Department (OPD2, see site map). If you would prefer to enter via the main mall, then Car Park 2A is more suitable. Both car parks can be accessed via Little France Crescent and Little France Drive.

There are two dedicated parking spaces directly outside OPD2 for emergency bleeding disorder patient use **only**. We ask all members of the public to be courteous to this and not to use the space unless told otherwise.

Taxi or Bike



Taxis can drop off right outside our nearest entry point, OPD2, Diabetes Clinic (once through the electric double doors follow the sign for our centre to the right). Cyclists can enter the same way after securing your bike to the cycling posts that are to the left of the entry way.

Buses

Lothian Buses

Hospital	Bus Number
The Royal Infirmary of Edinburgh	7, 8, N11,21,24,33,X33,38,46, 48,49,51, 400 & Skylink
The Royal Hospital for Children and Young People	7, 8, 24, 33, 38, 49

E&M Horsburgh Buses

Hospital	Bus Number
The Royal Infirmary of Edinburgh	40, X40
The Royal Hospital for Children and Young People	No stop available – 4 minute walk from RIE Bus Stop via main mall

Prentice of Haddington

Hospital	Bus Number
The Royal Infirmary of Edinburgh	111
The Royal Hospital for Children and Young People	No stop available – 4 minute walk from RIE Bus Stop via main mall

Travel Assistance

Travel Expenses

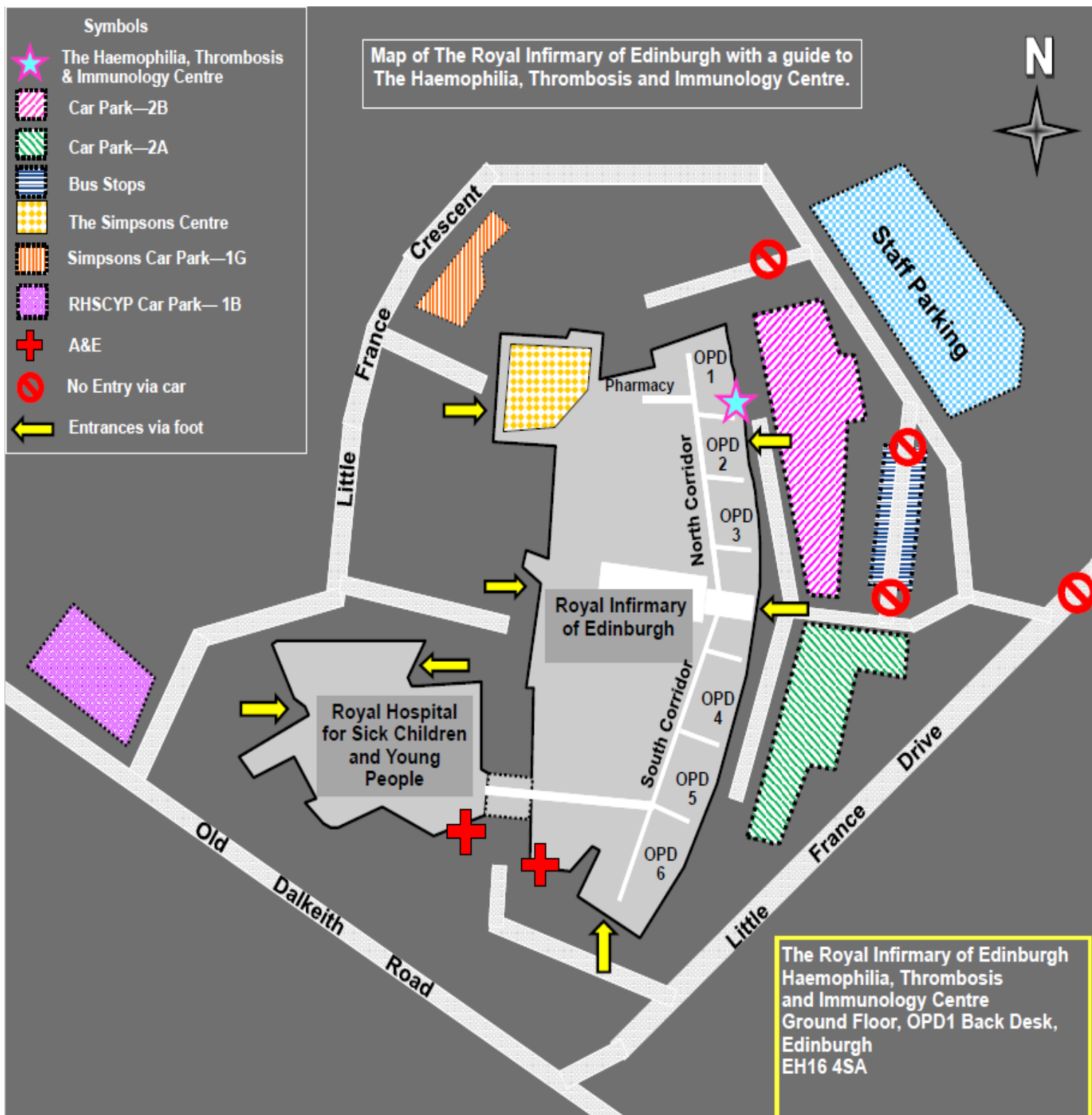
Some people can reclaim travel expenses for their journey to the hospital for NHS treatment. You may be eligible to reclaim travel expenses if you receive certain Benefits or Credits.

Please ask at the centre reception for more information about this.

Patient Transport

Some patients are eligible for free patient transport to collect you and bring you to your appointment and to take you home. Call **0300 123 1236 (standard network charges apply)** within 10 days of your appointment, to find out more. When you call the ambulance service, they will take you through an assessment to help understand your requirements and if you need to use their service.

Site Map



The Edinburgh Haemophilia Centre Staff

Medical and Nursing Team:

Adult

Dr Andrew Page	Centre Director & Consultant Haematologist
Dr Julia Anderson	Consultant Haematologist
Dr Alice Klauser	Consultant Haematologist
Dr Lea Haskins	Specialty Doctor
Bindu Abraham	Senior Charge Nurse
Angela Davanna	Haemophilia Specialist Nurse
Karen Robinson	Haemophilia Specialist Nurse
Ewe Korbanska	Staff Nurse
Flo Manzano	Staff Nurse
Emma Temperley	Staff Nurse
Jackie Gilchrist	Clinical Support Worker

Paediatrics

Dr Matt Howard-Jones	Consultant Haematologist
Dr Susan Baird	Consultant Haematologist
Dr Rosina Shujaat	Consultant Haematologist
Lucy Paterson	Haemophilia Specialist Nurse

Physiotherapy

Jenny Forsyth	Advanced Practitioner for Adults
Emma Gallagher	Physiotherapist for Paediatrics

Psychology

Dr Gráinne O'Brien	Senior Clinical Psychologist
Dr Sarah Kennedy	Consultant Psychiatrist

Coagulation Factor Team

Clare Constance	Haemophilia Contract Manager
Jacqui Gillard	Coagulation Factor Co-ordinator
Ellie Robertson	Coagulation Factor Co-ordinator

Receptionists and Medical Secretaries

Yvonne Crawford	Receptionist
Claudia Marchant-Lowe	Receptionist
Nina Shahroozi	Receptionist
Pat Straw	Medical Secretary

Clinical Services Offered

The Edinburgh Haemophilia Comprehensive Care Centre provides care and services for Adults and Children with inherited and acquired bleeding disorders, including the following:

- Emergency treatment of acute bleeding episodes for adult patients (paediatric patients would be seen in Lochranza ward, Royal Hospital for Children and Young People)
- Regular review clinics with experienced staff in bleeding disorder care
- Plans for treatment of bleeding disorders around surgical and dental procedures
- Genetic counselling and diagnosis for patients and families with bleeding disorders
- Assessment and advice from physiotherapists who specialise in Haemophilia
- Specialist Psychological services – emotional support, advice, assessment and psychological treatment for the challenges of living with a bleeding disorder
- Orthopaedic Service – joint assessment by Mr Graham Lawson (consultant orthopaedic surgeon) and a bleeding disorders specialist for those with joint problems
- Support and education on bleeding disorders for patients and families
- Factor and treatment education for patients/families starting or established on home treatment
- Organisation of home deliveries for patients with bleeding disorders – provided by Lloyd's pharmacy clinical homecare.

Clinical Services Offered (continued)

In addition, we work closely with the following specialist services:

- Hospital Special Care Dental Service – provides specialist advice, assessment and treatments for people with bleeding disorders requiring invasive dental procedures
- GI Liver – Professor Hayes provides advice, assessment and treatment for those with bleeding disorders and liver disease
- HIV Service – specialist care and treatment is provided by the Regional Infectious Diseases Unit at the Western General Hospital
- Obstetric/Haematology Joint Specialist Service – a weekly clinic is held in The Simpsons Centre for Reproductive Health, Royal Infirmary of Edinburgh and a monthly clinic is held in St John's Hospital, Livingston
- Clinical Genetics and Foetal Medicine – options for prenatal genetic diagnosis of inherited bleeding disorders can be discussed in bleeding disorders clinics with onward referral to these services as needed.

Weekly Clinic Timetable

Monday	Walk in emergency Clinic
Tuesday	Specialty Doctor Clinic (responsible consultant Dr Page) Nurse Telephone Clinic
Wednesday	Dr Page Clinic (2 Clinic lists, on with Specialty Doctor) Nurse Telephone Clinic Paediatric Telephone Clinic
Thursday	Dr Anderson Clinic Paediatric Telephone Clinic
Friday	Dr Page Clinic Paediatric Clinic Dr Anderson & Dr Armstrong Clinic (Obstetrics)

- Dr Gráinne O'Brien offers appointments via the Psychology Support Service on Monday, Wednesday afternoon, Thursday and Friday
- Jenny Forsyth offers Specialist Physiotherapy appointments on Tuesday, Wednesday and Friday
- Mr Lawson's Orthopaedic clinics occur in the centre once every two months.

People with moderate and severe bleeding disorders will usually be offered reviews **every 6 months**, whilst those with mild bleeding disorders will usually be offered reviews **every year** (either face to face or via the telephone clinic).

If you are on home treatment, we ask that you make sure treatment records are up-to-date via Haemtrack to ensure that you get the most from your review.

Psychology Support Service

We know that being diagnosed with and living with haemophilia or other bleeding disorders, can be hard at times. A little extra help and support is sometimes useful to get through a difficult period.

Psychology can offer support and counselling for:

- Coping with a bleeding disorder and treatments
- Supporting all family members adjusting to new diagnosis
- Feeling depressed or angry about your condition or treatment
- Anxiety or worries related to your health or the future
- Deciding on treatment options
- Difficulties with family and personal relationships
- Getting ready for going to college or moving on to adult services
- Pain management.

The psychology team work with children, adults and families to provide emotional support, advice, and talking therapies. You may meet a member of the team at your clinic appointment or a separate appointment can be organised. Meetings can be face-to-face, via video call or on the telephone. The first appointment is about finding out how things are for you. It is useful to find out about your bleeding disorder, your family life, and about life in general. Appointments last for about 60 minutes.

If you would like to know more, please speak to a member of the team or phone the centre on 0131 242 1270.

Specialist Physiotherapy Service

You can be referred for specialist physiotherapy by a member of the Haemophilia Team for problems in your joints and muscles related to bleeding.

An appointment with Physiotherapy will usually involve a physical assessment/examination so wearing loose, comfortable clothes will make this easier.

Our Physiotherapist can offer you:

Recovery after injury, bleed or surgery

Individual rehabilitation programmes and best management for your problem discussed and supervised/monitored.

Injury prevention

Advice on suitable sports and activity, how to increase your fitness level and how to use safety equipment/protective equipment, first aid and treatment of injuries.

Monitoring your joints

Monitoring of your joints at your regular clinic appointments allows early detection of joint issues, allowing a physiotherapy exercise programme or other intervention, to maximise your joint health.

Staying well and fit

Regular activity is known to have lots of health benefits. Your physio can guide you on how to safely increase your activity levels.

Splints and appliances

Advice on using walking aids, splints, slings for short or long-term use to support and maximise your joint function.

Home Treatment

Home treatment is provided by Lloyds Pharmacy Clinical Homecare who can be contacted on 0345 2636 135.

If there are any issues with your prescription, please contact the Factor Coordinator Team via reception on 0131 242 1270.

Haemtrack

Maintaining accurate records of home treatment is important to us as we are able to identify any patterns in bleeding episodes and make necessary changes to your treatment as a result.

The easiest way to do this is to record treatments at the time that you take them via the Haemtrack.

Training in this is offered by the Factor Coordinator Team – please contact us on 0131 242 1270 if you would like to arrange this.

Treatment of Bleeds

Early treatment of bleeds is crucial in reducing the amount of pain and damage that they cause. Your clinical team will have discussed symptoms that might indicate a bleed that would need urgent treatment.

If you are **on home treatment**, you should treat in accordance with your plan of care and record this on Haemtrack. If you need additional advice, contact the Haemophilia Centre team. This usually follows the POLICE guidelines of Protect, Optimise Loading, Ice, Compression and Elevate.

If you are **not on home treatment**, you will need to contact the Haemophilia Centre team for urgent review.

You should stop the activity that has triggered bleeding and follow **PRICE** guidelines for at least 24-48 hours after a joint or muscle bleed:

PROTECT the affected joint or muscle by reducing the load on it. Crutches or a splint may help.

REST the affected joint or muscle for 24-48 hours in a comfortable position. At this stage, the swelling should start to go down and it is

Treatment of Bleeds (continued)

important to start gradually moving the joint or muscle again. Physiotherapy is generally helpful to guide this process and can be arranged via the Haemophilia Centre.

ICE can help reduce swelling and pain and should be applied to the area for around 10 minutes. Gel packs, crushed ice or frozen peas wrapped in a towel are all suitable. Repeat application every 2-3 hours and take care to avoid ice burns.

COMPRESSION with an elasticated bandage or wrap may help to reduce swelling and so to help with pain. Not everyone finds this helpful, and any if it increases pain it should be removed immediately. Physiotherapy input is available to help with this.

ELEVATE the injured part of your body as much as possible. Raising it above your heart will help to reduce swelling but compression and elevation should not be used at the same time. Elevation is best done for around 20 minutes at a time, with rests in between.

Recovery after a bleed

It is important to gradually build back up to normal movement after a significant bleed. We recommend that you contact the Haemophilia Centre to arrange physiotherapy input to guide this process.

Surgery and Minor Procedures

Surgery and procedures for people with bleeding disorders requires the Haemophilia Centre team to work closely with your surgical team to keep you safe.

If you need surgery or a procedure, such as endoscopy, biopsy or dental surgery, you should contact the Haemophilia Centre once you have a date for the procedure. We will need the following information:

- Date and time (if known) of surgery
- Hospital and department where surgery is planned to happen
- The name of the consultant responsible for the surgery/procedure.

We may ask you to attend for blood tests prior to surgery. It can take up to a month to perform tests and make arrangements, so we ask that you let us know as soon as possible when you know that surgery is planned.

Often, we will need to arrange for treatment of your bleeding disorder on the day of surgery, shortly before the procedure starts. This may be given in the Haemophilia Centre, but sometimes the team performing the procedure will give this instead.

If your procedure is planned to happen at a hospital other than the Royal Infirmary of Edinburgh, we may contact the surgical team to rearrange things. However, this is not always necessary and sometimes it is not possible.

Most minor procedures can be performed on a day-case basis, but we will discuss this with you. You may be told by the surgical team initially that surgery can be done on a day-case basis, but it is not unusual that we will rearrange things for an overnight stay even for minor surgery.

Major surgery will generally require an admission of several days and you may need to come to the Haemophilia Centre on a daily basis for ongoing treatment for several days more after discharge if you are not able to self-treat.

Surgery and Minor Procedures (continued)

For dental procedures, we encourage all patients registered with the Haemophilia Centre to be registered with a community dentist. They will be able to perform your routine dental care but certain interventions, such as extractions and particular types of local anaesthetic technique, would need to be done in the hospital environment. Your dentist can contact the Royal Infirmary Special Care Dental team for advice if they are unsure, and you can always ask that they do this if you are unsure.

You can also contact us for advice and a separate information leaflet is available about dental care in people with bleeding disorders.

Travel Advice

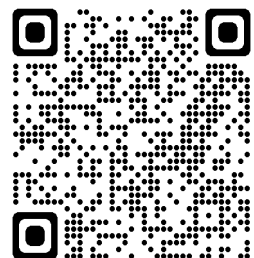
If you are travelling away from home, we recommend the following:

- Take your bleeding disorders card and a copy of your most recent plan of care with you
- Ensure you have enough treatment to cover the whole time that you are away (if necessary, arrange an additional home treatment delivery in advance)
- Make sure you know how your treatment should be stored. If you are unsure, contact us for information
- If flying, treatment should be kept in cabin baggage rather than being placed in the hold
- If travelling abroad, contact the Factor Coordinator Team in advance to arrange a letter to explain the treatment that you are carrying with you to airline/customs staff
- Ensure that you have taken out travel insurance that covers your pre-existing medical conditions including your bleeding disorder
- Check the address of the nearest Haemophilia Centre before you travel and take a record of their contact details with you.

To find the nearest Haemophilia Centre, check the following websites:

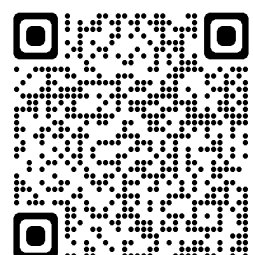
EUHANET(European Haemophilia
Network)

www.euhanet.org/centrelocator



WFH (World Federation of Haemophilia)

www.wfh.org/find-local-support



Vaccination Advice

Most vaccines can be given by deep subcutaneous injection, rather than the usual intramuscular route, and this is recommended for people with bleeding disorders. Vaccination would be arranged via the normal routes, and you should inform the vaccinator of your bleeding disorder and the need to give vaccination by the subcutaneous route.

The main exception to this is COVID-19 vaccinations, which can only be given by intramuscular injection. For people with more severe bleeding disorders, we would often recommend treatment to reduce any risk of bleeding with this approach.

For milder bleeding disorders, this is generally not necessary. Please contact us if you have an upcoming COVID-19 vaccination and you are unsure whether you need treatment prior to this.

In general, there are no specific requirements for people with bleeding disorders to have additional vaccinations. The main exception to this would be in people who are at high risk of needing products which have come from blood donations, where we would recommend vaccination against Hepatitis A and B. If you need advice about this, please contact the Haemophilia Centre by telephoning the main reception.

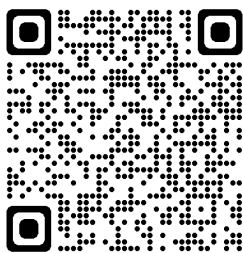
Transfer of Care from Paediatrics to Adult Services

Moving over from paediatric to adult services is a gradual process, which gives the patient and their family time to learn about and adjust to the different ways that these healthcare services work.

The team will support you in becoming more independent and confident in managing your own health. There will be lots of opportunities to ask questions and be part of the process.

The final move to the adult service generally occurs soon after your 16th birthday. The paediatric team will start to discuss this with you and your family, and prepare you for it, starting several years beforehand. At the Edinburgh centre we use the “Ready Steady Go” programme to support the transition journey.

You can visit www.readysteadygo.net/rsg.html for more information on this.



As both the paediatric and adult clinics happen in the Haemophilia Centre on a Friday morning, you may be introduced to members of the adult team long before this final move.

At the time of the move, you will be offered a joint appointment with both paediatric and adult teams. Following this meeting, you will officially join the adult service.

You would then contact adult bleeding disorders services for advice, and be reviewed by them in an emergency (including attending adult A&E in the Royal Infirmary of Edinburgh).

Leaving Home or Moving Away to Study

If you are moving away from home, you should inform the Haemophilia Centre team so that we can ensure that local bleeding disorder services have the necessary information to look after you safely, and so that we can update your contact details.

Sometimes, we will continue to oversee your care but would let your nearest Haemophilia Centre know about you so that they can get in touch with arrangements for what to do in an emergency.

For other people, it is more appropriate to transfer care to the centre where you are moving to. We will happily discuss what would work best for you.

When moving away or studying away from home, you will need to register with a local GP and Dentist, and you should contact the Haemophilia Centre with details so that we can let them know about your bleeding disorder and any changes to your care.

Healthy Living

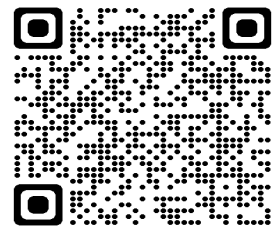
Living a healthy lifestyle will benefit your long-term health, and can also help with musculoskeletal problems that may have resulted from your bleeding disorder alongside other benefits.

If you have questions about safe exercise and sports participation, you can raise these with your clinical team. There is also specialist physiotherapy support available for people looking to increase their activity levels safely.

Below are details of some websites with information to help with some other aspects of living a healthy lifestyle.

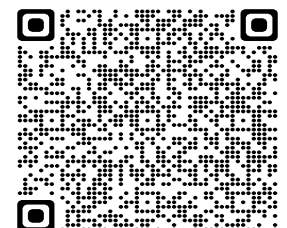
Healthy eating

www.nhsinform.scot/healthy-living/food-and-nutrition



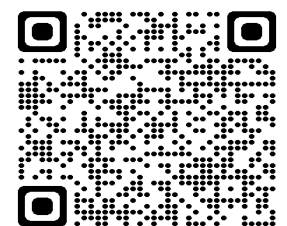
Weight management

www.nhsinform.scot/healthy-living/food-and-nutrition/healthy-eating-and-weight-loss/help-with-healthy-eating-and-weight-loss



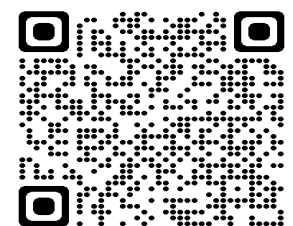
Alcohol use

www.nhsinform.scot/healthy-living/alcohol



Stopping smoking

www.nhsinform.scot/healthy-living/stopping-smoking



Feedback

We welcome feedback of all kinds. It is good to know what we are doing well and what we can improve.

The Edinburgh Haemophilia Centre is committed to improving the services it provides for patients and their families. As part of this commitment, we are keen to hear from you about your experience of our services.

We will respond to everyone who provides contact details. We cannot promise to do everything you suggest, but we will do what we can to improve your experience of our services.

Whilst we actively gather feedback on a regular basis, please feel free to use the suggestions box in the reception area to give feedback at any point.

Help Shape NHS Lothian

NHS Lothian is looking to create a network of people who are interested in working alongside us to help improve our services and develop a constructive dialogue on what needs to change.

You don't need any special knowledge, you just need to be enthusiastic about using your experience of NHS Lothian's services to help shape what we do and how we do it in the future.

We are keen to work directly with people who use NHS services throughout Lothian to improve the way we do things and to make sure decisions we make about changes and developments to services are properly informed by the people who use them.

With this aim in mind, we are seeking people who are interested in hearing from NHS Lothian about opportunities to get involved. We may invite you to focus groups and working groups, ask you for email feedback, send you links to online surveys or contact you about other opportunities for involvement related to specific developments or service changes.

You can decide on how involved you want to be. Please email us at get.involved@nhslothian.scot.nhs.uk

Feedback (continued)

Family Council

The Family Council was set up in 2000 and exists to represent the voices of parents, carers and families whose children are treated in the hospital or the community. Meetings are held every 2 months or so and hosted by NHS Lothian with partners from charities like Edinburgh Children's Hospital Charity, Kindred and Ronald McDonald House involved, and a range of staff from across Children's Services.

The Family Council has played an important role in representing parents' views during the planning and building of the new Royal Hospital for Children & Young People in Edinburgh. It works with NHS Lothian on several projects and discussions to improve patient and family engagement.

Youth Forum

Edinburgh Children's Hospital Charity is developing a **Youth Forum** for young people aged between 10-21 who are passionate about their health rights and who want their voices to be heard.

You can decide on how involved you want to be. Please email us at rhscfc@groups.outlook.com (Family Council) and contact **0131 536 0888** (Youth Forum).

Complaints

You can complain in person at the Haemophilia Centre to any member of staff. You can also communicate your complaint to us by phone, in writing, or by email. It is usually easier for us to resolve complaints if you make them quickly and directly to the staff concerned. Please talk to a member of our staff about any issues with your care and they will try to resolve any problems on the spot.

If you would like to **make a formal complaint** about the service that you have received, please contact the NHS Lothian Patient Experience Team. You can do this via several routes, including:

- In writing
- By telephone
- By email.

NHS Lothian Patient Experience Team is based at:

**Waverley Gate
2–4 Waterloo Place
Edinburgh
EH1 3EG**

Telephone: 0131 536 3370 (9am – 2pm)

Email: feedback@nhs.scot

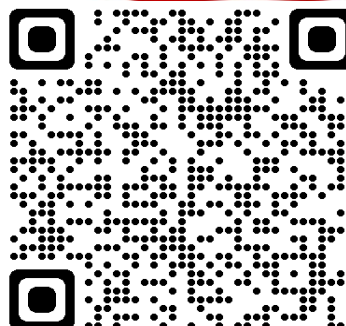
The NHS Complaints Procedure includes instructions in English, Arabic, Bengali, Chinese, Punjabi and Urdu.

Bleeding Disorders Support Groups



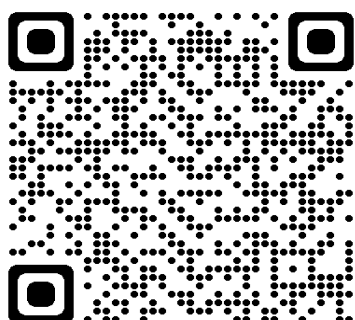
Haemophilia Scotland

www.haemophilia.scot



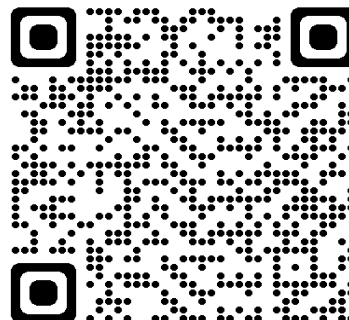
Haemophilia Society

www.haemophilia.org.uk



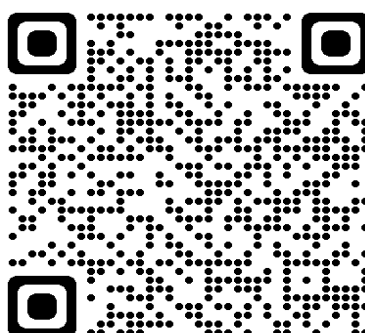
European Haemophilia Consortium

www.ehc.eu



World Federation of Hemophilia

www.wfh.org



Little Bleeders

www.littlebleeders.com

Cost of Living Support and Information

Organisational Name		Contact Details
Citizens Advice Edinburgh (CAE) Provides benefits, debt, and consumer advice. Website www.citizensadviceedinburgh.org.uk		0131 510 5510
The Advice Shop Professional information, advice and advocacy service, providing assistance to anyone living in Edinburgh.		0131 200 2360
The Action Group For children and adults with learning difficulties and their carers.		0131 475 2315
FAIR Information and advice service for people with learning disabilities and carers in Edinburgh.		0131 662 1962
Social Care Direct 1 st point of contact for a range of social services in Edinburgh.		0131 200 2324
Dumfries & Galloway Council	www.dumgal.gov.uk	030 33 33 3000
East Lothian Council	www.eastlothian.gov.uk	01620 827 827
Falkirk Council	www.falkirk.gov.uk	01324 50 60 70
Fife Council	www.fife.gov.uk	03451 55 00 00
Scottish Borders Council	www.scotborders.gov.uk	0300 100 18 00
Stirling Council	www.stirling.gov.uk	01786 40 40 40
West Lothian Council	www.westlothian.gov.uk	01506 28 00 00

Immigration

Organisational Name	Contact Details
Citizens Advice Scotland <ul style="list-style-type: none">• Applying to the EU Settlement Scheme• Getting visas for family members• Getting a visitor visa• Getting British citizenship• Benefits, services and your immigration status• Problems with a visa• Asylum and refugees• Trafficking• Deportation and living in the UK illegally• Windrush scheme	0800 028 1456

Mental Health

Organisational Name	Contact Details
<p>Breathing Space</p> <p>Breathing Space is a free, confidential phone and web-based service for people in Scotland experiencing low mood, depression or anxiety.</p> <p>Website</p> <p>www.breathingspace.scot</p>	<p>0800 83 85 87</p>
<p>Samaritans</p> <p>If you just want to speak with someone over the phone and are feeling suicidal or need emotional support. Your call is confidential and will be taken by a trained worker.</p> <p>Website</p> <p>www.samaritans.org/?nation=scotland</p>	<p>08457 90 90 90</p>
<p>Wellbeing Lothian</p> <p>Provides information and tools to help with your wellbeing and mental health.</p> <p>Website</p> <p>www.wellbeinglothian.scot</p>	<p>Directed online resources</p>

Pain Management

Organisational Name	Contact Details
<p>Pain Concern</p> <p>Work to improve the lives of people living with pain and those who care for them.</p> <p>Website</p> <p>www.painconcern.org.uk</p>	<p>0300 123 0789</p>
<p>Lothian Chronic Pain Services</p> <p>Provides the Chronic Pain Clinic and the Pain Management Programme (PMP) and is based across different sites in Lothian.</p> <p>Website</p> <p>www.services.nhslothian.scot/lcps</p>	<p>Directed online resources</p>

Spiritual Care

NHS Lothian

Members of the Spiritual Care Team are available during normal office hours and, for urgent requests, out of hours through an on-call system. We offer confidential, non-judgemental support to patients, families and staff whatever their beliefs or life situations. If you wish to be visited by someone from your own faith or belief group, we will be glad to help make arrangements.

Any member of staff can contact an on-call chaplain for you via the hospital switchboard. If for any reason you need to contact a chaplain from outside the hospital, please call:

- Royal Infirmary of Edinburgh
0131 242 1990
- Royal Hospital for Children and Young People
0131 312 0168

Translation Services

NHS Lothian

Support includes face-to-face interpreting, telephone interpreting, translation, transcription, British Sign Language / English interpreting lip reading, electronic note-taking and deaf blind communication services.

Interpreters will be arranged as soon as the need for one is known. Please let us know the language required and any other specific requirements so that we can book the right interpreter for you.

NHS Inform

Health information in different languages and formats - including BSL, Easy Read and translations.

Website

www.nhsinform.scot

If you require this information in an accessible format, such as large print or Braille, or in a community language, please use the contact us to let us know.

Advocacy

Organisational Name	Contact Details
<p>AdvoCard</p> <p>Provides independent individual and collective advocacy for people who use, or have used, mental health services in Edinburgh. AdvoCard also provides individual advocacy within Edinburgh prison.</p> <p>Website</p> <p>www.advocard.org.uk</p>	<p>0131 554 5307</p>
<p>Partners in Advocacy</p> <p>Provides independent individual advocacy to children and adults with learning and physical disabilities.</p> <p>Website</p> <p>www.partnersinadvocacy.org.uk</p>	<p>0131 478 7723</p>

Specific Support Groups

Organisational Name	Contact Details
Sexual Health Information Line Scotland Provides sexual health information including HIV and Hepatitis information and signposting for testing. Website: www.sexualhealthscotland.co.uk	0800 02 44 88
Waverley Care Information and provision of care and support for people living with HIV and hepatitis C, their partners, families and carers. Website www.waverleycare.org	0131 558 1425

Hepatitis B (HBV)

Organisational Name	Contact Details
Hepatitis B Foundation UK Offers advice and information to individuals with HBV infection or to their families and friends. Website www.hepbpositive.org.uk	07958 558 510

Specific Support Groups (continued)

Hepatitis C (HCV)

Organisational Name	Contact Details
The Hepatitis C Trust National UK charity for hepatitis C providing information; website with search facility for local support groups. Website www.hepctrust.org.uk	020 7089 6221

Human Immunodeficiency Virus (HIV)

Organisational Name	Contact Details
Terence Higgins Trust (THT Direct) For information, support and advice on HIV and sexual health. The website includes a clinic finder search for HIV testing and sexual health screening. Website www.tht.org.uk	0808 802 1221

Information for Carers

Organisational Name	Contact Details
<p>Borders Carers Centre</p> <p>Independent expert charity supporting adult carers in the Scottish Borders.</p> <p>Website www.borderscarerscentre.co.uk</p>	<p>01896 752 431</p>
<p>Carers of East Lothian</p> <p>Supporting carers in East Lothian by providing information and services to improve overall wellbeing.</p> <p>Website www.coel.org.uk</p>	<p>0131 665 0135</p>
<p>Carers of West Lothian</p> <p>Supporting carers by meeting the needs of unpaid carers and disabled people in West Lothian.</p> <p>Website www.carer-westlothian.com</p>	<p>01506 448 000</p>

Information for Carers (continued)

Organisational Name	Contact Details
<p>Dumfries and Galloway Carers Centre</p> <p>Provides information, advice and support to anyone who cares for a relative or friend.</p> <p>Website www.dgalcarers.co.uk</p>	<p>01387 248 600</p>
<p>Edinburgh Carers Council</p> <p>Provide independent individual and collective advocacy for carers supporting someone with mental health difficulties, a learning disability, dementia, physical disability and/or acquired brain injury.</p> <p>Website www.edinburghcarerscouncil.co.uk</p>	<p>0131 270 6087</p>
<p>Falkirk & Clackmannanshire Carers Centre</p> <p>Provides information and support to carers of all ages living in Falkirk district and Clackmannanshire.</p> <p>Website www.centralcarers.org</p>	<p>01324 611 510</p>

Information for Carers (continued)

Organisational Name	Contact Details
<p>Fife Carers Centre</p> <p>Supporting carers in Fife by providing information, practical and emotional support.</p> <p>Website www.fifecarerscentre.org</p>	<p>01592 205 472</p>
<p>Stirling Carers Centre</p> <p>Provides information, advice and support to unpaid Carers throughout the Stirling Council area.</p> <p>Website www.stirlingcarers.co.uk</p>	<p>01786 447 003</p>
<p>VOCAL - Voices of Carers Across Lothian</p> <p>For individuals looking for information and support to carers in Edinburgh and Midlothian, in addition to training and leisure events.</p> <p>Website www.vocal.org.uk</p>	<p>0808 196 6666</p>

Protecting your privacy

General Data Protection Regulation (GDPR)

The Haemophilia Centre is run and operated by NHS Lothian on behalf of National Service Scotland (NSS) and the Scottish Government.

The Centre is committed to ensuring privacy is protected and that users can be assured that any data will only be used in accordance with the data protection and privacy requirements outlined in this policy.

This policy outlines:

- What data we collect about you
- How we collect this data
- How we store this data securely
- Who we share it with
- How you can access it.

Data protection and security

For the purposes of the data protection legislation, NHS Lothian are the data controllers for personal data collected, stored and shared.

Compliance

This policy is compliant with the relevant data protection legislation, and we're committed to compliance procedures that demonstrate this.

The Haemophilia Centre deals with personal and special category (sensitive) data as classified under the relevant data protection legislation such as the UK General Data Protection Regulations (UK GDPR) and the Data Protection Act 2018.

At the Haemophilia Centre all our health professionals who handle personal data undergo Disclosure Scotland checks prior to employment and ongoing training is mandatory.

Processing your information

The Centre processes your information under a legal basis defined in the data protection legislation and considers there are several legal bases such as:

- The use of your personal data is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in us

- Processing is necessary to protect the vital interests of the data subject or of another natural person.

When we use more sensitive 'special category' types of personal information which includes health information then our legal basis is usually that the use is necessary for the provision of health or social care or treatment or the management of health or social care systems and services, amongst others.

Storing and sharing your data

Any data we collect is stored securely in accordance with NHS Scotland standards. This data will be kept no longer than is necessary and reasonable to do so. After this period, the data will be deleted.

Where it is deemed appropriate the Haemophilia Centre will share all relevant information with the appropriate organisations.

Any data we collect will only be shared for the purpose of:

- Investigating and responding to enquiries
- Monitoring the performance of the service
- Complying with our legal obligations as a Health Board within NHS Scotland.

Loss and misuse of data

We take appropriate technical and organisational measures to prevent the loss, misuse or alteration of your personal data.

Data protection and security

At the Haemophilia Centre, we adhere to all data security standards and protocols that apply to the NHS in Scotland. In addition, all systems that operate as part of our work have had a detailed system security policy assessment in line with nationally recommended standards. The outcomes of this assessment were accredited by the Scottish Government eHealth team.

This document has been adapted from Northern Ireland Comprehensive Care Haemophilia Centre and Thrombosis Centre leaflet with the kind permission from their team.

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