

Northern Ireland Haemophilia Comprehensive Care Centre and Thrombosis Unit



C Floor, Belfast City Hospital, Belfast, BT9 7AB 028 9504 0444



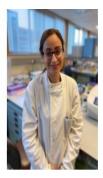
# INFORMATION BOOKLET FOR PATIENTS WITH BLEEDING DISORDERS











































#### PLEASE KEEP FOR REFERENCE

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#### 1) Haemophilia Centre Opening Hours & Contact Details



#### Northern Ireland Haemophilia Comprehensive Care Centre and Thrombosis Unit



**2** 028 9504 0444

(Monday to Friday, 9am to 5pm)

**2** 028 9504 0666

(Out of Hours Haematology Help Line)



C Floor, Belfast City Hospital, Belfast, BT9 7AB

The Northern Ireland Haemophilia Comprehensive Care Centre & Thrombosis Unit known locally as The Haemophilia Centre is open 9am to 5pm Monday to Friday. We are located on C Floor (Bridgewater Suite), Belfast City Hospital.

Outside of these hours, during weekends and bank holidays, a Help Line Service is available for emergency advice. This service can speed up your assessment and treatment in an Emergency Department and keep us informed of any issues you may have out of hours.

The Haemophilia Centre is a designated European Comprehensive Care Centre.



#### 2) Our Commitments To You





The seven commitments our team make to you are:

- 1) You will receive individual, safe, uninterrupted and high-quality care that meets your personal needs and is given by competent members of staff.
- 2) We will treat you with dignity, respect and compassion in an area that is clean and safe.
- 3) We will behave with courtesy and consideration towards you.
- 4) You will know who you are speaking to. We will communicate with you confidentially and in a way that best suits you and your needs.
- 5) You will feel respected and listened to. You will have the opportunity to share your opinions about the care that we provide.
- 6) Our decisions about your care will be made with you and with the people you wish to include. You will receive the information you need to make informed choices about your care.
- 7) You will be cared for by a team who are inspired by these commitments and have the authority to fulfil them.



#### 3) Meet The Team

#### **Medical Team**





**Dr Gary Benson** 

Consultant Haematologist & Haemophilia Centre Director



**Dr Claire Corrigan** 

**Consultant Haematologist** 



**Dr Richard Gooding** 

**Consultant Haematologist** 



**Dr Charlene Neill** 

**Coagulation Specialty Doctor** 

#### **Specialist Nursing Team**



Sr Helen Manson

Haemophilia Sister



**Christine Lynn** 

Haemophilia Nurse/Trials Co-ordinator



**Jackie Dodds Patterson** 

Haemophilia Nurse



#### **Deirdre Morgan**

Haemophilia Nurse



**Eimear Morgan** 

Haemophilia Nurse



**Alex Kelly** 

Senior Health Care Assistant

#### **Allied Health/Social Work Professional Team**



**Patricia McGrath** 

Haemophilia Social Worker



**Claire Forde** 

Haemophilia Occupational Therapist



Francis McMonagle

Haemophilia Physiotherapist



Rebecca Hill

**Specialist Clinical Psychologist** 

#### **Administration Team**



Ray McKeown

Haemophilia Data Manager



**Carolyn Matthews** 

**Medical Secretary** 



**Andrea Sands** 

Haemophilia Receptionist

#### **Specialist Laboratory Team**



**Katy McKee** 

**Clinical Scientist** 



**Annmarie Kearney** 

**Biomedical Scientist** 



**Alastair Brown** 

**Biomedical Scientist** 



**James Cheshire** 

**Biomedical Scientist** 

#### 4) What We Do

The Northern Ireland Haemophilia Comprehensive Care Centre & Thrombosis Unit, is the regional centre that cares primarily for adult patients with the following conditions:

#### **Inherited Bleeding Disorders\***

- Haemophilia A
- Haemophilia B
- von Willebrand Disease
- Factor VII Deficiency
- Factor VIII Deficiency
- Factor IX Deficiency
- Factor X Deficiency
- Factor XI Deficiency
- Inherited Platelet Disorders
- Bernard Soulier Syndrome
- Dysfibrinogenaemia

#### **Other Haematological Disorders**

- Acquired Haemophilia
- Acquired von Willebrand Disease
- Hereditary Haemorrhagic Telangiectasia (HHT)
- Immune Thrombocytopenia Purpura (ITP)
- Thrombotic Thrombocytopenia Purpura (TTP)
- Paroxysmal Nocturnal Haemoglobinuria (PNH)
- Venous Thromboembolism (VTE)

<sup>\*</sup> a full list of inherited bleeding disorders is available by contacting the Data Manager

We also provide the following services:

- 9am to 5pm assessment and treatment walk-in service for patients with inherited bleeding disorders
- Belfast City Hospital inpatient review
- Surgical treatment planning and delivery
- Dental procedure planning and delivery
- Facilitation of the ordering and collection of prescribed medication
- Genetic testing for inherited bleeding disorders
- Foetal DNA sex determination for prenatal screening for genetic bleeding disorders
- Travel advice and planning for patients with bleeding issues
- Home delivery support
- Acute treatments for patients who require:



- Blood transfusions
- Platelet transfusions
- Intravenous immunoglobulin
- Venesection
- Iron infusions

#### **Teaching Hospital**

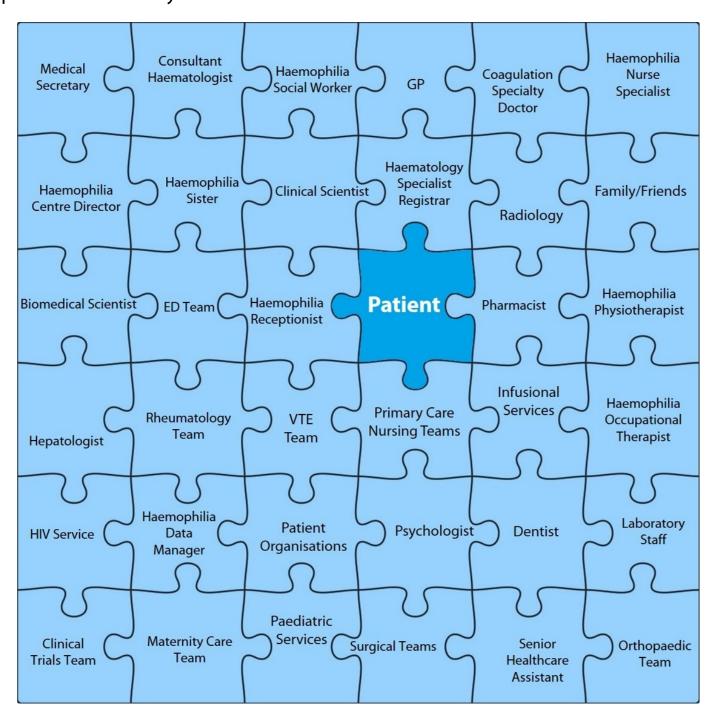
The Haemophilia Centre is involved in teaching associated with Queen's University Medical School & Nursing School, Nursing at University of Ulster and The Open University. Sometimes medical or nursing students may be present. Patients will be asked if they consent to students sitting in on consultations. You may be asked to speak to students about your condition. If you wish to participate in the teaching of students, please let us know.



#### 5) Your Health Care

Your health care involves many different people and teams across the service. Here in the Haemophilia Centre we aim to assist the coordination of the many complex requirements of your health care needs to promote safe effective care.

Our patients are looked after by a multidisciplinary team which include 3 Consultant Haematologists, all who have shared responsibility of your care. Other members of the team include a Coagulation Specialty Doctor, Haematology Specialty Registrar, Specialist Haemophilia Nursing Team, Physiotherapist, Social Worker, Occupational Therapist, Data Manager, Medical Secretary, Receptionist and Specialist Laboratory Team.



#### 6) Clinics

**Weekly Clinics** 

Monday PM Consultant Led Telephone Review

**Tuesday AM** Remote Phlebotomy Review

**Wednesday AM**New Patient Assessment

**Thursday AM/PM** Platelet Review & Treatment

**Fortnightly Clinics** 

Monday PM General Review

**Tuesday AM**Nurse Led Telephone Review

**Tuesday AM** Obstetric Review (RVH)

**Tuesday PM** Obstetric Review (BCH)

**Friday Clinics** 

**1st Friday (Monthly)** Haemophilia Review

**2nd Friday (Every 3 months)** PNH Review

3rd Friday (Monthly) ITP Review

**4th Friday (Every 2 months)** von Willebrand Review

#### Other Clinics Facilitated

MDT Altnagelvin Bleeding Disorders

Genitourinary Medicine (Dr Quah)



Clinics can be very busy at times and there may be unavoidable delays

We will do our best to see you as close to your appointment time as possible

Please ask at reception for information regarding time delays

If you cannot make your appointment, or are running late, please telephone the Haemophilia Centre Reception on 028 9504 0444

#### 7) Haemophilia & von Willebrand Clinics

The Haemophilia and von Willebrand clinics are multidisciplinary in nature, and as such can take longer than usual clinical reviews with your doctor. If you wish to be reviewed by multiple members of the Multidisciplinary Team (MDT) - please allow extra time for your appointment.

During these clinics, as well as being seen by the Medical Team, you have the opportunity to be reviewed by any member of the MDT such as the Specialist Haemophilia Nursing Team, Physiotherapist, Social Worker, Occupational Therapist and/or Data Manager.

Patients with severe and moderate bleeding disorders are reviewed every 6 months at a face-to-face appointment, whereas mild bleeding disorder patients are reviewed yearly at a face-to-face appointment or via the Nurse Led Telephone Review Clinic. At your face-to-face appointment, we will measure your factor trough levels and may ask you to adjust your prophylactic dose according to the result.

A trough level is the lowest concentration reached by a drug before the next dose is administered

#### 8) Nurse Led Telephone Review Clinic

- The Nurse Led Telephone Review Clinic was introduced in 2015 to improve communication and safety for patients with mild bleeding disorders.
- Suitability for the clinic is by consultant referral and exclusion criteria for telephone review is considered.
- Benefits for you will include:
  - less time off work
  - less costly travel expense
  - increased opportunity for education regarding managing your condition safely



#### 9) What We Do At Your Haemophilia Review Clinic

#### **Monitoring Your Haemophilia**

- Assessment of bleeding occurrences and patterns
- Factor level to ensure the effectiveness of your prophylactic treatment
- FBC (full blood count) and iron level to monitor for anaemia (when your body doesn't have enough red cells to meet the body's demand for oxygen)
- Inhibitor screen to detect the presence of an inhibitor
- Joint scores to monitor joint health
- Assessment of any upcoming procedures for surgical intervention



#### **General Health Screening**

- Monitoring blood pressure
- Monitoring weight and BMI
- Bloods
- Profile monitoring kidney function and liver function
- Blood glucose monitoring diabetes
- Cholesterol Over 40's well man check
- Prostrate Specific Antigen (PSA) Over 50's PSA check (prostrate cancer indicator)



#### 10) Inpatient Areas

Should you require an admission to hospital, a bed within the Haematology setting will be sought in either 6 North or 10 North. If this is not possible due to bed pressures, a bed will be found in an outlying ward. You will have daily reviews from the Haemophilia Team and from the on-call Haematology Team over weekends and bank holidays.

#### 11) Surgical Procedures For Patients With A Bleeding Disorder





- Surgical procedures require extensive planning to avoid bleeding complications.
- All members of the MDT are involved in planning care with the patient to ensure safe protocols.
- The Haemophilia Medical and Specialist Nursing Teams aim to foster good communication with the relevant surgical teams pre and post surgery.
- Timing of rehabilitation post surgery with physiotherapy needs to be tailored to patients' individual needs.

Please inform us as soon as you know the date of any upcoming procedures and ask your surgical team to contact us also

#### 12) Physiotherapy

You can contact the Haemophilia Centre directly to arrange a physiotherapy session. Alternatively you may be referred by any member of the team.

An appointment with Physiotherapy may involve a physical examination and will require suitable clothing. Physiotherapy will help you to...



**STAY WELL** - Being active is very important for good health. Your physiotherapist will help guide you on how to safely increase your activity levels in a way that suits you.



**PREVENT INJURY** - They can give you advice about sport and leisure activities such as risks, safety equipment, increasing fitness levels, footwear, first aid and treatment of any injury.



**MONITOR YOUR JOINTS** - Your regular clinic appointment is an opportunity to have a comprehensive review of your joints. Where necessary your physiotherapist may recommend treatment, eg exercise, manual therapy, splints.



**RECOVERY AFTER INJURY, BLEED OR SURGERY** - It is important to follow the recommended rehabilitation before and after surgery. This may involve a specific exercise programme.



**SPLINTS & APPLIANCES** - If you need to use splints or appliances, eg crutches, they will select the most appropriate type and size for your needs and show you how to use them.



**WORK & HOME** - To prevent or reduce joint or muscle problems they may give you advice about simple changes you can make at work or home.



#### 13) Occupational Therapy

If you require Occupational Therapy input, please ask any member of the team to refer you. The Occupational Therapist (OT) can help you with:



**DAILY LIVING TASKS** - If you have difficulty with everyday tasks, due to joint pain, fatigue or other symptoms, we can give hints or tips to make completing tasks easier. This might include self-care, tasks such as washing and dressing, getting in/out of the bath, showering and preparing meals. We can provide or advise on appropriate small aids to help maintain independence.



**UPPER LIMB PROBLEMS** - We can provide advice on splints which can help rest or support a painful joint such as an elbow or wrist. Hand activities can be completed to promote independence with self-care, work and leisure.



**JOINT PROTECTION** - We can look at techniques to reduce stress on your joints that may be weakened due to the effects of bleeds into joints, eg using adaptive devices.



**SELF-MANAGEMENT ADVICE** - It is important to devise ways to help manage a long term condition such as Haemophilia. The OT can work with you on learning new approaches to deal with issues, eg improving sleep and living with chronic pain.



**EMPLOYMENT** - If you are having any work related issues we can provide advice and information. This might include issues getting into work, returning to work or having problems with your current work role.



**LEISURE** - We can look at ways of engaging with leisure which can help improve your general health and wellbeing, eg participating in hobbies and/or socialising with friends.



**HOME ENVIRONMENT** - You can be seen by an OT in your own home to see if some changes can promote safe, independent living. This may include falls advice specific to your surrounding environment. A referral can also be made to Community OT Services for more complex adaptations.

#### Advice can also be provided to family and carers

#### 14) Social Worker

If you would like to meet with our Social Worker, please contact the Haemophilia Centre on 028 9504 0444. Alternatively you can ask any member of the team to refer you.

The Social Worker can offer you an appointment at hospital, in your own home or another suitable venue in your local community.

The Social Worker offers support and counselling with:

- Coping with the physical and psychological effects of managing a bleeding disorder
- Adjusting and adapting to change in your life
- Dealing with family issues
- Caring responsibilities



The Social Worker can offer advice with practical and financial issues and refer you to specialist agencies as appropriate

#### 15) Inherited Bleeding Disorders Clinical Psychology Service

#### What is it?

This is a dedicated service within the Belfast Trust for individuals aged 16 years and over living with an inherited bleeding disorder. The service is for people who are finding it difficult to cope and who feel that their usual daily life is negatively impacted by their condition.

A Specialist Clinical Psychologist provides the service. They are specifically trained and professionally qualified to help people with a range of emotional and behavioural difficulties connected to their life circumstances. They often see people who have physical health problems to help them cope with the stresses and demands of their condition.

#### Why might I see psychology?

Seeing a Clinical Psychologist does not mean that there is something wrong with you psychologically. It simply means that you are trying to improve your way of coping with common problems related to your condition, such as:

- Low mood/sadness
- Worries/anxiety/stress
- Problems associated with treatment
- Anger and frustration
- Managing upsetting memories
- Sleep difficulties
- Low self-esteem/confidence

#### The aim of sessions is usually:

- To help an individual gain a better understanding of themselves and their difficulties
- To explore and promote new ways of coping in order to maximise quality of life

#### What do sessions with psychology involve?

The first appointment with the Psychologist will involve an assessment. This is a chance for the Psychologist to learn about you and your unique experiences in relation to your health, family, life circumstances and the impact of your condition. If after assessment you and the Psychologist feel that further sessions might be helpful then these will be scheduled. For therapy to be of benefit it is important that all arranged appointments are attended.

Notes are taken at the appointments to guide the therapeutic work, which are stored securely on Encompass. A brief letter will be sent to the referrer at the end of the first contact. The Psychologist may liaise with other members of the multidisciplinary team or GPs id sharing knowledge will enable you to receive better care or maintain safety of individuals involved. Information sharing will always be discussed with you.

#### How do I access the service?

If you would like to arrange an appointment with the Clinical Psychology Service you can speak to any member of the Haemophilia Team who can complete a referral on your behalf.



Please note that this service is not appropriate for those with acute mental health needs, or who are currently receiving psychological therapy or mental health intervention elsewhere

#### 16) Data Manager

The Data Manager has a varied role within the Haemophilia Team and responsibilities include:

- Registering new patients with the National Haemophilia Database (NHD)
- Issuing of Bleeding Disorder Information Cards
- Monitoring patients' factor usage submitted by paper return or on Haemtrack
- Training patients in the use of Haemtrack
- Producing reports on individual patient factor usage for the Medical Team which is discussed at your clinic reviews
- Submission of quarterly factor concentrate usage to the NHD
- Registering patients with the chosen home delivery provider and being the point of contact for the company and the patient
- Issuing of travel letters for patients travelling with factor products

The Data Manager is available to meet at your clinic appointment or by contacting the centre reception.

#### 17) Administration Team

Along with the Data Manager, the Administration Team consists of the Receptionist and Medical Secretary. Their roles include:

- Providing secretarial support to the Medical Team
- Making and managing appointments
- Checking patients into clinic
- Booking of interpreters
- Liaising with the Medical Team with patient queries

The Administration Team is often the first point of contact either by phone or in person at clinic.

#### 18) Being Active

Participating in sport and leisure activities can bring many benefits including:

- Stronger muscles and joints
- Help towards maintaining a healthy body weight
- Prevent depression/anxiety
- Improved self confidence



Being active also helps prevent other medical conditions including:

- Heart disease
- Back pain
- Depression







Try to reduce the time you spend sitting down:

- Spend less time watching TV or being on the computer
- Take regular work breaks
- Use the stairs instead of the lift
- Walk part of the way to work



If you return to sport too soon following a joint/muscle bleed or injury you are at higher risk of a further bleed or injury. It is important that you:

- Gradually increase your exercise programme until you are fit enough to cope with the physical demands of your particular sport
- Use any protective equipment for your sports, eg goggles, braces, etc
- Check your sports shoes they should be in good condition and suitable for your sport

The staff at the Haemophilia Centre will be able to advise you regarding which activities/sports are most appropriate for you during any recovery period

#### 19) What You Should Do If You Have An Injury Or A Bleed

It is important that bleeds are treated quickly! You will have less pain, less damage to joints, muscles and organs and less treatment will be needed to control the bleeding.

**STOP** any activity that might have caused the bleed. Continuing the activity could cause further damage and prolong your recovery.

#### **FACTOR CONCENTRATE**

If you are on home treatment, please take your factor concentrate as previously explained by staff at the Haemophilia Centre. If you are not on home treatment, please contact the Haemophilia Centre for advice.

#### **MEDICATION**

Do not take Cyclokapron/Tranexamic Acid tablets if you have blood in your urine. Do not take Aspirin, or any medication containing Aspirin. Paracetamol is a safe alternative - but do not exceed the stated dose.

Some bleeds can be life-threatening and require prompt treatment. Contact the Haemophilia Centre immediately if you suspect a bleed in any of the following areas:

- . HEAD
- . EYE
- . NECK
- . ABDOMEN
- . GROIN
- . HIP

For 24-48 hours following a joint or muscle bleed, you should follow what are known as the PRICE guidelines:

**ROTECT** or support the injured joint or muscle. Using a sling, splint or crutches may help.

**EST** the injured joint or muscle for the first 24-48 hours, avoiding activities that cause additional pain, swelling or discomfort. If you are playing sport when an injury occurs you should stop playing immediately. Depending on the extent of the injury you may still be able to go about your normal daily activities. Avoid further strain by taking regular rests. Try to move your injured body part gently for 10-20 seconds every hour during the day.

**CE**: Apply ice to the injured area for approximately 10 minutes. You may use gel packs, crushed ice or a packet of frozen vegetables. Repeat ice applications every two to three hours. Make sure you use a damp towel between the ice and your skin to avoid ice burn.

**OMPRESS**: An elasticated bandage or wrap may help to reduce swelling and ease pain. Be careful not to put it on too tightly. Loosen it immediately if pain increases or if you develop numbness or tingling in the areas. Remove any compression bandage before you go to bed.

LEVATE: Raise the injured body part as much as possible (above the level of your heart). Make sure it is supported (eg with pillows or a sling). Do not use compression and elevation at the same time. After the first 24-48 hours it is important to gradually recover joint movement, together with muscle strength and flexibility. This will help to protect you from spontaneous bleeds and joint damage. You may also need to see physiotherapy and/or OT for treatment or advice. Once you have recovered from the bleed you should try to be as active as possible. As well as protecting your joints, this will help you to maintain a healthy weight.

#### 20) Transfer Of Care From Children's To The Adult Hospital

Welcome to the Adult Haemophilia Comprehensive Care Centre. You should already recognise some staff as our Physiotherapist, Occupational Therapist, Social Worker and Data Manager provide their services in both centres. The rest of the staff will be getting to know you and your individual needs over the coming years, helping you to overcome old and new challenges as you transition from the Children's Service.

Our focus will promote independence, responsibility and resilience as well as developing skills already explored in:

- Mixing own treatment and self infusion
- Bleed recognition
- Knowing how to contact the Haemophilia Centre
- Ordering treatment
- Managing hospital appointments independently
- Recognising the importance of early treatment and prophylactic doses
- Recognising the importance of physical activity and a healthy diet

Your first appointment with the adult centre will be an introduction to the team and a tour of the department

After that you will commence either 6 monthly or yearly reviews depending

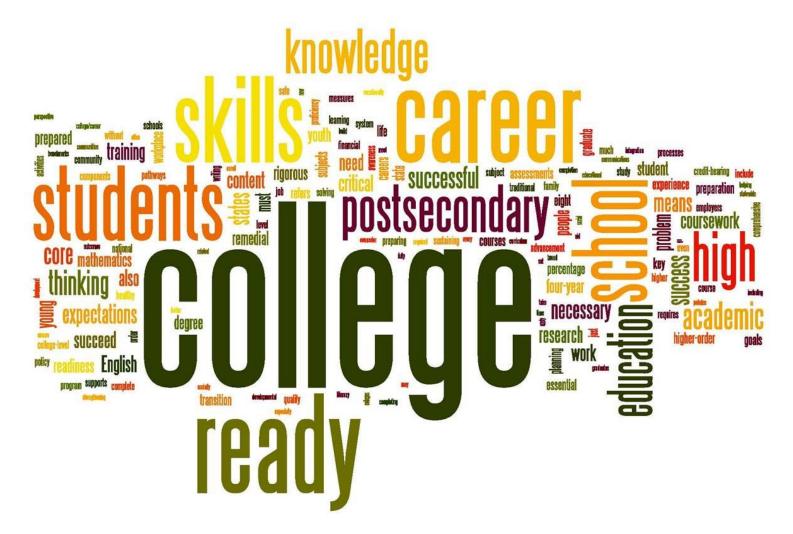


If you would like more information on the Children's Haemophilia Centre based at the Royal Belfast Hospital for Sick Children, please ask for a copy of the Parent Information Booklet For Children With Bleeding Disorders.

#### 21) Leaving Home - Moving To College/University

If you move out of Northern Ireland to go to college or university, you will need to:

- Register with a local General Practitioner (GP)
- Inform us of your new address
- Arrange scheduled clinic reviews with us during holiday periods or when you are back home
- Contact the Haemophilia Centre closest to your term time address for details of "out of hours" care arrangements



We can provide you with information regarding the closest Haemophilia Centre to your new address, and transfer your details to them for term time Emergency Care

#### 22) United Kingdom Haemophilia Centre Doctors' Organisation

The United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) is an association of medical practitioners who work within the Haemophilia Centres of England, Scotland, Wales and Northern Ireland, and have an interest in the care of people with Haemophilia or other bleeding disorders.

The aims of the organisation are:

- To preserve, protect and relieve persons suffering from Haemophilia and other bleeding disorders.
- To advance the education of the medical profession, the nursing profession, professions allied to medicine and general public in the knowledge of Haemophilia and other bleeding disorders and their treatment(s).
- To promote or assist in the promotion of audit and research into the causes, prevention, alleviation and management of Haemophilia and other bleeding disorders and to disseminate the useful result of such research.

The UKHCDO was established in 1968 to improve Haemophilia care and research into bleeding disorders.

The UKHCDO established a secretariat and a national database and has produced annual reports and many publications from the data generated.



www.ukhcdo.org/patientinformation/



#### 23) National Haemophilia Database

The National Haemophilia Database (NHD) holds information on people registered with a bleeding disorder within the United Kingdom (UK). It contains details of more than 40,000 people, both alive and deceased. The NHD is managed by the UKHCDO who work with practitioners who are based within the Haemophilia Centres in the UK and have an interest in the care of people with inherited bleeding disorders. The UKHCDO is the data controller and processor and determines the purpose and means of processing the personal data collected.

The information is collected to help your Haemophilia Centre treat you or your child's bleeding disorder and to allow the NHS to plan clinical services for people with bleeding disorders. The information is used for two important purposes: non-research activity which involves regular reporting to facilitate disease monitoring, health care planning, current and future needs and funding, safety, drug safety and efficacy. Secondary, research into bleeding disorders to understand the behaviour of bleeding disorders, the development of these conditions, the outcome of current treatment options and complications of the conditions and their treatments.

Your Haemophilia Centre sends information about what and how much treatment you have been given and whether any complications or problems have occurred. Complications may include treatment not working properly because of an inhibitor, allergic reactions to treatment and other rare complications. Monitoring the safety of drugs used for bleeding disorders is a very important feature of the database. We may also collect information about your joints and muscles because these can be affected by severe bleeding disorders.



#### 24) Database Consent

On their first visit to the Haemophilia Centre, the majority of patients with a bleeding disorder consent to having genetic testing performed. They also consent to having the results entered onto local and national confidential databases.

The NHD also require additional informed consent for patients in Northern Ireland and a separate consent form is required for each patient. The consent they ask for is that each patient:

- Confirms that they have read and understood the Patient Information Leaflet version 2.0 for the UK National Haemophilia Database.
- Gives permission for their clinical data, from any hospital that they attend, to be provided to the NHD by their Haemophilia Centre for clinic research purposes.
- Gives permission for the NHD to share their personal identifiers (name, H&C number and date or birth) with the Health & Social Care Northern Ireland (HSCNI) for the purpose of clinical and research purposes including death certification data.
- Understands that their participation in research is voluntary, and can be withdrawn at any time, without giving a reason, and without their medical care or legal rights being affected.
- Understands that their anonymised medical information may be looked at by authorised individuals from regulatory authorities including the European Medicines Agency (EMA) and the Medicines and Healthcare Products Regulatory Agency (MRHA) where it is relevant.

The NHD consent form was updated in 2022 and all patients registered on the NHD are being asked to consent to this. If you have not signed the new consent form or require further information, please contact the Haemophilia Data Manager.

#### 25) Bleeding Disorder Information Card

Patients with certain bleeding disorders, and who are registered on the NHD also receive a Bleeding Disorder Information Card, and are advised to carry this on them at all times in case of emergency.

Patients are advised to present the card upon any admission to hospital or for any dental treatment so that the Haemophilia Centre can be contacted.

#### **BLEEDING DISORDER INFORMATION CARD**

Name:

Date of Birth: NHS No:

Diagnosis:

Level: Current inhibitor:

**Usual Treatment Product:** 

**Contact**: Northern Ireland Haemophilia and Thrombosis Unit

**Tel**: 028 950 40444 **Out of hours**: 028 950 40666

The card contains important information regarding baseline factor level and the treatment product specific to each individual patient.

These cards are produced from the information that we supply to the NHD.

Replacement or additional cards can be requested directly from the Haemophilia Data Manager or by asking any member of the Haemophilia Team.

#### 26) Haemtrack

If you are on home treatment, you will have agreed to keep and return accurate home treatment records so that your haemophilia treatment can be assessed. Home treatment records are very useful for the Haemophilia Team because they help us work out whether you are on the best treatment and to advise you how to improve your treatment.

Instead of recording this information on paper and bringing it or sending it to the centre, we would prefer you to complete your records electronically after each treatment by way of the Haemtrack website. This easy to use system helps you to report all your bleed and treatment information as quickly as possible in order for the Haemophilia Centre to provide you with the best possible care.

#### What is Haemtrack?

- A secure treatment recording system connecting you to the NI Haemophilia Comprehensive Care Centre through the Haemtrack website on your laptop, tablet or mobile phone.
- It enables you to record all treatments as they occur.
- It allows the NI Haemophilia Comprehensive Care Centre to see your up to date treatment information to help improve your care.
- The treatment information will be stored securely on your phone or computer, the Belfast Trust computer system and the NHD.

To access Haemtrack visit:

https:// hometherapy.mdsas.com



#### 27) Home Treatment & Medication

Patients who receive their Home Treatment Factor products direct from the Haemophilia Centre must:

- Give 96 hours (4 working days) notice
- Place their order by phoning the Haemophilia Centre on: 028 9504 0444

Patients who receive Home Treatment Factor products may also wish to avail of the Home Delivery Service which the centre provides using a home delivery company called Sciensus.



#### 28) Home Delivery

Sciensus (formerly Healthcare at Home) is the home delivery company that the Haemophilia Centre uses to supply home treatment factor products direct to the patient.



If you choose to receive home delivery, a representative from Sciensus contacts you to arrange a delivery for a date/time convenient to you, and will supply you with your home treatment, usually a 6 to 8 week supply. They can deliver Monday to Friday, 8am to 8pm. Your treatment will be delivered direct to your home address, or an alternative address such as work should you wish.

As well as supplying your factor product, Sciensus will also supply any ancillary items that you may require and also a sharps bin, which they will also collect when full.

If you have not already signed up to the home delivery service and would like to do so, or require more information, then please contact the Haemophilia Data Manager or any member of the Specialist Nursing Team.

If you already receive home delivery from Sciensus and need to contact them direct, you can either email them or phone them:

□ generalenquiries@sciensus.com

**2** 033 103 9499

Monday to Friday 8am to 8pm Weekends & bank holidays 8am to 4.30pm

<u>www.sciensus.com</u>



#### 29) Travel Tips

- Take sufficient treatment for the whole period you are away.
- Request a travel letter from the Haemophilia Centre which explains the nature of your treatment you are carrying and how it should be stored whilst travelling.
- If you are HIV positive, you can check specific advice by visiting: <u>www.hivtravel.org</u>



 Always carry your Bleeding Disorder Information Card detailing your condition. These are available from the Haemophilia Centre. Alternatively you could wear a medic alert bracelet, which is internationally recognised. You can order various alert tags from <a href="https://www.medicalert.org.uk">www.medicalert.org.uk</a> or from other registered charities.



- Visa requirements should be checked well in advance of travel if you need one for the country you are travelling to.
- To find where the nearest Haemophilia Centre is to where you are travelling, check the EUHANET Centre Locator:

www.euhanet.org/centrelocator or scan the QR code:





If you are thinking of going away, whether for business or pleasure, it is essential that you take out travel insurance for pre-existing medical conditions. This will give you peace of mind so that you can enjoy your travel experience to the full, knowing that you have all the cover you require. Without taking out insurance to cover existing conditions, including your bleeding disorder, you may be liable for any healthcare costs incurred, whether related to your bleeding disorder or not.

The Haemophilia Society list the following companies that provide cover for people travelling with pre-existing medical conditions:

Travel Insurance 4 Medical www.travelinsurance4medical.co.uk	0345 908 0121	
Staysure www.staysure.co.uk	0800 033 4902	
All Clear Travel Insurance www.allcleartravel.co.uk/	0808 281 2989	
MIA www.miatravelinsurance.co.uk/	0800 999 3333	
Avanti www.avantitravelinsurance.co.uk/pre-	0800 888 6195	

<u>insurance</u>

existing-medical-conditions-travel-

Insure and Go www.insureandgo.com/	0808 281 0057	
insurefor.com www.insurefor.com/	0343 658 0220	
Able2Travel www.able2travel.com/	0148 380 6826	
JustTravelCover www.justtravelcover.com/	0800 294 2969	
JS Travel Insurance www.jsinsurance.co.uk/	0800 466 1174	
Insurance With www.insurancewith.com/	0333 005 1069	



## Haemoghilia Centre

The *My Haemophilia Centre* app is full of practical information and useful features, to help you better manage your haemophilia.

The *My Haemophilia Centre* app is available on iOS and Android, and can be downloaded from the App Store or Google Play – just search for 'My Haemophilia Centre'.

### Download the app today





Enter your centre access code 5943 in order to view messages from your clinic



The *My Haemophilia Centre* app has been developed and funded by Pfizer, in collaboration with The Royal London Hospital. This has been provided as a Donation from Pfizer to the haemophilia centre.

PP-UNP-GBR-0565 Date of Preparation: April 2022



#### 31) Belfast Health and Social Care Trust



Belfast Health and Social Care Trust, also known as the Belfast Trust and referred to as the Trust, is one of the largest integrated health and social care trusts in the United Kingdom.

We deliver integrated health and social care to approximately 358,000 citizens in Belfast and provide the majority of regional specialist services to all of Northern Ireland at over 100 facilities across Belfast. These facilities include:

- Large hospital complexes providing acute services
- Health centres
- Day centres
- Wellbeing and treatment centres
- Residential accommodation
- Supported housing



We have an annual budget of £1.9 billion and a workforce of over 22,000. The Belfast Trust also comprises the major teaching and training hospitals in Northern Ireland.

For more information visit:

www.belfasttrust.hscni.net



or scan the QR code:

# 32) Getting To Belfast City Hospital



The Belfast City Hospital is situated to the southwest of Belfast City Centre.

**From the South via the M1.** Leave at Junction 1 and join the Donegall Road. Travel for just under 1 mile and the entrance to the hospital will be on your right.

From the North via the M2. Travel through Junction 1 to the next intersection and take the second slip road onto Nelson Street. Take the third turning right and continue straight ahead to join the Westlink. Travel for approximately 3 miles to Junction 1 of the M1 and at the roundabout, turn left onto the Donegall Road. Travel for just under 1 mile and the entrance to the hospital will be on your right.



Translink Metro Bus routes 9A and 9B pass the Lisburn Road entrance while route 9E takes you to the Donegall Road entrance at the Abingdon Drive stop. Some Ulsterbus routes also stop near the main entrance.



Northern Ireland Railways have a special railway stop immediately adjacent to the hospital running regular train service connections on the Bangor, Derry/ Londonderry, Larne, Newry, Portadown and Portrush lines via Great Victoria Street and Lanyon Place Stations.



For up to date travel information and



www.translink.co.uk or scan the QR code:

#### **Belfast City Hospital Car Parking** 33)



There are a number of car parking areas across the Belfast City Hospital site, as shown on the map on the opposite page. Disabled car park provision is available in the main car park opposite the hospital tower. Pay stations are located in the main foyer.

# 34) Map Of Belfast City Hospital



# 35) Belfast City Hospital Catering







#### THE TERRACE RESTAURANT

The Terrace Restaurant is located on D Floor of the main hospital tower. It is open every day from 8am to 5.30pm. It serves cooked breakfasts, lunches, snacks and drinks. Meal times are:

**Breakfast** 8am to 11am

**Lunch** 12pm to 2pm

**Tea** 3.45pm to 5pm

Tea, coffee and pastries are available at other times.

#### **CHAT COFFEE**

There is a CHAT coffee shop on the ground floor of the main hospital tower. It sells a range of hot drinks, snacks and tray bakes.

#### **CHAT CAFÉ**

There is a CHAT café on the ground floor of the Cancer Center. It sells a range of hot and cold drinks, sandwiches, scones, snacks and tray bakes.

#### **CHAT NEWSAGENTS**

The CHAT Newsagents on the ground floor of the main hospital tower sells a wide range of newspapers, magazines, snacks, sweets and drinks.

#### **VENDING MACHINES**

There are vending machines located in the Outpatient Wing on the ground floor of the hospital tower and also outside the Terrace Restaurant on D Floor.

### 36) Interpreting Service

Health & Social Care Northern Ireland provides the Regional Interpreting Service which is available for all Health & Social Care Organisations throughout Northern Ireland and can be accessed by the Haemophilia Centre.

If a patient attends a clinic appointment and does not speak English as a first or competent second language, we will contact the Regional Interpreting Service to arrange a face to face interpreter.

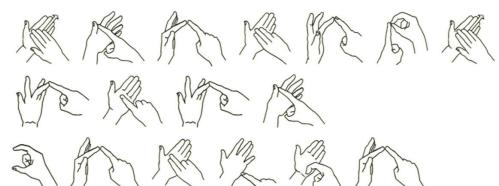
The service has over 200 trained, provisional interpreters, covering 33 registered languages.



#### 37) Sign Language



For patients whose first language is sign language, an interpreter can be arranged via Sign Language Interactions.



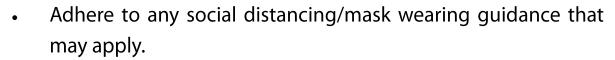
#### 38) Written Translation

Several of the patient information leaflets available in the Haemophilia Centre Reception are also available in various languages. Please ask at Reception.

### 39) Being A Patient

Please help us fight infection by following these simple rules when you come into the hospital:

- Sanitise your hands before and after visiting the centre.
- Do not attend the hospital if you have symptoms of an infectious illness your appointment can be rescheduled.





Please stick to your given appointment time.

Contact us to let us know if you are unable to attend your appointment.





The Belfast Trust operates a zero tolerance policy in respect of violence and racism. Patients or visitors displaying threatening or abusive behaviour will be required to leave.



Do we have your correct details?

Please inform Reception of any change(s) to your address, telephone number or GP.



Visitors with any recording equipment such as mobile phones, cameras or camcorders should ensure that they are turned off whilst in the hospital.

No photography or video recording is permitted. Please respect patient and staff confidentiality.



Smoking or the use of e-cigarettes and/or vapes is not permitted anywhere on the Belfast Trust sites including buildings, entrances, exits, grounds and car parks.



The Belfast Trust offers a stop smoking service which supports patients and staff to do the single most important thing they do can to improve their quality of life.



For more information, visit:

www.belfasttrust.hscni.net/service/stop-smoking-service/

#### 40) Hospital Travel Costs Scheme



A Hospital Travel Costs Scheme is available to help patients who are entitled to reclaim travel costs to and from hospital for NHS treatment. You may be eligible to reclaim travel expenses if you receive benefits or credits, or are on a low income. Please ask us about this at Reception.

## 41) Chaplaincy Service

There is a chaplaincy service available to offer confidential pastoral, religious and spiritual care to all who request it. It is available to everyone regardless of faith, belief, lifestyle or cultural background. The Chaplaincy teams on site comprise of representatives from a range of Christian denominations. Buddhist, Hindu, Jehovah's Witness, Jewish and Muslim traditions as well as Humanist and non-religious pastoral support representatives are also available on request.

# 42) Breastfeeding

The Northern Ireland Haemophilia Comprehensive Care Centre & Thrombosis Unit welcomes breastfeeding in our waiting area, and can also provide a private space should you require.

- Breastfeeding is acceptable in all areas
- Breastfeeding mums will not be asked to move or stop feeding
- Staff are aware and supportive of the needs of breastfeeding mums

# We've joined the scheme!



#### 43) Patient and Client Council



The Patient and Client Council (PCC) was created on 1 April 1999 as part of the reform of Health and Social Care in Northern Ireland and acts as a powerful, independent voice for patients, clients, carers and communities.

The role of the PCC is to be an independent, informed and influential voice that makes a positive difference and advocates for people across Northern Ireland in Health and Social Care.

"Our vision is for a health and social care service actively shaped by the needs and experiences of patients, clients, carers and communities to enable them to live the best lives they can."

If you have a concern or issue about health or social care, or would like to get involved and make your voice heard, they would like to hear from you. They have a team of trained practitioners who can help you find a solution or connect you to those that can.

**2** 0800 917 0222

Monday to Friday 9am to 4pm

www.pcc-ni.net











# 44) Care Opinion

You can give anonymous feedback on "Care Opinion".





Please tell us about your experience of

The Northern Ireland
Haemophilia
Comprehensive Care
Centre

Your story can make a difference

www.careopinion.org.uk

#### 45) What Matters To You?

The Haemophilia Centre regularly takes part in the "What Matters To You?" initiative.

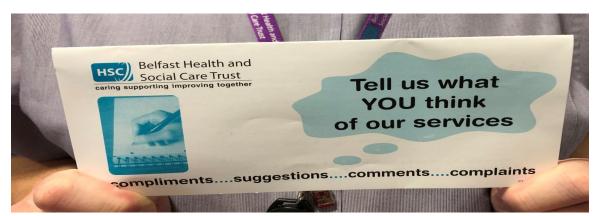
Posters displaying feedback and results are displayed in the Reception area.



# 46) Compliments & Complaints

You can tell us what you think of our service using the Belfast Trust's "Compliments... Suggestions... Comments... Complaints" form. You can get information on this from any member of the Haemophilia Centre team or on www.belfasttrust.hscni.net/contact-us/compliements-and-complaints





# 47) Encompass





Health and Social Care Northern Ireland (HSCNI) is committed to improving the way we care for people in Northern Ireland. Modernising key health and social care IT systems will help provide an improved service.

Encompass is a new computer programme which uses electronic health care records and is currently being used by The Belfast Health & Social Care Trust and the South Eastern Health and Social Care Trust. It will be implemented in the 3 remaining Health & Social Care Trusts in Northern Ireland by 2025.

# One person. One record. One system. One future.

What you need to know. When you need to know it.

One single, secure record in the

Visit <a href="https://encompass.hscni.net/">https://encompass.hscni.net/</a> or scan here for more information:



# encompass

A digital health and care record for every citizen in Northern Ireland

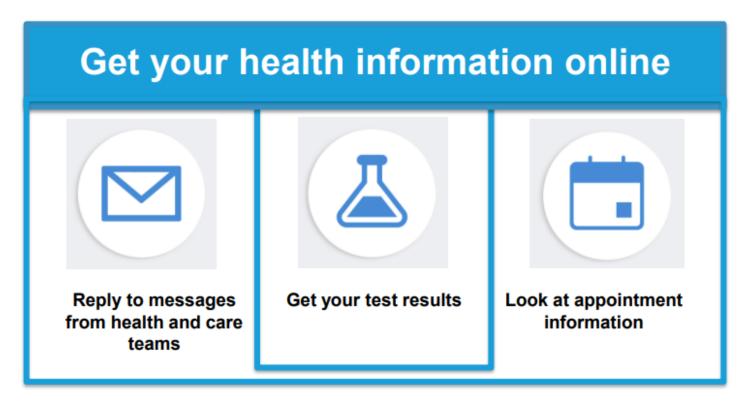


#### 48) My Care App





With the implementation of Encompass, you will be able to safely see some of your health information online using My Care which is a patient portal accessed on your computer, tablet or mobile phone.



You will be able to see information such as medications, treatments and things you are allergic to. You will be able to reply to messages from health and care teams, look at some test results and see appointment information and clinic letters about your health and care.

For more information on My Care, visit:

https://mycare.encompass.hscni.net/MyChart/Authentication/Login?
mode=stdfile&option=fag or scan the QR code:

#### 49) Data Protection

In order for the Belfast Health & Social Care Trust to help provide a service for you, we need to know some information about you .

Personal information that we process about you is governed by The Data Protection Act 1998 and the General Data Protection Regulation (GDPR)

At the Belfast Health & Social Care Trust, we take your privacy seriously. Staff will only access your information when they are involved in a period of your care.

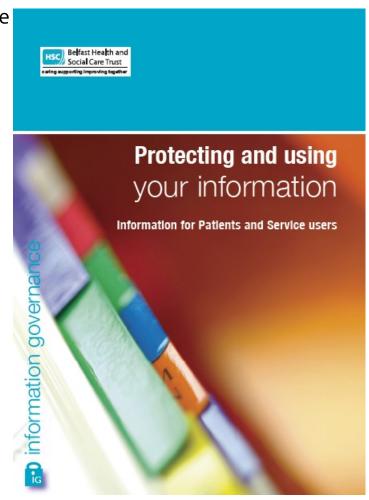
All staff have a legal duty to keep your information safe and confidential, as does anyone who receives information about you from the Trust.

In line with legislation, the Trust has a range of measures and strict standards to protect paper and electronically held information.

If you want to know more about how we use your information, please contact:

Data Protection Office
Belfast Health & Social Care Trust
1st Floor Administration Building
Knockbracken Health Care Park
Saintfield Road
Belfast
BT8 8BH

**28** 028 9504 6955



#### 50) Useful Contacts & Support Groups





#### **World Federation of Hemophilia**

The World Federation of Hemophilia (WFH) is a non-profit organisation dedicated to improving and sustaining care for people with inherited bleeding disorders around world.



www.ehc.eu



#### **European Haemophilia Consortium**

The European Haemophilia Consortium (EHC) is an international non-profit organisation representing 48 national patients' organisations for people with rare bleeding disorders from 27 Member States of the European Unit and most Member States of the Council of Europe.

#### **Haemophilia Centre Locator**

An EAHAD and EHC project

www.euhanet.org/centrelocator



#### **Haemophilia Centre Locator**

The Haemophilia Centre Locator will give information on where the nearest Haemophilia Comprehensive Care Centre or Haemophilia Treatment Centre is anywhere in the world.



www.haemophilia.org.uk



## The Haemophilia Society

The Haemophilia Society (THS) is the only UK-wide charity and free membership organisation for everyone affected by a bleeding disorder.

#### www.haemophiliani.org



#### Haemophilia NI

Haemophilia NI is an independent regional charity whose focus is to provide information, support and advocacy to everyone with Haemophilia, von Willebrand's and other bleeding disorders.



www.haemophilia.ie



#### Irish Haemophilia Society

The Irish Haemophilia society represents people with Haemophilia, von Willebrand's and other inherited bleeding disorders.



www.haemophilia.scot



#### Haemophilia Scotland

Haemophilia Scotland is Scotland's registered charity for individuals and families with Haemophilia, von Willebrand's and other bleeding disorders.



www.haemophiliawales.org



#### **Haemophilia Wales**

Haemophilia Wales provides information, support and advocacy to everyone with Haemophilia, von Willebrand's and other bleeding disorders, including their families and carers.



# www.nhs.uk/live-well/exercise/get-



Exercise guidelines and workouts to help improve your fitness and wellbeing.





#### **Little Bleeders**

Little Bleeders is a charity that supports young people with blood disorders to "move more and be more". It was set up by professional cyclist Alex Dowsett, who himself has severe Haemophilia.





#### Why Sit It Out?

Multichannel communications campaign that has successfully inspired more participation in physical activity for boys with Haemophilia.



www.hhtuk.org



HHT UK Patient Support provides information and support to those with Hereditary Haemorrhagic Telangiectasia (HHT), their families and loved ones.



#### www.itpsupport.org.uk



#### **ITP Patient Association**

The ITP Support Association is a wholly independent UK organisation and registered charity giving support and information for patients with Immune Thrombocytopenic Purpura (ITP).





#### **TTP Network**

TTP Network is a registered charity that supports patients with the condition Thrombotic Thrombocytopenic Purpura (TTP).



www.helplinesnetworkni.com



#### **Helplines Network NI**

Helplines Network NI is an organisation consisting of over 30 different helplines operating across Northern Ireland. The helplines provide a variety of vital support services including information, advice and counselling.



www.adviceni.net



#### Advice NI

Advice NI is the independent advice network, providing advice to those who need it most.



#### www.advicespace.me



#### **Advice Space**

Offering free, confidential and up-to-date factual advice to anyone who needs it, and help people to find a way forward.



www.carersuk.org/northernireland





#### **Carers NI**

An advice and information service for carers and professionals, dealing with a range of issues such as carers' benefits, community care and services for carers.



www.lifelinehelpline.info



#### Lifeline

The Northern Ireland crisis response helpline service for people who are experiencing distress or despair. Counsellors are available 24 hours a day, 7 days a week to listen and help in confidence.



www.samaritans.org



#### **Samaritans**

Offering listening and support without judgement or pressure to people and communities in times of need.



#### www.womensaidni.org





#### Women's Aid

The lead voluntary organisation in Northern Ireland addressing domestic and sexual violence and providing services for women and children.



www.nidirect.gov.uk/contacts/make-call



#### Make The Call

The service that makes sure you are getting all the benefits, services and support you are entitled to.



www.brysonintercultural.org



#### **Bryson Intercultural**

The leader in working with and empowering minority ethnic families and their communities in Northern Ireland, including newly arrived minority ethnic individuals and also indigenous Irish Travellers, by promoting and supporting racial and ethnic integration in Northern Ireland.



www.migrantcentreni.org



# **The Migrant Centre**

Tackling racism and eliminating barriers against new and settled migrant communities in Northern Ireland.



# Raise funds for

Northern Ireland Haemophilia Centre

# every time you shop online

Find us on easyfundraising to start:

https://www.easyfundraising.org.uk/causes/nihaemophilia/

















Booking.com M&S Boden







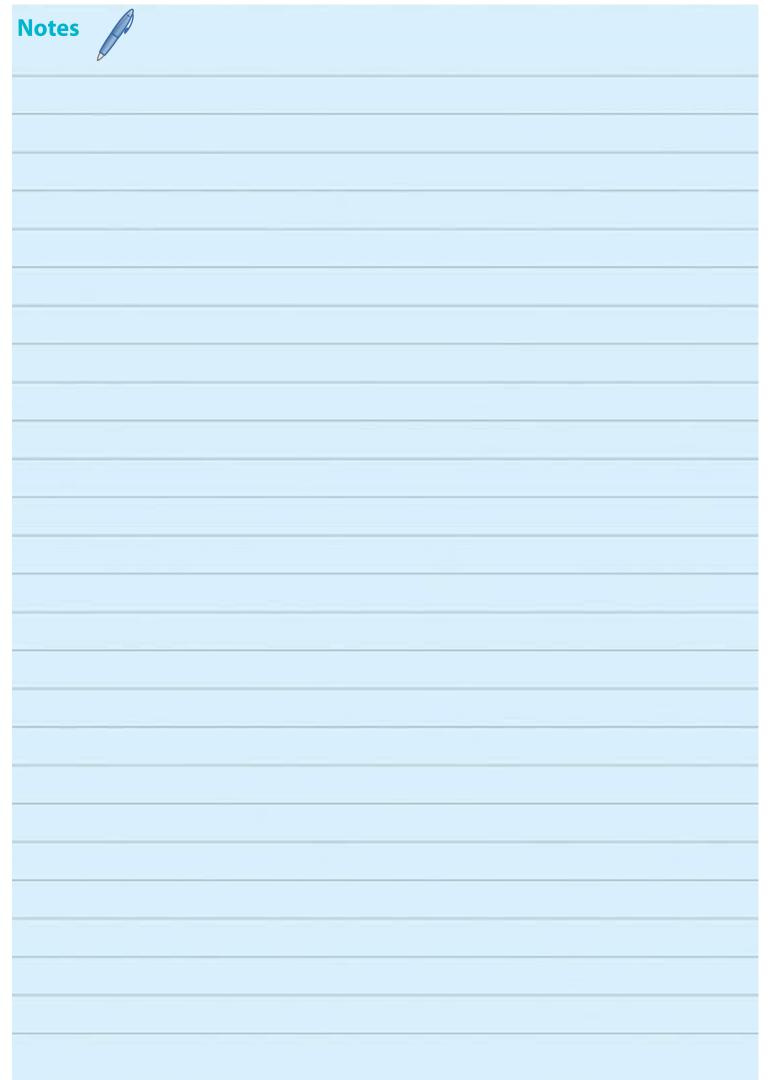














This information booklet has been produced by the Northern Ireland Haemophilia Comprehensive Care Centre & Thrombosis Unit and is intended for use by it's patients, families and carers.
All information is correct at time of publication. To ensure that you have the correct information, please dispose of any previous copies of this booklet that were published prior to the below date.
Please contact the Centre if you require an electronic copy of this booklet.
Version 6 - October 2024