



THE
HAEMOPHILIA
SOCIETY



**Ageing with a bleeding
disorder - social care and support**

Contents

Introduction	3
Part 1	4
What is ageing?	4
Is this booklet for you?	5
Finding the right social care	6
What is an assessment?	6
How do I apply for a care needs assessment?	7
Can I apply if I'm a carer?	7
What does the care needs assessment involve?	7
Preparing for your care needs assessment	9
Do I need homecare or home help?	10
What happens at a care needs assessment?	10
How to complain about a care needs assessment	10
What happens after the care needs assessment?	11
About your care plan	12
Help for carers – information and support	12
Carer's Allowance	12
Part 2	13
What care support can I get?	13
Homecare	13
I need help with self-infusion at home	13
Will I have to pay for my homecare?	13
Can I arrange my own homecare?	13
Employing your own carer	14
Home adaptations	16
Disabled Facilities Grant	16
Residential care home	17
Types of care home	18
Specialist housing	19
Types of specialist housing	19

More information you might find useful	20
Finding residential care or care agencies	20
Things you should consider before choosing a care home	21
Moving into a care home	22
Problems with your care	24
Escalating a complaint: self-funder	24
Escalating a complaint: local authority funded care	24
Ombudsmen for care providers	24
Care regulators	25

Introduction

This booklet is designed to help our ageing members to plan their specific needs as they reach older age. Elderly people with bleeding disorders may have chronic joint damage that brings about falls and fractures, so it's important to get the right care and support either at home or in residential care.

Fall prevention practices should be considered as part of ageing with a bleeding disorder and this booklet aims to help our members be confident in seeking advice and support.

Social care can be complicated, but we hope that this booklet will simplify the process and give you several paths to choose from.

Please note local council care services may vary if you live in Wales, Northern Ireland or Scotland.

Part 1 - What is ageing?

Ageing is an inevitable part of the life cycle: a person is born, goes through childhood, adolescence, adulthood and at some point in life begins to age. The process of ageing doesn't start at the same time for everyone; some age more quickly, others more slowly and we should not generalise.

Every individual's experience is unique. Ageing is not just a physical process; it also has psychological, social and financial implications. Although ageing can involve loss of faculties that doesn't mean it's a negative experience as it can also bring positive values like knowledge, wisdom and experience.

People with bleeding disorders born before the 1970s spent most of their early lives without the benefits of effective replacement therapy treatment. This treatment was replaced with a revolutionary new product, factor concentrate, which could be administered at home with an injection. For the first time, people with bleeding disorders could be treated before a bleed (prophylactically) reducing the likelihood of a bleed and the resulting joint damage.

While great progress has been made, it came at a high human cost, with widespread infections of HIV and hepatitis viruses during the contaminated blood scandal of the 1970s and 80s. Many of our ageing community face additional health complications as a result of that period.

Advances in care mean there is now safe, effective treatment and the life expectancy of people with bleeding disorders has improved dramatically.

This makes it even more important that people get the right information on finding and arranging social care in later life.



Is this booklet for you?

Everybody needs a little help sometimes. If things are getting harder to manage, you may be able to get the extra care and support you need through social care.

It's never too early or too late to talk about social care. Talking about getting some extra help doesn't mean you can't live an independent or active life. People often feel anxious about having this conversation but talking about social care before you think you or someone you care for may need it helps you to be prepared. You will be more informed to make your own decisions and be in control of your own future.

Here are some tips for having an early conversation with family, friends, carers or healthcare professionals at your haemophilia centre about social care preferences:

- Find a time and place when you will not be disturbed.
- Focus on what you want in the future and how you can work together with your haemophilia centre, family, friends and GP to support your way of life.
- Talk about the benefits of advanced planning so you will know what to do if you need care unexpectedly.
- Talk about the services that may help you at home such as nursing care, gardening or home maintenance.
- Understand each other's concerns.

Possible conversation starters:

- 'I want to stay in my own home as I grow older. How can I make that happen?'
- 'I've been reading about aged care. I would like to talk about the options and services that may be available.'
- 'I've been struggling with self-infusion; I'd like to talk about how my haemophilia centre can help me.'
- 'Some things around the house are getting a bit hard for me. I would like to talk about adapting my home.'
- 'I want to find out more about residential care – I'd like to look at my options.'

Finding the right social care

There are four types of services available to you:

- Homecare (sometimes called home help) (page 10)
- Home adaptations (page 16)
- Residential care home (page 17)
- Specialist housing (page 19)

If you are thinking about home adaptations or a care home, a care needs assessment should be your first step towards getting the help and support you need with managing your everyday life.

These are your potential options – how do you find out what’s best for you? Normally a first assessment is needed, then a care plan is produced which is needed on a periodic basis.

What is an assessment?

An assessment is to work out how much help you need to enable you to live your life as independently as possible. There are two types of assessment:

- a care needs assessment
- a home adaptation assessment

There are **no** costs attached to an assessment; everyone is entitled to one regardless of their income or savings.

It’s worth knowing that your local council has a legal duty to carry out an assessment to find out what help you need. An assessment isn’t a test you can pass or fail; it’s just a tool used to find a way of working out your individual care and support needs. Your local authority also has a legal process to follow for your care needs assessment.

An assessment can take some time to finalise so the earlier you do it the better.

How do I apply for a care needs assessment?

You must contact the adult social services department of your local council and ask for a care assessment (also known as a needs assessment). Tell them you need support managing everyday tasks and help to remain living independently. You can call them or do it online.

You can find your local council using this link: www.gov.uk/find-local-council

Can I apply if I'm a carer?

You can arrange a care needs assessment for the person you are caring for, but they must agree to this (unless they don't have the capacity to make the decision or communicate this).

What does the care needs assessment involve?

Someone from your local council such as a social worker, nurse or occupational therapist will come to see you and ask you how you are managing everyday tasks such as:

- cleaning your home
- collecting prescriptions or your pension
- general house maintenance (changing a light bulb or fixing a leaking tap etc.)
- getting in and out of bed or a chair
- getting out of bed in the morning
- getting settled in the evening and ready for bed
- managing and maintaining nutrition
- managing toilet needs
- preparing meals and drinks
- remembering to take your medicines/injections
- shopping
- washing and dressing

They will also look at:

- any health or housing requirements
- any physical difficulties you may experience or associated risks
- the emotional and social side of your life
- what you would like to happen
- your needs and wishes
- your skills and abilities
- your views, religious and cultural background and support network

If it seems you may need some alterations in and around your home such as a stairlift, grab rails, bath seat etc. you might also be referred for a separate assessment of your home (see Home adaptations).

If you want to talk to someone over the phone about needs assessments, you can call:

Age UK's free helpline on **0800 678 1602**

Independent Age's free helpline on **0800 319 6789**



Preparing for your care needs assessment

Talk to a friend or relative before your care needs assessment to discuss what to say. Think about what you need help with and what could help. You could:

- Make a list of things that might help you live more comfortably at home.
- Look at your local council's eligibility criteria. (All councils must publish details of their eligibility criteria and make them available. Use the same words they do to describe your needs.)
- If you can, keep a diary for a few days before the assessment, writing down the things that are difficult to do or things that you can no longer do at all.
 - * If you have good and bad days, tell them about the help you need on bad days (even if it is difficult to admit). Tell them about your care and support needs because of a physical or mental condition
 - * What medical problems do you have currently
 - * What medication do you take?
 - * Do you have any physical health problems or difficulties with mobility?

If you find it difficult to understand things ask a friend or relative to be with you, as it may help if you aren't confident about explaining your situation. They can also take some notes for you during your assessment. If you can't get a friend or relative, you can use an advocate.

Contact adult social services at your local council and ask about advocacy services. Your council must provide an advocate to sit with you during an assessment and speak for you.

They can help you understand the care and support process; talk about how you feel about your care; make decisions; challenge decisions about your care and support if you don't agree with them; stand up for your rights.

If you have requested a care needs assessment, you may be offered this via a telephone or online assessment. If you would prefer a face-to-face assessment, then please ask for this.

Do I need homecare or home help?

Home help is slightly different to homecare and means day-to-day household chores that you may need a help with such as:

- cleaning (including putting on clean bed sheets)
- gardening
- laundry
- running errands, e.g. prescription collection
- washing up

You might want some home help instead of or as well as homecare. Home help services are flexible and can be tailored to suit your needs. However, most councils do not provide free home help.

For more information contact **Age UK** on **0800 678 1602** (8am to 7pm, 365 days a year).

What happens at a care needs assessment?

When you have a care needs assessment a social care professional will visit you at your home. They will ask you questions and walk around with you to see what you struggle with.

You will work out what you need together, so make sure you tell them everything you find difficult, even small things such as opening a cupboard. The assessments usually take at least an hour.

Your assessor will also talk need to talk to other health professionals who care for you such as your haemophilia doctor, nurse, physio or GP etc. to ensure you get the correct support.

How to complain about a care needs assessment

If you are unhappy about your care needs assessment, you have a right to complain.

First, complain to your local council. They should have a formal complaints procedure on their website.

What happens after the care needs assessment?

You will receive a written copy of your care plan explaining which needs the local authority will meet. You must check this document to make sure you agree with what your needs are and what help you require to meet those needs. There will be a financial assessment (means test) to find out if you need to contribute financially towards your care and support. This will look at your income, savings and property to calculate how much you need to pay towards the cost of your care and support.

It is important to remember your local council has a limited budget and you may not get everything you need.

Your local council write to you about their decision on what you will have to pay and what they will pay, and how they calculated it. How much you will have to pay will depend on what type of care and support you need and your personal circumstances.

If you disagree with the outcome of your care needs assessment or how it was done, you must contact your local council. There should be a formal complaints procedure on your local council's website.

If your needs assessment finds that you don't qualify for care and support, your local council should give you free advice about where you can get help in your community. If this doesn't happen, please contact them.



About your care plan

If you have a care plan and care needs, your care plan should cover:

- what your assessed needs are
- outcome of your needs
- the needs your local council has agreed to meet and how they will meet them
- information and advice on how to prevent, reduce or delay your future needs for social care
- your finances and the amount of money to arrange the care and support you need
- details of any direct payment that is agreed

To find out more about personal budgets and direct payments **Age UK** can offer support: www.ageuk.org.uk/information-advice/care/paying-for-care/financial-assessment/personal-budgets-and-direct-payments/

If your local council has arranged support for you, they must review it within a reasonable time frame (usually within three months). After this, your care plan should be reviewed at least once a year or more often if needed.

Help for carers – information and support

If you are a carer you may be entitled to a carer's assessment. Many carers find it easier to continue in their caring role if they get some support.

If you need information and guidance as an unpaid carer **Carers UK** will give you expert advice tailored to your situation.

Website: www.carersuk.org/home

Telephone Helpline: **0808 808 7777** (Monday to Friday, 9am – 6pm)

Carer's Allowance

You could get weekly financial support if you care for someone at least 35 hours a week. You don't have to be related to, or live with, the person you care for.

To see if you are eligible call **0800 731 0297** or visit: www.gov.uk/carers-allowance/eligibility

Part 2 - What care support can I get?

Following your care needs assessment, your care plan will detail what needs you have and what could help to meet those needs.

Homecare

Having a carer coming to your home can make a big difference to your life, especially if you have difficulty walking or getting around. It can help you stay living independently in your own home. Homecare is a lot more flexible, offering different levels of care. You may need a carer for only an hour a week or for several hours a day, or you might need a live-in carer.

I need help with self-infusion at home

In older age, people living with bleeding disorders may have restricted movement in their joints, elbows and hands and therefore struggle to self-infuse. If you feel like you need help with self-infusing at home, you should ask your haemophilia centre for help. They will be able to discuss your options and you may be able to get help with administering your treatment at home.

Will I have to pay for my homecare?

Your local council usually charge for the services they provide; some place an upper weekly limit on the amount you must pay. Before charging you for services, your local council must work out how much you can afford to pay and this amount should leave you with a reasonable level of income.

You can check your local council's website for their charging information at: www.gov.uk/find-local-council

Can I arrange my own homecare?

If your local authority/council is paying for some or all your homecare, they must give you a care and support plan as discussed above. This will include your personal budget, which is the amount the council thinks your care should cost. You can choose to receive your personal budget as a direct payment each month.

This gives you the control to employ someone you know to care for you at home rather than using a homecare agency, although you will then have responsibilities as an employer.

If you aren't eligible for the council to contribute to your homecare costs, you will have to pay for it yourself. If you are arranging your own homecare, there are two main ways to do this:

- use a homecare agency
- employ your own care.

Homecare agencies employ trained carers and arrange them to visit you in your home. You may not always have the same carer visiting but the agency will try to match you to someone suitable.

If you are paying for yourself, ask your local care agencies for a clear price list and billing arrangements. See: www.homecare.co.uk/

Employing your own carer

Instead of using an agency, you can hire your own carer, sometimes called a private carer or personal assistant.

If you employ a carer you have the legal responsibility of an employer. This includes a range of things you must do. Some include operating PAYE, registering as an employer, carrying out employee checks, holidays, statutory sick pay, workplace pension and more.

However, if the carer you find is self-employed, you are only buying a service and those responsibilities will lie with the carer.

It's your choice whether you want to use an agency to find a carer or employ someone independently. However, there are certain things you should beware of before hiring help:

- As an employer, you must take out employer's liability insurance and public liability insurance.
- If you aren't using an agency, you won't have the added protection of staff training and vetting, or complaint procedures to resolve any issues.
- You could be left without any replacement cover if the helper/carers is absent from work, whereas an agency will usually find cover.

- You must get a copy of the DBS check for anyone you are looking to employ before you interview them or let them into your home.
- You will take on employer responsibilities and legal obligations. You may have to deal with disciplinary issues and possibly having to dismiss someone.

This is not a complete list and if you or the person you are looking after are considering becoming an employer, you should seek advice on the full responsibilities.

Other types of help I may need

This is slightly different to homecare and means day-to-day domestic tasks that you may need a helping hand with such as:

- gardening
- laundry
- washing up
- cleaning

Unfortunately, most councils do not provide home help.

For more information contact your local **Age UK** or local council.



Home adaptations

Home adaptations are changes you make to your home that make it safer and easier to move around and do everyday tasks.

Your local council offers a service that assesses your home and recommends changes to help. Having a home assessment is free and these changes can be small or big. They include:

- adding a bath lift, walk-in shower or a rail you hold to pull yourself out of the bath (grab rail)
- small aids for daily living (e.g. adapted cutlery, turners to help you use taps, turn keys or undo jars etc.)
- fitting a stairlift or a banister on the stairs
- lowering kitchen worktops
- putting in an outdoor ramp or step rail
- security, such as outside lights and intercom systems
- widening doorways

Home adaptation assessment

If you or someone you know needs help to do everyday tasks you can apply to your council for equipment or help online. Visit: www.gov.uk/apply-home-equipment-for-disabled

Which? also offer a guide to home adaptations to help you continue to live independently. Visit: www.which.co.uk/after-life-care/home-care/home-adaptations

Disabled Facilities Grant

If your home assessment recommends you need minor adaptations to your home that cost less than £1,000 (such as grab rails, short ramps, a dropped curb or outside lights), these are provided and fitted free of charge by your local council.

If you live in England, Wales and Northern Ireland and need major work carried out in your home you may be eligible for a Disabled Facilities Grant (DFG). To be eligible for a DFG you must own the property or be a tenant. You can also apply for a grant if you are a landlord and have a disabled tenant. You can apply for a DFG on your council's website.

A Disabled Facilities Grant will not affect any benefits you get. It is means-tested and there is a maximum amount you can get, although your local council may agree to top this up in some circumstances. If you are a council tenant, the council should pay for major adaptations that you have been assessed as needing.

You might not get any grant if you start work on your property before the council approves your application.

Age UK Advice Line on 0800 678 1602 will be able to provide you with more information about the DFG.

Residential care home

Moving into a care home, or choosing one for a loved one, can feel daunting and it can cost a lot of money. Before choosing a care home for you or someone you know it's worth considering all the options.

Care homes (also known as residential homes) provide accommodation and personal care for people who need extra support in their lives. Personal care might include help with washing, dressing, eating, going to the toilet or taking medication. Some care homes also offer social activities such as day trips or outings.

A care home may be the best option if you or someone you know:

- is struggling to live alone – even with help from friends, family or paid carers
- has had a needs assessment that suggested a care home is the best choice
- has a complex medical condition that needs specialist attention during the day and night.

Many people feel they don't need to move into a care home or are worried about moving out of their home. You may want to consider other options, which could be cheaper or help you feel more independent. Some different options are listed over the page.

Types of care home

- **Residential homes:** These provide accommodation and personal care, such as help with washing, dressing, taking medicines and going to the toilet. Some also offer activities, such as day trips.
- **Nursing homes:** These provide personal care but there will always be one or more qualified nurses on duty to provide nursing care. These are sometimes called care homes with nursing. Some nursing homes offer services for people who may need more care and support, such as people with severe physical disabilities.
- **Care homes with dementia:** These are designed to make people with dementia feel comfortable and safe. They often have a qualified nurse with dementia training.
- **Dual registered care homes:** These accept residents who need both personal care and nursing care. This means that someone who at first just needs personal care but later needs nursing care will not have to change homes.

To find out more about how to get started in finding a care home that suits your needs, paying for it, and what life in a care home is like, your local **Age UK** will be able to help.



Specialist housing

Types of specialist housing

- **Exchanging a council/housing association property.** Your council or housing association may be able to help you find more suitable accommodation by arranging an exchange or 'swap' for another council or housing association property.
- **Retirement villages.** These are large-scale developments; many of these complexes include a care home and communal facilities.
- **Home share schemes.** If you don't want to move out of your home and have a spare room, an option is to share your home. Usually you don't charge rent but share the household bills. In return, the home sharer helps by cooking meals, running errands and doing your shopping.
- **Close care.** This is retirement accommodation attached to a care home, with residents buying in meals/care as needed.
- **Sheltered housing** (a type of 'housing-with-support'). Sheltered housing schemes don't offer any medical or nursing care. They are suitable if you are normally able to live quite independently but need occasional help or support.

Many have a warden you can call and 24-hour emergency help through an alarm system. Some may have communal facilities such as a laundry, lounge and garden. They are usually only available to those aged 55 and over.

- **Supported living.** This is a combination of suitable accommodation – which can be your own home – with some forms of personal care. Supported living is designed to help disabled people live independently in their local community and is an alternative to residential care for people who are eligible.

Supported living homes are shared by two or three people with similar health problems. Staff usually visit the home to help you get out of bed and do simple tasks such as shopping, housework and repairs. They can also help with administrative tasks and personal care.

- **Extra care housing** (also known as sheltered housing/assisted living/supported living). This offers more support than sheltered housing but still allows you to live independently. Extra care housing schemes may have a scheme manager (previously called wardens) who live either on or off site. There should be 24-hour emergency help via an alarm system to support each individual's independence, as well as care and support.

You live in a self-contained flat, but you may have services provided on site such as meals or personal care and domestic support. The level of assistance you get can be increased as your needs change. While some housing is available to rent privately, most sheltered housing for rent is provided by councils or housing associations that allocate housing based on need and there is often a waiting list.

More information you might find useful

Finding residential care or care agencies

There are various ways to find care and support depending on what you are looking for. Your council should be able to provide you with a list of residential care homes or care agencies in the area. This will also depend on where you plan to live.

- In **England** the Care Quality Commission (CQC) is the social care regulator and has an online directory of registered residential care homes.

www.cqc.org.uk/

Telephone: 03000 616161

- In **Wales** the Care and Social Services Inspectorate Wales is responsible for inspecting social care services and has an online directory of registered residential care homes.

<https://careinspectorate.wales/?lang=en>

Telephone: 0300 7900 126

- In **Scotland** the Care Inspectorate regulates and inspects care services and has an online directory of registered residential care homes.

www.careinspectorate.com/
Telephone: 0345 600 9527

- In **Northern Ireland** the Regulation and Quality Improvement Authority is the social care regulator and has an online directory of registered residential care homes.

www.rqia.org.uk/
Telephone: 028 9536 1111

Which? Later Life Care also has a website that allows you to search online for care agencies anywhere in the UK.

www.which.co.uk/late-life-care/care-services-directory

Things you should consider before choosing a care home

- Location – base this on what your priorities are. Do you value being near your family and friends or the local shops?
- First impressions
- How much does it cost?
- Does it meet your care needs?
- Do they offer the right services or activities you need?
- How visiting and leaving the care home works – for example, do you want to be able to go out on your own or with staff assistance?
- Feedback and complaints

A good home care should include:

- Staff and managers with the right time, skills and experience to do their jobs
- Clean buildings, rooms and bathrooms
- A wide range of activities for residents at home and outside
- Good quality food choices and options about where to eat meals
- Fast and easy access to health professionals (such as your haemophilia centre when needed or your GP)
- Makes sure any cultural, religious or lifestyle needs are met

To get more information about a care home you could:

- Phone them
- Request a brochure
- Request a temporary stay
- Visit them
- Visit their website

Before you move, it may help to:

- Ask family or friends to help you move and settle you in
- Contact the benefits office, if you have one (including disability benefits, as these can be affected by care home stays)
- Tell all other services at your old address you are moving
- Let friends and family know your new address and when you might feel up to receiving visitors
- Let the care home know about any health problems or disabilities you have (your haemophilia centre can help explain your care needs to the care home)

Moving into a care home

Moving to a care home can be an emotional time for both residents and their families. To help make the day run smoothly try to fill out forms and carry out important tasks beforehand.

It's not always easy getting used to new places, new routines and new people. Here are a few ideas to help you make yourself at home.

- **Bring in home comforts.** Have shelves put up so that ornaments, photos and other personal items can be displayed. Fill the walls with treasured pictures or paintings.

You could bring a soft furnishing (cushions, rugs, throws etc.) or a comfortable armchair to make things feel more familiar. You may also be able to bring a television and even your own bed. Speak to the care home manager about your options.

- **Clothing.** Label your clothes so they don't get muddled up in the laundry.



- **Finding your way around.** Ask for help to find where things are until you feel more confident in walking around alone. It might take you a while to remember where things are.
- **Talk to staff.** When you move in, staff will write a care plan for you. Tell them what you like to do and when. If you prefer to have lunch in your room or like a lie-in at weekends, staff should be able to help.
- **Stay connected – get a phone.** It may be possible to install a phone line in your room or you can use a mobile phone to call friends and family. This will give you another way to stay in touch with people.
- **Keep your family involved.** Lots of care homes encourage your relatives to attend relative and resident meetings to talk about any issues affecting residents. They may also have a regular newsletter.

Problems with your care

You have consumer rights regardless of whether you pay all the costs of your care or whether some or all the costs are paid for by the local authority. If you are upset with your care, speak to the care home/agency manager to give them a chance to investigate, explain and put things right. Don't be worried about raising issues. Care home providers have certain obligations that they must fulfil.

Most problems can be easily resolved at this stage. However, you may wish to agree a time frame for a resolution. If you need to make a complaint about a care home or homecare agency, there are procedures in place to help you take your concerns further.

Escalating a complaint: self-funder

If you are a self-funder and unhappy with how the care provider resolves your complaint, your next step should be to complain to the local government ombudsman.

Escalating a complaint: local authority funded care

If the local authority is funding your care and you're not satisfied with how the care provider resolves your complaint, your council is required by law to have an official complaints procedure. This should be found on their website.

Ombudsmen for care providers

For complaints about care providers that you haven't been able to resolve with your service provider directly.

In **England**: Local Government and Social Care Ombudsman
Telephone: 0300 061 0614

In **Northern Ireland**: Northern Ireland Public Services Ombudsman
Telephone: 0800 34 34 24

In **Scotland**: Scottish Public Services Ombudsman (SPSO)
Telephone: 0800 377 7330

In **Wales**: Public Services Ombudsman for Wales
Telephone: 0300 790 0203

Care regulators

For information about minimum standards and how to report concerns.

In **England**: Care Quality Commission (CQC)

Telephone: 030 00 616161 (national customer service centre)

In **Northern Ireland**: Regulation and Quality Improvement Authority (RQIA)

Telephone: 028 9051 7500

In **Scotland**: Care Inspectorate

Telephone: 0845 600 9527

In **Wales**: Care Inspectorate Wales (CССИW)

Telephone: 0300 790 0126

This booklet is an overview of important points to bear in mind when managing later life with a bleeding disorder. It is not a complete guide; the relationship between you and your haemophilia centre is paramount and will ensure a smooth transition into social care. The Haemophilia Society is always happy to answer any further questions, provide additional information or refer you to an expert if necessary.

About The Haemophilia Society

We are the only UK-wide charity for all those affected by a genetic bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For almost 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

We want to ensure that everyone affected by a bleeding disorder:

- Has equality of opportunity
- Has the opportunity to connect with others in the community
- Has the knowledge to feel empowered

We do this by:

- Raising awareness about bleeding disorders
- Providing information and support throughout our members lives
- Influencing and advocating on health and social care policy and access to treatment

More than 36,000 men, women and children in the UK have a diagnosed bleeding disorder, and the number rises every year. Membership of The Haemophilia Society is free and open to all.

Our peer support through local groups around the UK, global family network, and online community, offers friendship and a listening ear when needed, as well as enabling people to share their views and experiences. By bringing people together for information and support at events tailored to all life stages, we amplify their voices to reduce isolation and influence government, welfare and health care policy.

Our community are at the heart of everything we do – we work collaboratively with members and health professionals to ensure we make decisions influenced by their valued input and direction.

As bleeding disorders are rare, many people will never encounter The Haemophilia Society; we are largely invisible beyond the communities we serve. So, we have to work doubly hard to raise both awareness and understanding of bleeding disorders and vital funds needed to give those affected the services they deserve and need to live the best life they can.

To find out more, or to become a member for free, visit our website at haemophilia.org.uk or call us on **020 7939 0780**.



THE HAEMOPHILIA SOCIETY

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The Haemophilia Society makes every effort to make sure that its services provide up-to-date, unbiased and accurate information about bleeding disorders. We hope that this information will add to the medical advice you have received and help you to take part in decisions related to your treatment and care. Please do continue to talk to your doctor or specialist nurse if you are worried about any medical issues.

Give us your feedback

If you have any comments about this booklet or any of our other information, please write to the Head of Services at the address below.

Everything we do is free because of fundraising and donations of our incredible supporters. If you would like to fundraise for us or find out more about how you can get involved send us an email to fundraising@haemophilia.org.uk

Your Society: getting in touch

The Haemophilia Society

52b Borough High Street

London SE1 1XN

Phone: 020 7939 0780

Email: info@haemophilia.org.uk

Web: haemophilia.org.uk



HaemophiliaSocietyUK



HaemoSocUK



thehaemophiliasociety

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