Ageing with a bleeding disorder and other health conditions

The Haemophilia Society

Contents

The production of this publication was funded by a grant from Octapharma Ltd. They had no input in the writing or development of the content.

Introduction

As people with a bleeding disorder get older, they may face more challenges. They need to deal with the usual problems of ageing and manage the complexities of their condition.

To manage getting older with a bleeding disorder, a comprehensive approach is important. This approach should address both immediate bleeding-related issues and the complex health challenges associated with ageing.

What is ageing?

Ageing involves biological, psychological, and social changes over time. It can show in various ways, including physical changes such as wrinkles and grey hair, brain problems, and an overall decline in health. Ageing is a natural part of life that brings challenges and wisdom.

What is the ageing process?

The ageing process involves a complex interaction of genetic, environmental, and lifestyle factors that lead to changes over time. Here are some of these changes as we age:

Cellular changes: Our cells begin to function less well due to the accumulation of DNA damage and a decrease in cell division efficiency.

Skin: Wrinkles and sagging skin become a natural part of our lives. Collagen and elastin are responsible for maintaining firm and elastic skin, and these tend to break down as we age. Sun exposure and unhealthy lifestyle choices, such as smoking, can accelerate this process. So it's essential to wear sunscreen and stop smoking to keep your skin healthy.

Bones and joints: As we age, our bones become less dense, making them more brittle. Crackly joints are common.

Sensory changes: Our eyesight may decline because the lenses in our eyes become stiff. This can mean needing reading glasses or bifocals. Our hearing might also be affected, so we may ask others to repeat what they have said.

Grey matter: The brain undergoes changes that can impact memory and cognitive function. Mental exercise, social interaction, and puzzles can help keep the brain sharp.

Metabolism: As we age, our metabolism slows down, making it more challenging to maintain a healthy weight. Therefore, it's important to adopt a balanced diet and exercise routine.

Emotions: Growing older can bring a mix of feelings. Some people feel free and wise, while others struggle with deep thoughts about life. It's a personal journey, and everyone experiences ups and downs at their own pace.

What are comorbidities?

You may sometimes hear the term 'comorbidities' used, particularly when discussing health as we age. But what exactly does it mean?

In simple terms, comorbidities are other health conditions that someone may have in addition to their primary health condition.

It's important to remember that comorbidities can happen at any age, not just as we grow older. While some conditions might be more common with age, anyone can experience them.

Ageing well

Getting older with a bleeding disorder requires a comprehensive approach to address the challenges. You can stay healthy and active by managing your condition, taking care of yourself, and getting support from healthcare providers and your community.

This approach includes medical care, lifestyle changes, and emotional support. Regular monitoring of bleeding symptoms, sticking to treatment plans, and managing other health conditions, like high blood pressure, diabetes, and joint problems, are important for ageing well with a bleeding disorder. It's also important to attend screening tests and well man/woman clinics with your GP.

Physical activity, such as swimming, walking, and yoga, is important for maintaining joint and muscle health and enhancing overall fitness. A healthy, balanced diet has been shown to support healthy ageing in the general population.

Building strong social connections and getting support from others who understand what you're going through is important for ageing well with a bleeding disorder. This can help ease feelings of loneliness, anxiety, and depression that often come with long-term health conditions.

Taking a proactive and comprehensive approach to care, which includes addressing physical, emotional, and social needs, can help people with a bleeding disorder age well, remain independent, and lead a fulfilling life despite the challenges.

Working together for better care: shared decision-making

Living with a bleeding disorder means that you are the expert on your own body. You understand how your condition affects you and what activities are essential in your daily life. However, when making treatment decisions, there's another expert in your corner: your healthcare team.

Shared decision-making is a powerful tool for navigating your health journey. It involves a collaborative approach where you and your healthcare team work together to make informed choices about your care. This is crucial when managing a bleeding disorder and comorbidities.

It allows you and your healthcare team to work together. You share your experiences, preferences, and treatment goals. Your healthcare team will share their knowledge of the latest treatments, as well as potential risks and benefits. You can make informed decisions about the best course of action for your treatment.

This approach allows you to control your care and helps ensure that your chosen treatment plan suits your needs and lifestyle.

Preventing and treating bleeds

Preventing and treating bleeds in ageing people with a bleeding disorder involves careful management of underlying bleeding disorders, regular monitoring, adherence to treatment regimens, lifestyle changes, and prompt medical intervention when necessary to minimise complications and promote overall well-being.

Vein access

As you age, you may have difficulty accessing veins for medical procedures, treatments, and monitoring. This is important because you may need frequent access to veins for IV treatments and blood tests.

Over time, veins may become less reliable and more challenging to access because of ageing, repeated needle insertions, and complications from the bleeding disorder. Changes related to ageing, like less elastic skin and thinner vein walls, can make it harder to access veins and increase the risk of problems like blood clots or swelling.

It's important to keep veins healthy and accessible for medical care. To help with this, you can use strategies like:

Hydration

Being well hydrated can make veins plumper and easier to find. Drink plenty of water before your appointment.

Rotation of venous access sites

Avoiding repeated use of the same vein can help reduce the risk of vein damage and improve the longevity of accessible veins.

Gentle handling

Careful technique and gentle handling during venous access procedures can help minimise trauma to the veins and reduce the risk of complications.

Collaboration with healthcare providers

Working closely with experienced healthcare providers who specialise in managing bleeding disorders can ensure that venous access procedures are performed safely and effectively, with minimal risk of bleeding complications. If your healthcare provider approves, use a warm compress, heating pad, or forced-air warming blanket on the potential IV site for 10-15 minutes.

When cold, the body constricts the veins to prevent heat loss, making it more difficult to access them. If a tourniquet is used, it can stop blood from reaching the veins if it is too tight; if it is too loose, it won't build up enough pressure in the veins.

You may find it helpful to use alternative ways to access veins, such as central venous catheters or a port-a-cath, especially if there isn't a suitable alternative non-intravenous product (e.g. subcutaneous). These methods can provide reliable access to medical treatments while causing less harm to peripheral veins. By addressing the unique challenges of vein access, your healthcare providers can ensure you receive the necessary medical care and treatments while minimising the risk of complications and preserving vein health for the long term.

Comorbidities and bleeding disorders

Comorbidities mean having two or more medical conditions at the same time. When someone has both comorbidities and a bleeding disorder, it can be more complicated.

Bleeding disorders can make it harder to manage other medical conditions, especially during surgery. This creates a higher risk for people with a bleeding disorder. Your bleeding disorder team and other specialists will work closely to control bleeding during surgery.

Also, medications commonly used for other conditions, like blood thinners for heart problems, could make bleeding disorders worse. Managing one condition without making the other worse can be a challenge. Healthcare professionals from different areas need to work together to ensure that people with bleeding disorders get well-managed, personalised care for both aspects of their health.

Here are some common comorbidities that can affect people with bleeding disorders as they age. It's important to remember that this is a partial list, and you may experience other health issues not covered in this booklet that are not related to having a bleeding disorder.

Anaemia

As we grow older, anaemia and bleeding disorders can be especially challenging.

Anaemia is a condition defined by a shortage of red blood cells or haemoglobin, leading to symptoms like tiredness and weakness. This shortage makes it more difficult for the body to transport oxygen to its tissues. In older adults, anaemia can result from a lack of essential nutrients, chronic illnesses, or certain medications. It is important to monitor and address these underlying causes to effectively manage and prevent anaemia.

Anaemia can cause several symptoms:

- tiredness and lack of energy
- shortness of breath
- noticeable heartbeats (heart palpitations)
- paler than usual skin.
- headaches

The treatment of anaemia and bleeding disorders depends on the underlying cause. For example, if a lack of iron causes anaemia, you can take iron supplements, and if a lack of vitamin B12 causes it, you might need vitamin B12 injections. Eating a balanced diet rich in iron, vitamins, and minerals can help prevent and manage these conditions.

Both anaemia and bleeding disorders can affect overall health and quality of life. Regular health check-ups and tests are important to detect and treat them early. Your GP and the bleeding disorders team must work together.

Bowel issues

Ageing with a bleeding disorder may mean challenges related to bowel problems, which can encompass a range of gastrointestinal

issues. Signs and symptoms of bowel problems include:

Sign/symptom	Description
Blood in your poo (stools) or bleeding from your bottom	Blood may be bright red or dark.
Change in your regular bowel habit	This could be due to needing to go to the toilet more often, having looser stools (diarrhoea), or constipation lasting more than three weeks.
Unexplained weight loss	Losing weight without trying.
Pain in your tummy (abdomen) or back passage	This could be a persistent ache or a cramping pain.
Feeling like you haven't emptied your bowels properly after going to the toilet	This is sometimes called incomplete emptying.
Unexplained tiredness, dizziness or breathlessness	Anaemia, a low red blood cell count, can cause this.

Managing bowel problems requires a comprehensive approach. This means keeping a close eye on bowel symptoms, the consistency of your poo (stools), and bleeding through regular check-ups. Treatment options may include changing your diet, fibre supplements, retraining techniques, medications, or procedures to address underlying causes such as haemorrhoids. Your bleeding disorder team, gastroenterologists, and other healthcare providers must work closely to create personalised treatment plans that get the best results.

Cancer

Cancer is a disease in which abnormal cells grow uncontrollably and can spread to other parts of the body. Recognising symptoms and getting regular check-ups is important, as this can significantly affect treatment options and overall wellbeing.

Bleeding disorders are not usually directly linked to an increased risk of cancer. But there are certain factors and associated conditions that may increase the risk of developing certain cancers for individuals with bleeding disorders, particularly as they age.

It's important to note that cancer risk is influenced by various factors, including genetic predisposition, lifestyle, and comorbid conditions, rather than bleeding disorders themselves.

In the past, some people with haemophilia contracted viral infections like hepatitis C and HIV through contaminated blood products. These infections can increase the risk of certain cancers, such as liver cancer (in the case of hepatitis C) and some lymphomas.

It's important to act when you get an invitation for cancer screening. Finding cancer early saves lives; most screening tests are quick and easy. Read the invitation carefully, make an appointment promptly, and discuss any concerns with your doctor.

Cancer symptoms can include unexplained weight loss, fatigue, persistent cough, changes to peeing and pooing, skin changes, and abnormal bleeding or discharge. If you experience these symptoms, go and see your GP.

Having a bleeding disorder can make cancer diagnosis and treatment more complex, as bleeding tendencies can interfere with surgical procedures, biopsies, and chemotherapy. Cancer treatments like surgery, radiotherapy, or chemotherapy, may bring extra challenges.

Surgeries may need special plans to reduce bleeding risk. If you need cancer surgery, your surgical team will prepare a personalised plan to minimise the risk of bleeding during that time.

Radiotherapy can make existing tissue damage worse and increase the risk of bleeding complications. Chemotherapy drugs may also reduce your platelet count, leading to an increased risk of bleeding.

You may need supportive care, such as blood transfusions, clotting factor replacement treatment, and preventive medications to improve treatment results and reduce complications. Regular check-ups and follow-up care are important to see how effective the treatment has been, watch for potential complications, and make any necessary changes to the treatment plan.

The most important thing to remember is that your bleeding disorder should not affect the cancer treatment you receive. It just means that there needs to be good communication and coordination between your cancer doctors, your bleeding disorders team and you.

Diabetes

Type 1 and Type 2 diabetes are conditions that affect how your body uses sugar (glucose) for energy. This can lead to high blood sugar levels, which can be dangerous. But there are some key differences between the two:

Type 1 diabetes:
Your body doesn't make insulin, a hormone that regulates the sugar levels in your blood.

Treatment: Insulin is vital. You'll need to take insulin for the rest of your life. Different types of insulin work at varying rates, depending on your needs.

Type 2 diabetes:

Your body either doesn't make enough insulin or can't use it effectively.

Treatment: There are a few ways to manage type 2 diabetes: a healthy lifestyle, eating a balanced diet, exercising regularly, and maintaining a healthy weight are all crucial.

Medications: Doctors often prescribe metformin as a first treatment option to help the body use insulin more effectively. Other medications may also be prescribed.

Insulin: Some people with type 2 diabetes may also need to take insulin, especially if lifestyle changes and medications aren't enough.

Signs to look out for (both type 1 and 2):

- feeling very thirsty all the time
- peeing more often than usual, especially at night
- feeling very hungry, even though you've just eaten
- losing weight without trying
- feeling very tired
- blurred vision.

If you notice any of these signs, you must see your GP to get checked out. Early diagnosis and treatment can help prevent serious health problems from diabetes.

Cognitive decline/dementia

As we age, our brains undergo natural changes that can increase the risk of specific age-related brain problems. Here are some of the common brain problems associated with ageing:

Cerebrovascular disease is when blood vessels that supply blood to the brain are affected. This can reduce blood flow to the brain and cause damage. Examples of cerebrovascular diseases include stroke, transient ischemic attacks (TIAs), and dementia.

Transient ischaemic attack (TIA)

A transient ischemic attack (TIA) is a short-lasting reduction in blood flow to a part of the brain. TIAs are often called 'mini-strokes' because they can cause temporary symptoms similar to those of a stroke (see page 22). Symptoms usually disappear within 24 hours, but TIAs can indicate serious blood vessel problems like hardening of the arteries or blood clots.

Getting older is a major risk factor for TIAs because ageing can lead to vascular disease and stiff arteries. To lower the risk of TIAs, it's important to have regular medical check-ups, make healthy lifestyle changes, and manage any existing health conditions.

As people age, there is a risk of these attacks. Ageing affects blood vessel health and may increase the use of certain medications or worsen existing health problems.

Dementia

Dementia is a general term for a decline in thinking abilities that gets in the way of daily life.

It's essential to speak to your GP if you are concerned that you may have dementia. It's important to remember that not all forgetfulness is due to dementia, so don't be scared and do seek medical advice. Here are some important tips:

1. Make an appointment with the GP.
2. Keep a record of any changes you notice.
3. The GP will check your physical health, including blood pressure and heart rate, and may order blood tests. They will also assess memory and thinking skills.
4. If the GP suspects dementia, you will be referred to a specialist, usually a memory clinic.
5. The specialist will do a more detailed assessment and may arrange a brain scan.
6. If dementia is diagnosed, you will be told what type it is, what to expect, and how to live well with the condition.
7. Remember that waiting times for memory assessments can be lengthy and you may need several appointments before getting a diagnosis.

Cardiovascular (heart) disease and related conditions

As we age, our heart naturally undergoes changes that can increase the risk of specific heart problems. Here are some of the most common heart problems associated with ageing:

Cardiovascular disease (CVD) refers to conditions affecting the heart and blood vessels. It often involves the build-up of fatty plaques in arteries (atherosclerosis – see page 19), leading to problems like heart attacks, strokes, and heart failure.

The relationship between hypertension (high blood pressure) and cardiovascular disease (CVD) is very strong. When you hear 'CVD', it's referring to this broad group of diseases that affect the heart and circulatory system. High blood pressure is a leading risk factor for CVD, which causes heart attacks, strokes, and other cardiovascular events.

Controlling CVD and high blood pressure involves a combination of lifestyle changes and medical interventions. These include a healthy diet, regular physical activity, weight management, low alcohol consumption, and stress management. It's crucial to take medications as prescribed and to follow up with your doctor regularly. Make sure you attend health checks for high blood pressure, even if it has not been previously diagnosed.

Atrial fibrillation

Atrial fibrillation (AF) is a common heart rhythm disorder and can affect anyone aged 55 or older. Common risk factors for AF include age, high blood pressure and heart disease. Sometimes there are no symptoms, and AF is found as part of a routine check-up or when you're having tests for something else.

If AF is diagnosed, blood thinning medicine (anticoagulation therapy) may be needed to prevent stroke. Close monitoring and management of blood thinners are crucial to reduce the risk of excessive bleeding while also managing the increased risk of clots forming due to AF. This should be done in close collaboration with your bleeding disorder team. Discuss any proposed medications with them, especially blood thinners or aspirin.

Hypercholesterolemia (high cholesterol)

As people age, they may also develop high cholesterol in their blood, which can increase the risk of cardiovascular disease. High cholesterol often doesn't have symptoms, but over time, it can lead to heart disease, stroke, or peripheral artery disease.

When cholesterol is high, fatty deposits can build up in your arteries. These deposits narrow the arteries, making it harder for blood to flow through. This can lead to serious health problems, including:

Heart attack: Restricted blood flow can increase your risk of a heart attack or a sudden blockage of a coronary artery (a blood vessel that supplies oxygen-rich blood to the heart). (See page 21)

Stroke: A stroke happens when a blood clot blocks an artery that supplies blood to the brain.

High cholesterol is often manageable. Here are some steps you can take:

Get tested: A simple blood test can check your cholesterol levels. Talk to your GP about the option of getting tested, especially if

you're at a higher risk due to a family history or other health conditions.

Healthy lifestyle: Healthy choices, such as eating a balanced diet, exercising regularly, and maintaining a healthy weight, can significantly improve your cholesterol levels.

Medication: If lifestyle changes aren't enough, your GP may prescribe medication to lower your cholesterol.

Managing high cholesterol requires a comprehensive approach. This includes closely monitoring cholesterol levels, heart risk factors, and bleeding measures through regular check-ups and tests. Close collaboration between haematologists, cardiologists, and other healthcare providers is essential to develop personalised treatment plans that optimise cardiovascular health while minimising risks.

Hypertension (high blood pressure)

High blood pressure, or hypertension, is a serious condition that often doesn't present noticeable symptoms. High blood pressure often has no clear cause, but it can develop from factors such as diet, lifestyle, or underlying health issues. You may be more at risk if you:

- are over 65 years old
- have a family history of high blood pressure
- smoke
- drink too much alcohol
- eat a lot of salt and not enough fruits and vegetables
- don't get enough exercise
- are overweight, especially around your stomach.

Regularly checking your blood pressure with your GP is crucial for early detection and management. This is especially important for people with bleeding disorders.

Most people with high blood pressure won't experience any symptoms. However, in rare cases, very high blood pressure can cause some of the following:

- headaches - particularly in the morning
- blurred vision
- nosebleeds
- shortness of breath
- chest pain
- dizziness

Safer treatment options: The frequency of blood pressure checks depends on various factors, including age and overall health. Your GP will advise you on the best schedule for you.

Atherosclerosis

This is the build-up of plaque inside your arteries. Plaque is made of fatty substances, cholesterol, and other materials. It narrows the arteries, making it harder for blood to flow. If left untreated, atherosclerosis can potentially lead to serious health problems, such as angina/heart attacks, heart disease and stroke.

Angina/heart attacks

Angina is typically characterised by chest pain or discomfort that occurs when blood flow to the heart is reduced. While it is not dangerous on its own, it can indicate an underlying heart problem, such as coronary heart disease.

Common signs of angina are pressure, tightness, or squeezing in the chest. The sensation may be painful or resemble a dull ache. You might also experience discomfort in your shoulders, arms, neck, jaw, back, or stomach. Other symptoms of angina include:

- fatigue
- dizziness
- sweating
- nausea
- shortness of breath.

Heart attacks occur when fatty material breaks down and becomes a blood clot, which can block an artery and cut off the blood supply to the heart.

Symptoms of a heart attack can vary from person to person and may include:

- Sudden chest pain or discomfort that does not go away.
- Pain that spreads to the left or right arm, neck, jaw, back, or stomach. For some people, this pain may be severe, while others may experience it as uncomfortable. It may feel heavy or resemble a burning pain, similar to indigestion.
- Feelings of nausea, sweating, light-headedness, or shortness of breath.

Stroke

A stroke happens when not enough blood gets to your brain. There are various types of strokes, and they can occur in different ways. But all strokes disrupt blood flow to the brain. When blood flow to the brain is interrupted, brain cells may get damaged because they aren't receiving the oxygen and nutrients they need.

- **Ischaemic strokes,** also known as 'blood clot strokes', occur when a blood clot blocks an artery that supplies blood to the brain.
- **Haemorrhagic strokes,** or 'brain bleed strokes', happen when a blood vessel bursts, causing bleeding in the brain. This results in less blood reaching nearby brain cells, which can lead to cell death. People with bleeding disorders have a higher risk of haemorrhagic stroke.
- **Mini-strokes**, called transient ischaemic attacks (TIAs), occur when blood flow to a part of the brain is temporarily interrupted. This can cause symptoms such as temporary speech loss, but TIAs typically resolve within a few seconds or minutes.

Regular medical check-ups, lifestyle changes, and managing underlying health conditions are essential for lowering the risk of these conditions. Recognising and treating bleeding disorders and TIAs quickly can prevent complications and improve results.

High blood pressure is a major risk factor for all types of stroke. Keeping your blood pressure under control is crucial to prevent stroke.

Several things can increase your stroke risk:

- diabetes
- family history of heart disease or stroke
- heavy alcohol use
- lack of exercise
- obesity
- physically demanding jobs (manual labour)
- smoking
- stressful lifestyle (high-pressure jobs, long working hours)
- unhealthy diet (high fat, salt, low in fruits and vegetables)

While strokes are more commonly associated with conditions such as high blood pressure or atherosclerosis, people with a bleeding disorder face unique challenges due to potential bleeding complications or interactions with clotting factor concentrates or other medications used to manage the bleeding disorder.

Signs of a stroke

It's called **F.A.S.T.** because timing is important if you're having a stroke. The longer you wait, the less chance there is of speech, movement, and abilities coming back to what they were. Acting **F.A.S.T**. is life-saving.

Recognise the signs:

- **Facial weakness:** can the person smile? Has their mouth or eye drooped?
- **Arm weakness:** can the person raise both arms?
- **Speech problems:** can the person speak clearly and can they understand what you're saying?
- **Time:** it's time to call 999 immediately if you see any of these symptoms.

If the person experiencing a stroke has a bleeding disorder, tell the emergency services your bleeding disorder team must be contacted as well.

Joint problems

As we age, many of our joints naturally undergo changes that can increase the risk of movement and mobility problems. Joint problems, however, are common in people with bleeding disorders, due to repeated joint bleeds in earlier years that have a lasting impact on joint, cartilage, and bone health over time.

Reduced mobility

As people with bleeding disorders age, they experience more joint problems and may experience reduced mobility. This can lead to muscle weakness, reducing the ability to put weight on bones and maintain bone strength. Physical activity is essential for maintaining bone density; limited movement can contribute to bone thinning.

Haemarthropathy

Haemarthropathy is a condition where the joints degenerate because of repeated exposure to blood. This process causes inflammation, cartilage damage, and deterioration of the joint architecture and bone health.

You may have experienced bleeding into your knees, ankles, or elbows, leading to joint damage over time. The blood in the joint triggers swelling, which, if not appropriately managed, can result in chronic pain, stiffness, and limited motion.

Symptoms of arthropathy may include

- joint pain
- stiffness
- swelling
- redness
- warmth
- decreased range of motion.

Haemarthropathy can significantly affect mobility and overall joint function, which can have an impact on independence and quality of life. Chronic joint pain and stiffness resulting from arthropathy can limit participation in daily activities, reduce physical ability, lead to social isolation, and decrease overall wellbeing.

A comprehensive approach is necessary to manage arthropathy and joint damage resulting from a bleeding disorder. This may include preventive treatment with clotting factor concentrates, physiotherapy, and joint-preserving interventions such as orthopaedic surgery or joint injections.

These interventions can help reduce the frequency and severity of bleeding episodes, as well as relieve associated symptoms.

You can help manage arthropathy by keeping a healthy weight, doing gentle exercise, and using tools to ease pressure on your joints. Regular check-ups with a physiotherapist at your haemophilia centre are very important. During these check-ups, your joints will be assessed, and you will have imaging tests to find and address joint problems early and prevent long-term complications.

Osteoarthritis

Osteoarthritis is a joint disease where the cartilage and bone in the joints break down. It is a different form of joint damage to haemarthropathy and is a common condition. It often affects weight-bearing joints, such as the knees, hips, and spine. Symptoms may include joint pain, stiffness, swelling, limited range of motion, and a grating sensation during joint movement. Ageing contributes to osteoarthritis, as natural joint changes occur over time. This means people with bleeding disorders can have osteoarthritis alongside haemarthropathy.

There is no cure for osteoarthritis, but treatments can help manage symptoms and improve your quality of life. Below is a list of treatment options:

Self-management:

- **Exercise:** Regular exercise strengthens muscles and improves joint flexibility, reducing pain and stiffness.
- **Weight management:** Losing weight, if overweight, reduces stress on weight-bearing joints, such as the knees and hips.
- **Supportive devices:** Crutches, braces, or splints can help relieve joint pressure during daily activities.
- **Pain relief techniques:** Applying heat or cold packs to sore joints can provide temporary relief.

Medication:

- **Paracetamol:** A first-line painkiller with minimal bleeding risk.
- **Topical creams:** Non-steroidal anti-inflammatory drugs (NSAIDs) applied directly to the joint can provide localised pain relief with a lower bleeding risk than oral NSAIDs. Ask your haemophilia centre team about suitable creams.

Treatments needing specialist input:

- **Corticosteroid injections:** These are powerful anti-inflammatory injections directly into the joint. Your doctor will assess the benefits and risks.
- **Joint replacement surgery:** This may be an option for severe osteoarthritis. Careful planning and blood factor replacement therapy are needed to minimise bleeding risk during surgery, so a multidisciplinary team approach is necessary.

Your haemophilia centre will offer expert advice and management for bleeding disorders, working alongside rheumatologists and orthopaedic surgeons for a holistic approach to your osteoarthritis.

Osteoporosis

Ageing people with a bleeding disorder are susceptible to osteoporosis, a condition characterised by weakened bones that are prone to fracture. Osteoporosis commonly occurs in post-menopausal women and older adults. Symptoms of osteoporosis may include back pain, loss of height over time, stooped posture, fractures that occur with minimal trauma, and bone fractures. People with a bleeding disorder may face an increased risk due to factors such as chronic inflammation, being less mobile, or the use of medications that affect bone density.

Bones reach their peak density around your late twenties. This is when your bones are strongest and most resistant to fracture. While genetics plays a role, there are steps you can take to maximise your peak bone density, setting yourself up for lifelong bone health.

Here are some key strategies to maximise your peak bone density:

- **Weight-bearing exercise:** Focus on activities that require your body to work against gravity, such as walking, jogging, dancing, or stair climbing. Aim for at least 30 minutes of moderate-intensity exercise daily.
- **Calcium-rich diet:** To support bone health, eat plenty of calcium-rich foods, such as dairy products (milk, cheese, yoghurt), leafy green vegetables (kale, broccoli), fortified plant-based milk, and tofu.
- **Smoking and drinking too much alcohol** can hinder bone development and increase bone loss. Here's what you can do:
  - **Stop smoking:** Smoking reduces calcium absorption and weakens bones. If you smoke, stopping smoking is one of the best things you can do for your overall health, including your bones.
  - **Limit alcohol:** Drinking too much alcohol can interfere with calcium absorption and bone formation.

People with a bleeding disorder may experience bone loss at a faster rate, particularly if they have experienced joint bleeds or prolonged immobility. Osteoporosis is more common in people with a bleeding disorder. Doctors don't really understand why, but there are some risk factors for its onset, including impaired mobility and weight bearing due to haemarthropathy, a decrease in regular exercise and outdoor mobility, vitamin D deficiency, and HIV and HCV infections.

Vitamin D supports bone health, helps prevent osteoporosis, reduces joint inflammation, and strengthens muscles, all of which are critical for maintaining mobility and quality of life.

People with bleeding disorders may have a higher risk of low vitamin D levels. Vitamin D is important for the body. In the UK, this is because people may not get enough sunlight, especially in winter.

Deficiency in vitamin D can lead to weakened bones, muscle weakness, and an increased risk of fractures. This is of particular concern for older people with bleeding disorders who already have compromised joints.

Supplements: If your vitamin D level is low, you may be advised to take vitamin D supplements. The recommended daily allowance varies, but 800–1000 IU/day is generally considered beneficial for older people, particularly during the winter months.

Dietary sources: While vitamin D is found in foods such as fatty fish (e.g. salmon, mackerel), fortified dairy products, and egg yolks, it can be challenging to get enough from your diet alone, so supplements may be necessary.

Bone density assessment and management

Bone density issues can be a significant concern for people living

with bleeding disorders. The long-term effects of joint bleeding, reduced mobility, and medication side effects can all contribute to bone thinning and osteoporosis. So careful management, including vitamin D and calcium supplementation, regular physical activity, and ongoing monitoring of bone health, is crucial to help reduce these risks and maintain overall wellbeing as you get older.

Regular monitoring of bone density and overall bone health is essential, as it can help identify issues early and allow for appropriate interventions. This may involve:

- **Bone density scans** (e.g. DEXA scans) to measure bone mineral density and assess the risk of osteoporosis.
- **Monitoring vitamin D** levels and calcium intake to support bone health.
- **Strengthening exercises** to maintain muscle mass and improve mobility, which in turn helps to support bone density.

Kidney problems

As we age, our bodies undergo changes, including in our kidneys, which tirelessly filter waste products from our blood to keep us healthy. But kidney problems can develop over time. The types of kidney disorders include:

- **Chronic kidney disease** (CKD) is a gradual loss of kidney function that often goes unnoticed in its early stages.
- **Urinary tract infections** (UTIs) are infections of the urinary system, including the kidneys. They are more common in older adults, especially women.

Working with an OT can help you to develop strategies to maintain independence and continue doing what you enjoy.

Chronic kidney disease (CKD)

Chronic kidney disease (CKD) occurs when the kidneys become damaged and can no longer filter waste as effectively as they should. This can lead to a build-up of toxins in the blood, which can affect overall health. CKD is a progressive condition, meaning that the loss of kidney function is gradual.

Symptoms of CKD may include tiredness, swelling, changes to peeing, nausea, loss of appetite, itching, muscle cramps, and difficulty concentrating.

Several factors can increase the risk of CKD in people with a bleeding disorder, particularly haemophilia. These include:

- **High blood pressure:** Uncontrolled high blood pressure can damage your kidneys over time.

- **Obesity:** Being overweight or obese can also increase your risk of CKD.
- **HIV infection and treatment:** HIV infection can affect the kidneys, while some medications used to treat HIV can also contribute to CKD.
- **Ethnicity:** People of African descent are more likely to develop CKD than other races.
- **Haematuria (blood in the urine):** Blood in the urine can be a sign of kidney problems.
- **HCV (Hepatitis C) infection:** Chronic HCV infection can also cause kidney damage.

It's important to note that this is not a complete list and other factors may also play a role

Having CKD and a bleeding disorder can worsen health risks and complicate medical management. CKD can lead to abnormalities in platelet function, impaired production of clotting factors, and vascular calcifications. These can all increase the risk of bleeding complications.

Managing CKD in ageing people with a bleeding disorder requires a multidisciplinary approach that addresses the unique needs and challenges associated with both conditions. Haematologists and nephrologists (kidney specialists) must carefully balance the management of CKD-related complications, such as anaemia, hypertension, and mineral bone disorders, with strategies to prevent and manage bleeding episodes effectively.

This may involve checking kidney function, blood pressure, clotting parameters, and tailored treatment regimens that minimise bleeding risk while optimising kidney health.

In addition to medical treatment, lifestyle adjustments can help, such as the following:

- **Manage other health problems:** Keep your blood pressure under control and maintain a healthy weight.
- **Stay hydrated:** Drink plenty of water throughout the day.
- **Healthy diet:** Eat a balanced diet low in salt and processed foods.
- **Regular check-ups:** See your doctor regularly to monitor your kidney function.
- **Talk to your haemophilia centre:** They can help you manage your bleeding disorder and CKD risk together.

Urinary tract infections (UTIs)

Urinary tract infections (UTIs) occur when germs enter the urinary tract. This can cause different parts of the tract, such as the bladder or kidneys, to become sore and inflamed. UTIs are particularly common among people over 70. There are a few reasons for this:

- **Weaker urine flow:** Sometimes, our muscles don't squeeze as tightly as they used to, leaving some urine (pee) behind in the bladder. This gives germs a chance to grow.
- **Changes in hormones:** After menopause in women and natural changes in men, the tissues around the tubes that carry urine can become thinner and less resistant to infection.

- **Catheters:** If you have a tube (catheter) to help you pee, you might be more prone to UTIs.

While some UTIs may cause a burning sensation when peeing, older people's symptoms can differ. Here's what to look out for:

- **Feeling confused or agitated:** This can be a sign of a UTI, especially if it's a new change.
- **Wetting yourself (incontinence):** If you suddenly start wetting yourself more than usual, it could be a UTI.
- **Pain in your lower tummy or back:** This might be a sign the infection has reached your kidneys, so it's important to see a doctor.
- **Changes in your usual toilet habits:** You might need to pee more often, even at night, or feel like you can't empty your bladder completely.
- **Feeling generally unwell:** You might have a fever, feel shivery, or lose your appetite.

If you think you might have a UTI, see your GP as soon as possible. Early antibiotic treatment can clear it up quickly and stop it getting worse.

There are some simple things you can do to help prevent UTIs:

- **Drink plenty of fluids:** Aim for around eight glasses of water or clear fluids daily. This helps flush out any germs.
- **Wipe from front to back:** This prevents the spread of germs from your bottom to your genitals.
- **Empty your bladder when needed:** Don't hold on for ages!
- **Keep clean below:** Wash gently with soap and water daily.
- **Wear loose-fitting cotton underwear:** This allows your skin to breathe.

Renal problems

Urinary issues often become more common due to changes in bladder function, muscle tone, and hormonal levels. Some of the most common problems include incontinence, urinary tract infections (UTIs), and erectile dysfunction. Older people with a bleeding disorder may experience reduced bladder control and need to pee more often.

Erectile dysfunction

Erectile dysfunction (ED), sometimes called impotence, is a condition where men have trouble getting or keeping an erection firm enough for sex.

Men with haemophilia are more likely to experience bleeding during sex, especially after repeated injuries to specific muscles. This fear of bleeding can lead to anxiety and ultimately affect their ability to get an erection.

Medications used to treat high blood pressure can sometimes cause erectile dysfunction as a side effect. This can be particularly challenging for men who have both conditions.

Open communication: The key is open communication with your doctor. They can help identify the cause of your ED and discuss treatment options that are safe for you, considering your haemophilia.

Erectile dysfunction can significantly impact a man's emotional wellbeing and intimate relationship. By understanding the connection between bleeding disorders, high blood pressure medications, and ED, men and their doctors can work together to find solutions.

Prostate issues in men

Prostate issues, such as benign prostatic hyperplasia (BPH) and prostate cancer, are common concerns among ageing men. BPH, characterised by an enlarged prostate gland, can lead to urinary symptoms such as frequent peeing, urgency, and difficulty emptying the bladder. Prostate cancer, while less common than BPH, is still a significant health risk for older men and requires early detection and management for the best outcomes.

There is currently no national screening programme for prostate cancer in the UK. If you're over 50 and you're worried about your risk, speak to your GP about a prostate specific antigen (PSA) blood test.

Urinary incontinence

Urinary incontinence, also known as 'urinary leakage', is the unintentional release of urine (pee). It is a common problem, affecting approximately 1 in 3 elderly people in the UK, and is more common in women. There are different types of incontinence:

- **Stress incontinence:** Leaking urine when you cough, sneeze, laugh, or exercise.
- **Urge incontinence:** Having a sudden, strong urge to pee that you can't always hold.
- **Mixed incontinence:** Having both stress and urge incontinence.
- **Overflow incontinence:** Having urine dribble because your bladder can't empty completely.

There are many reasons why incontinence might happen, including:

- **Weakening of pelvic floor muscles:** These muscles help support your bladder and prevent urine leakage. They can weaken with age, childbirth, menopause due to hormonal changes, or being overweight.
- **Urinary tract infections (UTIs)**: These can irritate your bladder and cause leakage.
- **Medical conditions:** Diabetes, prostate problems, and neurological conditions can affect bladder control.
- **Medications:** Certain medications can increase urine production or make it more difficult to control your bladder.

Urinary incontinence is a treatable condition. Talking to your GP is the first step. They can help you understand the cause and recommend the best treatment options. Treatment options include:

- **Pelvic floor muscle exercises (Kegels):** Strengthening these muscles can improve bladder control. Specialist women's health physiotherapy can help with this.
- **Lifestyle changes:** Drinking less fluid before bed, managing constipation (when you find it hard to poo), and losing weight (if needed) can all help.
- **Bladder retraining:** This involves techniques to hold urine for longer periods.
- **Medication:** Certain medications can help relax or strengthen the muscles of the bladder.
- **Pads or liners:** Absorbent products can help manage leakage.

Liver disease

Liver disease is a known complication in some bleeding disorders. It's more common with conditions like haemophilia, where liver function can be affected by prolonged treatment with blood products (such as some factor concentrates). It can also result from viral infections (e.g. hepatitis).

Hepatitis C

Hepatitis C is a virus that mainly affects the liver. It can lead to liver damage and severe problems like cirrhosis and liver cancer. People with bleeding disorders may have been exposed to hepatitis C through contaminated blood products.

Taking care of hepatitis C in elderly people with a bleeding disorder needs a thorough approach. This may include keeping a close watch on liver function, virus levels, and how the condition is progressing with regular blood tests and scans.

Treatment for hepatitis C has improved greatly, with new antiviral drugs that work well and have fewer side effects than older treatments. Doctors specialising in blood and liver diseases must work together to make a treatment plan that fits the person and lowers the risks. Changes to diet and lifestyle, and emotional support can help manage both conditions and promote overall wellbeing.

Mental health issues

Living with other health conditions and bleeding disorders can make people feel more stressed and anxious. Dealing with a long-term health condition, getting older, and concerns about the possibility of bleeding episodes, complications, and ongoing medical care can lead to increased levels of anxiety, impacting everyday life and overall quality of life. Additionally, anxiety about the future and the potential impact of ageing on health and independence can cause distress and further affect your mental health.

The challenges associated with living with a bleeding disorder, such as pain and physical limitations, can lead to feelings of sadness, hopelessness, and loss of interest in activities you once enjoyed.

Low mood or depression can significantly impact quality of life, impair functioning, and contribute to social isolation. Balancing medical appointments, treatment regimens, and potential complications with other responsibilities and commitments can be overwhelming, leading to increased stress levels and feelings of frustration.

Addressing psychological issues in ageing requires a comprehensive medical and psychological approach. Accessing mental health support services, such as counselling or therapy, can help you develop coping strategies, enhance resilience, and improve overall psychological wellbeing. Additionally, making social connections, engaging in enjoyable activities, and practising stress-reduction techniques can help ease psychological concerns and promote overall quality of life.

Living with pain

The challenges of ageing with a bleeding disorder can be compounded by the experience of living with pain. As you get older, you may experience various age-related health issues, such as arthritis, joint degeneration, and chronic pain conditions. These can all exacerbate the symptoms and complications of a bleeding disorder.

Chronic pain may arise from a variety of sources, including recurrent joint bleeds, soft tissue damage, and inflammation. These persistent pain symptoms can significantly impact daily functioning, mobility, and overall quality of life, making it crucial to address pain management strategies tailored to an individual's specific needs.

Chronic joint pain and inflammation caused by repeated bleeding episodes or joint damage can result in a sedentary lifestyle, which negatively impacts bone health. Lack of exercise and weight-bearing activity can lead to reduced bone density.

Pain management

Managing pain in people with a bleeding disorder presents unique challenges. Due to the potential for adverse effects, such as gastric ulcers and platelet-related bleeding risks, non-steroidal anti-inflammatory drugs (NSAIDs) are typically avoided. However, in cases of arthritic joint pain, specific NSAIDs can be considered and may play a crucial role in pain management.

Paracetamol may be an option for managing chronic pain in older people with a bleeding disorder.

Any changes to treatment should be made in consultation with your bleeding disorders team.

Multidisciplinary pain management approaches that combine medical interventions, physiotherapy, psychological support, and lifestyle changes can help people with a bleeding disorder effectively manage pain and improve overall wellbeing. This may involve pain-relieving medications, joint injections, or other targeted treatments to relieve pain symptoms and reduce inflammation.

Some people may find complementary therapies such as acupuncture, massage therapy, and mindfulness-based practices helpful. They may provide additional relief from pain as well as promote relaxation and stress reduction.

General tips for managing ageing with a bleeding disorder

- **Regular check-ups** with a multidisciplinary team, including haematologists, physiotherapists, geriatrician, cardiologists, and other specialists, are essential for addressing the complex needs of older adults with bleeding disorders.
- **Self-management:** You can actively manage your health by following prescribed treatment plans, attending appointments, and making lifestyle adjustments.
- **Education:** Understanding the potential challenges of ageing with a bleeding disorder and staying informed about the latest treatment options can empower you to manage your condition more effectively.

This booklet provides a brief overview of health concerns that may arise as you age, either due to your bleeding disorder or as a natural part of the ageing process. It's important to remember that this is a partial list, and you may experience other health issues not covered in this booklet.

If you have any questions or concerns about your health, no matter how big or small, please don't hesitate to contact your haemophilia centre team. They are there to support you and provide personalised advice to help you age well.

Notes

About the Haemophilia Society (THS)

We are the only UK-wide charity and free membership organisation for everyone affected by a genetic bleeding disorder.

We aim to empower people affected by a bleeding disorder to live life to the fullest; offering support, including events and local groups, the latest news and in-depth information resources, and campaigning and advocacy to demand the best possible care, safe and effective treatment, and equitable access for everyone affected by a bleeding disorder.

There are over 5,500 members of the Haemophilia Society, including people and families living with bleeding disorders, as well as healthcare professionals.

The charity's supporters help fundraise the costs that are vitally needed to be able to offer membership – and services such as events and printed publications – entirely free to all members.

What we do:

Support each other
We understand each other. We offer advice and support from personal experience. Our growing community is there for each other because we're in it together.

Raise awareness
We rally together because every little thing we do makes a difference and gives hope to people living with a bleeding disorder.

Make a lasting difference
We influence and advocate on what matters to our community, health and social care policy, access to treatment and much more.

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 production of this publication was funded by a grant from Octapharma Ltd. They had no input in the writing or development of the content.

This booklet is for our UK audience and was created with healthcare professionals. It supports the information you receive from your clinical team but does not replace it. Always speak to your haemophilia centre before making any changes to your care.

We want to express our sincere gratitude to the following individuals for their invaluable contributions to this information booklet:

- Dr Susie Shapiro, Consultant Haematologist and an Associate Professor of Haematology, Oxford Haemophilia and Thrombosis Centre
- Dr Paul McLaughlin, Clinical Specialist Physiotherapist in Haemophilia, Royal Free Hospital
- Cathy Harrison, Advanced Nurse Practitioner in Haemophilia & other Haemostasis Disorders, Sheffield Haemophilia & Thrombosis Centre
- Dr Gary Benson, Director NI Haemophilia Comprehensive Care Centre and Thrombosis Unit, Consultant Haematologist/ Clinical Director Blood Sciences BHSCT

Their expertise and dedication have been instrumental in ensuring we provide current, unbiased and accurate information.

Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia

Review date 2028

The Haemophilia Society
52B Borough High Street
London
SE1 1XN

Email: info@haemophilia.org.uk
Phone: 0207 939 0780
Web: haemophilia.org.uk

HaemophiliaSocietyUK

HaemoSocUK

thehaemophiliasociety

TheHaemophiliaSociety

The Haemophilia Society

Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia
Review date: 2028