SPORT, EXERCISE & HAEMOPHILIA

Contents

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Introduction

Historically physical activity for fitness or in relation to exercise was discouraged in people with haemophilia. This was due in part to the perception of the risk of bleeding associated such activities and the subsequent lack of effective treatment for active bleeding[1]. Even physiotherapy was deemed 'vigorous exercise' and was only to be done under protective treatment in a hospital environment[2].

However, with the advent of safe, effective and freely available treatment this message is no longer appropriate. People with haemophilia are living longer. Older individuals are living longer with the haemophilia related arthritis that started in their younger life whilst younger patients now only know prophylaxis and a life of mostly no bleeding at all.

However, for all people with haemophilia - activity, fitness and exercise should be a key feature of their lives, in helping to promote health and well-being.

This booklet aims to encourage you to consider improving your level of physical activity. For some this may be as simple as using the stairs more, for others it may include some degree of higher level sporting activity. In all instances though, you must be aware of your current physical abilities, have clear goals of what you would like to achieve, know your limits, but also know when to safely push those limits to get improvement.

Consider too your life with haemophilia - be mindful of your current haemophilia treatment and if you need to tailor new activity to your prophylaxis days, for example, do you need to discuss new activities with your treatment centre, do you know what to do if you do get an injury or a bleed (for example do you know what your treatment dose of factor replacement should be if this happens).

How active are Irish people?

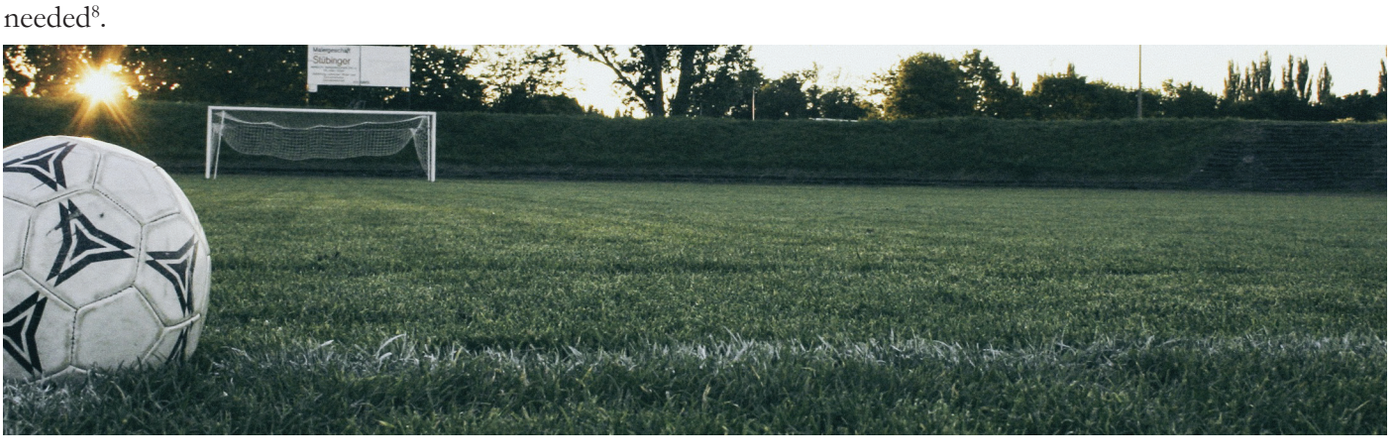
A study showed that only 41% of Irish adults took part in moderate or strenuous physical activity for at least 20 minutes three or more times a week[3]. This level of activity has not changed much over the past few years.

Over half of primary school age children did not achieve the recommended level of physical activity[4]. By 15 years of age, almost nine out of 10 girls and seven out of 10 boys don't achieve the recommended level. There is no specific data for people with disabilities taking part in physical activity[5] [6].

What about Irish people with haemophilia?

One study involving adults with haemophilia in Ireland reported that 52% avoided exercise because of their arthritis and pain[7].

A recent review looking at exercise in haemophilia reported that it was safe to do but that more research was needed[8].



What Is Haemophilia?

The general term haemophilia describes a group of inherited blood disorders in which there is a life-long defect in the clotting mechanism of the blood. Blood contains many proteins called clotting factors, and these work to stop bleeding. The lack of clotting factor causes people with haemophilia to bleed for longer periods of time, than people whose blood factor levels are normal. However, people with haemophilia do not bleed faster than other people.

Most bleeding in haemophilia occurs internally, into the joints or muscles. The joints that are most often affected are the knee, ankle and elbow. Repeated bleeding without prompt treatment can damage a joint. The incidence of haemophilia in the general population is 1 in 10,000 (therefore about 1 in 5,000 of the male population has haemophilia).

There are two types of haemophilia. Haemophilia A which is a deficiency in factor VIII and haemophilia B (sometimes called Christmas Disease) is a deficiency in factor IX. Both types of haemophilia share the same symptoms and inheritance pattern, only blood tests can differentiate which factor is affected. The severity of the condition is related to the degree of deficiency of the relevant clotting factor in the blood.

Haemophilia A

They don't have enough clotting factor VIII

Affects 1 in every 5,000 males

Haemophilia B

They don't have enough clotting factor IX

Affects 1 in every 30,000 males

Severe
Less than 1% of normal clotting factor

- Bleed often into muscles or joints
- Might bleed 1 or 2 times a week
- Might bleed spontaneously

Moderate
1-5% of normal clotting factor

- Might bleed for a long time after surgery, a bad injury or dental work
- Might bleed about once a month
- Rarely bleed spontaneously

Mild
5-40% of normal clotting factor

- Might bleed for a long time after surgery or a bad injury
- Might never have a regular bleeding problem 1 or 2 times a week
- Don't bleed often

What To Look Out For

Haemophilia & Muscle / Joint Bleeding

Most common types of bleeding in relation to haemophilia are bleeding into the joints or muscles (musculo-skeletal). Repeated or untreated bleeding into joints and muscles can cause permanent damage such as arthritis, chronic pain and may lead to the need for surgery in some cases.

Joints and Muscles

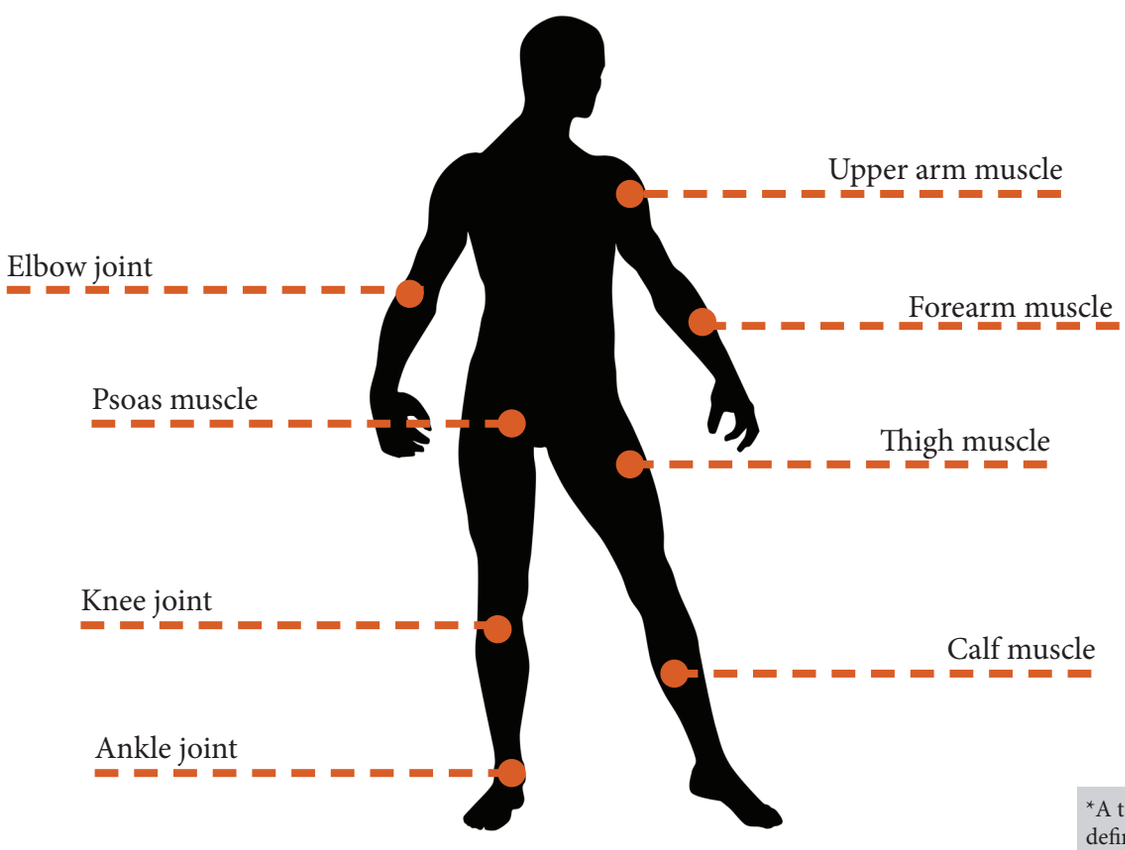
It is normal in humans that we stress and strain our joints and muscles in small ways in our activities of everyday life. Most people repair that damage automatically. For the person with a bleeding disorder, however, these tiny breaks in the blood vessels in joints and muscles may continue to bleed as a result of normal everyday activity An ache or irritation in an affected area can be an indication that a person with haemophilia is getting a bleed.

In the case of joint bleeding, the blood which has escaped into the joint has a very damaging effect on the cartilage surface of that joint. Once a joint becomes damaged then bleeding can sometimes occur more frequently resulting in a 'target joint'* (especially if prophylaxis is not used to best effect). Traditionally (in the era before good treatment) the majority of bleeds into joints were in the ankle, knee and elbow; this is why older people with haemophilia have such widespread joint damage.

Muscles that cross two joints are most at risk of bleeds caused by sprains and strains. Such as:

- the upper arm (biceps/triceps)
- trunk and hip (ilipsoas)
- upper thigh (quadriceps and hamstrings)
- lower leg (calf)

Bleeding Most Often Occurs in these Areas



With contact injury, any soft tissue or joint is at risk of bleeding if enough force occurs, with bleeding likely if factor levels are lower than normal.

*A target joint is defined as a joint into which you have at least 3 bleeds in a 6 month period

Physical Activity & Exercise

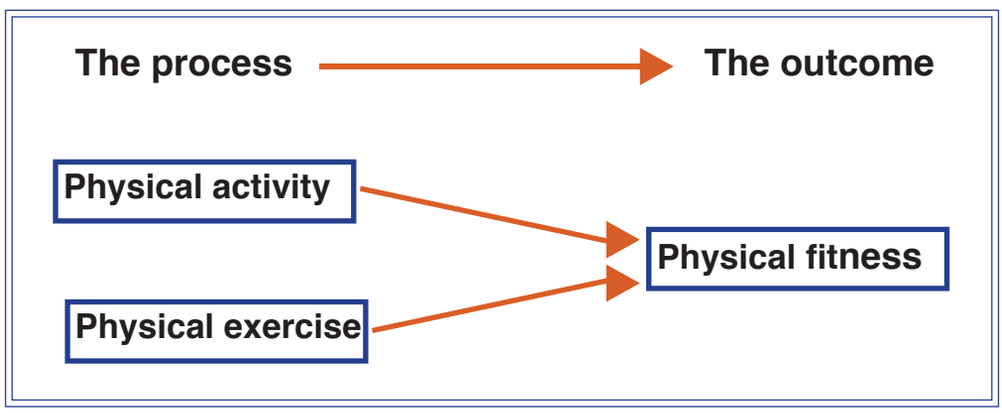
'Physical activity' is any body movement produced by muscles that requires using energy.

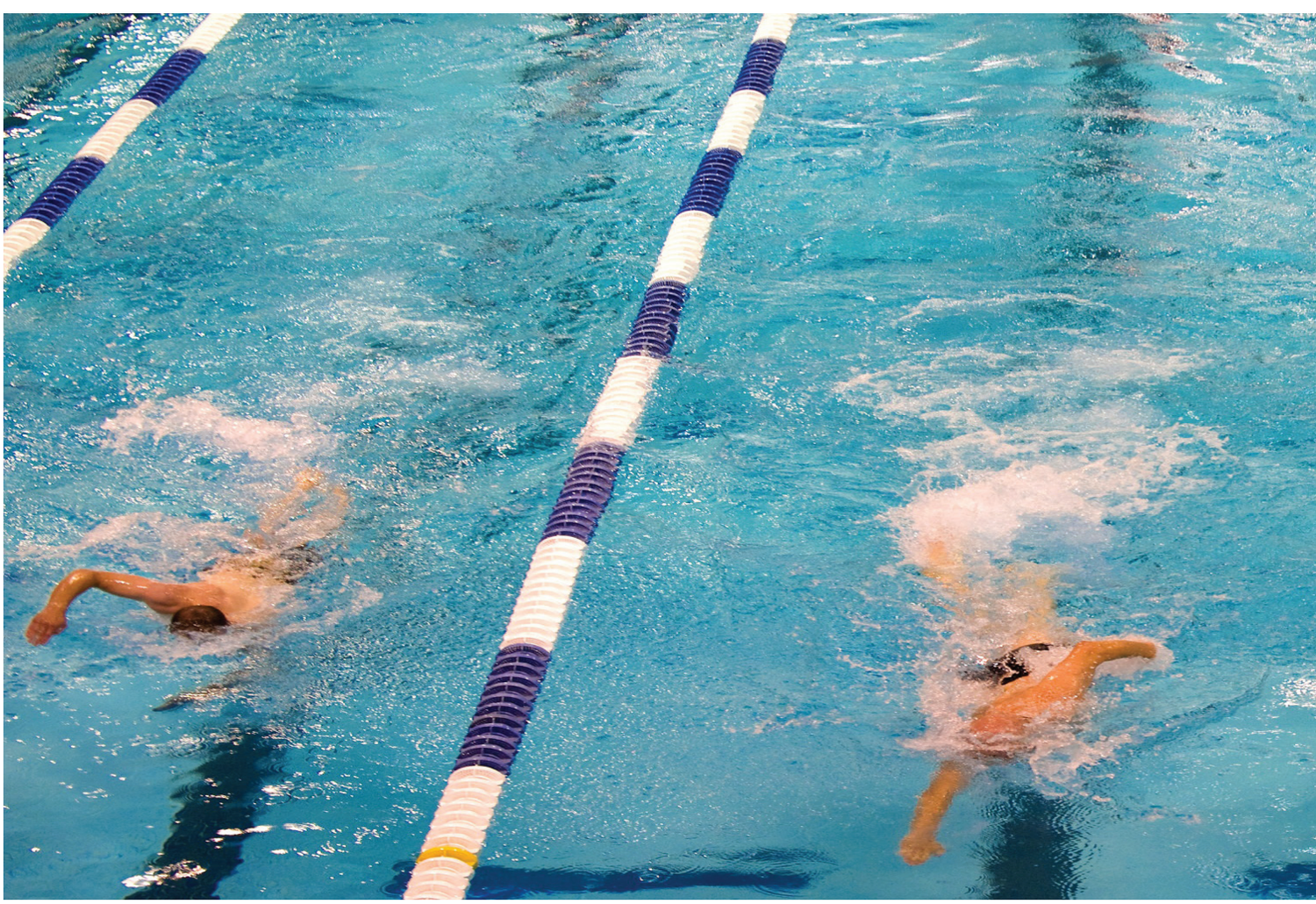
It is an important means of improving physical and mental health.

It reduces the risks of many diseases (such as diabetes, some cancers, dementia).

Being more physically active benefits society too as it increases community engagement and social interaction[9].

Physical activity includes exercise as well as other activities which involve bodily movement and are done as part of playing, working, active transportation, house chores and recreational activities[10].





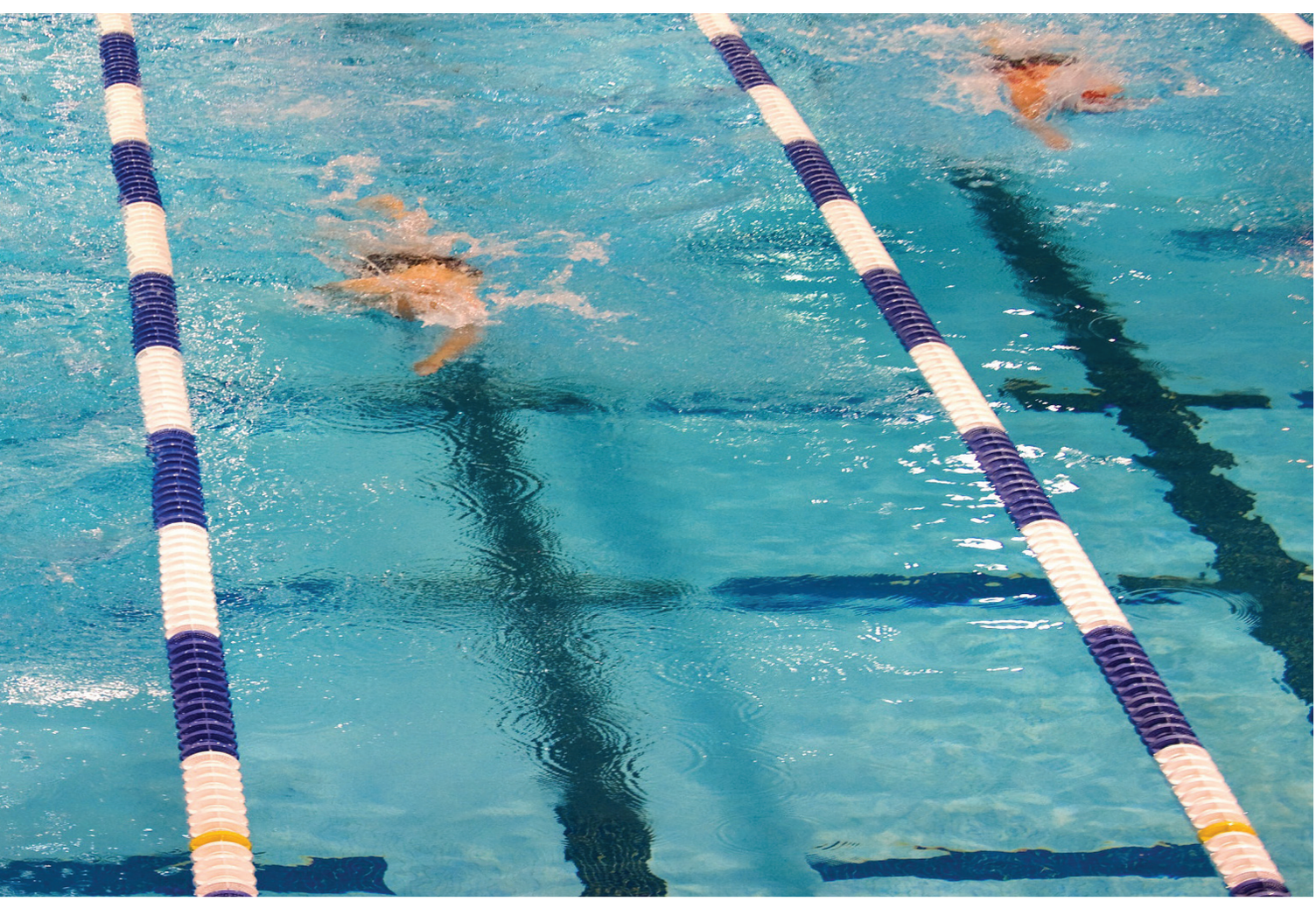
Haemophilia & Activity

Haemophilia or not, the health benefits of being more active are becoming more significant. This is especially important as we get older.

Depending on your age and the severity of your haemophilia, you may have come across many mixed or negative messages about being active and exercising.

Not knowing if you can or should do an activity, how to do it, or even where to start are all very common experiences. Joint arthritis, fear of bleeding and pain all play their part in this experience.

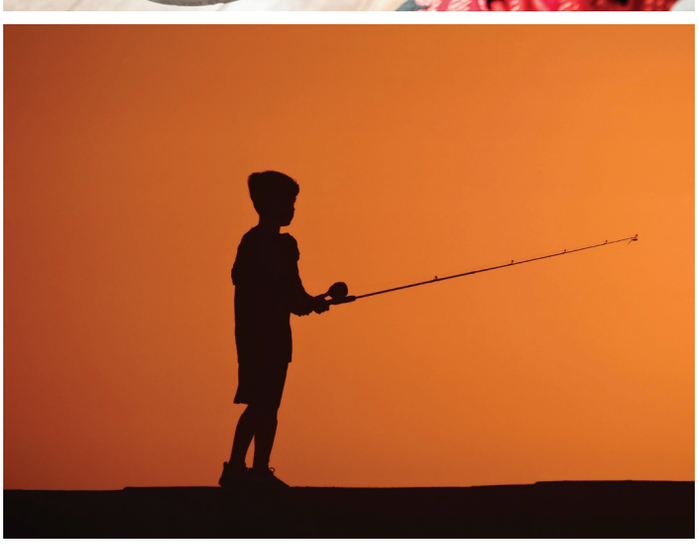
But what is important to know now, is that for many with haemophilia, being active is good!!



Choosing an Activity

Find something that works for you![11]

At Home	At Work	In School	In the Community
Cleaning counts as part of physical activity!	Physical activity at work increases productivity!	Physical activity can improve children's concentration	Community gardens increase social interaction and physical activity
Try balancing or stretching while watching TV or brushing your teeth	Get off public transport a few stations before your destination	Safe walking and biking routes to school benefit both children and parents	Enjoy outdoor activities all year round
Gardening is a good way to be physically active	Use the stairs not the lift	After school activities, such as sports and playground games give children opportunities to be active	Access to green spaces, pavements and cycle routes make physical activity part of daily life



Choosing the Right Activity

This table highlights that your activity of choice can be anything and be done anywhere!

It must be enjoyable, accessible, and be something you will want to continue with.

Some activities (such as higher level sporting activities) bring with them a higher risk of injury (irrespective of haemophilia) and subsequently bleeding (when considering haemophilia).

Some of these activities have been stratified into low to higher risk by the National Hemophilia Foundation (NHF) of the USA below[12] (our table has been modified to include Gaelic Football and Hurling).

When choosing activities such as these be mindful of YOUR current physical abilities!

The physiotherapist at your haemophilia centre will be well placed to help you decide what you may want to do. They can give advice on your current joint health, be able to assess your current fitness levels and help you develop an activity plan.

Table of Activity Ratings

1	1.5	2	2.5	3
Low Risk	Low to Moderate Risk	Moderate Risk	Moderate to High Risk	High Risk

Activity	Category
Aquatics	1
Archery	1
Badminton	1
Basketball	1.5 - 2
BMX Racing	3
Body Sculpt Class	1.5
Boot Camp Workout	2
Bowling	2
Boxing	3
Canoeing	1.5 - 2.5
Cardio Kickboxing Class	2
Circuit Training	1.5
Cycling	1.5 - 3
Dance	1.5 - 3
Diving Competitive	2.5 - 3
Diving Recreational	2
Ellipictal Machine	1
Fishing	1.5
Football (American)	3
Football (Gaelic)	2.5

Activity	Category
Frisbee	1 - 1.5
Golf	1
Gymnastics	2.5 - 3
Handball	2.5
Hiking	1 - 1.5
Hockey (Street/Field)	2.5 - 3
Horseback Riding	1.5 - 2
Hurling	3
Indoor Cycling	1.5 - 2
Jet–sking	2.5 - 3
Jumping Rope	2
Karting	2.5
Kayaking	1.5 - 2
Lacrosse	3
Martial Arts, Tai Chi	1
Martial Art, Mixed / Trad	3
Motorcross / Motorcycle	3
Mountain Biking	2.5
Pilates	1.5 - 2
Power Lifting	3
Rock Climbing (Indoor)	1.5 - 2
Rock Climbing (Outdoor)	2.5 - 3
Rowing / Rowing Machine	1.5
Rugby	3
Running /Jogging	2
Scuba Diving	2 - 2.5
Skateboarding / Skating	1.5 - 2
Snowboarding	3
Soccer	2-3
Surfing	2 - 2.5
Swimming / Snorkling	1
Tennis	2
Track & Field	2 - 2.5
Trampoline	2.5 - 3
Treadmill	1.5
Volleyball	2 - 2.5
Walking	1
Water Polo	2.5
Wrestling	3
Yoga	1.5 - 2

Before Physical Exercise

Just some things to consider before you exercise:

- **Know your current factor regime**
- **Prophylaxis**
- **Treatment dose for mild and major bleed**
- **Contact details of your HTC**

- **Where are you going?**
- **Is it far from home?**
- **How will you get there?**
- **Consider parking, public transport etc.**
- **What time of day?**

- **Do you have/need specialist equipment? Shoes, clothing etc?**
- **Do you need to bring an extra dose of factor with you?**

- **Is it Indoors? Or outdoors?**
- **Temperature**
- **Slippy, smooth, carpeted or sticky floor**
- **Is the ground smooth, bumpy, slippy?**

The Warm Up

It is a good idea to get into the habit of doing a warm up before your exercise/activity and a cool down when you are finishing. You should try and do 5-10 mins for both. A warm up aims to get your heart rate raised, get the body moving (muscles and joints that you will be using) and help you get 'in the zone' for your activity.

- Prepares the body with gradual exercise
- Raises the body temperature
- Facilitates circulation from the heart to the muscles
- Increases muscle, tendon and ligament elasticity that is required for the exercise
- Avoids muscle pulls and sprains

A warm up may help prevent injury to muscles and joints as well as limit some muscle soreness that can happen after exercise.

- Walking briskly to the park or the gym for example can be helpful. Some people may want to try an exercise bike for 5-10 mins before their gym routine, or a gentle jog can be used (if your ankles are OK to do this).
- Speak to your physiotherapist to discuss what kind of warm up and cool down would fit with your body and haemophilia.
- Gentle stretching of the muscles and joints can be used in both the warm up and cool down.

We have included a few examples here in this booklet. You can find more examples from the World Federation of Haemophilia website (wfh.org). It is also worth speaking to your physiotherapist about any specific stretches or mobility exercise that you may benefit from doing as well.

Warming Up

1. Calf Stretch (Lying or Standing)

Standing: Stand with your hands against a wall. Put one leg out in front, knee bent and the other out behind you with the knee straight. Gently push your heel down in to the ground, feeling the pull in long your calf muscle.

Sitting: Sit comfortably on the floor or on your bed. Place a towel around the ball of your foot, holding either end with both hands. Keeping your knee straight, gently pull on the towel feeling the stretch in your calf muscle. Hold for 20-30 secs. Repeat on the other leg. Do 3-4 stretches on each leg.

2. Calf Stretch Over Step

Stand with both feet on a step and holding on to a hand rail or the wall for support. Move one foot back so that only the ball of the foot is on the step, and the heel is off the step. Gently lower the heel off the step until you feel a pull along the calf muscle.

Hold for 20-30 secs. Repeat on the other leg. Do 3-4 stretches on each leg.

3. Quadriceps Stretch

To help you keep your balance, stand holding on the back of a sturdy chair, table or the kitchen bench. Bend one knee, bringing your foot up behind you. Grasp your foot with your hand. Gently pull on your foot so that you can feel a stretch along the front of your thigh.

Hold for 20-30 secs. Repeat on the other leg. Do 3-4 stretches on each leg.

4. Quadriceps and Glutes Warm-up Chair Squatting

Stand with both hands on the back of a chair or the kitchen worktop, with your feet comfortably hip width apart. Slowly bend both knees to a squat position. Hold for 3 secs in this bent position and straighten both knees.

Repeat this movement 10 times. Do 3 sets of these with a minute rest in between each set.

The Cool Down

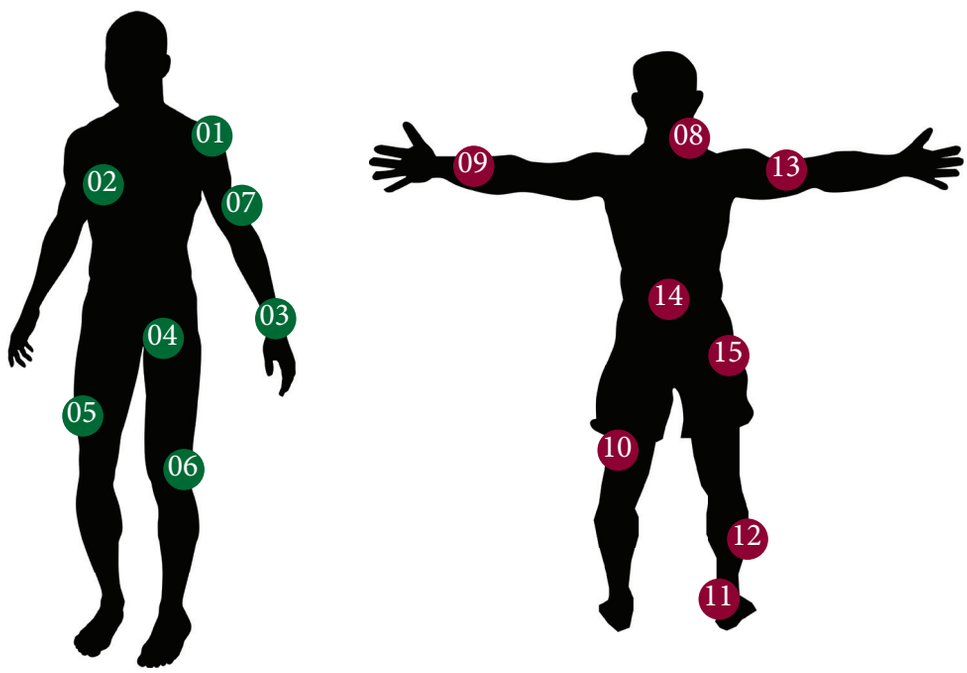
The cool down phase after exercise is very important for recovery and to avoid injury. It aims to lower body temperature and bring the body back to its resting state.

The cool down stretches on page 15 are designed to relax and lengthen the muscles. As with warm up stretches, these stretches should be done smoothly and gently.

These stretches will become more effective the more they are done (at least twice per muscle group). Each stretch should be held for at least 30 seconds.

The main muscles and joints to focus on during warm up and cool down:

01 Shoulders
02 Pectorals
03 Wrists
04 Adductors
05 Quadriceps
06 Knees
07 Biceps
08 Neck
09 Forearms
10 Hamstrings
11 Ankles
12 Calves
13 Triceps
14 Lower back
15 Gluteals



Remember

1. If you are new to these exercise you may find that you feel stiff when you are starting out.
2. At no point should any of these stretches be painful.
3. If you experience pain or have difficulty in doing any of these stretches – please speak to your physiotherapist who will help make a plan that works for you.

Cooling Down

5. Lower Back and Hip

Lying knees to chest: Lie on your back on your bed or comfortably on a carpeted floor. Have you head well supported on a pillow or cushion.

Bend both knees up toward your chest and place both hands on your knees. Gently pull your knees further towards your chest until you feel a stretch along the bottom of your back and along your buttocks.

Breathe normally whilst you do this. Hold this position for approx. 20-30 secs and then let go slowly. Repeat this 4 times with a 30 second break in between each set.

6. Shoulder Range of Movement

Back of shoulder stretch: Sit upright or stand in a comfortable position. Bring one arm across your body. Use the other arm and hand to pull this arm across your chest until you feel a stretch along the back of the shoulder. Hold for 20-30 seconds, relax and repeat on the opposite side. Do 3-4 stretches on each shoulder.

Chest and front of shoulder stretch: Sit upright or stand in a comfortable position. Bring both of your arms out behind you and if you can, try and clasp your hands together. Gently push your chest forward and raise your hands up behind you until you feel a stretch across your chest and shoulders.

7. Hamstring Stretch

Sitting upright on a chair place with your hands on your hips, place one leg out straight in front of you. Make sure only the heel of your foot is on the ground. Keep your back straight and lean forward slowly towards your leg until you feel the stretch on the back of your thigh. Hold for 20-30 secs and repeat on the other leg. Do 3-4 stretches per leg with 3-40 seconds rest in between.

8. Lower Back / Trunk Rotation Stretches

Lower back stretch: Lie on your back on your bed/floor with a pillow/cushion under your head. Bend your hips and knees up so your feet are flat on the floor/bed. Rest your hands on your tummy or to the side of your body.

Keeping both knees together, gently roll your knees to one side until you feel a gentle stretch on the opposite side of your trunk. Hold this position for 20-30 seconds, keeping your chest and upper back relaxed against the floor or bed, move your knees to the other side.

Lower back mobility: Starting with the same position as above, instead of holding at the end of movement to stretch, try and rotate your legs to the right and left side in a gentle continuous movement. Do this for 2-3 mins.

How to Recognise a Bleed

Despite the health benefits, sport and exercise carries a certain degree of risk for people with haemophila. Joint bleeds can be diffilcult to recognise. Here are some things to look out for:

Joint or Muscle Bleed

- **Tingling or Tightness**
- **Pain**
- **Redness**
- **Swelling**
- **Warmth**
- **Tenderness**
- **Reluctance to Move Affected Limb**

Head Bleed*

- **Headache**
- **Drowsiness**
- **Nausea**
- **Vomiting**
- **Unsteady Balance**
- **Irritable**
- **Confusion**
- **Seizures**
- **Loss of Consciousness**

*NB: A head bleed requires immediate medical attention in a hospital

What To Do In Case Of A Bleed?

If you suspect a joint or muscle bleed – **STOP**, and treat it with factor as soon as you can.

KNOW what your treatment dose is for a mild or severe bleed.

For bleeds in joint or muscles, use **P.R.I.C.E.** to manage pain and healing as best as possible (see page 17).

If you have ongoing symptoms for more than 24 hours after doing a new activity or exercise – you should make **contact** with your haemophilia centre for further advice.

If you are at school or work – think about having a **spare treatment** dose kept there.

If you are at the gym or travelling for sport – think about bringing an extra treatment dose (for the just in case moments) with you in your sports bag. That way you can get treatment as soon as you get an injury or bleed.

Pain after doing a new activity can be a very normal event!

It is good to remember that pain as a sensation does not always mean there is danger to the body area in question. Pain does not always mean there is a bleed – especially if you already have arthritis in a joint.

Discomfort in muscles and joints after exercise is normal – and usually eases as you do more activity regularly.

If you have concerns about pain – you should talk to you physiotherapist or haemophilia centre about it.

Treating Acute Bleeds Using P.R.I.C.E.

P

PROTECTION / REST

- Following injury - you should definitely unload and protect the area from further trauma
- How long - depends on the severity of the injury
- Avoid any of the movements that caused the injury
- Time resting should be kept to clinical minimum
- Can be as simple as not weightbearing on a limb (using crutches), or putting your arm in a sling

R

ICE

- Primary effect is for **pain relief**
- **Apply**: crushed ice in a bag, with a damp cloth/tea towel wrapped around it, applied to injured area for 10 minutes
- **NEVER** longer than 20 minutes
- Can be **reapplied** every 1-2 hours if required

I

COMPRESSION

- Using this depends on your **personal preference**
- **Use gradual compression** that shapes comfortably to the affected area - no lumps, bumps or tightness
- **DO NOT USE** high levels of compression AND elevation at same time
- **Monitor** the injured area closely when using compression

C

ELEVATION

- **Pain relief** comes from decreasing pressure from swelling on the injured tissues
- Areas further away from the body (lower legs for example) will need longer periods of time in elevated position
- Discomfort or throbbing sensation when taking the limb out of elevation to normal positions (e.g. standing up) is normal (as this is the tissue pressure increasing again with gravity)

E

REHABILITATION: With a significant injury - it is advised that you seek expert advice from your Physiotherapist on recovery as well as advice on how to rehabilitate from the injury[13] [14].

Getting Started.....

When getting started with physical activity some things to remember are[15]:

- Some activity is good – more is better!
- Low intensity better than sedentary, moderate activity better than low!
- New activities should have relative level effort that is light or moderate.
- Adding 5-15 min walk 2-3 days a week = reasonable beginning for people who are unfit or older.
- Building a 20-30 min/session for several weeks should be achieved BEFORE considering an increase in relative intensity.
- Fitness improvements to an activity programme may take as long as 20 weeks or more for older people – **SO KEEP GOING!**

About the Author

Paul works as a Clinical Specialist Physiotherapist in Haemophilia at the Katharine Dormandy Haemophilia Centre at Royal Free Hospital in London. In 2000 he completed his undergraduate degree at the University of Ulster in Belfast, and his Master's degree in Advanced Physiotherapy (Neuromusculoskeletal Rehabilitation) at King's College London in 2009. He is currently undertaking a National Institute for Health Research funded PhD investigating the use of rehabilitation in the management of chronic joint pain in people with haemophilia.

He is a member of the Musculoskeletal Association of Chartered Physiotherapists (MACP), a specialist group of expert physiotherapists providing excellence in examination, treatment and management of people with neuromusculoskeletal problems. His clinical interests are management of chronic musculoskeletal pain in haemophilia, the use of exercise as a rehabilitation tool, enhancing patient knowledge and understanding of their musculoskeletal disorder, and patient reported outcomes assessment.

He is a past chairman of the HCPA - a UK group of specialist physiotherapists working in haemophilia. He is a current member of the EAHAD physiotherapy committee, and the musculoskeletal working party of the UKHCDO.

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Sponsored by an unrestricted educational grant from Roche