Prophylaxis is not the only answer

Caring for your joints

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Haemophilia Background

A life-long bleeding disorder

A condition of joint and muscular bleeding

85% of all bleeding episodes within musculoskeletal system

Accelerated joint destruction due to bleeds prior to epiphyseal fusion

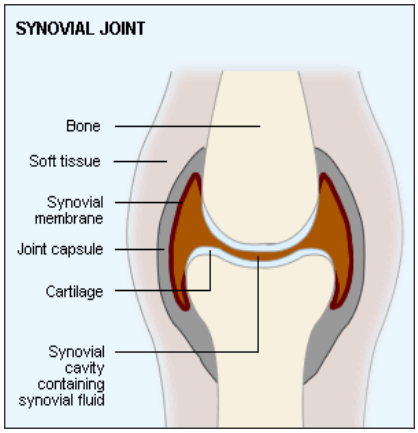
Haemophilia Background

Most long-term joint damage occurs because of bleeds in childhood

How do I get a joint bleed?

Bleeding Mechanism

Joint bleeds occur when the small blood vessels in the synovium are damaged



Myth #1

Myth #1

Joint bleeds are ‘spontaneous’

Haemophilia Background

Synovial impingement may be non-traumatic, but is never spontaneous

There is always a reason why the synovium is trapped and torn

This is most often due to the pattern of movement and ‘biomechanics’ affecting the joint

Haemophilia Background

Shear and rotational forces affect hinge joints

Damage to synovial blood vessels

Ineffective haemostatic response

Blood fills joint cavity

Haemophilia Background

Normal joints do not contain blood

Haemophilia Background

Joint damage rapid following exposure to blood

Fewer than four joint bleeds starts cycle of joint destruction

Joint damage proportional to number of bleeds, speed of rehabilitation

Frequency of bleeding rises with each unmanaged episode

Haemophilia Background

Problems at one joint quickly become problems at others

Haemophilia Background

Delayed action increases risk of more bleeds and long-term problems

Speed is important

Bleeding damages joints quickly

It is really important that you act quickly once you feel a bleed starting

Why?

Blood is very destructive for your joint, and it only takes a small number of bleeds to lead to long-term damage

This damage may be with you for life

Bleeding damages joints quickly

Every bleed must be reported because every bleed must be rehabilitated

Why manage early: children

Changes in muscles and joints occur rapidly following a bleeding episode

The longer it takes to commence rehabilitation, the more these changes persist

These increase the likelihood of further bleeding episodes and life-long joint damage

Rapid assessment essential

Factor, then first aid from earliest opportunity

Now make the call to your HTC or Physio

Rapid assessment to differentiate bleed from other sources of pain: not all pain is a bleed

Ensure correct diagnosis and therefore correct management approach

Bleeding damages joints quickly

Normal

20yr old PWH

Historical management

Patients were actively discouraged from exercise

Sent to bed after a bleed for weeks, metabolised muscle proteins, flexion deformities

Patients only reviewed if there was a problem or on request

The weaker, stiffer, less coordinated a patient, the higher the risk of bleeding, joint damage

And Now…

Aim to provide rapid response to all bleeding episodes

Minimise joint damage, break cycle of bleeding

Rehabilitate quickly to reduce long-term risk of bleeds, accelerated joint damage

What can you do?

So what can you do…?

Let's focus on two key points:

1. Treating bleeds quickly if they occur
2. Minimising the risk of bleeds

What you do makes a big difference

So…

The sooner you treat the bleed with factor and start the PRICE regimen to minimise joint damage from blood

But…

Treatment is NOT just factor

Myth #2

Myth # 2

Factor doesn't just stop bleeding, it gets rid of blood from a joint too

"I had a bleed this morning but I treated it and it has gone now"

Myth #3

Myth #3

"I don't need rehabilitation because I have taken Factor, and the blood won't damage my joint"

Rehabilitate every bleed

After a bleed has settled, your joint is still weaker and stiffer than it was before

If a joint is weaker/ stiffer, you are more likely to have another bleed

Things that you could do easily before may lead to a bleed if the joint is weak or stiff

If one joint is weak/ stiff, it makes other joints more likely to bleed and become damaged

Do not ignore the problem

So…

EVERY SINGLE BLEED MUST BE REHABILITATED

This means that you will need to see your physiotherapist and you will need to do exercises at home to get your joint back to normal

If you do not do your exercises, do not expect physiotherapy to help!

Minimising the risk of bleeding

1. Prophylaxis: make sure you take this at the right time of the day

   Do not have your prophylaxis before you go to bed – even if it seems easier at this time of day

   Prophylaxis should be taken before school or sports, otherwise it is wasted

   Do not skip treatments

Minimising the risk of bleeding

2. Keep fit, keep your weight down

   Strong muscles protect the joints from bleeding

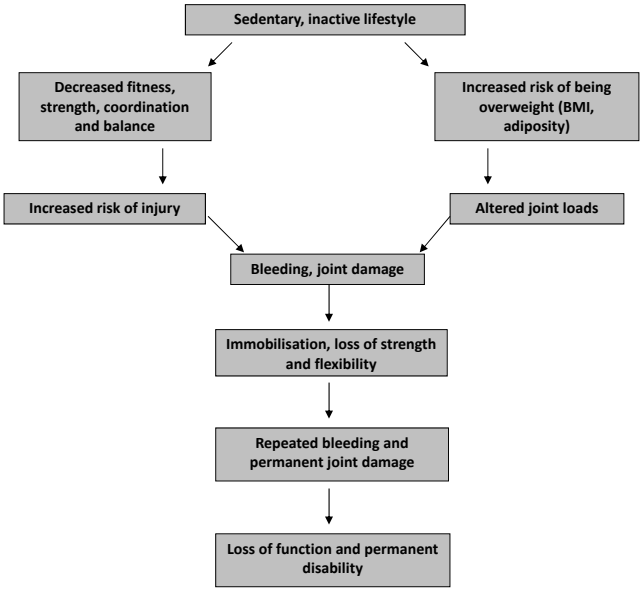
   Make sure the exercise is sensible – avoid heavy contact or high impact sports

   The heavier you are, the more easily your joints are damaged

Prophylactic exercise

Couch potatoes bleed more easily, more frequently and are more expensive to treat

Rationale



Adapted from: Wittmeier K, Mulder K. Enhancing lifestyle for individuals with haemophilia through physical activity and exercise: the role of physiotherapy. *Haemophilia.* 2007; 13 (suppl. 2): 31-37

Weight is important

Here's an example…

When you walk down hill, you take at least 8x your body weight through your knees

If you are 10kg overweight, that is an extra 50kg load through these joints with every step

How long do you think joints will last with all this extra load?

Minimising the risk of bleeding

3. Make sure you wear sensible shoes

It is important that your feet and ankles have good support to protect them from bleeding

Most trainers or running shoes have very good support

These shoes will only help if you tie your shoelaces!

Minimising the risk of bleeding

Trainers are good because they have an arch support, a shock absorbing pad under the heel and a firm upper to keep your foot in a good position

Skate shoes do not have these things (even if they look cool)

Thongs are also very poor at protecting your ankle and change how your walk, increasing the risk of bleeding

Minimising the risk of bleeding

4. Be sensible and listen to your body

Watch out for trampolines and high impact activity

Adapt your footwear to suit the terrain – if you are walking on an uneven bush track, make sure to wear proper boots

If your body is telling you that an exercise is hurting you or starting a bleed, listen!