

**BETTER HEALTH AND  
FITNESS: LAYING THE  
FOUNDATION FOR POSITIVE  
AND INDEPENDENT  
MANAGEMENT OF  
HAEMOPHILIA**

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# Haemophilia 2007

- ◆ Clotting factor available for prevention and treatment of bleeding episodes
- ◆ Optimise joint function
- ◆ Allows for normal activity including participation in most sports

# Early issues, lasting impact

- ◆ Adjusting to the diagnosis
- ◆ Uncertainty, “on demand”
- ◆ Venous access in infants/toddlers
  - ◆ Distress of multiple attempts
  - ◆ Fear of next bleeding episode & treatment
  - ◆ Barrier to boys independently managing condition

# Empowering families

- ◆ New diagnosis
  - ◆ Early education
  - ◆ Establishing support networks
  - ◆ Improved psychosocial care
    - ◆ Consumer feedback: social work & access to psychology/counselling
- ◆ Strategies for managing painful procedures





*Unlike his elder brother at the same age, he doesn't cry as we enter Emergency. Nor does he scream when anaesthetic patches are applied to his hands. He slept through his first treatment cradled in my arms and in subsequent treatments, he has sat cuddled on my knee while we sing songs.*

*We know they always did their best with Alex with the knowledge that they had at the time, but to have been able to give Hamish the opportunity not to be scared has changed our lives. It's immeasurable."*

## Procedural pain techniques change treatment experience

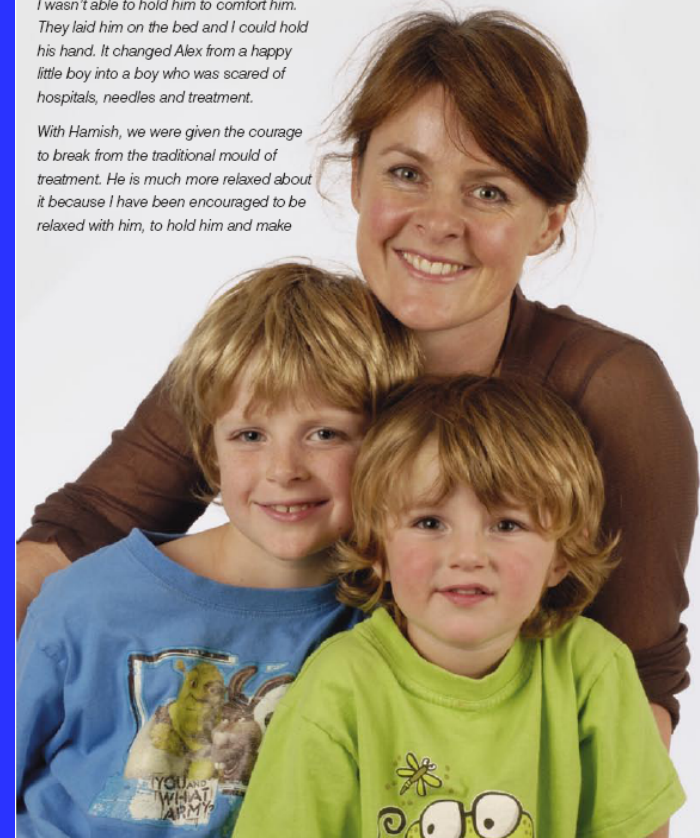
Liz Bishop is mum to Alex nine, and Hamish three and a half, who both have severe haemophilia, the treatment for which involves frequent injections and blood tests. She says the new approach to managing procedural pain at RCH, in particular the principles of positioning for procedures and music therapy, has meant Hamish's experience of treatment has been very different to that of his brother.

*"When Alex was first diagnosed, we were much more hospital-based and treatment was always in Emergency. He used to be wrapped in a sheet if he got distressed. I wasn't able to hold him to comfort him. They laid him on the bed and I could hold his hand. It changed Alex from a happy little boy into a boy who was scared of hospitals, needles and treatment.*

*With Hamish, we were given the courage to break from the traditional mould of treatment. He is much more relaxed about it because I have been encouraged to be relaxed with him, to hold him and make*

*him feel comfortable and make it an easy part of his life, rather than a separate part. Unlike his elder brother at the same age, he doesn't cry as we enter Emergency. Nor does he scream when anaesthetic patches are applied to his hands. He slept through his first treatment cradled in my arms and in subsequent treatments, he has sat cuddled on my knee while we sing songs.*

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# Early Home Therapy

- ◆ Infusaports
  - ◆ Easy access, reduces anxiety & fear
  - ◆ Home infusion of clotting factor
  - ◆ Prevent & treat bleeds at home
  - ◆ Life changing, parents gain control

# Clotting factor via infusaport





# Preparation for independence

- ◆ Involve boys in their own treatment from an early age
- ◆ Progress from port to peripheral early, gradual transition
- ◆ Self infusion from around 8-9 years of age
- ◆ Gradually take on ownership of condition
- ◆ Clinic time alone for older boys

# Maintaining home therapy

- ◆ Regular HTC review
  - ◆ Clotting factor dosage
  - ◆ Keep up with current recommendations
  - ◆ Update – prevent/managing bleeds
  - ◆ Joint health
  - ◆ General health
- ◆ Isolation – HFV/HFA

# School Camp

- ◆ Important step (for kids & parents) towards managing haemophilia outside of home
- ◆ Key elements to successful camp: Preparation and communication between the school, family & HTC
- ◆ HTC assists with individual plan



# School Camp

## ◆ Year 6 Camp

- ◆ Developing venepuncture skills

- ◆ Support plan in place

  - ◆ Local hospital for prophylaxis

  - ◆ Teachers aware of plan

- ◆ Communication - documentation

## ◆ Year 7 Camp

- ◆ Confidently self infusing

- ◆ Communication with new school/teachers

# Travel

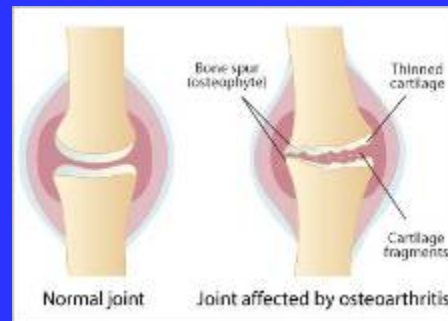
- ◆ With family, then independently
- ◆ Preparation (HTC there to help!):
  - ◆ Appropriate amount of clotting factor
    - ◆ Prophylaxis &/or bleed doses
  - ◆ Storing/travelling with clotting factor
    - ◆ Documentation, airport security
  - ◆ I.D. card/letters of introduction
  - ◆ Treating bleeds, local medical contacts
    - ◆ Global Treatment Centre Directory (WFH)

# Independent Management

◆ Acute



◆ Chronic



◆ Play, Sport and Leisure



# If you do have a bleed

- ◆ Treat with Factor ASAP
- ◆ Please remember **FACTOR IS ONLY ONE ASPECT OF TREATING A BLEED**
- ◆ RICE
- ◆ Rehabilitation

# If you do have arthropathy

- ◆ See your Physio
- ◆ Aims of PT
  - ◆ Reduce pain and strategies to deal with pain
  - ◆ Increase movement as able
  - ◆ Increase function
- ◆ Improved muscle strength assists with pain

# Child Development

- ◆ Normalising childhood development.
- ◆ Baby
  - ◆ Tummy time
  - ◆ Crawling
- ◆ Toddler
  - ◆ Walking



# Child Development



- ◆ Pre school
  - ◆ Exploring the environment
  - ◆ Taking risks
  - ◆ Establishing the foundation of motor skills

# Skill Acquisition

- ◆ Primary school 5-12 years
- ◆ Learn skills in controlled setting
- ◆ Modified sporting opportunities
  - ◆ Auskick
  - ◆ Goalkick
  - ◆ Kanga Cricket
- ◆ Uncontrolled play



# Consolidation of sport and leisure activities



- ◆ Secondary school  
12-18 years
- ◆ Structured sporting activities
- ◆ School or community based
- ◆ Less uncontrolled play

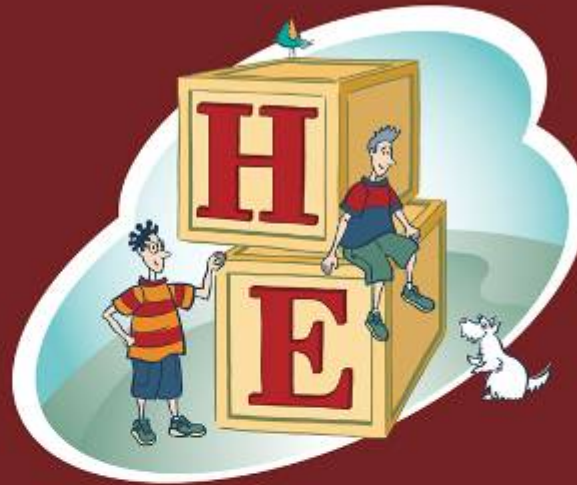
# Why sport is so important.

- ◆ Increased muscle strength and endurance
- ◆ Improved joint stability.
- ◆ Improved confidence and self esteem
- ◆ Improves normal motor development and enhances skill acquisition and co-ordination.
- ◆ Gives greater opportunities for socialisation at school and during sport and leisure activity.
- ◆ Maintenance of appropriate body weight.

# Why sport is so important.

Sport and Physical Activity  
reduce bleeding episodes!!!!!!

- ◆ Research
- ◆ Anecdotally



# Boys will be boys

A guide to sports participation  
for people with haemophilia and  
other bleeding disorders



Bayer HealthCare  
Biological Products



The Royal Children's Hospital  
Melbourne, Australia  
Physiotherapy Department and  
Henry Ebert Haemophilia Treatment Centre

# Sports Played

- ◆ Late 90's, early 00's
  - ◆ Increase number of sports being played
  - ◆ We would occasionally hear about this directly, before participation was to begin.
  - ◆ However more often we found out after the fact
- ◆ Aim was to minimise risk

# Risk

## what sports can I play?

Factors that influence a person with haemophilia's choice of activities include age, frequency and site(s) of bleeding, existing muscle and joint damage, general body build of the individual, geography, culture, social attitude, convenience of facilities and personal preferences.

The following list of sports has been divided into categories according to suitability.

### CATEGORY A:

Highly recommended as most persons with haemophilia can safely participate.

- *Swimming*
- *Bicycling*
- *Tai Chi*
- *Golf*

### CATEGORY B:

Suitable for the majority of persons with mild-moderate haemophilia. In these activities the benefits outweigh the risks.

- *Tennis*
- *Bowling*
- *Table tennis*
- *Scuba diving*
- *Aqua aerobics*
- *Weightlifting*
- *Volleyball*

- *Archery*
- *Dancing*
- *Basketball*
- *Fishing*
- *Yoga*
- *Aerobics*
- *Fencing*
- *Ice-skating*
- *Gymnastics*
- *Running and jogging*

### CATEGORY C:

Suitable for persons with mild haemophilia. Participation should only be considered following adequate preparation and supervision.

- *Sailing*
- *Soccer*
- *Squash*
- *Roller-skating*
- *Horseback riding*
- *Cross country skiing*
- *Skiing (snow and water)*

### CATEGORY D:

**NOT** recommended as the risks outweigh the benefits.

- *Boxing*
- *Football*
- *Hockey*
- *Judo*
- *Wrestling*
- *Skate-boarding*
- *Motorcycle riding*

# Cycling

## Participation

Cycling is a highly recommended sport for people with bleeding disorders. Participants are able to increase lower limb muscle strength without putting weight-bearing stresses through their joints. However injuries are common, accounting for more than 500 000 visits to the United States emergency rooms a year. Cycling can be inexpensive and can easily involve the whole family. Most metropolitan centres have designated bike tracks to allow for safe riding. Competitive cycling is also very accessible in most communities.

[www.cycling.org.au](http://www.cycling.org.au)

## Common injuries

- Most injuries from cycling are caused by a fall.
- Fractures and abrasions/lacerations are common during a fall. It is also important to be aware of head injuries as these may lead to serious complications in the person with a bleeding disorder.
- The remainder of the injuries are a result of overuse, including the neck, back, and lower limb joints.
- 'Saddle-sores' are also common in cyclists.



89 | Rays will be boys | 30

# Cycling



## Injury prevention

### Warm-up

- A good general warm-up activity for cyclist may be to ride at a low intensity on a flat course, or to jog on the spot.
- Stretches 1 4 6 8 10 12 16 17 18 20 21 22 23

### Protective equipment

#### Mandatory

Helmet.

#### Strongly recommended

Padded shorts with mountain biking.

#### Optional

- Protective eyewear
- Padded bicycle shorts
- Extra clothing
- Cycling footwear.

#### Additional protective considerations

- Learn to ride in a safe environment.
- Be very aware of road rules and begin riding on the road under strict supervision until very competent.
- Avoid falls by anticipating errors.
- Ride at a controlled speed.
- Maintain bicycle in top mechanical condition.
- Consider not riding around busy streets and keep the sport to areas where there is little traffic or potential obstacles. Use bike tracks whenever possible.



89 | Rays will be boys

# Which sport is appropriate?

- ◆ What do you or your son have an interest in?
- ◆ You have to consider the risk of injury/bleed
- ◆ There are many factors that may influence how a person with Haemophilia copes with physical activity.
- ◆ Intrinsic: These are factors that are related to your body
- ◆ Extrinsic: These are factors related to the inherent nature of the sport or environment in which the sport or activity is being played.



# Summary

- ◆ Encourage independence in all aspects of haemophilia care
  - ◆ Improved psychosocial care
  - ◆ Self-infusion
  - ◆ Acute and chronic musculoskeletal care
  - ◆ Normalising early play
  - ◆ Sport and leisure choice