

PLAYING FOR A SUCCESSFUL HTC VISIT

Teaching and supporting children with haemophilia

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Tom is 5 years old and has mild haemophilia A. He has had a minimal number of injuries in the past that have required the intervention of factor. He is normally very happy to come in to his Haemophilia Treatment Centre (HTC) to see staff and looks curiously at staff if he does require treatment.

Tom was wrestling with his brother 3 days ago and has a swollen shin on his left leg. He presented to the hospital over the weekend and has had two doses of factor, each on consecutive days. On arrival to the HTC for review and a likely third dose of factor he is clingy to his caregiver and panicky about the possibility of more factor...

A child with haemophilia passes through many stages of childhood, as does any child. Generally, a child's ability to understand their disorder will relate directly to the stage of childhood they are currently experiencing. Babies to adolescents all have different needs and requirements both for learning about their haemophilia and how to manage their treatment.

Child Life therapy or **play therapy** is therapy offered by specialist professionals across many children's hospitals across Australia. Child Life Specialists work with other health care staff to adequately prepare children and families in hospitals and other settings to cope with hospitalisation, procedures and understanding their condition. The Child Life Specialist has an extensive knowledge about the differing stages of child development and how each stage can affect treatment. At John Hunter Children's Hospital the Haematology Child Life Therapist has been working with the Haematology Clinical Nurse Specialist to develop specific activities to support children with haemophilia.

One way of supporting a child with haemophilia we have been exploring is the utilisation of a **busy bag**. This play or activity bag is one that comes with the child to the HTC or hospital and is used at home for infusions. This bag of activities has specific play items in it only to be used for hospital or treatment days. Devices can have specific apps that are only used on these days. The bags described below are designed specifically for each developmental stage that children to adolescent's experience.



BABIES (UP TO ONE YEAR)

Babies need comfort and support during their infusions and examinations. This may mean a **position of comfort** for the baby, where the parent holds the baby in a specific position to allow a hugging hold. This hold gives comfort and security while giving health care staff safe access to the child for infusions and examination of limbs. The upright position promotes a sense of control for the child. The utilisation of calming music and distractions such as bubbles can also be useful. The introduction of picture books about factor and infusions can be beneficial at this time.

Busy Bag Contents

Pacifier (dummy, cuddly etc)

Bubbles

Special toys that are only used for HTC trips and infusions

Calming music



TODDLERS (1 TO 3 YEARS OLD)

Toddlers of this age understand their world through touching, seeing and hearing. We know that toddlers do not understand cause and effect, so they are often very surprised that an adventure has ended up in their HTC.

Comfort for the toddler remains paramount at this time, so a position of comfort is very important, as is the nomination of *one voice* – nominating one person only to speak to the child. To enhance the child's sense of security, a parent who has been educated on what will happen prior to the intervention is ideal to talk during the procedure. This allows the child to feel secure and validated and gives positive reinforcement. The involvement of parents/caregivers is vital. Using numbing cream pre-infusion and distraction can be beneficial at this time.

As soon as the child is able, they should be involved in the procedure - holding band-aids® and helping staff set up (if appropriate). The use of medical kits to play with at home are encouraged as are the continued reading of board books about haemophilia.

Toddlers will also benefit (if able) from a trip to the HTC when nothing happens. The opportunity to come to a centre and have no infusions and play is very comforting to the toddler and may allay fear that the HTC is a place where you always get held and are given infusions.

Busy Bag Contents

- Cuddly toy (if wanted)
- Special busy toy
- Bubbles
- Specific App on IPAD/ phone that is only used for HTC trips/ infusions
- Calming music
- Making a small photo book of the child's trips to hospital can also be beneficial

PRESCHOOL (3 TO 7 YEARS)

Children of this age group have what is called 'magical thinking'. This can be explained as the six-year-old who only draws from his own experiences to explain the world around him. When asked what is haemophilia, he may reply 'when I get hurt and need a needle'. Pre-schoolers are very egocentric - meaning that they understand that these things are happening to them but do not have the capacity to know that what happens to a doll might happen to them. Preparation toys at home and practicing factor administration are very successful for this age group.

Positions of comfort are still very important during this age group as is the involvement of the children in setting up for their procedure and asking them to hold band-aids etc. Numbing cream (if used) remains important as do distraction techniques.

Education involves the reading of books, making a social story about going to hospital and the use of colouring in pages. A medical kit at home and time spent acting out infusion scenarios can be beneficial, with play being directed and initiated by the child. Trips to the HTC that do not require treatment are also beneficial at this age.

Busy Bag Contents

- Cuddly toy
- Art and/ or craft activity
- Playdough
- Special app on device
- Using a photo book to document experiences

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SCHOOL-AGED (7 TO 11 YEARS)

This age group is entering into the realm of logical thinking - meaning that they can start to think in a step-by-step process. This enables them to start to think about self-infusion. They are less egocentric in the way that they view the world - this is when demonstrating on a doll or arm makes sense to the child. School-aged children are able to read more and understand relevant teaching steps.

This age group is perfect for books and simplified teaching about their haemophilia. Encourage participation in the transfusion process - working towards self-infusion. Involve the child in decision-making regarding sports and activities that may be offered and ask for their input early about activities offered. This can mitigate the way that children approach sporting activities and perhaps making the wrong decisions about what lunchtime sport they should join in for.

Busy Bag Contents

- Special cuddly toy
- Craft/ building activities
- IPAD/device
- Music devices
- Knowledge of deep breathing and visualisations.

ADOLESCENT (11 YEARS AND OVER)

Adolescence is an area of great growth and with this brings opportunities for learning, experiences and experimentation. Adolescents continue to be able to think logically (step-by-step) and to understand that there are consequences for their actions.

Talk openly and honestly with the adolescent about both their treatment and their plans for the future. This is the age where most adolescents are self-infusing and starting to take control of their own haemophilia.

Busy Bag Contents

- Personal devices
- Knowledge of deep breathing/visualisations
- Specific games activity - cards etc.

If we look back to the example of 'Tom 'given in the first paragraph, we can see a child who is worried and nervous about the possibility of factor. Luckily, he didn't need any more factor that day and the experience was turned into a positive one with a trip to the Starlight room and spending time playing with nursing staff before leaving the Unit. This positive experience was very beneficial to Tom

The utilisation of play in the ongoing care of children and adolescents with haemophilia is important to promote trusting relationships with healthcare providers.

If you have any questions, please see your local HTC for further information.

FURTHER READING

Association of Child Life Therapists Australia - Childlife.org.au

Child Development:

The Center for Parenting Education – centerforparentingeducation.org Child Development Institute - childdevelopmentinfo.com