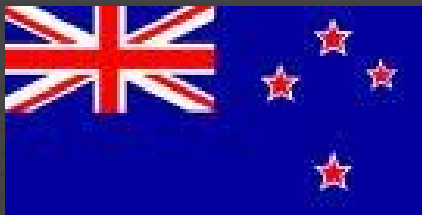


The Impact of the Diagnosis of a Bleeding Disorder on the Family



Colleen McKay, HFNZ

Overview:

- Planning trip to Italy
- Arriving in Holland
- How it feels to arrive in Holland
- How to deal with life in Holland



Impact on the Family

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- Emily Perl Kingsley



Impact o the Family

Welcome to Holland?



Impact on the Family

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- **Grief Process is triggered by:**
 - Death & bereavement
 - Significant loss or trauma
 - Loss of a job
 - Break-up of relationship
 - Illness, injury or disability
- Emotional responses vary - one person to another
- It is normal to experience a grief response to the diagnosis of a chronic illness such as a bleeding disorder



Impact on the Family

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- **Common emotions or stages that may be experienced:**
 - Shock
 - Denial
 - Anger
 - Depression
 - Guilt
 - Adjustment
- Process is not rigid, or linear
- Some stages might be revisited many times
- Some stages might not be experienced at all



Impact on the Family

- **Shock:**

- 'Emotional numbness'
- May show no reaction, no outward changes in behaviour
- Form of protection
- Parent still able to function at a basic level



Impact on the Family

- **Denial:**

- Period of disbelief
- The diagnosis must be a mistake
- Powerful, defense mechanism
- Gives parents temporary control over their life
- Creates an invisible barrier around parent
- Pushes the problem outside the barrier
- Parent has time to deal with the diagnosis in their own time



Impact on the Family

□ Anger:

- Born of feelings of frustration that the parent cannot control the course of events
 - Realisation that the bleeding disorder is here to stay
 - Can be directed at self, spouse or partner,
 - Can be directed at Clinicians or staff at the Haemophilia Treatment Centre
 - Can be directed at others who are not living in Holland
- Important to note that experiencing anger can result in the parent behaving in ways that are uncharacteristic, and that he / she may later regret.



Impact on the Family

- **Depression:**

- Often characterised by periods of feeling sadness, crying and despair
 - 'Why me?'
 - 'Why my child?'
 - Is a sign that the parent is learning to accept the diagnosis
-
- Should the depression become severe, or persist for a long period of time, it is important to seek medical or professional help.



Impact on the Family

- **Guilt:**

- Genetic nature of the disorder
- Mothers often blame themselves for passing on the gene
- Fathers often feel guilt because they are not able to fix everything and protect their child / family
- Can make some parents want to compensate their child for his / her bleeding disorder

- Guilt is a normal reaction for parents



Impact on the Family

- **Adjustment:**

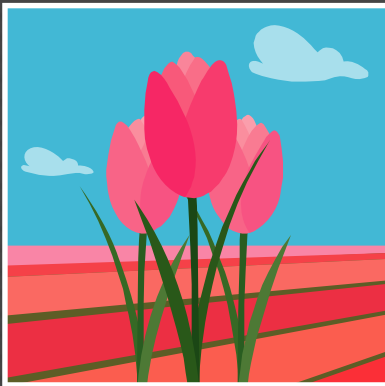
- Characterised by acceptance of the reality of the diagnosis
- Acceptance of the loss being dealt with
- Some feeling of control over life returns
- Times of sadness, fear and worry may still occur on occasion

- Men and women often have different reactions to handling stress and trauma.



Strategies

- How do families cope with the change and learn to embrace their life in Holland?



One Step at a Time.....



Strategies

- **Critical coping strategies must be in place and new skills must be learned in order:**
 - For effective parenting to take place,
 - To foster the medical, physical, emotional and social growth of all members of the family,
 - To be an effective advocate for the child with the bleeding disorder and for the family as a whole,
 - To ensure adherence to the recommended treatment regimen



Strategies

- **Get Educated:**

- Become informed
- Learn the new language in Holland
- Parents become more active and involved in care of the child
- Parents are better advocates for their child

- **Where to get the knowledge?**

- Clinicians
- Other health professionals
- Ask questions
- Books
- Haemophilia Foundation Newsletters
- Internet



Strategies

■ Get Connected:

- Invaluable source of support
- Can reduce levels of anxiety
- Can reduce feelings of isolation
- Everyone's journey is different
- Can be overwhelming when attending the first Support Group Meeting or Camp



Strategies

- **Develop a Support System:**

- Every support system will be different
- Parents must look after themselves
- Parents should be honest with their feelings
- No-one can be super-parent 24 hours a day
- Embrace respite



Strategies

- **Get organised:**

- Develop a strong partnership with health professionals
- Follow agreed course of action
- Keep records

- **Communication:**

- Exchange of information
- Seek clarification if necessary
- Stay balanced and open



Strategies

- **Develop a plan for emergency situations:**
 - Enlist assistance from Support System
 - Follow instructions of the Haemophilia Centre
 - Carry a letter from your Haemophilia Centre
 - Participate in the treatment / infusion
 - Be prepared – take nappies, formula, snacks, favourite toys
 - Stay calm



Living in Holland

