




## *Empowering Parents - PEP in Australia*



Anne Jackson  
Clinical Practice Consultant –Haemophilia  
Women's & Children's Hospital, Adelaide

16<sup>th</sup> Australian & New Zealand Haemophilia Conference  
Session: Caring for Parents & Carers  
22<sup>nd</sup> October 2011



## Overview

- > Challenges of Parenting a Child with Haemophilia
- > Parents Empowering Parents Program
- > PEP in South Australia
- > Importance of "World View"
- > Benefits & Impact of PEP program
  - Parent
  - Parent Facilitators
  - Research





## Parent Facilitators - Parenting a child with haemophilia

- > Challenging
- > Impact on whole family
- > Unpredictability – disruption to our lives that it brings about – school, work, holidays, leisure time
- > Extra planning for trips.
- > Balancing independence and freedom and managing our anxiety about this”
- > Sport – “We want them to have a go and try things without holding them back but not to the point of allowing them to put themselves in a dangerous situation”

Women's & Children's Hospital



## Parent Facilitators - Parenting a child with haemophilia

“Guilt is a big thing but I don't think that is unique to us I think that it's a default mode for all parents! I feel guilty for having passed this onto my sons although I understand it as not a choice to do so. This feeling arises especially when they are having a difficult time due to an injury or they are in pain”

Women's & Children's Hospital



## Parent Facilitators - Parenting a child with haemophilia

“I think that we have to come to terms with their condition and deal with the fact that they are sometimes angry and frustrated and this can be a challenge especially if we also feel angry and frustrated.”

“In my negative moments I worry about their future, how will it impact on them, their career, opportunities , relationships, will the high level of care always be available to them?”


Women's & Children's Hospital



## Parent Facilitators - Parenting a child with haemophilia

“ On a more positive note, I think that some of the experiences that we have had have made me try to make the most of opportunities and not to take things or people for granted. Overall I think that it is much the same as parenting a child without haemophilia with an added extra, Really we are lucky to have such great, caring and healthy boys”



Women's & Children's Hospital



## Parents Empowering Parents



> Offers tools to:


- Build relationships that are supportive and encouraging
- Establish goals for their child and how they parent
- Identify their thoughts & feelings about their child's diagnosis & their own experiences of parenting
- Skills to effective parenting leading to confident successful happy children.

## PEP Course sessions:



1. The Basics of Bleeding Disorders
2. Child Development
  - identifies the different stages that children go through in growing up
  - Parental changes required to adapt to their child's changing attitudes and behaviours
3. Compassionate Discipline
  - How to discipline according to their different developmental ages
  - Behaviour management principles
  - Begin to map out goals for their children







## PEP Course sessions


4. Fine-Tuning Behaviour Management
  - Additional skills for avoiding problems, limit setting and offering choices
5. Understanding your World View
  - Key pivotal session
  - Gives parents information and skills to understand and deal with a plethora of issues that may cause stress anger and feelings that could result in unhealthy and negative parenting
6. How thoughts and Feelings Affect Parenting
  - Encourages insightfulness in how the influences of their world view can exert on thoughts, feelings and behaviours





## PEP Course sessions:

7. Building Self-Esteem
  - Identifies the factors contributing to self esteem and to teach skills to enhance a child's self esteem
  - Importance of respectful discipline and effective communication
8. Understanding the Process of Communication
  - Concepts for developing effective communication



## PEP Course sessions:

- 9. Refining Communication Skills and Conflict Resolution
  - Emphasises the destructive consequences of negative communication skills
  - Teaches the skills for conflict resolution
- 10. Parenting Styles
  - Gives insight into their parenting styles
  - Opportunity to develop a parenting plan



## SA PEP Team




Raelene




Caroline




Sharon



Peter






Anne  
Women's & Children's Hospital




## PEP in South Australia

- > Funded by
  - Novo Nordisk,
  - Pfizer
  - Haemophilia Foundation SA
  - Haemophilia Foundation Australia
- > Offered as a 3 day program
- > 11 parents attended
  - 6 mothers & 5 Fathers
  - 4 couples
- > Age range of children with haemophilia
  - 7 months to 6 years.



## World View

- > Critical element of the program
- > Unique to individuals
- > Key to understanding our past experiences and the impact
- > Emotional reflection



Women's & Children's Hospital

## World View – Guiding Questions

- > Introducing yourself & any history of bleeding disorder
- > Cultural & spiritual beliefs
- > Socialisation
- > Life experiences
- > Financial experiences



## Parent Facilitators View

- “World view is the most important and the sessions that follow I used the most”
- “Helps us within the group to have more insight and empathy towards each other.”
- “Helped me re-think some of the views I held about how my parents dealt with my brother and his haemophilia issues. I think it was a good opportunity to re-evaluate my beliefs and memories from my past.”

Women's & Children's Hospital

## Benefits of doing PEP

“ I found the course to be very useful and helpful. Gave me a chance to reflect about myself and my parenting techniques. It was a comfort to know there are others in the 'same boat'.”

“The course has encouraged me to reflect on my parenting skills and has contributed to broadening my perspective in relation to how I can utilise the techniques that were highlighted”



“All parents would benefit from this course, not just parents of children with bleeding disorders. I feel grateful to have been allowed access to this information/course”

“This weekend has been a real eye opener and highlighted how much we need to learn, or should I say 'we don't' know'! Listening to the other parents really enforced our belief in 'they're boys first, haemophilia is second' and treat them as such”

Women's & Children's Hospital

## Evaluation

- > Questionnaire completed by 8 of the 11 participants
- > All agreed or strongly agreed:
  - Material covered in the course has relevance to my parenting
  - The course offered me an opportunity to develop or enhance skills that I will now use at home
  - Met its stated goals and the material was useful



## Evaluation

- > This program provided me with new insights about parenting a child with a bleeding disorder
  - 7/8 parents agreed or strongly agreed
- > Make changes in how I parent
  - 6 parents identified extremely likely or very likely and 2 somewhat likely
- > How would they rate the program
  - 5 rated the PEP program very valuable and 3 rated the program somewhat valuable
- > I would recommend this course to other parents
  - All parents agreed or strongly agreed:

Women's & Children's Hospital

## Parent Quotes

- > Useful tips, provided a chance to self evaluate and reflect
- > I will be surprised in the future how much I have taken on board and will put in place and use or change within myself
- > The reassurance of other parent's situations as well as covering all scenarios relating to parenting your child gives the time to answer all those questions that you never get time for with the doctor



## Improvements

- > From my perspective, being new to parenting and having a child with haemophilia.....a bit more focus on 'being a parent of a child with haemophilia' and how to provide the best environment with them and situations that may be faced.
- > More haemophilia related information/experience information in place of general parenting info

## Facilitators perspective

- > “Meeting other parents of children with haemophilia, sharing experiences and forming friendships”
- > “ I found the experience inspiring, the questions I was asked are the same concerns I had only a few years earlier.”



Women's & Children's Hospital


## Facilitators perspective

“Overall I really enjoyed it. The chapters I had to present were interesting.....”

....While planning for the presentation, it was interesting for me to try and think about my family's experiences and how it could be useful to share with the group.”



Women's & Children's Hospital




## Facilitators perspective

“ I think that going on a course like PEP gives me time out from the everyday routines to think about how things are going and what would I like to change or do more with my family”

“I love hearing Raelene speaking in such a positive and sensible way about dealing with a child with severe haemophilia, it helps keep my anxieties in perspective. Hearing other parents talking about their children getting on with life, sports, fun. The chance to keep in touch and help each other out”


Women's & Children's Hospital



## Facilitators perspective

“The blue print was a good exercise to do even with my children being a bit older as it made me think about how my hopes and dreams may or may not match up to their developing interests and skills. It was good to hear how to get my sons to take more control of their bleeding disorder and this is something we are trying to put into practice”

Women's & Children's Hospital



## PEP Article Findings

**Haemophilia**

Haemophilia (2011), 17, e895-e900 DOI: 10.1111/j.1365-2516.2011.02512.x

ORIGINAL ARTICLE *Clinical haemophilia*


### Parents Empowering Parents (PEP) Program: understanding its impact on the bleeding disorders community

S. DUTREIL,\* J. RICE,† D. MERRITT‡ and E. J. KUEBLER§

\*Louisiana Center for Bleeding and Clotting Disorders, Tulane University School of Medicine, New Orleans, LA, USA; †Department of Biostatistics Tulane University School of Public Health, New Orleans, LA, USA; ‡Hemostasis Thrombosis Treatment Center Children's Hospital of Michigan, MI, USA; and §Gulf States Hemophilia and Thrombophilia Center University of Texas - Houston, TX, USA

---

Women's & Children's Hospital



## Findings

- > Parents who attended PEP had a perceptual awareness of positive changes in their relationships and parenting styles
- > Need for PEP to be more available to more parents of children with bleeding disorders

Women's & Children's Hospital

## Findings

- > Parents who feel supported and safe in a parenting group can feel comfortable enough to admit and explore their use of less effective parenting practices and this encourages them to be more receptive to positive approaches
- > Parents who attended PEP received the core messages of PEP which may have resulted in less use of the less effective and negative techniques.

Women's & Children's Hospital

## PEP - Article Conclusion

- *“ We believe these are notable findings in establishing the efficacy of the PEP program in accomplishing the goal of giving parents support in handling the stressors of raising a child with a bleeding disorder and confirming the importance of making PEP more available to more parents of children with bleeding disorders.”*

S Dutreil et al Haemophilia (2011)



## Conclusion

- > Parenting programs in particular PEP provide support and are beneficial to the individuals attending and to the relationships they are developing with their child and how families manage
- > Advocate for programs to be implemented at your centre to support parents with the challenges of raising a child with a bleeding disorder

Women's & Children's Hospital

## Acknowledgements

- > Parent Facilitators – Raelene Kennewell & Caroline Sheppard
- > HFSA
- > Novo Nordisk
- > Pfizer
- > HFA – Sharon Caris & Natasha Coco
- > Sharon Hawkins
- > SA Haemophilia Treatment Team – Amanda Hoppenbrouwers & Peter van der Linden
- > Parents who participated in PEP SA



Women's & Children's Hospital