



# **CARRIERS**

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# Carrier Testing

**Carriers and Non-Carriers**

**Making informed decisions**

**Family History**



# **Women and Teenage Girls who are Carriers**

**Carrier diagnosis**

**Recognised medical condition**

**Support services and information**

# Genetic Counselling



**The process of helping women affected by a genetic disorder to understand the condition, how it is passed through the generations, and other issues which may impact on family planning.**

# Diagnosis as a Teenage Girl



- Wide range of emotional reactions
- May be afraid
- Sense of loss, feeling different
- Denial and refusal to accept
- Anger at own body and parents
- Parents and listening
- Acceptance of own carrier status by mother
- Sense of relief
- Learning how to manage symptoms

# Diagnosis as an Adult



- **Adult diagnosis on birth of baby with haemophilia**
- **Reactions vary from shock to anger**
- **Time to adapt to diagnosis of self and baby**

# Siblings and extended Family



- **No family history-sisters are possible carriers**
- **Families deal with issues differently**
- **Cultural differences**
- **Effect of carrier testing on extended family**
- **Informing possible carriers**



# **Normal Emotional Reactions**

**Shock plus fear of impact on immediate relationships and within extended family**

**Anger at carrier status**

**Denial and refusal to accept**

**Loss at feeling different**





# Coping with Emotions

**Acknowledge all emotions**

**Importance of Communication:**

- **Young girls may need help to overcome embarrassment**
- **Older women with heavy periods need to discuss their symptoms with their doctor**



# Carriers

**Symptomatic carrier:**

**Low factor levels and increased bleeding tendency**

**Non-symptomatic carrier:**

**Normal factor levels without  
increased bleeding tendency**

**Factor level check done at young age**

**Carrier testing done at 16 years of age**

# Symptomatic Carriers



- Carriers can bleed more than other women particularly after medical interventions
- Women who grew up in families with haemophilia may see their bleeding symptoms differently from women in general
- In families where blood loss is the '*normal*', abnormal bleeding may be overlooked
- Clotting factor levels may vary in different circumstances like pregnancy and stress :  
F8 increases in pregnancy, F9 does not.

# Symptomatic Carriers



- All possible and obligate carriers need their factor levels checked before any medical interventions, and at a young age
- Surgeons and carriers need to know the clotting factor level prior to any surgery
- Factor levels in carriers are independent of family severity
- Important to measure factor levels during carrier testing

# Symptomatic Carriers



- Day-to-day basis most carriers will have no symptoms
- Know your factor level and if FVIII or FIX
- Low level carriers and bleeding after trauma
- Always carry a medical ID card with treatment details and contact for Treatment Centre
- Inform Treatment Centre yourself of any planned surgery or dental work
- Pregnant carrier and birth plan
- Regular follow-up at Treatment Centre



# Tips for Teenage Girls

**Coping with Bruises – do not hide away**

**Loss of Virginity – consider carefully**

**Disclosure – individual and important**

**Tattoos & Piercings – not recommended**

# Living Positively with Bleeding Disorders



**Empowerment important through education and information**

**Acceptance of support**

**Stay physically and mentally active**

**Maintain social contact with family and friends**

**Being more than a diagnosis**



# References

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**Thank you**  
**Any comments or questions?**