

47. DISORDERS OF BLOOD CLOTTING IN CHILDREN

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47.2 Introduction

47.2.1 Haemophilia A is the most common disorder of blood clotting for which DLA may be sought. Others are **Haemophilia B (Christmas disease)** and **von Willebrand's disease**. Their effects are similar. Due to deficiencies of certain blood factors which are important for the normal clotting of blood, there may be a requirement for these to be replaced by injection

47.3 Care Needs

47.3.1 The presence of a bleeding disorder does not of itself mean that a child has care or mobility needs. At least half of those affected by haemophilia are able to live a normal life; they require special attention only at particular times as, for example, when they require tooth extraction or surgical operation. However, more severely affected children often require a great deal of attention and supervision.

47.3.2 In cases in which the factor deficiency has been assessed as severe (ie. less than 5% Factor VIII) and there is a history of repeated spontaneous or accidental bleeds, there is need for continual supervision to avoid situations likely to provoke further bleeds and to take action when bleeding does occur; the need is likely to continue to about the age of 12 years. By this age the child should be sufficiently aware of the limitations imposed by his condition to be relied upon to avoid dangerous situations and to summon help if required. In cases in which the factor deficiency has been assessed as moderate or mild and bleeding has been occasional, for example once or twice a year following injury, it is unlikely that the child will have care or mobility needs substantially greater than those of a healthy child.

47.3.3 Exposure to injury is greatly reduced at night. In the event of a spontaneous bleed starting at night, the child can call for assistance.

47.3.4 Modern treatment is usually successful in avoiding permanent damage to joints. However, where this has occurred, there may well be a significant need for attention and problems with mobility.

47.4 Mobility Considerations

47.4.1 For children with severe haemophilia (less than 5% Factor VIII) there is a significant danger of spontaneous and serious bleeding into joints when they walk.

47.5 Children Who Are HIV Positive

47.5.1 Some children with severe haemophilia have become Human Immunodeficiency Virus positive (HIV+) as a result of being given contaminated blood products. As they grow up and become aware of their condition, resentment builds up to the extent that they may refuse to give their own injections for a period or to take necessary care to avoid injury. In these circumstances they may require supervision to a later age. Some have now developed symptomatic HIV Infection or AIDS and may have care and mobility needs because of this. [See Chapter 32].

47.6 Further Evidence

47.6.1 Affected children are under the care of a special centre. A diagnosis specific factual report from such a centre may well help to establish the level of need.