

## Psychosocial Care for People with Hemophilia

Individuals with hemophilia commonly face a number of psychosocial challenges and providing psychosocial support is an important part of their comprehensive care. The ultimate goal is to empower the affected individuals to manage the challenges autonomously. Quality of life depends largely on the ability to adjust to having a chronic medical disorder.

Psychosocial functioning and well-being of children develops with age and cognitive development. Advice and support needs to be tailored to the developmental level of the child. Different issues and stressors arise at different stages.

A key issue that arises early on is coping with the diagnosis. Help parents to accept the diagnosis and understand that hemophilia is just one aspect of an individual's life. Encourage them to educate themselves about the disorder. Familiarize them with the services available, and make sure that they know first-aid measures for treating a bleed. Help the family adapt to the fact that hemophilia is a life-long chronic condition.

Counsel parents to set a healthy pattern of response that will calm the child's fears. Overreaction to a bleed or blaming can cause the child to feel guilty and develop poor self esteem.

Guide the development of the child's confidence in basic activities such as crawling, walking, running and playing; It is important to balance vigilance and overprotectiveness.

Encourage parents to create opportunities for family and social interactions, which are important for building the child's self-confidence and sense of belonging.

As the child grows older, encourage him to take an active role in the management of his bleeding disorder. Encourage the child to take responsibility for his health and avoid dangerous situations and risks.

Help the child deal with his feelings about physical changes and health issues.

Identify degree of liberties and limitations, taking into consideration level of maturity and psychological readiness.

Encourage gradual autonomy, self-management in treatment and care, and independence.

Guide the adolescent towards academic and vocational pursuits that do not involve significant physical risk. Help him through common adolescent challenges such as self-esteem issues and relationships.

Guide him as the adolescent makes the transition into adulthood and the workplace.

Provide couples with information on the genetics of hemophilia and help them make informed decisions.

Encourage the individuals to participate in social or support groups for people with hemophilia