

Benefits of Comprehensive Care for the Treatment of Bleeding Disorders

Hemophilia is a complex and rare bleeding disorder. The World Health Organization (WHO) and the World Federation of Hemophilia (WFH) recommend that optimum treatment for people with bleeding disorders is provided by a multidisciplinary team of healthcare providers in a specialized hemophilia treatment centre (HTC).

The core comprehensive care team includes a lead clinician, usually a hematologist, nurse coordinator, physical therapist (and sometimes orthopedist), social worker/psychologist, and laboratory scientist with access to a coagulation laboratory. Other specialists who may be consulted include dentists, genetic counsellors, physiatrists, rheumatologists, hepatologists, infectious disease specialists, and immunologists.

Functions of a comprehensive care program

The comprehensive care team provides or coordinates care and services to people with bleeding disorders and their families. These include:

- Carrying out all tests necessary for the definitive diagnosis of hemophilia and other inherited bleeding disorders.
- Educating patients and parents regarding safety precautions for prevention of bleeds and early identification of bleeds.
- Managing bleeding episodes with appropriate treatment products and first aid.
- Promoting regular exercise to maintain good muscle and joint health and providing rehabilitative services for restoring function following bleeds.
- Developing and reviewing a management plan for each patient.
- Monitoring and managing complications of hemophilia and its treatment such as arthropathies, inhibitors, and transfusion transmitted infections.
- Providing genetic counselling and genetic diagnostic services for patients and family members.
- Educating, advising, and counselling patients, family members (parents, spouse, children, and others), healthcare workers, educators, and employers to ensure that the patient's needs are met.
- Conducting research to further knowledge and improve the management of bleeding disorders. This is often best conducted in collaboration with national and international hemophilia research centres.

Benefits of comprehensive care

- Studies show that mortality and hospitalization rates of people with hemophilia decrease when they are treated at a hemophilia treatment centre.¹
- A multidisciplinary comprehensive care team develops and maintains the necessary experience to provide appropriate treatment for these rare bleeding disorders.
- Prompt treatment leads to more effective use of replacement therapy, which can actually decrease the cost of treating specific bleeding episodes.
- Resources, such as hospitals, diagnostic laboratories, and emergency services, are used more appropriately.
- Implementing preventive care and exercise programs in a timely fashion helps strengthen joints and muscles, which can prevent bleeding and reduce the consequences of recurrent bleeding episodes.
- Taking into account special considerations for treating complications such as HIV and hepatitis C in people with hemophilia improves their overall quality of life.
- Carrier detection and genetic counselling can identify the possibility of having a child with a bleeding disorder.
- Proper education improves the recognition and prevention of bleeds and recovery time.

Comprehensive care is central to treating the physical, emotional, psychological, social, and educational needs of patients with bleeding disorders and their families.

¹ Soucie JM, et al. Mortality among males with hemophilia: relations with source of medical care. *Blood* 2000; 96:437-442.