



Checklists for Disabilities in woman and girls with blood disorders

For Educators

Title: Supporting Students with Bleeding Disorders: Practical Tools for the Classroom

Focus: Accessibility, inclusion, and safety within the school setting.

Checklist Highlights:

- 504 Plan in place with flexibility for attendance and mobility needs
- Modified PE curriculum and alternate activities
- Permission for use of elevator and additional transition time
- Private access to nurse for medication or symptom management
- Rolling backpack or book drop accommodations
- Awareness of signs of joint pain or fatigue
- Encouragement of participation in safe, inclusive activities

Visual Cue Panel:

Extra time for transitions | Elevator access | Modified PE | Teacher awareness sessions

For Parents and Caregivers

Title: Making Daily Life Easier for Your Daughter with a Bleeding Disorder

Focus: Home modifications, medical advocacy, emotional resilience.

Checklist Highlights:

- Adaptive bathroom tools (non-slip mats, stools, shower chairs)
- Orthotic or mobility device fitting and follow-up
- Lightened household chores with built-in rest breaks
- Organized medical folder for symptom tracking and appointments
- Encourage open discussion about pain and limitations
- Connect with local or online bleeding disorder support groups
- Advocate for school accommodations

Visual Cue Panel:

Orthotic support | Rolling baskets | Rest and stretching | Peer and family support

For Healthcare Providers

Title: Holistic Care Planning for Pediatric Patients with Bleeding Disorders

Focus: Cross-disciplinary coordination, device prescription, psychosocial outcomes.

Checklist Highlights:

- Assess for chronic joint instability or pain
- Refer to pediatric PT/OT for bracing, gait training, or wheelchair evaluation
- Track hemarthrosis history with attention to long-term function
- Screen for anxiety, fatigue, depression
- Collaborate with school teams for IEP/504 plans
- Educate families on safety tools and activity pacing
- Connect patients with advocacy and transition programs (e.g., Steps for Living)

Visual Cue Panel:

Multidisciplinary care | Bracing referral | Psychosocial screening | School-medical liaison

For Patients (Kids and Teens)

Title: You Are Strong: Tips to Feel Better and Do the Things You Love

Focus: Empowerment, self-knowledge, fun visuals, kid-friendly language.

Checklist Highlights:

- Use your brace or device to keep your joints safe
- Take breaks if you're feeling tired
- Tell someone if you're hurting or need help
- Try cool tools like rolling backpacks or grabbers
- It's okay to rest—and it's okay to play too
- You are not alone—meet others like you online or in person

Visual Cue Panel:

Knee brace = power gear | Break time = recovery mode | Friends with similar stories = strength team

Sample Case: Aisha, Age 10 – Knee Instability from von Willebrand Disease

Background:

Aisha is a bright and active 10-year-old girl diagnosed at age 7 with Type 2 von Willebrand disease. Since age 8, she's experienced recurrent spontaneous bleeds in her right knee, especially after physical activity like recess or dance class.

Medical and Functional Impact:

Symptoms:

- Swelling and pain during and after bleeds
- Difficulty bearing weight on the affected leg
- Frequent limping and favoring of one side

School Functioning:

- Missed 15 days in one semester due to flare-ups
- Avoids group physical education due to fear of injury
- Emotional Impact:
- Reports feeling "embarrassed" wearing braces
- Worries about falling in public, leading to social withdrawal

Clinical Assessment:

- Orthopedic and rehab evaluation confirms ligament laxity and mild joint degeneration in the right knee.
- Pediatric physical therapist notes quadriceps weakness, reduced range of motion, and muscle imbalance.

Interventions and Assistive Devices:

Custom Pediatric Knee Orthosis:

- Hinged brace with lateral supports and adjustable straps
- Designed to stabilize the knee and reduce risk of reinjury during walking or standing
- Fitted and adjusted by a pediatric orthotist

Physical Therapy Program:

- Focus on strengthening, proprioception, and gait training
- Includes aquatic therapy to reduce stress on joints

School-Based Accommodations:

- 504 Plan implemented
- Modified gym activities and use of rolling backpack and elevator
- Rest periods during field trips or transitions

Psycho-social Support:

- Referred to child psychologist to address anxiety and body image
- Peer mentoring group through the local Hemophilia Treatment Center

Outcome:

After 6 months, Aisha has improved strength and confidence using her brace. She hasn't had a joint bleed in over 4 months, and she's rejoined her school's adaptive dance group with modifications.