Therapeutic Management of Pediatric Hypermobility Spectrum Disorder

Objective

The purpose of this guideline is to provide a comprehensive, evidence-based resource for clinicians and therapists for the therapeutic management of joint hypermobility (JH) and hypermobility spectrum disorder (HSD), including hypermobile Ehlers-Danlos syndrome (hEDS).

Target Population

Inclusion Criteria

Children and adolescents 5 to 21 years of age with joint hypermobility or with a family history of joint hypermobility

Exclusion Criteria

Children and adolescents with greater than mild hypotonia or progressive neuromuscular conditions

Children less than 5 years of age are generally hypermobile

Evidence-Based Care Recommendations

Care recommendations for screening and assessment are made in an accompanying Evidence-Based Care Guideline:

- *Screening and assessment of hypermobility spectrum disorder including hypermobile-type Ehlers-Danlos syndrome*

Multidisciplinary Approach

1. ***It is recommended that a multidisciplinary approach be taken in the overall medical management of patients with HSD or hEDS.***
   Recommendation Strength ***Moderate***
   (Bale et al., 2019 [2a]; Bale et al., 2015 [2b]; Bathen et al., 2013 [4b]; Black et al., 2024 [5a]; Black et al., 2023 [5b]; Castori et al., 2012 [5a]; Celletti et al., 2013 [5a]; Dockrell et al., 2021 [4a]; Engelbert et al., 2017 [5a]; Jones and Carrieri, 2025 [1a]; Mittal et al., 2021 [5a]; Nicholson et al., 2022 Hypermobility [5a]; Nicholson et al., 2022 International [5a]; Simmonds, 2022 [5a]; Van Meulenbroek et al., 2020 [4b]; Yew et al., 2021 [5a])

   Note 1: A multidisciplinary team may include primary care physicians, occupational therapists, physical therapists, and psychologists *(behavioral medicine/clinical psychology–BMCP; counseling services)*.
   (Bale et al., 2019 [2a]; Bale et al., 2015 [2b]; Bathen et al., 2013 [4b]; Black et al., 2024 [5a]; Black et al., 2023 [5b]; Castori et al., 2012 [5a]; Celletti et al., 2013 [5a]; Dockrell et al., 2021 [4a]; Nicholson et al., 2022 Hypermobility [5a]; Nicholson et al., 2022 International [5a]; Mittal et al., 2021 [5a]; Simmonds, 2022 [5a]; Van Meulenbroek et al., 2020 [4b]; Yew et al., 2021 [5a])

   Note 2: If indicated and based on the recommendation of the primary care physician, other disciplines or specialties may be involved in the multidisciplinary approach, such as cardiology, gastroenterology, genetics, immunology/allergy, neurology, orthopedics, pain management, or rheumatology *(Bale et al., 2019 [2a]; Bathen et al., 2013 [4b]; Black et al., 2024 [5a]; Black et al., 2023 [5b]; Castori et al., 2012 [5a]; Van Meulenbroek et al., 2020 [4b]; Yew et al., 2021 [5a])*.

   Note 3: The Community Practice Support Tool provides clinical considerations and red flags to help determine where patients may be referred for diagnosis and subsequent treatment. *(See also Algorithm for image and link to this tool)*
   (Local Consensus, 2025 [5]).

   Note 4: If the patient/family has concerns about referrals or therapeutic management, the patient/family should communicate with the primary care physician for subsequent treatment, referrals, and/or diagnosis
   (Black et al., 2024 [5a]; Local Consensus, 2025 [5]).

2. ***It is recommended that patients with symptomatic HSD or hEDS receive physical and/or occupational therapy interventions.***
   Recommendation Strength ***Moderate***
   (Englebert et al., 2017 [5a]; Garreth Brittain et al., 2024 [1a]; Kemp et al., 2010 [2a]; Minjas et al., 2021 [5a]; Reychler et al., 2021 [1a]; Russek et al., 2019 [5a]; Scheper et al., 2014 [4a]; Yew et al., 2021 [5a])

   Note 1: Physical and/or occupational therapy interventions should be focused specifically on joint hypermobility and its associated comorbidities *(Local Consensus, 2025 [5])*.

   Note 2: For patients with asymptomatic hypermobility, provide education on joint protection and self-management of condition *(Local Consensus, 2025 [5])*.

3. ***It is recommended that patients presenting with chronic pain be referred to psychology or counseling services as a component of the global treatment interventions.***

Recommendation Strength **Moderate**

(Baezo-Velasco et al., 2018 [1b]; Bathen et al., 2013 [4b]; Bulbena-Cabré et al., 2021 [1b]; Bulbena et al., 2017 [1b]; Castori et al., 2016 [5a]; Cederlof et al., 2016 [4a]; Celletti et al., 2021 [3b]; Celletti et al., 2013 [4b]; Clark et al., 2023 [1a]; Feldman et al., 2020 [5a]; Ghibellini et al., 2015 [1b]; Grahame 2009 [5a]; Ishiguro et al., 2021 [5a]; Javadi-Parvaneh et al., 2020 [4a]; Kindgren et al., 2021 [4a]; Pasquini et al., 2014 [4a]; Russek et al., 2019 [5a]; Sanches et al., 2012 [1b]; Sinibaldi et al., 2015 [1b]; Smith, 2017 [1b]; Smith et al., 2013 [1b]; Song et al., 2023 [1a]; Van Meulenbroek et al., 2021 [1b]; Van Meulenbroek et al., 2020 [4b])

Note 1: Pediatric, evidence-based psychology interventions for mood, pain management, and chronic health problems have been found to be effective in treating adolescents and teens with HSD or hEDS *(Ishiguro et al., 2021 [5a]; Van Meulenbroek et al., 2021 [5a])*.

Note 2: HSD or hEDS may be correlated with anxiety as well as with the potential for psychological disorders in adulthood, such as panic disorders or agoraphobia *(Bulbena et al., 2017 [1a]; Cederlof et al., 2016 [4a]; Ghibellini et al., 2015 [1b]; Grahame, 2009 [5a]; Javadi-Parvaneh et al., 2020 [4a]; Pasquini et al., 2014 [3a]; Sanches et al., 2012 [1b]; Scheper et al., 2016 [1a]; Sinibaldi et al., 2015 [1b]; Smith et al., 2013 [1b]; Van Meulenbroek et al., 2021 [5a])*.

Note 3: Kinesiophobia or fear of pain due to movement is a common symptom in HSD or hEDS *(See Appendix 1: Proprioception and Pain Cycle)* *(Bathen et al., 2013 [4b]; Celletti et al. 2013 [4b]; Song et al., 2023 [1a]; Van Meulenbroek et al., 2020 [4b])*.

Note 4: Consider the potential impact of patient's anxiety and family dynamics in treatment approach and overall management *(Baezo-Velasco et al., 2018 [4b]; Bulbena et al., 2017 [1a]; Cederlof et al., 2016 [4a]; Sanches et al., 2012 [1b]; Smith, 2013 [1b]; Tran et al., 2020 [3b])*.

Patient/Family Education

4. ***It is recommended that a therapist focus patient/family education on the following principles:***

Recommendation Strength **Moderate**

(Engelbert and Scheper, 2011 [1b]; Smith, 2017 [1b]; Local Consensus, 2025 [5])

- Joint protection *(Castori et al., 2012 [5a]; Russek et al., 2019 [5a]; Smith, 2017 [1b])*
- Core stability *(Smith, 2017 [1b]; Local Consensus, 2025 [5])*
- Tailored therapeutic approach that addresses full spectrum of HSD or hEDS *(Castori et al., 2012 [5a]; Celletti et al., 2013 [5a]; Smith, 2017 [1b])*
- Differentiation of joint dislocation, subluxation, and instability *(Hakim, 2024 [5a]; Murray, 2006 [5a]; Russek et al., 2023 [5a]; Smith, 2017 [1b])*
- Return to function often occurs prior to resolution of pain *(Friedrichsdorf et al., 2016 [5a])*
- Focus on what patients/families can do to manage symptoms and support daily function, while considering the goals for treatment *(Camerota et al., 2023 [4a]; Russek, 2022 [5a]; Simmonds et al., 2022 [5a])*
- Importance of self-management, which has been shown to improve outcomes in chronic conditions *(Castori et al., 2012 [5a]; Russek et al., 2019 [5a]; Simmonds, 2022 [5a])*.

  Note 1: Level of readiness of the individual to initiate and implement targeted intervention is fundamental to achieving successful outcomes *(Simmonds, 2022 [5a])*.
- Importance of lifestyle modifications to manage a chronic condition *(Russek et al., 2019 [5a])* including application of the following as appropriate:
  - Regular physical activity

    Note 2: Physical activities that facilitate neuromuscular control are beneficial and can be pain free *(Scheper et al., 2013 [1b])*. Partner with the patient/family to identify accessible and meaningful activities. Examples include walking, swimming *(Frydendal et al., 2018 [3b]; Liaghat et al., 2018 [3b])*, Pilates, yoga, dance *(Day et al., 2011 [5a]; Filipa et al., 2018 [5a]; Mayes et al., 2021 [4b]; Simmonds, 2022 [5a])*, some martial arts, and biking *(Local Consensus, 2025 [5])*.

    Note 3: Participation in high-impact physical activities should be considered with caution, due to decreased proprioception and hypermobility *(Castori et al., 2012 [5a]; Hakim, 2024 [5a]; Zabriskie et al., 2022 [1b])*.
  - Activity modification *(See Appendix 2: Exercises and Supportive Interventions)*

    Note 4: Modification and ergonomic training activities include school, jobs, sports, and/or recreational activities *(Castori et al., 2012 [5a]; Friedrichsdorf et al., 2016 [5a]; Russek et al., 2019 [5a])*.

- Activity pacing

  Note 5: The goal is to slowly change the cycle of over-activity and/or under-activity to improve function *(Antcliff et al., 2018 [5a])*.
- Hydration/electrolyte replenishing *(Local Consensus, 2025 [5])*
- Relaxation *(Local Consensus, 2025 [5])*
- Sleep hygiene

  Note 6: Education includes: *(Castori, 2012 [5a]; Hakim et al., 2017 [5a]; Sedky et al., 2019 [1b])*
  - Establish a consistent sleep routine.
  - Avoid caffeine intake after 12 pm.
  - Optimize the sleeping environment.
  - Avoid use of electronic devices prior to bedtime.
  - Ensure proper sleep ergonomics.

Therapeutic Intervention

5. *It is recommended that patient reported outcome measures (PROM) be administered to establish baseline function and establish relevant patient-centered goals.*

Recommendation Strength ***Moderate***

(Clark et al., 2024 [4a]; Kashikar-Zuck et al., 2011 [4a]; Maarj et al., 2021 [1a]; Quinlan et al., 2025 [4a]; Shotwell and Moore, 2022 [4a]; Van Meulenbroek et al., 2020 [4b]; Local Consensus, 2025 [5])

Note 1: Recommended measures include COPM, PODCI, FDI, PROMIS: Pain Interference, Physical Function Upper Extremity and/or Physical Function Mobility *(Clark et al., 2024 [4a]; Kashikar-Zuck et al., 2011 [4a]; Maarj et al., 2021 [1a]; Quinlan et al., 2025 [4a]; Shotwell and Moore, 2023 [4a]; Local Consensus, 2025 [5])*.

Note 2: Administer outcome measures at the initial visit, at the midpoint of therapy, and at the end of each episode of care *(Local Consensus, 2025 [5])*.

Note 3: Re-assessing measures at the midpoint and at the end of the episode of care provides assessment of progress towards goals and function and helps determine if additional referrals are indicated *(Local Consensus, 2025 [5])*.

6. *It is recommended that a home exercise program (HEP) is tailored toward the patient's identified functional goals and is initiated at evaluation.*

Recommendation Strength ***Moderate***

(Birt et al., 2014 [4a]; Ferrell et al., 2004 [4b]; Palmer et al., 2021 [1a]; Spanhove et al., 2023 [2b]; To and Alexander, 2019 [3b]; Local Consensus, 2025 [5])

Note 1: Use PROM *(patient-reported outcome measure)*, such as COPM, to tailor the patient home exercise program *(To and Alexander, 2019 [3b]; Local Consensus, 2025 [5])*.

Note 2: Consistent and independent practice of the tailored HEP is best to achieve maximum benefit *(Ferrell, 2004 [4b]; Local Consensus, 2025 [5])*.

Note 3: Therapists should progress the tailored HEP over time, based on the patient's tolerance, pain, and progress *(Buryk-Iggers et al., 2022 [1a]; Feldman et al., 2020 [5a]; Pacey et al., 2013 [2b]; Local Consensus, 2025 [5])*.

7. *It is recommended that a therapist provide therapeutic exercises targeted at joint stability, joint protection, and restoration of muscular balance.*

Recommendation Strength ***Moderate***

(Buryk-Iggers et al., 2022 [1a]; Fatoye et al., 2011 Gait [4a]; Grahame, 2009 [5a]; Kemp et al., 2010 [2b]; Minhas, 2021 [5a]; Russek, 2000 [5a]; Tinkle et al., 2019 [5a]; Zabriski et al., 2022 [1b])

Note 1: Therapeutic exercise in patients with HSD or hEDS is not intended to alter joint laxity, but to increase stabilization of lax joints through muscular strength, endurance and functional control *(Local Consensus, 2025 [5])*.

Note 2: The therapeutic approach should focus on whole body rather than specific joints *(Smith, 2017 [1b])*.

8. *It is recommended that exercises be modified to ensure proper technique and/or minimize pain symptoms based upon the patient's needs and assessment.* *(See Appendix 2: Exercises and Supportive Interventions)*

Recommendation Strength **Moderate**

(Daman et al., 2019 [2b]; Hakim, 2024 [5a]; Kemp et al., 2010 [2b]; Pacey et al., 2013 [2b]; Simmonds, 2022 [5a]; Smith, 2017 [1b]; Van Meulenbroek et al., 2020 [4b]; Local Consensus, 2025 [5a])

Note 1: Patients with HSD or hEDS may exhibit compensatory movement patterns due to joint laxity and decreased proprioception; thus, proper technique should be reinforced *(Simmonds 2022 [5a], Local Consensus, 2025 [5a])*.

Note 2: Therapeutic exercises should be introduced with low repetitions and progress as tolerated, reinforcing proper technique *(Daman et al., 2019 [2b], Kemp et al., 2010 [2b]; Smith, 2017 [1b]; Local Consensus, 2025 [5a])*.

9. *It is recommended that therapists focus on helping patients improve postural awareness through:* *(See Appendix 2: Exercises and Supportive Interventions) (Reychler et al., 2021 [1a]; Smith, 2017 [1b]; Van Meulenbroek et al., 2020 [4b])*

Recommendation Strength **Moderate**

- Recognizing proper joint position with exercises *(Peterson et al., 2018 [1a]; Rombaut et al., 2010 [4b]; Local Consensus, 2025 [5])*
- Identifying and activating key joint stabilizing muscles *(Zorlular et al., 2024 [2b]; Local Consensus, 2025 [5])*
- Performing selective and isolated muscle stretching *(Local Consensus, 2025 [5])*
- Enhancing middle range proprioception *(Reychler et al., 2021 [1a]; Local Consensus, 2025 [5])*.

10. *It is recommended therapists consider the impact of patient breathing patterns and breath control on functional endurance and core stability.*

Recommendation Strength **Moderate**

(Engelbert et al., 2017 [5a]; Massery et al., 2016 [5b]; Massery et al., 2013 [4b]; Palmer et al., 2021 [1a]; Reychler et al., 2021 [1a]; Reychler et al., 2019 [1a]; Local Consensus, 2025 [5])

Note 1: Observing patients' breathing patterns can help to determine limitations such as overuse of accessory muscles (upper breathing) or poor use of diaphragm *(Local Consensus, 2025 [5])*.

Note 2: The diaphragm is the body's primary pressure regulator that supports ventilation, controls posture, decreases reflux forces, increases gastrointestinal motility, and increases venous return *(Massery et al., 2016 [5a]; Local Consensus, 2025 [5])*.

Note 3: Proper use of the diaphragm can improve balance, through deeper core control mechanisms and proprioceptive feedback *(Massery et al., 2016 [5a]; Local Consensus, 2025 [5])*.

Note 4: Inspiratory Muscle Training may be used for increased exercise capacity *(Massery et al., 2016 [5b]; Massery et al., 2013 [4b]; Palmer et al., 2021 [1a]; Reychler et al., 2021 [1a]; Reychler et al., 2019 [1a])*.

11. *It is recommended that a therapist focus therapeutic exercise on the following principles (Appendix 2: Exercises and Supportive Interventions):*

Recommendation Strength **Moderate**

- Neuromuscular re-education to reduce compensatory movement patterns *(Smith, 2017 [1b]; Zech et al., 2009 [1b]; Local Consensus, 2025 [5])*
  Note 1: Common compensatory movement patterns include locking of the joints in hyperextension for stability *(Smith, 2017 [1b]; Local Consensus, 2025 [5])*.
- Strength-based exercises *(Engelbert et al., 2017 [5a]; Ferrell et al., 2004 [4b]; Palmer et. al., 2021 [1a]; Smith, 2017 [1b])*
  Note 2: Evidence supports the pairing of strength with endurance training during the rehabilitation program *(Keer and Simmonds, 2010 [5a]; Simmonds, 2022 [5a]; Smith, 2017 [1b]; Local Consensus, 2025 [5])*.
  Note 3: Include both open and closed chain tasks *(Engelbert et al., 2017 [5a]; Ferrell et al., 2004 [4b]; Palmer et. al., 2021 [1a]; Smith, 2017 [1b]; Thomas, 2023 [5a])* and dynamic and static exercises *(Local Consensus, 2025 [5])*.
  Note 4: Home-based closed kinetic chain exercises were found to alleviate symptoms *(Engelbert et al., 2017 [5a]; Ferrell et al., 2004 [4b])*.
  Note 5: Strengthening in both neutral and hypermobile ranges, with proper alignment, may be significantly effective in increasing muscle strength, improving high-related quality of life, and reducing pain *(Keer and Simmonds, 2010 [5a]; Pacey et al., 2013 [2b]; Palmer et al., 2021 [1a]; Simmonds, 2022 [5a]; Smith, 2017 [1b]; To and Alexander, 2018 [3b])*.
- Proprioception Training *(See Appendix 2: Proprioception) (Celletti et al., 2011 [5a]; Engelbert et al., 2017 [5a]; Fatoye et al., 2009 [4b]; Ferrell et al., 2004 [4b]; Galli et al., 2011 [4b]; Sahin et al., 2008 [4b]; Smith, 2017 [1b]; Van Meulenbroek et al., 2020 [4b])*
  Note 6: Home-based closed kinetic chain exercises were found to improve proprioceptive performance and quality of life *(QOL) (Engelbert et al., 2017 [5a]; Ferrell et al., 2004 [4b]; Simmonds, 2022 [5a])*.

12. *It is recommended that therapists consider the possibility of other comorbidities that may occur due to limited joint protection and limited core stability.*

Recommendation Strength **Moderate**

(Murray, 2006 [5a]; Russek et al., 2023 [5a]; Russek et al., 2019 [5a]; Smith, 2017 [1b]; Local Consensus, 2025 [5])

Note 1: Common musculoskeletal comorbidities may include:

- Dislocations or subluxations *(Hakim, 2024 [5a]; Rombaut et al., 2012 [4b])*
- Fractures, sprains, or strains *(Banica et al., 2020 [4b]; Castori and Colombi, 2015 [5a])*
- Tendonitis in upper or lower extremities *(Russek et al., 2019 [5a])*
- TMJ dysfunction *(Celletti et al., 2013 [5a]; Kalaykova et al., 2006 [4b]; Pasinato et al., 2011 [4b]; Winocur et al., 2000 [4a])*
- Headaches related to muscle tightness, posture deviations, or cervical instability *(Mehta et al., 2024 [5a]; Rozen et al., 2006 [4b])*
- Scoliosis, spondylolysis, spondylolisthesis, or disc prolapse *(Atwell et al., 2021 [5a]; Mehta et al., 2024 [5a]; Murray, 2006 [5a]; Russek et al., 2019 [5a]; Local Consensus, 2025 [5a])*
- Pelvic floor dysfunction including constipation and urinary incontinence *(Hastings et al., 2019 [4a]; Local Consensus, 2025 [5a])*
- Chiari malformations *(Milhorat et al., 2007 [3a]; Local Consensus, 2025 [5a])*

Note 2: There is a positive correlation between HSD/hEDS and these conditions with adult onset:

- Carpal tunnel syndrome *(Aktas et al., 2008 [4a])*
- Osteoarthritis *(Booshanam, 2011 [4b]; Murray, 2006 [5a]; Simonsen, 2012 [4b])*

Sport-Specific Exercise

13. *It is recommended that therapists provide education regarding the impact of hypermobility on safe sports participation and on reduction of injury risk.*

Recommendation Strength **Moderate**

(Antcliff et al., 2018 [5a]; Armstrong, 2020 [3b]; Armstrong, 2020 [4a]; Armstrong and Greig, 2018 [4a]; Bukva et al., 2019 [3a]; Chan et al., 2018 [3a]; Dhuri and Usman, 2016 [4b]; Engelbert et al., 2017 [5a]; Frydendal et al., 2018 [3b]; Junge et al., 2015 [3a]; Liaghat et al., 2018 [3b]; Nicholson et al., 2022 [5a]; Peterson et al., 2018 [1a]; Sanches et al., 2015 [4a]; Schroeder and Lacallee, 2006 [5a]; Simmonds et al., 2019 [4a]; Smith, 2017 [1b]; Soper et al., 2015 [4a]; Steinberg et al., 2016 [4a]; Stracciolini et al., 2017 [5a]; Vaishya and Hasija, 2013 [4a]; Vera et al., 2020 [4b]; Local Consensus, 2025 [5a])

14. *It is recommended that, when patients are returning to a higher level athletic activity after pause or injury, the therapist considers underlying hypermobility as a factor in the sport-specific training program.*

Recommendation Strength **Moderate**

(Filipa and Barton, 2018 [5a]; Zsidia et al., 2023 [4a]; Local Consensus, 2025 [5a])

Note 1: Highly trained, competitive athletes with JH in sports *(e.g., dance, gymnastics, soccer, swimming)* should be assessed for compensatory patterns due to the level and frequency of training *(Filipa and Barton, 2018 [5a]; Local Consensus, 2025 [5a])*.

Note 2: Training in non-compensatory end range can be beneficial to the athlete to allow for full sports participation *(Local Consensus, 2025 [5a])*.

Orthotics

15. *It is recommended that therapists consider upper extremity finger and/or thumb orthotics.* *(Hakim, 2024 [5a]; Jensen et al., 2021 [4b]; Smith, 2017 [1b]; Song et al., 2020 [4a]; Local Consensus, 2025 [5])*

Recommendation Strength **Moderate**

Note: Finger orthotics for hypermobile phalangeal joints may be used to promote optimal joint positioning and limit overuse/strain and pain with specific activities *(Jensen et al., 2021 [4b]; Hakim, 2024 [5a]; Song et al., 2020 [4a]; Susanne and Lisbeth, 2024 [2b]; Local Consensus, 2025 [5])*.

16. *It is recommended that therapists consider lower extremity (LE) orthotics for symptomatic pes planus.* *(Atwell et al., 2021 [5a]; Bozkurt et al., 2019 [4a]; Evans et al., 2022 [1a]; Smith, 2017 [1b]; Song et al., 2020 [4a]; Local Consensus, 2025 [5])*

Recommendation Strength ***Moderate***

Note 1: Clinical experience with this population has consistently shown a reduction in pain and fatigue with the use of minimal control, over the counter, or semi-customizable shoe orthotics *(Evans et al., 2022 [1a]; Local Consensus, 2025 [5])*.
Note 2: If a patient presents with moderate to severe pronation and calcaneal valgus *and* minimal control orthotics along with therapeutic interventions do not provide a reduction in pain and fatigue, therapist may consider use of higher-level orthotics such as University of California at Biomechanics Laboratory *(UCBL)* or supramalleolar orthotics *(SMO) (Local Consensus, 2025 [5])*.

- With therapeutic intervention, patients may be gradually transitioned from higher-level orthotics to minimal control or semi-customizable orthotics, based on patient tolerance and response *(Local Consensus, 2025 [5])*.

17. *It is recommended that, if a patient presents with asymptomatic pes planus, consider targeted postural interventions to address LE alignment instead of orthotics.* *(Evans et al., 2022 [1a]; Tas et al., 2021 [4b]; Local Consensus, 2025 [5])*

Recommendation Strength ***Moderate / Consensus***

Frequency of Therapy

18. *It is recommended that the frequency of therapy is determined by the symptoms the patient is exhibiting and the functional status of the patient* *(See Appendix 3: Models of Therapy)*.
(Atwell et al., 2021 [5a]; Hjalmarsson et al., 2023 [4a]; Lindholm et al., 2025 [4a]; Palmer et. al., 2021 [1a]; Peterson et al., 2018 [1a]; Quatman et al., 2008 [4a]; To and Alexander, 2018 [3b]; Local Consensus, 2025 [5])

Recommendation Strength ***Moderate***

Note: When determining the frequency of therapy, consider the following factors *(Local Consensus, 2025 [5])*:

- Changes in physical demands on the biomechanical structures through physical activity *(sports- /work- related activities) (Quatman et al., 2008 [4a])*
- Change in functional status or decrease in physical activity associated with pain and fatigue *(Atwell et al., 2021 [5a]; Peterson et al., 2018 [1a])*
- Stage of readiness *(Clark & Knight, 2017 [5a]; Local Consensus, 2025 [5])*

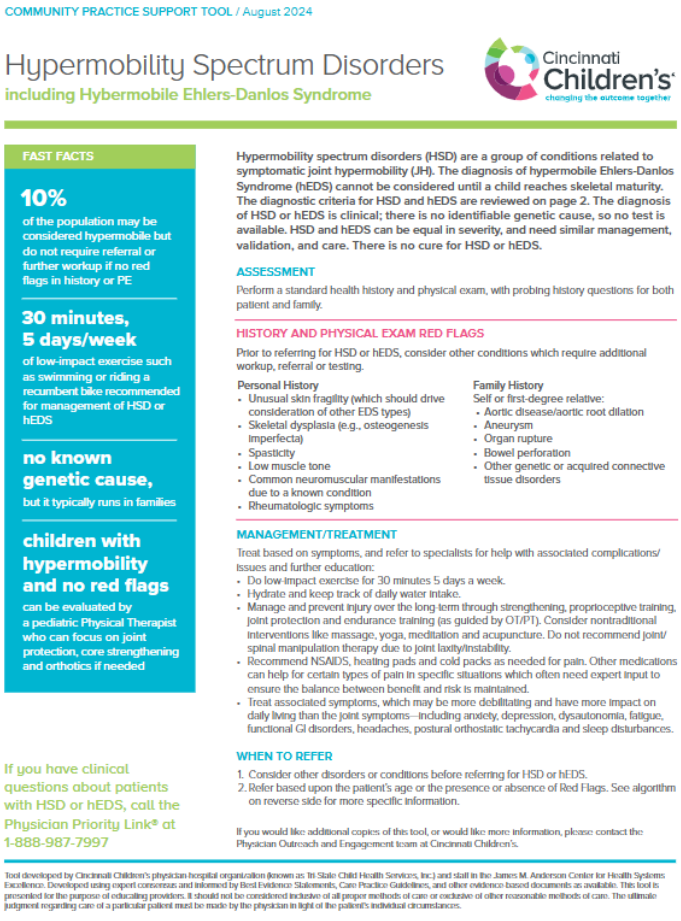
Referral

19. *It is recommended that, if patients are not responding to therapeutic management or if other symptoms are negatively impacting therapeutic progress, therapists should encourage patients to seek care from their primary care physicians and/or other disciplines involved in their care.*
(Atwell et al., 2021 [5a]; Bale et al., 2019 [2a]; Buryk-Iggers et al., 2022 [1a]; Clark et al., 2024 [1a]; Kulas Soborg et al., [1a]; Legerlotz, 2020 [1a]; Palmer et al., 2020 [1a]; Zabriskie, 2022 [1a]; Local Consensus [5])

Recommendation Strength ***Moderate***

Algorithm

Community Practice Support Tool: Hypermobility Spectrum Disorders



COMMUNITY PRACTICE SUPPORT TOOL / August 2024

Hypermobility Spectrum Disorders
including Hybermobile Ehlers-Danlos Syndrome

Cincinnati Children's
changing the outcome together

FAST FACTS

10%
of the population may be considered hypermobile but do not require referral or further workup if no red flags in history or PE

30 minutes, 5 days/week
of low-impact exercise such as swimming or riding a recumbent bike recommended for management of HSD or hEDS

no known genetic cause,
but it typically runs in families

children with hypermobility and no red flags
can be evaluated by a pediatric Physical Therapist who can focus on joint protection, core strengthening and orthotics if needed

If you have clinical questions about patients with HSD or hEDS, call the Physician Priority Link® at 1-888-987-7997

Hypermobility spectrum disorders (HSD) are a group of conditions related to symptomatic joint hypermobility (JH). The diagnosis of hypermobile Ehlers-Danlos Syndrome (hEDS) cannot be considered until a child reaches skeletal maturity. The diagnostic criteria for HSD and hEDS are reviewed on page 2. The diagnosis of HSD or hEDS is clinical; there is no identifiable genetic cause, so no test is available. HSD and hEDS can be equal in severity, and need similar management, validation, and care. There is no cure for HSD or hEDS.

ASSESSMENT

Perform a standard health history and physical exam, with probing history questions for both patient and family.

HISTORY AND PHYSICAL EXAM RED FLAGS

Prior to referring for HSD or hEDS, consider other conditions which require additional workup, referral or testing.

Personal History
- Unusual skin fragility (which should drive consideration of other EDS types)
- Skeletal dysplasia (e.g., osteogenesis imperfecta)
- Spasticity
- Low muscle tone
- Common neuromuscular manifestations due to a known condition
- Rheumatologic symptoms

Family History
Self or first-degree relative:
- Aortic disease/aortic root dilation
- Organ rupture
- Bowel perforation
- Other genetic or acquired connective tissue disorders

MANAGEMENT/TREATMENT

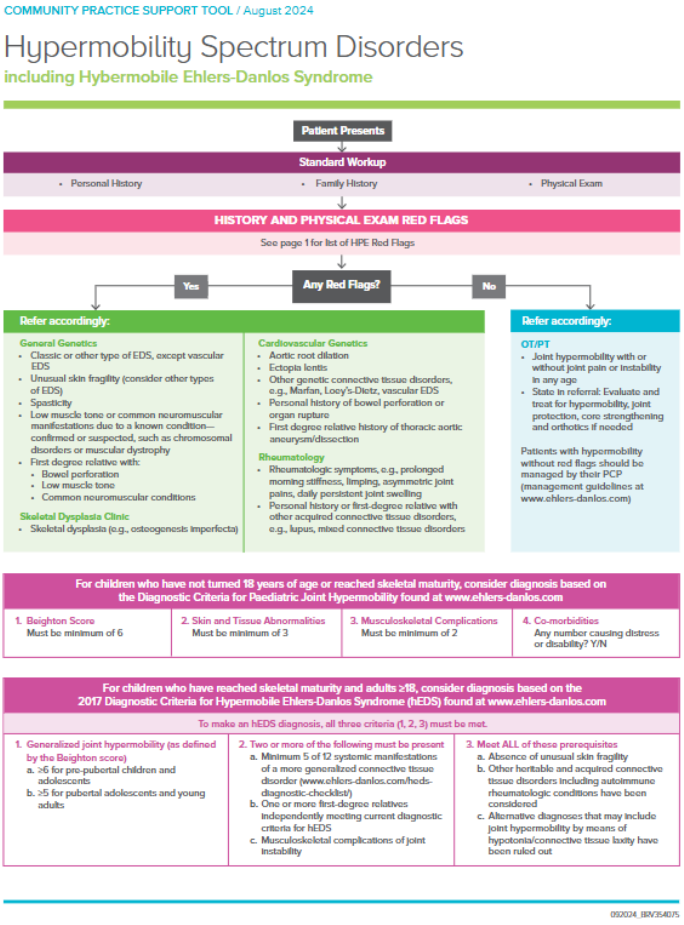
Treat based on symptoms, and refer to specialists for help with associated complications/issues and further education:
- Do low-impact exercise for 30 minutes 5 days a week.
- Hydrate and keep track of daily water intake.
- Manage and prevent injury over the long-term through strengthening, proprioceptive training, joint protection and endurance training (as guided by OT/PT). Consider nontraditional interventions like massage, yoga, meditation and acupuncture. Do not recommend joint/spinal manipulation therapy due to joint laxity/instability.
- Recommend NSAIDS, heating pads and cold packs as needed for pain. Other medications can help for certain types of pain in specific situations which often need expert input to ensure the balance between benefit and risk is maintained.
- Treat associated symptoms, which may be more debilitating and have more impact on daily living than the joint symptoms—including anxiety, depression, dysautonomia, fatigue, functional GI disorders, headaches, postural orthostatic tachycardia and sleep disturbances.

WHEN TO REFER

1. Consider other disorders or conditions before referring for HSD or hEDS.
2. Refer based upon the patient's age or the presence or absence of Red Flags. See algorithm on reverse side for more specific information.

If you would like additional copies of this tool, or would like more information, please contact the Physician Outreach and Engagement team at Cincinnati Children's.

Tool developed by Cincinnati Children's physician-hospital organization (known as Tri State Child Health Services, Inc.) and staff in the James M. Anderson Center for Health Systems Excellence. Developed using expert consensus and informed by Best Evidence Statements, Care Practice Guidelines, and other evidence based documents as available. This tool is presented for the purpose of educating providers. It should not be considered inclusive of all proper methods of care or exclusive of other reasonable methods of care. The ultimate judgment regarding care of a particular patient must be made by the physician in light of the patient's individual circumstances.



COMMUNITY PRACTICE SUPPORT TOOL / August 2024

Hypermobility Spectrum Disorders
including Hybermobile Ehlers-Danlos Syndrome

Patient Presents
↓
Standard Workup
- Personal History
- Family History
- Physical Exam

↓
HISTORY AND PHYSICAL EXAM RED FLAGS
See page 1 for list of HPE Red Flags

↓
Any Red Flags?
Yes / No

Refer accordingly:

General Genetics
- Classic or other type of EDS, except vascular EDS
- Unusual skin fragility (consider other types of EDS)
- Spasticity
- Low muscle tone or common neuromuscular manifestations due to a known condition—confirmed or suspected, such as chromosomal disorders or muscular dystrophy
- First degree relative with:
  - Bowel perforation
  - Low muscle tone
  - Common neuromuscular conditions

Skeletal Dysplasia Clinic
- Skeletal dysplasia (e.g., osteogenesis imperfecta)

Cardiovascular Genetics
- Aortic root dilation
- Ectopia lentis
- Other genetic connective tissue disorders, e.g., Marfan, Loey's-Dietz, vascular EDS
- Personal history of bowel perforation or organ rupture
- First degree relative history of thoracic aortic aneurysm/dissection

Rheumatology
- Rheumatologic symptoms, e.g., prolonged morning stiffness, limping, asymmetric joint pains, daily persistent joint swelling
- Personal history or first-degree relative with other acquired connective tissue disorders, e.g., lupus, mixed connective tissue disorders

Refer accordingly:

OT/PT
- Joint hypermobility with or without joint pain or instability in any age
- State in referral: Evaluate and treat for hypermobility, joint protection, core strengthening and orthotics if needed

Patients with hypermobility without red flags should be managed by their PCP (management guidelines at www.ehlers-danlos.com)

For children who have not turned 18 years of age or reached skeletal maturity, consider diagnosis based on the Diagnostic Criteria for Paediatric Joint Hypermobility found at www.ehlers-danlos.com

1. Beighton Score	2. Skin and Tissue Abnormalities	3. Musculoskeletal Complications	4. Co-morbidities
Must be minimum of 6	Must be minimum of 3	Must be minimum of 2	Any number causing distress or disability? Y/N

For children who have reached skeletal maturity and adults ≥18, consider diagnosis based on the 2017 Diagnostic Criteria for Hypermobile Ehlers-Danlos Syndrome (hEDS) found at www.ehlers-danlos.com

To make an hEDS diagnosis, all three criteria (1, 2, 3) must be met.

1. Generalized joint hypermobility (as defined by the Beighton score)	2. Two or more of the following must be present	3. Meet ALL of these prerequisites
a. ≥6 for pre-pubertal children and adolescents b. ≥5 for pubertal adolescents and young adults	a. Minimum 5 of 12 systemic manifestations of a more generalized connective tissue disorder (www.ehlers-danlos.com/heds-diagnostic-checklist/) b. One or more first-degree relatives independently meeting current diagnostic criteria for hEDS c. Musculoskeletal complications of joint instability	a. Absence of unusual skin fragility b. Other heritable and acquired connective tissue disorders including autoimmune rheumatologic conditions have been considered c. Alternative diagnoses that may include joint hypermobility by means of hypotonia/connective tissue laxity have been ruled out

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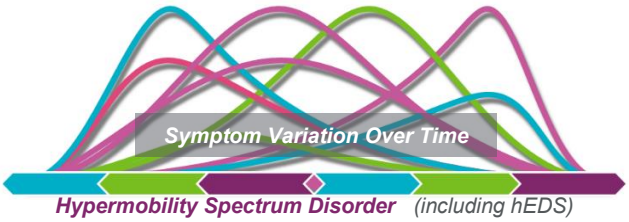
Cincinnati Children's Hospital Medical Center:

- [Hypermobility Spectrum Disorders](https://cincinnatichildrens.widen.net/s/9kbnvd8xgg/cchmc-2225-cpst-hypermobility-ehlers-danlos-heds_11-2023-final) (https://cincinnatichildrens.widen.net/s/9kbnvd8xgg/cchmc-2225-cpst-hypermobility-ehlers-danlos-heds_11-2023-final)
- [Community Practice Support Tools | Healthcare Professional Resources](https://www.cincinnatichildrens.org/professional/resources/community-practice-support-tools) (https://www.cincinnatichildrens.org/professional/resources/community-practice-support-tools)

Introduction

The term “hypermobility” refers to joints which are more flexible or with a greater range of motion than is expected. Hypermobility is very natural in most babies and children, and decreases gradually over time. However, up to 15-20% of individuals continue with hypermobility into adulthood, with a greater prevalence in females. For most adults with hypermobility, increased flexibility does not cause pain or other symptoms.



However, hypermobility that is accompanied by joint instability and pain or other joint issues (i.e., symptomatic hypermobility) is classified as hypermobility spectrum disorder, ranging from only symptoms of hypermobility to meeting current diagnostic criteria for hEDS.

The 2017 Diagnostic Criteria for hEDS is very specific to those features most associated with hEDS. Other problems such as chronic fatigue, gastrointestinal issues, autonomic dysfunction, headaches, anxiety, mast cell disorders and chronic pain are known to be experienced by many along the hypermobility spectrum – yet these issues are not specific enough for the diagnosis of hEDS. HSD refers to symptomatic hypermobility in those who do not meet criteria for hEDS. Symptoms for HSD and hEDS may be identical. Based on learnings from the 2017 Diagnostic Criteria, revisions were made to formal classification criteria for HSD and hEDS.

Each person’s journey with hypermobility is unique and may include a variety of symptoms which require multiple providers in different specialties to help them toward the goal of self-management. While there are currently no disease-specific treatments for HSD or hEDS, care is the same for each with a focus on managing each individual’s symptoms. Both HSD and hEDS require awareness, recognition, validation and care to help patients with symptomatic hypermobility lead their best lives. The bedrock of symptomatic hypermobility management includes joint protection through hypermobility-focused physical therapy and occupational therapy and staying active in joint sparing ways within the individual’s limits of endurance.

Target Users for the Recommendations

Target Users include, but are not limited to, Physicians (Geneticists, Orthopedists, Primary Care Physicians, Rheumatologists, Sports Medicine), Patient Care Clinicians (Nurses, Nurse Practitioners), Dentists, Orthodontists, Occupational Therapists, Physical Therapists, Psychologists, Physician Assistants, and Other Health Care Professionals involved in the care of patients with joint hypermobility.

Abbreviations

hEDS	Hypermobile Ehlers-Danlos syndrome	**CMC**	carpalmetacarpal instability	**LLAS**	lower limb assessment scale
HSD	Hypermobility spectrum disorder	**CR**	cardiorespiratory	**MCP**	metacarpalphalangeal joints
	G–HSD generalized HSD	**EE**	eosiniphilic esophagitis	**MPFL**	medial patellofemoral ligament
	P–HSD peripheral HSD	**ER**	external rotation	**NDPH**	new daily persistent headaches
	L–HSD localized HSD	**GI**	gastrointestinal	**PJH**	peripheral joint hypermobility
	H–HSD historical HSD	**IP**	interphalangeal joints	**ROM**	range of motion
JH	joint hypermobility	**DIP**	distal IP joints	**SLS**	single limb stance
	GJH generalized JH	**IR**	internal rotation	**TMD**	temporomandibular dysfunction
	LJH localized JH	**LE**	lower extremity	**TMJ**	temporomandibular joints
				UE	upper extremity

Clinical Question

For children and adolescents with joint hypermobility *(JH)*, hypermobility spectrum disorder *(HSD)*, generalized joint hypermobility *(GJH)*, or hypermobile Ehlers-Danlos syndrome *(hEDS)*, what are the components of effective, targeted, therapeutic management?

Additional Clinical Questions for hEDS

Among children with hEDS,

- What interventions or treatments may be most effective to improve clinical or other patient outcomes?
- What criteria determine referral to OT, PT, or specific specialists, and how are those criteria prioritized by patient symptom constellation, to improve clinical or other patient outcomes?
- When is it appropriate or what criteria are relevant to shift care back to the primary care provider/PCP compared to continuing care in a specialist setting to improve patient self-management and PCP management and to provide effective care with the specialists?

Among children with hEDS who are being treated by clinicians with an intervention or therapy,

- What outcomes and/or measures are most relevant or efficient/effective to show improvement in the patient or for the desired patient outcomes being monitored?
- How is success or improvement defined for the measures to show improvement for the desired patient outcomes being monitored?

Among children with joint hypermobility or Ehlers-Danlos syndrome – hypermobility type,

- What interventions or treatments may be most effective to improve clinical or other patient outcomes?
- What criteria determine referral to OT compared to referral to PT to improve clinical or other patient outcomes?
- What criteria determine referral to specific specialists and how are those criteria prioritized by patient symptom constellation to improve clinical or other patient outcomes?
- When is it appropriate or what criteria are relevant to shift care back to the PCP compared to continuing care in a specialist setting to improve patient self-management and PCP management and to provide effective care with the specialists?

Among children with hEDS who are being treated by clinicians with an intervention or therapy,

- What outcomes are most relevant or efficient/effective to show improvement in the patient?
- What measures are most relevant or efficient/effective to show improvement for the desired patient outcomes being monitored?
- How is success or improvement defined for the measures to show improvement for the desired patient outcomes being monitored?

Future Research Questions

For children and adolescents with JH, HSD, or hEDS:

- Do targeted interventions improve pain, fatigue, and quality of life?
- What are the perceived impacts of the condition on quality of life?
- What are valid and effective ways of measuring fatigue?
- What biomechanical deficits are identified using 3D motion analysis?
- Do specific orthotic interventions effectively improve lower limb biomechanical deficits?

Implementation Plan

Implementation of this evidence-based care guideline includes use of the following tools, some of which are available externally and are included in the appendices or on our website (links below). These have been developed, adapted or revised for incorporation of these recommendations into practice.

Relevant Cincinnati Children's Tools

***Cincinnati Children's Hospital Medical Center**: www.cincinnatichildrens.org & www.cincinnatichildrens.org/evidence*

- Community Practice Support Tool: Hypermobility (HSD & hEDS)
- OT/PT – HSD & Hypermobile EDS

***CenterLink** (Cincinnati Children's Internal Website – internal staff only): Genetics | Knowing Notes (cchmc.org)*

- Hypermobility Spectrum Disorder / HSD *(KN1315)*
- Hypermobile Ehlers-Danlos Syndrome / hEDS *(KN1169)*
- Anxiety in HSD including hEDS *(KN1219)*
- Dizziness with HSD including hEDS *(KN1218)*
- Dysautonomia with HSD including hEDS *(KN1180)*
- Fatigue from HSD including hEDS *(KN1200)*
- Functional Abdominal Pain from HSD including hEDS *(KN1228)*
- Headaches from HSD including hEDS *(KN1167)*
- Gastroparesis and HSD including hEDS *(KN1229)*
- Ibuprofen Use for HSD including hEDS *(KN1220)*
- Managing Constipation with HSD including hEDS *(KN1226)*
- Pain from HSD including hEDS *(KN1168)*
- Pregnancy and hEDS
- Proper Posture for Work and School Settings *(KN1239)*
- Proprioception Issues with HSD including hEDS *(KN1221)*
- Reflux and Stomach Acid in HSD including hEDS *(KN1227)*
- Sleeping Problems Associated with HSD including hEDS *(KN1217)*
- Slipping Rib and HSD including hEDS *(KN1277)*

Outcome Measures

Providers may see an impact in patient-reported outcomes over time through use of PRO tools such as:

- Peds QL *(Pediatric Quality of Life Inventory)*
- PROMIS *(Patient-Reported Outcomes Measurement Information System)*
- FDI *(Functional Disability Inventory).*

Patient-Centered Goals are being intentionally set with the patient using COPM *(Canadian Occupational Performance Measure)* to develop a treatment plan.

Functional assessments using PODCI *(Pediatric Outcomes Data Collection Instrument)* and FDI identify patient-reported changes over time. PROMIS–Function & Pain Interference may also help identify differences in measures for improvement in functional goals and measures for improvement pain goals.

Process Measures

Due to the chronic nature of this condition, it is expected that there will be dynamic changes throughout the lifespan of the patient (e.g., during growth, activity changes, acute illnesses). It is also anticipated that there could be an improvement in function prior to an improvement in pain. Over time, resolution of symptoms and/or pain and improvement in quality of life is achievable. However, episodes of care are recommended to help manage the condition when the patient is experiencing functional deficits related to the condition.

Search Strategies & Results

Search Strategy

To select evidence for critical appraisal for this Evidence Summary, the databases below were searched using search terms, limits, filters, and date parameters to generate an unrefined, "combined evidence" database. This search strategy focused on answering the clinical questions addressed in this document and employing a combination of Boolean searching on human-indexed thesaurus terms (e.g., MeSH) as well as "natural language" searching on words in the title, abstract, and indexing terms.

Databases Searched	Search Terms	Limits, Filters, and Search Dates & Parameters
• MedLine (EBSCO) • CINAHL (EBSCO) • Cochrane Database for Systematic Reviews • Google Scholar • EMBASE • Footnote Crawling, Reference List and/or Hand Searching	• Joint hypermobility, hypermobility spectrum disorder, Ehlers-Danlos syndrome, joint instability • *and* Occupational therapy *or* physical therapy • Benign *and* joint hypermobility, ligamentous laxity, joint laxity, pronation, foot *and* pronation, Stickler's syndrome • Orthotics, orthoses, stretching, posture, proprioceptive training, proprioception, balance, strength, joint stabilization, neuromuscular control, postural control, handwriting, gait abnormalities, joint alignment	Date of Most Recent Search • 9/17/2025 Publication Dates Searched • Search dates not restricted Age Groups in Evidence • Primarily Pediatric Evidence • *Adult evidence included for pediatric patients 4-21 years of age* English Language Other Criteria • *All study types/designs considered* • *Population inclusion/exclusion criteria applied* • *No additional filters, limits, or other criteria applied to search*

Search Results & Methods

The searches *(electronic search engines, manual searches of citations/references)* for evidence identified a total of 4,446 articles. Duplicate citations were removed during each iteration of searches, leaving only unique citations in the final screening list. Based on title and abstract screening, 3,745 articles were discarded, as they were not related to the clinical questions of interest. The remaining 814 articles were reviewed in full text then critically appraised. Of these, 658 articles were discarded as they were not related to the clinical questions and therapeutic management recommendation statements. The remaining 156 articles met the inclusion criteria above and were cited in one or more recommendation statements and evidence syntheses. The evidence table for study characteristics of included articles is available upon request *(email: EBDMinfo@cchmc.org)*.

Team Members | Conflicts of Interest | External Funding

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** Special thanks to parents who contributed to this guideline process.*

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Conflicts of Interest were declared for each team member and:

No financial or intellectual conflicts of interest were found.
Conflict of interest *(COI)* declaration information is maintained in Cincinnati Children's HRS/Huron COI system.

External Funding

No external funding was received for development of this guideline.
Recommendations were developed through hospital funding via salaries.

Evidence-Based Clinical Care Recommendation Development Process

Recommendation statements were developed in accordance with Cincinnati Children's Evidence-Based Care Guideline Development Process *(for more details, contact EBDMinfo@cchmc.org)*. The recommendations contained in this guideline were formulated by a multidisciplinary working group based on best-available and peer-reviewed evidence, patient and family values, clinical expertise, and stakeholder consensus. The team performed a systematic search and critical appraisal of the literature using the LEGEND Evidence Evaluation System *(see next section below)*. During formulation of these recommendations, the team members have remained cognizant of controversies and disagreements over the management of these patients. Controversial issues were resolved by stakeholder and team member consensus where possible *(using a pre-defined consensus process)* and, when not possible, were offered optional approaches to care in the form of information that includes best supporting evidence of efficacy for alternative choices.

LEGEND Evidence Evaluation System (Let Evidence Guide Every New Decision)

Evidence Levels of Individual Studies by Domain, Study Design, & Quality *(Link to Full Table)*

Individual studies are appraised for reliability, validity, and applicability, using standardized appraisal forms, to determine the Quality Level or Evidence Level (**a** vs **b**)†.

Quality Level	*Definition*
1**a**† or 1**b**†	Systematic review, meta-analysis, or meta-synthesis of multiple studies
2a or 2b	Best study design for domain
3a or 3b	Fair study design for domain
4a or 4b	Weak study design for domain
5a or 5b	General review, expert opinion, case report, consensus report, or guideline
5	Local Consensus

†***a*** *= good quality study OR* ***b*** *= lesser quality study*

Grade for the Body of Evidence *(Link to Full Table)*

The Body of Evidence *(BOE)* is evaluated for quantity, quality, and consistency to determine the grade of the BOE and what the impact of the BOE is on our confidence in the precision of the answer to the clinical question (and its associated recommendation statement).

Grade	*Definition*
High ⊕⊕⊕⊕	Good quality, High-level studies with consistent results
Moderate ⊕⊕⊕◯	Good quality, Lower-level OR Lesser quality, Higher-level studies with consistent* results
Low ⊕⊕◯◯	Good or lesser quality, Lower-level with results that may be inconsistent
Very Low ⊕◯◯◯	Few Good or Lesser quality, Lower-level studies that may have inconsistent results
Consensus	Local Consensus, No published evidence

Dimensions for Judging the Strength of the Recommendation *(Link to Full Table)*

1. Safety versus Harm
2. Clinically Effective / Benefits Patient
3. Adherence
4. Cost
5. Impact of Quality of Life, Morbidity, or Mortality
6. Directness of the Evidence
7. Grade of the Body of Evidence

Language and Definitions for Recommendation Strength *(Link to Full Table)*

Language for Strength	Definition
It is strongly recommended that… It is strongly recommended that… not…	When the dimensions for judging the strength of the recommendation are applied *(including safety/harm, health benefit, body of evidence, etc.)*, there is high support that benefits clearly outweigh risks and burdens. *(or visa-versa for negative recommendations)*
It is recommended that… It is recommended that… not…	When the dimensions for judging the strength of the evidence are applied, there is moderate support that benefits are closely balanced with risks and burdens.
It is suggested that… It is suggested that… not…	When the dimensions for judging the strength of the evidence are applied, there is weak support that benefits are closely balanced with risks and burdens.
There is insufficient evidence to make a recommendation…	

Review Process

All feedback received from internal and external reviewers was appropriately discussed and addressed by the development team.

Guideline Review

This guideline has been reviewed against quality criteria by independent peer reviewers from Cincinnati Children's including, but not limited to, evidence methodologists, relevant subject matter experts, or other stakeholders who were not involved in the development process using the **AGREE II instrument** *(Appraisal of Guidelines for Research and Evaluation II)*.

Revision Process

The guideline will be removed from the Cincinnati Children's website if content has not been revised within five years from the most recent publication date. A revision of the guideline may be initiated at any point within the five year period that evidence indicates a critical change is needed. Team members reconvene to explore the continued validity and need of the guideline.

The most recent details for the search strategy, results, and review are documented in this guideline. Details of previous review strategies are not documented. However, all previous citations and content were reviewed for appropriateness to this revision. Experience with the implementation and monitoring of earlier publications of this guideline has provided learnings which have also been incorporated into this revision.

Review History

Date	*Event*	*Outcome*
9/22/2025	**Guideline Revisions**	*Original guideline revised into two guidelines: (1)* Screening/Assessment EBCG and *(2)* Therapeutic Management EBCG. Evidence-Based Care Recommendation Statements have been revised, removed, and added. All evidence was reviewed. New evidence has been added to multiple recommendation statements. A new template was used for this guideline including revisions aligned with Cincinnati Children's Hospital System. *Local Consensus is confirmed.*
3/1/2016	**Original Publication**	New guideline developed and published.

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An electronic version of this EBCG is available online at *www.cincinnatichildrens.org/evidence or https://www.cincinnatichildrens.org/research/divisions/j/anderson-center/evidence-based-care*.

Notification to CHMC (EBDMInfo@cchmc.org) is appreciated for all uses of this EBCG or its related implementation tools which are adopted, adapted, implemented, or hyperlinked.

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For more information

For more information about this guideline, its companion documents, or the Cincinnati Children's Evidence-Based Care Recommendation Development process, contact the Cincinnati Children's Evidence-Based Decision Making team at EBDMinfo@cchmc.org.

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Evidence Syntheses & Dimensions for Judging the Strength of the Recommendations

Evidence Synthesis for Care Recommendation 1

Therapeutic management of HSD and hEDS in pediatric and adolescent populations presents a unique clinical challenge due to the complex, multisystemic nature of these conditions. Children often experience a constellation of symptoms, such as chronic musculoskeletal pain, joint instability, gastrointestinal dysfunction, autonomic disturbances, and psychological distress. Shifting the approach to management from siloed, symptom-based care to a collaborative, multidisciplinary model will enable comprehensive and coordinated care to meet patients' needs more effectively and efficiently *(Bale et al., 2019 [2a]; Bathen et al., 2013 [4b]; Black et al., 2023 [5b]; Castori et al., 2012 [5a]; Simmonds, 2022 [5a]; Van Meulenbroek et al., 2020 [4b]; Yew et al., 2021 [5a])*.

Current research supports the efficacy of multidisciplinary care in improving outcomes for patients with HSD *(Bale et al., 2019 [2a]; Bathen et al., 2013 [4b]; Black et al., 2023 [5b]; Castori et al., 2012 [5a]; Simmonds, 2022 [5a]; Van Meulenbroek et al., 2020 [4b]; Yew et al., 2021 [5a])*. For example, Bale et al. *(2019 [2a])* demonstrated that a multidisciplinary strategy significantly improved outcomes in children with symptomatic joint hypermobility. Bathen et al. *(2013 [4b])* and Van Meulenbroek et al. *(2020 [4b])* found that combining physical and cognitive behavioral therapy *(CBT)* reduced disability and enhanced daily functioning. Black et al. *(2024 [5a], 2023 [5a])* and Mittal et al. *(2021 [5a])* described successful implementation of multidisciplinary clinics, such as the GoodHope EDS Clinic, which integrates rheumatology, pain management, physiotherapy, psychology, and genetics.

Multidisciplinary teams often include core or primary care team members and specialist referrals *(Bale et al., 2019 [2a]; Bathen et al., 2013 [4b]; Black et al., 2023 [5b]; Castori et al., 2012 [5a]; Simmonds, 2022 [5a]; Van Meulenbroek et al., 2020 [4b]; Yew et al., 2021 [5a]; Local Consensus [5])*. Team members can be primary care physicians, physiotherapists, occupational therapists, psychologists, pain specialists, and social workers. Based on individual needs, specialist referrals may include cardiology (e.g., for POTS), gastroenterology, genetics, immunology/allergy, neurology, orthopedics, pain management, and rheumatology.

Each discipline participating in the care of these patients contributes a unique perspective *(Local Consensus [5])*. Physiotherapists focus on joint stabilization and proprioception *(Engelbert et al., 2017 [5a], Russek et al., 2019 [5a])*. Psychologists address the emotional burden of chronic illness, including anxiety, depression, or kinesiophobia *(i.e., Care Recommendation 3)*. Primary care providers coordinate referrals and ensure continuity of care *(Yew et al., 2021 [5a])*.

Tools such as Cincinnati Children's Community Practice Support Tool provide guidance and help streamline diagnosis and referral. Open communication between families and primary care providers ensures that care decisions remain aligned with patient/family needs *(Local Consensus [5])*. Barriers to comprehensive multidisciplinary care, such as a shortage of trained specialists in hypermobility disorders, limited interprofessional collaboration, and financial barriers, should be identified and mitigated early to improve implementation effectiveness. This multidisciplinary, holistic approach to managing pediatric patients with HSD and hEDS addresses the physical and psychological dimensions of care, while fostering patient-centered interprofessional collaboration, care continuity, and patient empowerment *(Local Consensus [5])*.

Dimensions: *Care Recommendation 1*

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☒ Beneficial/Effective	☐ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective	☒ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☒ Directly Related	☐ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 2

Multiple studies and expert opinion review articles have consistently supported the use of physical therapy (PT) and/or occupational therapy OT) as key components as part of an effective therapeutic management plan for patients with HSD and hEDS, particularly for patients presenting with symptoms *(Englebert et al., 2017 [5a]; Kemp et al., 2010 [2a]; Minjas et al., 2021 [5a]; Reychler et al., 2021 [1a]; Russek et al., 2019 [5a]; Scheper et al., 2014 [4a]; Yew et al., 2021 [5a])*. Patients often experience joint instability, chronic pain, proprioceptive deficits, and functional limitations. Quality of life may also be significantly impaired; however, occupational and physical therapy can improve function and quality of life *(Englebert et al., 2017 [5a])*.

Therapies that address patient symptoms and functional limitations, such as joint hypermobility, muscle weakness, proprioceptive deficits, and functional limitations, have been shown to be effective *(Englebert et al., 2017 [5a]; Russek et al., 2019 [5a])*. The use of individualized, targeted therapeutic interventions can address these complex challenges and promote long-term functional improvement *(Russek et al., 2019 [5a])*. Therapy focused on joint stabilization, posture correction, and movement control significantly reduces pain and improves proprioception *(Kemp et al., 2010 [2a]; Reychler et al., 2021 [1a])*. Strength-building interventions can counteract compensatory low-strain activity patterns in hypermobile individuals *(Scheper et al., 2014 [4a])*. Goals are both therapeutic and preventive to reduce injury risk and enhance long-term outcomes.

Asymptomatic patients also benefit from education on joint protection, self-management strategies, and preventive exercises, which may delay symptom onset and reduce injury risk *(Local Consensus, 2025 [5])*.

Dimensions: Care Recommendation 2

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☒ Beneficial/Effective	☐ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective	☒ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☒ Directly Related	☐ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☒ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 3

Adolescents with HSD or hEDS may experience the complex combination of physical and psychological symptoms or distress. Increased rates of psychological distress in patients with joint hypermobility have been consistently reported *(Baezo-Velasco et al., 2018 [1b]; Bulbena et al., 2017 [1b]; Clark et al., 2023 [1a]; Ghibellini et al., 2015 [1b]; Sanches et al., 2012 [1b]; Sinibaldi et al., 2015 [1b]; Smith et al., 2013 [1b]; Van Meulenbroek et al., 2021 [1b])*. Adolescents with chronic pain are at increased risk of developing anxiety disorders, panic attacks, depression *(Bulbena et al., 2017 [1a])*, which reinforces the need for early psychological intervention in pediatric populations *(Feldman et al., 2020 [5a]; Ishiguro et al., 2021 [5a])* or it may evolve into panic disorder or agoraphobia in adulthood, if left untreated *(Bulbena et al., 2011 [4a]; Cederlof et al., 2016 [4a]; Ghibellini et al., 2015 [1b]; Grahame 2009 [5a]; Javadi-Parvaneh et al., 2020 [4a]; Pasquini et al., 2014 [3a]; Scheper et al., 2016 [1a]; Sinibaldi et al., 2015 [1b]; Van Meulenbroek et al., 2021 [5a])*. Patients may develop kinesiophobia (i.e., fear of movement-induced pain), causing avoidance behaviors, deconditioning, or increased disability, which could be associated with chronic fatigue *(Bathen et al., 2013 [4b]; Celletti et al. 2013 [4b]; Song et al., 2023 [1a]; Van Meulenbroek et al., 2020 [4b])*. Kindgren et al. *(2021 [4a])* reported an association with HSD/hEDS and attention deficit hyperactivity disorder or autism spectrum disorders that could benefit from early identification and intervention with routine screening for neuropsychiatric symptoms.

Psychological therapies have been shown to improve mood, coping strategies, daily functioning, and quality of life *(Bathen et al., 2013 [4b]; Castori et al., 2016 [5a]; Cederlof et al., 2016 [4a]; Celletti et al., 2021 [3b]; Celletti et al., 2013 [4b]; Clark et al., 2023 [1a]; Feldman et al., 2020 [5a]; Grahame 2009 [5a]; Ishiguro et al., 2021 [5a]; Javadi-Parvaneh et al., 2020 [4a]; Kindgren et al., 2021 [4a]; Pasquini et al., 2014 [4a]; Russek et al., 2019 [5a]; Van Meulenbroek et al., 2020 [4b])*. Reducing kinesiophobia and reintroducing movement over time, improving physical therapy adherence, managing pain symptoms, and increasing patient confidence in therapy have been

reported along with tailored therapy as effective management strategies for adolescents or youth *(Feldman et al., 2020 [5a]; Ishiguro et al., 2021 [5a])*.

Psychological and physiotherapy interventions combined in an outpatient or community setting have been shown to reduce both the physical and psychological aspects of pain and improve quality of life *(Clark et al., 2023 [1a])*. Joint physical therapy h and CBT for patients with chronic pain also improved daily functioning, reduced fatigue and pain symptoms, and enhanced muscle strength *(Bathen et al., 2013 [4b]; Celletti et al., 2021 [3b]; Clark et al., 2023 [1a])*. Multidisciplinary rehabilitation therapy has been shown to significantly improve functional disability, physical functioning, perceived harmfulness, and pain intensity in adolescents with generalized HSD/hEDS *(Van Meulenbroek et al., 2020 [4b])*. Likewise, tailored therapy focused on recovery of movement and pain perception can improve coping skills, kinesiophobia, and therapy adherence *(Bathen et al., 2013 [4b]; Celletti et al., 2021 [3b])*.

The need for more rigorous evaluations of psychological interventions for HSD and hEDS remains *(Clark et al., 2023 [1]; Song et al., 2023 [1a])*. Evidence for psychological interventions from smaller observational/case studies focused on pain management, self-destructive behavior, or other issues *(e.g., depression, anxiety)* using CBT, dialectical behavioral therapy, psychoeducation, intensive interdisciplinary pain treatment, and acceptance commitment therapy *(Song et al., 2023 [1a])*.

Additionally, family dynamics can influence therapy adherence and therapeutic management for patients with HSD or hEDS. If psychologists are involved in family-centered care, improvements may be seen in communication, stress reduction, and treatment outcomes *(Baezo-Velasco et al., 2018 [4b]; Bulbena et al., 2017 [1a]; Cederlof et al., 2016 [4a]; Sanches et al., 2012 [1b]; Smith, 2013 [1b]; Tran et al., 2020 [3b])*. Adolescents' coping mechanisms and adherence to care plans are often influenced by parental stress and communication patterns. Engaging families in the therapeutic process with education and involvement in care encourages improved patient outcomes and family support *(Bulbena et al., 2017 [1a])*.

Dimensions: Care Recommendation 3

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm		☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☒ Beneficial/Effective		☐ Neutral Effect or Benefit		☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden		☒ Moderate/Neutral Burden		☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective		☒ Cost–Neutral		☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact		☐ Negative Impact
6. Directness of Evidence	☒ Directly Related		☐ Somewhat Related		☐ Indirectly Related
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 4

Education provided by the patient's therapist is an important care component in the management of HSD and hEDS, not just an adjunct to therapy *(Local Consensus, 2025 [5])*. Patients and families receive knowledge and tools needed to navigate a complex, chronic condition *(Camerota et al., 2023 [4a]; Engelbert and Scheper, 2011 [1b])*. Education on therapeutic principles included in the recommendation statement can improve outcomes, self-efficacy, and long-term self-management as well as establish trust with the patient and family *(Castori et al., 2012 [5a]; Engelbert and Scheper, 2011 [1b]; Russek et al., 2019 [5a]; Simmonds, 2022 [5a]; Smith, 2017 [1b]; Local Consensus, 2025 [5])*.

Principles of joint protection and core stability complement the multisystemic nature of HSD and hEDS and can include education about, and exercises for, muscle strength, improved movement patterns, physical function, and proprioception *(Hakim, 2024 [5a])*. Pain and injury can be significantly reduced by patients learning how to maintain joint positions and engage core musculature *(Engelbert and Scheper, 2011 [1b])*. Core strength and stability enhance postural control, reduce compensatory movement patterns, and improve function *(Friedrichsdorf et al., 2016 [5a]; Smith, 2017 [1b])*. Targeted approaches to care provide neuromuscular re-education, proprioceptive training, and gradual strengthening, while acknowledging the interactions between physical symptoms, psychological well-being, and social participation *(Castori et al., 2012 [5a]; Celletti et al., 2013 [5a])*.

Understanding differences between joint dislocation, subluxation, and instability can be critical for patients and families *(Hakim, 2024 [5a]; Murray, 2006 [5a]; Russek et al., 2023 [5a]; Smith, 2017 [1b])*. Communication with healthcare providers improves with this knowledge and awareness. The patients are empowered to respond appropriately to symptoms, fear can be reduced, and therapy compliance can be enhanced.

Additionally, functional improvement often precedes pain reduction or resolution *(Friedrichsdorf et al., 2016 [5a]; Local Consensus, 2025 [5])*. Focusing on improving quality of life, adding meaningful and functional activities into daily life, and not solely focusing on pain reduction will help achieve targeted care goals *(Smith, 2017 [1b])*. Self-management education equips patients with strategies and identifies the patient's level of readiness for successful therapy at assessments and throughout the therapeutic process *(Castori et al., 2012 [5a]; Simmonds, 2022 [5a])*. Effective strategies and lifestyle modifications are essential for symptom management with HSD or hEDS and include regular physical activity, activity modification, and activity pacing *(Castori et al., 2012 [5a]; Friedrichsdorf et al., 2016 [5a]; Russek et al., 2019 [5a]; Scheper et al., 2013 [1b])*.

Planning, goal setting, acceptance of current abilities, plus identifying accessible and meaningful activities will enhance therapeutic management. Children and adolescents with 'generalized joint hypermobility' often experience decreased participation in physical activities and increased musculoskeletal complaints *(Scheper et al., 2013 [1b])*. For patients who are dancers, hypermobility may increase injury risk or vulnerability, due to differences in bone health, ligament tension, muscle tone, and proprioception *(Day et al., 2011 [5a])*. Authors consistently conclude the value and importance of education and individualized activity planning. Activities *(e.g., walking, **swimming** (Frydendal et al., 2018 [3b]; Liaghat et al., 2018 [3b]), **Pilates, yoga, dance** (Day et al., 2011 [5a]; Filipa et al., 2018 [5a]; Mayes et al., 2021 [4b]; Simmonds, 2022 [5a]), **some martial arts, biking** (Local Consensus, 2025 [5])* have been shown to be effective. Higher-impact activities can be harmful, due to decreased proprioception and balance *(Castori et al., 2012 [5a]; Hakim, 2024 [5a]; Russek et al., 2019 [5a]; Zabriskie et al., 2022 [1b])*, but can also be effective when focused on muscle fitness or on joint position. Activity modification and pacing can establish greater motion and postural control and decrease pain over time *(Antcliff et al., 2018 [5a]; Castori et al., 2012 [5a]; Hakim, 2024 [5a]; Zabriskie et al., 2022 [1b])*.

Education on principles of hydration or electrolyte replenishing, relaxation techniques, and sleep hygiene are also helpful for patients with HSD and hEDS *(Local Consensus, 2025 [5a])*. Chronic fatigue, pain, sleep apnea, and other symptoms can affect sleep quality *(Castori et al., 2012 [5a]; Hakim et al., 2017 [5a]; Sedky et al., 2019 [1b])*. In one systematic review *(Sedky et al., 2019 [1b])*, patients with Ehlers-Danlos syndrome or Marfan syndrome were six times more likely to be diagnosed with obstructive sleep apnea compared to the general population *(Odds Ratio 6.28 [95% Confidence Interval 3.31–11.93], P<0.001, Z=5.61)*. Education and interventions focused on sleep or bedtime routines, caffeine intake, sleep environment, and sleep ergonomics can have a beneficial impact on sleep hygiene *(Local Consensus, 2025 [5])*.

Comprehensive patient and family education addresses joint protection and differentiation, core stability, targeted care, functional goals, self-management, and lifestyle strategies. Therapists can empower patients to manage their health, while improving outcomes, fostering resilience, and enhancing quality of life.

Dimensions: Care Recommendation 4

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☒ Beneficial/Effective	☐ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective	☐ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☒ Directly Related	☐ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☒ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 5

Children and adolescents with HSD and hEDS often experience a complex and fluctuating array of symptoms that significantly impact daily functioning and quality of life. Patient-Reported Outcome Measures *(PROM)* are increasingly recognized in clinical practice and research as essential tools to capture patient experiences, guide goal setting, and monitor progress over time *(Local Consensus, 2025 [5])*.

A growing body of literature supports the use of PROMs to assess domains such as pain interference, physical mobility, functional disability, and psychosocial well-being in this population. Commonly used instruments include the Canadian Occupational Performance Measure *(COPM)*, Pediatric Outcomes Data Collection Instrument *(PODCI)*, Functional Disability Inventory *(FDI)*, PROMIS: Pain Interference or Physical Function Mobility, and Pediatric Quality of Life Inventory *(PedsQL)*. Disease-specific validation of these tools for HSD/hEDS remains limited.

Outcome measures specific to symptomatic children with hypermobility were reviewed in a systematic review *(Maarj et al., 2021 [1a])*. Key constructs included identifying pain, function, quality of life, and fatigue. However, despite the use of validated tools, none were specifically validated for children with generalized joint hypermobility and associated symptoms.

Shotwell and Moore *(2022 [4a])* evaluated the reliability and validity of a functional outcome measure *(PODCI subscales)* in adolescents with HSD, demonstrating strong test-retest reliability and concurrent validity with PROMIS measures. Their findings support the use of standardized PROMs, although the need for tools that better reflect episodic symptom patterns and psychosocial complexity is highlighted.

Validity and utility of the FDI was evaluated in a large multicenter sample of youth with chronic pain *(Kashikar-Zuck et al., 2011 [4a])*, identifying distinct categories of disability and confirming strong psychometric properties. Although not disease-specific, the FDI offers clinically useful insights into functional limitations in pediatric populations with chronic pain.

Applying the Fear-Avoidance Model *(FAM)* to adolescents with HSD/hEDS, Van Meulenbroek et al. *(2020 [4b])* emphasized the importance of PROMs that capture psychological dimensions and multi-systemic symptoms. Their model added a biopsychosocial perspective to evaluating outcomes of multidisciplinary interventions for hypermobile adolescents with chronic musculoskeletal pain.

Recent consensus efforts have informed PROM implementation. Clark et al. *(2024 [4a])* developed a core outcome set for HSD/hEDS through a Delphi process, identifying key domains of pain, fatigue, mental health, participation, and quality of life as critical for assessment. Quinlan et al. *(2025 [4a])* further refined this by recommending specific tools such as the PedsQL Pain Questionnaire and the 6-minute walk test, emphasizing child-reported outcomes and feasibility in clinical settings. Clinicians and researchers consistently identify PROMs as appropriate to identify changes in patients, with the repeated administration over time and visits to capture progress and use the results to inform care and care plans *(Quinlan et al., 2025 [4a])*.

Key implementation strategies include administering PROMs at the start, midpoint, and end of care episodes to track progress and inform decisions *(Local Consensus, 2025 [5])*. Despite their utility, many PROMs lack disease-specific validation and sensitivity to episodic symptoms, underscoring the need for continued refinement.

PROMs are useful in the management of pediatric HSD/hEDS. Routine use of PROMs can enhance communication, support shared decision-making, and align patient care with measurable indicators of treatment effectiveness. Standardized use and further validation, particularly in disease-specific contexts, will impact clinical and research outcomes and quality of life for affected children and adolescents.

Dimensions: Care Recommendation 5

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective	☒ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☒ Directly Related	☐ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 6

Initiating a goal-directed home exercise program *(HEP)* at the time of evaluation, guided by patient-identified functional goals and patient-reported outcome measures *(PROMs such as COPM)*, is strongly supported by clinical evidence and expert consensus for adults and children with musculoskeletal and chronic conditions, including HSD and hEDS *(Birt et al., 2014 [4a]; Feldman et al., 2020 [5a]; Ferrell et al., 2004 [4b]; Palmer et al., 2021 [1a]; Spanhove et al., 2023 [2b]; To and Alexander, 2019 [3b]; Local Consensus, 2025 [5]).* This approach enhances engagement, supports self-management, and facilitates early integration of therapeutic activities into daily routines *(Palmer et al., 2021 [1a]; Spanhove et al., 2023 [2b]).*

Key themes from the evidence included early initiation and goal alignment, effectiveness of HEP, role of PROM and goal-setting, tailoring and adherence, supervised and multidisciplinary approaches, and consistency and progression:

- Early HEP initiation improves pain and function in individuals with syndromic hypermobility *(Palmer et al., 2021 [1a]).* Patients with joint hypermobility may progress more slowly, reinforcing the need for early, sustained intervention *(To & Alexander, 2019 [3b]).*
- Home-based programs are superior to no intervention and generally comparable to expert-led therapy, unless specialized care is needed *(Palmer et al., 2021 [1a]; Spanhove et al., 2023 [2b]).* Intensive multidisciplinary programs *(e.g., physical therapy plus CBT/cognitive behavioral therapy)* improve strength, function, and reduce kinesiophobia *(Bathen et al., 2013 [4b]; Buryk-Iggers et al., 2022 [1a]).*
- PROMs, like COPM, enhance relevance and adherence by aligning therapy with patient priorities *(Feldman et al., 2020 [5a]).*
- Tailored programs that fit daily routines improve adherence and outcomes, especially in pediatric populations *(Birt et al., 2014 [4a]).* Barriers include pain, lack of feedback, and environmental challenges; facilitators include education, family support, and collaborative goal-setting *(Birt et al., 2014 [4a]; Ferrell et al., 2004 [4b]).*
- Supervision may be more effective for addressing psychological barriers such as fear of movement *(Spanhove et al., 2023 [2b]; Thomas, 2023 [5a]).* Multidisciplinary rehabilitation improves strength and function, with measurable gains in tasks like stair climbing and toe raises *(Buryk-Iggers et al., 2022 [1a]).*
- Regular, independent practice supports motor learning and long-term benefit *(Pacey et al., 2013 [2b]; Ferrell et al., 2004 [4b]).* Progression should be individualized based on pain, tolerance, and functional gains, with regular reassessment *(Buryk-Iggers et al., 2022 [1a]; Feldman et al., 2020 [5a]).*

A personalized, goal-oriented HEP initiated at evaluation—supported by PROMs, consistent practice, and adaptive progression—is a best-practice strategy for managing HSD and hEDS. When appropriate, supervised or multidisciplinary approaches may further enhance outcomes, particularly in the presence of psychological or functional barriers.

Dimensions: Care Recommendation 6

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm		
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit		
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden		
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective	☐ Cost–Neutral	☐ Cost–Prohibitive		
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact		
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related		
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 7

Therapeutic exercise is vital for management of HSD and hEDS. The primary therapeutic goals are to enhance joint stability, protect joint structures, and restore muscular balance. These interventions do not aim to reduce joint laxity but instead promote neuromuscular adaptations to compensate for it *(Local Consensus, 2025 [5])*.

Current evidence supports a multifaceted approach to therapeutic exercise in pediatric HSD and hEDS, emphasizing stabilization, proprioception, and whole-body movement strategies. Progressive resistance and neuromuscular training have been shown to improve pain, function, and quality of life, particularly when delivered through individualized and supervised programs *(Buryk-Iggers et al., 2022 [1a]; Zabriskie, 2022 [1b])*.

Both generalized and targeted physiotherapy approaches are effective, with a randomized trial demonstrating reductions in pain and improvements in function, although differences between methods were not significant *(Kemp et al., 2010 [2b])*. Whole-body movement strategies, such as Pilates and yoga, are also advocated to enhance postural control and coordination *(Smith, 2017 [1b])*.

Children with hypermobility often exhibit altered gait patterns and increased passive joint range of motion *(ROM)*, highlighting the importance of proprioceptive and motor control retraining *(Fatoye et al., 2011 [4a])*. Structured exercise programs have demonstrated efficacy in reducing knee pain and improving functional outcomes *(Pacey et al., 2012 [5b])*.

Joint protection principles are important for management, including avoiding end-range joint positions, using branches or splints when necessary, and focusing on controlled, mid-range movements *(Hakim, 2024 [5a]; Minhas, 2021 [5a])*. Education on activity modification and graded return to function further supports safe and sustainable progress.

Effective management requires individualized, progressive programs tailored to each child's presentation. Multidisciplinary care (including physical therapy and occupational therapy) is critical, alongside patient and family education to support adherence. High-impact activities should be avoided to minimize injury risk. Despite promising outcomes, further multicenter randomized trials are needed to establish optimal exercise parameters in pediatric populations *(Engelbert et al., 2017 [5a]; Scheper et al., 2013 [1b])*.

Dimensions: Care Recommendation 7

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm		☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective		☒ Neutral Effect or Benefit		☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden		☐ Moderate/Neutral Burden		☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective		☐ Cost–Neutral		☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact		☐ Negative Impact
6. Directness of Evidence	☐ Directly Related		☒ Somewhat Related		☐ Indirectly Related
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 8

Rehabilitation for children with HSD and hEDS should be individualized, technique-focused, and responsive to clinical presentation. The evidence consistently emphasizes the importance of reinforcing proper movement patterns to address joint instability and prevent maladaptive compensation. Poor technique often stems from joint laxity and can be mitigated through consistent training *(Simmonds, 2022 [5a]; Local Consensus, 2025 [5])*. Maintaining neutral joint positions—rather than allowing hyperextension—has been shown to reduce pain and improve function *(Pacey et al., 2013 [2b])*.

Early-stage interventions should prioritize movement quality over intensity. Visual feedback, tactile cues, and slow, controlled movements are recommended to promote mid-range joint control and retrain neuromuscular pathways. These strategies help prevent reinforcement of poor motor habits and support long-term functional improvement.

Exercise programs must be tailored to individual tolerance, with modifications to reduce pain and encourage participation. A retrospective study integrating multidisciplinary care and personalized pain management demonstrated improved engagement and outcomes *(Van Meulenbroek et al., 2020 [4b])*. Similarly, tailoring interventions based on symptom presentation ensures exercises remain both effective and well-tolerated *(Hakim, 2024 [5a])*.

Gradual progression starting with low repetitions and minimal resistance allows patients to build strength and proprioception without exacerbating symptoms *(Kemp et al., 2010 [2b]; Smith, 2017 [1b])*. Daman et al. *(2019 [4b])* reported improvements in knee proprioception, pain levels, and overall quality of life through a combined exercise therapy regimen.

Clinically, these findings underscore the importance of assessment-driven modifications. Monitoring patient responses in real time and adjusting exercises can prevent maladaptive patterns and ensure safety. Reinforcing technique remains a core component of therapy, and pain monitoring can guide progression. Motivational techniques can also improve adherence, especially in younger patients, while education on body mechanics empowers families to recognize instability and implement preventive strategies in daily life and sports. Appendix 2 provides practical examples of these modifications and supportive strategies.

Effective rehabilitation for pediatric patients with HSD or hEDS is directly connected to individualized, technique-driven exercise programs that emphasize safety, gradual progression, and holistic support. This comprehensive approach not only minimizes pain but also enhances functional outcomes and fosters sustained engagement in physical activity.

Dimensions: Care Recommendation 8

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm		☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective		☒ Neutral Effect or Benefit		☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden		☒ Moderate/Neutral Burden		☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective		☐ Cost–Neutral		☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact		☐ Negative Impact
6. Directness of Evidence	☐ Directly Related		☒ Somewhat Related		☐ Indirectly Related
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☒ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 9

Postural awareness plays an important role in the clinical management of pediatric and adolescent patients with HSD and hEDS. These conditions are characterized by joint hypermobility, impaired proprioception, and compensatory movement patterns that compromise joint stability and functional mobility. A growing body of evidence supports a multifaceted rehabilitation approach that integrates proprioceptive retraining, muscle activation, selective stretching, and mid-range control to improve outcomes and reduce injury risk.

Children with HSD/hEDS frequently demonstrate deficits in joint position sense and motor coordination. Peterson et al. *(2018 [1a])* identified decreased proprioceptive acuity in this population, although the evidence base remains limited due to small sample sizes and methodological constraints. Similarly, Rombaut et al. *(2010 [4b])* reported significantly impaired knee joint position sense in individuals with hEDS compared to healthy controls, reinforcing the need for targeted proprioceptive interventions. These findings underscore the importance of movement-based therapies (e.g., mirror feedback, closed-chain exercises, slow and controlled motions) to retrain sensory pathways and enhance joint awareness.

Muscle activation strategies have also shown promise in improving postural control and dynamic stability. External attentional focus significantly enhanced postural stability and balance performance in individuals with generalized joint hypermobility (GJH), outperforming internal focus techniques *(Zorlular et al., 2024 [2b])*. The use of physiotherapy has also been shown to activate stabilizing musculature, reporting improvements in proprioception, pain, and quality of life among hEDS patients *(Reychler et al., 2021 [1a])*. These findings suggest that incorporating external verbal cues and biofeedback-assisted activation may optimize motor performance and facilitate safer movement patterns.

Direct evidence on selective stretching in hypermobile populations is limited. However, clinical consensus supports its use to address muscle imbalances and reduce compensatory movement strategies *(Local Consensus, 2025 [5])*. Stretching tight muscle groups, such as the hip flexors and upper trapezius, in mid-range positions, combined with relaxation and breathing techniques, may improve flexibility without exacerbating joint laxity.

Mid-range proprioceptive training has emerged as a critical component of rehabilitation for hypermobile individuals. Reychler et al. *(2021 [1a])* noted improvements in proprioception following physiotherapy interventions that included mid-range control exercises. Positive outcomes from multidisciplinary rehabilitation in adolescents with hEDS include enhanced postural control and reduced pain, although further validation is needed due to small sample sizes *(Van Meulenbroek et al., 2020 [1a])*. These findings support the use of balance training on stable and unstable surfaces, resistance band exercises, and functional tasks with feedback to reinforce proprioceptive input within safe ranges of motion.

Claire Smith *(2017 [1b])* provides a comprehensive overview of HSD and hEDS therapeutic management, emphasizing the importance of postural awareness, exercise, and physiotherapy. This integrative perspective aligns with emerging evidence and local consensus, advocating for a holistic rehabilitation framework that includes proprioceptive training, muscle activation, selective stretching, and mid-range control.

A structured, evidence-informed rehabilitation strategy that addresses the unique anatomical and functional needs of pediatric and adolescent patients with HSD/hEDS is essential *(Local Consensus, 2025 [5])*. By enhancing joint stability, reducing injury risk, and improving functional mobility, these interventions support safe participation in daily activities and contribute to long-term quality of life. As research continues to evolve, individualized therapy plans remain critical to optimizing clinical outcomes.

Dimensions: Care Recommendation 9

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective	☐ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 10

Breathing mechanics play a critical role in the functional capacity and postural control of individuals with hypermobility-related conditions. Altered breathing patterns *(e.g., upper chest breathing, poor diaphragmatic engagement)* are common in this population and contribute to fatigue, decreased endurance, and impaired core stability *(Kepenek-Varol et al., 2023 [4b]; Massery et al., 2016 [5b]; Local Consensus, 2025 [5])*.

Pulmonary assessments in individuals with generalized joint hypermobility in one small case-control study revealed reduced forced expiratory volume *(FEV1)*, forced vital capacity *(FVC)*, and maximal expiratory pressure *(MEP)*, along with decreased chest expansion and lower six-minute walk test *(6MWT)* distances, compared to similar healthy participants *(Kepenek Varol et al., 2023 [4b])*. These findings suggest that a structural and functional impact of connective tissue differences in GJH can affect respiratory mechanics, muscle strength and chest wall mobility, in turn limiting functional capacity.

The diaphragm functions as a central pressure regulator, supporting ventilation, spinal alignment, venous return, and gastrointestinal motility *(Massery et al., 2016 [5b])*. Its activation is essential for engaging deep core musculature, which stabilizes the spine and pelvis and enhances proprioceptive feedback *(Massery et al., 2013 [4b])*. Massery et al. *(2013 [4b])* described that glottal control *(i.e., an airway mechanism linked to breath regulation)* can improve postural stability, reinforcing the connection between respiratory and musculoskeletal systems. In individuals with joint hypermobility, compromised diaphragmatic function may lead to compensatory movement patterns and increased injury risk *(Engelbert et al., 2017 [5a])*.

Inspiratory Muscle Training *(IMT)* has demonstrated significant benefits in improving lung function, respiratory muscle strength, and exercise capacity in patients with hEDS *(Palmer et al., 2021 [1a]; Reychler et al., 2021 [1a]; Reychler et al., 2019 [2b])*. These improvements are clinically relevant for enhancing endurance and reducing pain, particularly in populations with multisystem involvement. IMT improved lung function in patients with hEDS in one randomized, controlled trial *(Reychler et al., 2019 [2b])*. These findings were supported by Palmer et al. *(2021 [1a])*, concluding that conservative interventions such as IMT enhance exercise capacity and reduce fatigue in individuals with syndromic hypermobility. Integrating respiratory training into physical therapy protocols for hypermobility *(e.g., HSD, hEDS)* is also recommended by Reychler et al. *(2021 [1a])*, for improvements in inspiratory strength and postural control.

The importance of breath control strategies in managing multisystem symptoms *(e.g., fatigue, pain, and autonomic dysfunction)* is highlighted in an evidence-based rationale for physical therapy in HSD and hEDS *(Engelbert et al., 2017 [5a])*. Authors advocated for a holistic approach that includes breathing mechanics as a core component of rehabilitation. Additionally, autonomic symptoms such as orthostatic intolerance further highlight the need for effective breath control to support physical function. Holistic approaches like yoga and Pilates, which emphasize breath and movement integration, offer promising strategies for improving multisystem regulation and overall quality of life *(Engelbert et al., 2017 [5a])*.

Optimizing breathing mechanics—particularly through diaphragmatic training and IMT—is a therapeutically important strategy for enhancing core stability, functional endurance, and multisystem resilience in individuals with hypermobility-related conditions.

Dimensions: Care Recommendation 10

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden	☐ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective	☒ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 11

Therapeutic exercise is an evidence-based tool in conservative management for this population with HSD and hEDS. Over time, the evidence has grown in the support of structuring therapeutic exercise around an individualized approach with key principles of neuromuscular re-education, strength and endurance training, proprioceptive enhancement, and psychosocial support. These principles interact dynamically to support motor control, joint stability, and functional resilience.

Neuromuscular re-education is essential for correcting compensatory movement patterns commonly adopted by hypermobile individuals, such as joint locking in hyperextension for perceived stability. These maladaptive strategies may increase joint stress and injury risk. Techniques including slow, controlled movements, mirror feedback, and tactile cues are used to retrain motor control and improve movement quality. Smith *(2017 [1b])* and Zech et al. *(2009 [1b])* have emphasized the importance of this approach, restoring proper motor patterns to enhance joint stability and prevent injury. Seo et al. *(2023 [1a])* and Uzunkulaoğlu and Çetin *(2019 [4b])* have highlighted the interdependence between proprioception and motor learning, suggesting that improvements in one area may positively influence the other.

As patients begin to move with greater control, strength-based exercise is equally vital in addressing the muscular deficits observed in youth with joint hypermobility. These individuals often present with reduced strength in key muscle groups, particularly the quadriceps and hamstrings, which can make every day tasks like climbing stairs or rising from a chair more difficult *(Akaras et al., 2025 [4b])*. Tailored strength training programs that incorporate both open and closed kinetic chain tasks, as well as static and dynamic exercises, have demonstrated efficacy in improving joint stability and reducing pain.

Training across both neutral and hypermobile ranges is supported by evidence showing improvements in muscle strength, pain reduction, and quality of life *(Pacey et al., 2013 [2b]; Palmer et al., 2021 [1a]; To & Alexander, 2018 [3b])*. Ferrell et al. *(2004 [3b])* and Engelbert et al. *(2017 [5a])* supported the role of strength training, while Henriksen et al. *(2022 [4a])* also shared that supervised heavy resistance training can be well tolerated and potentially beneficial for young women with hypermobility-related knee pain, leading to improvements in muscle strength, proprioception, and knee pain.

Endurance training complements strength development by addressing fatigue and enhancing overall functional capacity. Low-impact aerobic activities, when gradually progressed in duration and intensity, can improve cardiovascular fitness and support sustained physical activity. This is particularly relevant for younger patients with HSD or hEDS, who may experience reduced lung volumes and early fatigue during exercises *(Smith, 2017 [1b]; Local Consensus, 2025 [5])*. Combining strength and endurance training is recommended to optimize rehabilitation outcomes.

Proprioception training is an essential component of rehabilitation for this population, given the compromised joint position sense associated with hypermobility. Akaras et al. *(2025 [4b])* attribute these deficits to altered mechanoreceptor function in ligaments and joint capsules. Pacey et al. *(2014 [3b])* found that proprioceptive acuity is comparable in both flexion and hyperextension, supporting the inclusion of training across the full range of motion. Tools such as balance boards, foam pads, and functional tasks are commonly used to enhance proprioceptive feedback and mid-range joint control. Home-based closed kinetic chain exercises have also been shown to improve proprioceptive performance and quality of life *(Ferrell et al., 2004 [3b]; Simmonds, 2022 [5a]; Engelbert et al., 2017 [5a])*. In pediatric populations, engaging modalities *(such as a computerized force platform for postural assessment)* may be effective in improving motivation and adherence *(Monteleone et al., 2018 [4b])*.

Comprehensive, individualized, and evidence-based therapeutic exercise for pediatric and adolescent patients with HSD and hEDS can target neuromuscular control, strength, endurance, and proprioception – potentially improving function, reducing pain, and enhancing quality of life.

Dimensions: Care Recommendation 11

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective	☒ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 12

Musculoskeletal and systemic comorbidities in individuals with HSD or hEDS merit a high level of clinical suspicion for therapists. These conditions are characterized by connective tissue laxity, joint instability, and impaired core function, which collectively predispose patients to a broad spectrum of complications *(Murray, 2006 [5a]; Russek et al., 2023 [5a]; Russek et al., 2019 [5a]; Local Consensus, 2025 [5])*.

Musculoskeletal manifestations are prevalent and may be clinically significant. Pediatric patients frequently experience joint dislocations and subluxations, especially in elbows and knees, due to hypermobility *(Hakim, 2024 [5a]; **Rombaut et al., 2012 [4b]**)*. Altered biomechanics and diminished proprioception contribute to an elevated risk of fractures, sprains, and strains *(Banica et al., 2020 [4b]; Castori **and Colombi**, 2015 [5a])*. Tendonitis and tendinopathy in shoulders, knees, and ankles are common due to repetitive strain and compensatory movement patterns *(Russek et al., 2019 [5a])*.

Temporomandibular joint *(TMJ)* dysfunction is another common concern, often resulting in chronic pain and functional limitations due to jaw hypermobility and poor muscular coordination *(Celletti et al., 2013 [5a]; Kalaykova et al., 2006 [4b]; **Pasinato et al., 2011 [4b]; Winocur et al., 2000 [4a]**)*. Headache due to cervical instability, postural deviations, or muscle tightness may also

compound the symptom burden *(Mehta et al., 2024 [5a]; **Rozen et al., 2006 [4b]**)*. Spinal conditions such as scoliosis, spondylolysis, and disc prolapse are more prevalent as well and may be exacerbated by poor spinal support *(Atwell et al., 2021 [5a]; Mehta et al., 2024 [5a]; **Murray, 2006 [5a];** Russek et al., 2019 [5a])*.

Pelvic floor dysfunction is increasingly being recognized in this population as well, including urinary incontinence and constipation *(Local Consensus, 2025 [5])*. Women with myofascial pelvic pain and stress urinary incontinence were reported as having a 3.76-fold increased odds of HSD *(95% CI: 1.35 – 10.5, p=0.02)* in a retrospective case-control study *(Hastings et al., 2019 [4a])*.

Chiari malformations represent a serious structural comorbidity associated with connective tissue disorders, warranting neuroimaging when clinically indicated *(Milhorat et al., 2007 [3a]; Local Consensus, 2025 [5])*.

In adolescents transitioning into adulthood, additional clinical vigilance is warranted for adult-onset comorbidities. Prevalence of carpal tunnel syndrome and early-onset osteoarthritis may be higher due to chronic joint stress and repetitive strain *(**Aktas et al., 2008 [4a]; Booshanam 2011 [4b];** Murray, 2006 [5a]; **Simonsen 2012 [4b]**)*.

Dimensions: Care Recommendation 12

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm		☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective		☒ Neutral Effect or Benefit		☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden		☐ Moderate/Neutral Burden		☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective		☐ Cost–Neutral		☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact		☐ Negative Impact
6. Directness of Evidence	☐ Directly Related		☒ Somewhat Related		☐ Indirectly Related
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☒ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 13

Children and adolescents with HSD or hEDS may experience increased risks in sports participation due to joint instability, altered biomechanics, proprioceptive deficits, and chronic pain. These risks can be more significant in high-impact or multidirectional sports where joint loading and rapid directional changes could exacerbate injury susceptibility *(Peterson et al., 2018 [1a]; Schroeder and Lacallee, 2006 [5a]; Smith, 2017 [1b]; Vaishya and Hasija, 2013 [4a])*.

When therapists provide education to children, families, and coaches regarding the implications of hypermobility on safe sports participation and injury prevention, therapists can help hypermobile children engage in physical activity safely, improving their quality of life while minimizing injury risk. Educational components may include joint protection strategies *(Engelbert et al., 2017 [5a]; Nicholson et al., 2022 [5a])*, neuromuscular and proprioceptive training *(Frydendal et al., 2018 [3b]; Junge et al., 2015 [3a])*, biomechanical training *(Stracciolini et al., 2017 [5a])*, activity pacing strategies *(Antcliff et al., 2018 [5a]; Simmonds et al., 2019 [4a])*, balance testing and functional screening tools *(Armstrong, 2020 [3b]; Armstrong, 2020 [4a]; Armstrong and Greig, 2018 [4a]; Soper et al., 2015 [4a])*, sport-specific considerations *(Chan et al., 2018 [3a]; Liaghat et al., 2018 [3b]; Sanches et al., 2015 [4a]; Steinberg et al., 2016 [4a]; Vera et all 2020 [4b])*, and the role of training volume and proper technique *(Armstrong, 2020 [4b]; Bukva et al., 2019 [3a]; Dhuri and Usman, 2016 [4b])*. *(These interventions have also been summarized in other areas of this guideline.)*

Children with HSD or hEDS face complex challenges in sports participation due to increased injury risk and chronic pain. Benefits of physical activity for children with hypermobility include improved muscle strength, proprioception, coordination, and psychosocial well-being. A comprehensive, individualized, and multidisciplinary approach can safely provide benefits of physical activity. Risks may also be significant, as children with generalized joint hypermobility are at increased risk for joint sprains, dislocations, and ligament injuries. Injury risk may be influenced by training duration more than hypermobility alone *(Bukva et al., 2019 [3a])*. Thus, therapists are pivotal to educating families, implementing neuromuscular and proprioceptive training, and guiding biomechanical corrections.

Dimensions: Care Recommendation 13

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm	☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☒ Beneficial/Effective		☐ Neutral Effect or Benefit	☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden		☒ Moderate/Neutral Burden	☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective		☐ Cost–Neutral	☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact	☐ Negative Impact
6. Directness of Evidence	☐ Directly Related		☒ Somewhat Related	☐ Indirectly Related
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☒ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯ ☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 14

When pediatric patients with generalized joint hypermobility *(GJH)*, particularly those diagnosed with HSD or hEDS, resume higher-level athletic activity following a pause or injury, sport-specific training programs should be adapted to account for the patient's unique biomechanical and physiological characteristics, individualizing rehabilitation strategies for this population *(Filipa and Barton, 2018 [5a]; Local Consensus, 2025 [5])*. Hypermobile athletes often present with increased joint range of motion, proprioceptive deficits, and compensatory movement patterns. These adaptations, while initially protective, may predispose athletes to reinjury, muscle imbalances, and chronic dysfunction if not addressed *(Local Consensus, 2025 [5])*.

Tailored return-to-protocols would include gradual reintroduction of sport-specific movements and an emphasis on neuromuscular control, core stability, and joint protection. Pacey et al. *(2010 [1a])* found that children and adolescents with generalized joint hypermobility participating in contact sports had a 4.69-fold increased risk of knee joint injury, underscoring the importance of joint laxity assessment in return-to-play decisions. However, no increased risk for ankle injuries was reported, suggesting that injury risk could be joint-specific or influenced by the type of sport. Bukva et al. *(2019 [3a])* found no significant correlation between Beighton scores and injury rates in elite artistic gymnastics, suggesting that training duration and sport-specific demands may be more predictive of injury risk than hypermobility alone. This reinforces the need for individualized risk assessments, compared to reliance on screening tools alone.

Children with GJH had a 5.5-fold increased risk of sustaining a second ACL injury within 12 months of returning to sport after ACL reconstruction, compared to non-hypermobile peers, according to Zsidia et al. *(2023 [4a])*. Enhanced neuromuscular control strategies, progressive loading, and ongoing monitoring during rehabilitation could significantly benefit these patients. The multisystemic nature of hypermobility disorders was also reviewed, including fatigue, autonomic dysfunction, and impaired motor control, which could complicate athletic recovery and performance *(Castori and Colombi, 2015 [5a])*. Children with HSD or hEDS were reported to have a higher prevalence of fractures and reduced bone size, also suggesting the need for cautious and progressive loading strategies *(Banica et al., 2020 [4b])*.

Hypermobile athletes also demonstrate sensorimotor and neuromuscular deficits, especially in high-demand sports. Frydendal et al. *(2018 [3b])* and Liaghat et al. *(2018 [3b])* reported altered shoulder control and fatigue-related strength deficits in competitive swimmers with GJH, suggesting the need for targeted strengthening and stability training.

Training within non-compensatory end ranges, where control and alignment are maintained, can be beneficial to these patients, with emphasis on controlled eccentric loading, mid-range strength development, and dynamic stability drills. Common compensatory patterns may be identified through functional movement screening and analysis, then corrected to prevent overuse injuries and chronic pain *(Local Consensus, 2025 [5])*.

Filipa and Barton *(2018 [5a])* report effectiveness of a structured, phase-based rehabilitation approach in an adolescent preprofessional dancer following *os trigonum excision*. Their program also emphasized progressive loading, neuromuscular control, and sport-specific retraining, aligning with the practices from other evidence in hypermobile athletes returning to high-level performance. These approaches support therapeutic management toward full sports participation following a pause or injury while minimizing injury risk *(Local Consensus, 2025 [5a])*.

Dimensions: Care Recommendation 14

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm		☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective		☒ Neutral Effect or Benefit		☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden		☐ Moderate/Neutral Burden		☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective		☐ Cost–Neutral		☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact		☐ Negative Impact
6. Directness of Evidence	☐ Directly Related		☒ Somewhat Related		☐ Indirectly Related
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☒ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 15

Pediatric patients with HSD or hEDS often experience joint instability, pain, and fatigue, especially in the small joints of the hands, interfering with daily activities. Orthotic intervention is increasing in clinical interest as a non-invasive, functional strategy to support joint health and function, reduce symptom burden, and improve quality of life *(Local Consensus, 2025 [5])*. Orthotics help maintain optimal joint alignment in hypermobile phalangeal and thumb joints, reducing strain on ligaments and tendons . This is particularly beneficial during repetitive fine motor tasks, where joint stress is high such as writing, typing, playing instruments, or gripping tools *(Hakim, 2024 [5a]; Jensen et al., 2021 [4b])*. Orthotics may help prevent overuse injuries while preserving joint mobility and strength *(Local Consensus, 2025 [5])*.

Hand orthotics were shown to be effective in a randomized clinical trial of adults with HSD or hEDS with symptoms of pain and/or paresthesia in the hands *(Susanne and Lisbeth, 2024 [2b])*. Hand orthotics were also reported as more effective than wrist-stabilizing exercises in improving function and reducing symptoms *(Susanne and Lisbeth, 2024 [2b])*. Finger orthoses were found to improve hand function and reduce cognitive load during manual tasks in individuals with hEDS, joint hypermobility syndrome, or Classical EDS *(Jensen et al., 2021 [4b])*.

The inclusion of finger and thumb orthotics as a therapeutic option for pediatric patients with HSD or hEDS is supported by a growing body of clinical research and expert consensus *(Smith, 2017 [1b]; Song et al., 2020 [4a])*. These devices optimize joint positioning, reduce strain and pain during activities, improve function and quality of life, and support well-being.

Dimensions: Care Recommendation 15

1. Safety versus Harm	☒ Safety > Harm		☐ Balanced Safety & Harm		☐ Safety < Harm
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective		☒ Neutral Effect or Benefit		☐ Ineffective/No Benefit
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden		☒ Moderate/Neutral Burden		☐ High Burden
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective		☒ Cost–Neutral		☐ Cost–Prohibitive
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact		☐ Moderate/Neutral Impact		☐ Negative Impact
6. Directness of Evidence	☐ Directly Related		☒ Somewhat Related		☐ Indirectly Related
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☒ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***	

Evidence Synthesis for Care Recommendation 16

Use of foot orthoses as a conservative, first-line treatment for pediatric flexible pes planus is common, including with children with HSD or hEDS presenting with symptomatic pes planus *(Evans et al., 2022 [1a])*. Pes planus was also identified as the most prevalent clinical finding among children with joint hypermobility in one retrospective study *(Bozkurt et al., 2019 [4a])*. Local consensus aligns with available evidence, which supports the potential role of orthotics in managing hypermobility-related foot issues, although the quality and certainty of available evidence is low *(Atwell et al., 2021 [5a]; Evans et al., 2022 [1a]; Smith, 2017 [1b]; Song et al., 2020 [4a]; Local Consensus, 2025 [5])*.

As a first-line intervention, comparing customized foot orthoses *(CFO)*, prefabricated foot orthoses *(PFO)*, and shoes, both custom-made and prefabricated orthotics reduced pain and improved function, particularly in symptomatic children *(Engelbert et al., 2017 [5a]; Evans et al., 2022 [1a]; Smith, 2017 [1b])*. Minimal control, over-the-counter, or semi-customizable orthotics are recommended as first-line interventions, leading to consistent reductions in pain and fatigue *(Evans et al., 2022 [1a]; Local Consensus, 2025 [5])*. Integrating orthotic management with other therapeutic interventions, as part of a multimodal management strategy for Ehlers-Danlos syndrome, can improve joint stabilization and symptom relief *(Song et al., 2020 [4a])*.

Higher-level orthotics may help children with moderate to severe pronation and calcaneal valgus or those who do not respond adequately to minimal control orthotics *(Local Consensus, 2025 [5])*. Options such as University of California Biomechanics Laboratory *(UCBL)* orthotics or supramalleolar orthotics *(SMOs)* offer increased structural support and alignment control. These devices are particularly beneficial for children with significant joint laxity or those who experience persistent symptoms despite initial interventions.

As children respond to treatment, a gradual transition from higher-level orthotics to less restrictive options is recommended, guided by individual tolerance and clinical response *(Local Consensus, 2025 [5])*. This adaptive approach ensures that orthotic support evolves in tandem with the child's developmental needs and therapeutic progress.

Beyond symptom relief, effective orthotic management contributes to improved participation, mobility, and quality of life. This aligns with evidence in the previous recommendation that orthotic interventions can reduce cognitive load and improve function in hypermobility-related conditions *(Hakim, 2024 [5a]; Higo et al., 2023 [5a]; Jensen et al., 2021 [4b]; Maarj et al., 2023 [3a]; Smith, 2017 [1b]; Susanne and Lisbeth, 2024 [2b])*.

Dimensions: Care Recommendation 16

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☐ Low Burden	☒ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☐ Cost–Effective	☒ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 17

Asymptomatic pes planus *(also known as flat feet)* can be a frequent and typically benign finding in children with HSD or hEDS. Evans et al. *(2022 [1a])* synthesized evidence with low to very low certainty, finding that custom foot orthoses *(CFO)* and prefabricated foot orthoses *(PFO)* offer no clinically meaningful differences over standard footwear in asymptomatic cases. They reported little or no difference in pain reduction at one year and no difference in withdrawals due to adverse events. Additionally, in cross-sectional study of adults with and without generalized joint hypermobility *(Tas et al., 2021 [4b])*, the mechanical properties of muscles and tendons were reported as similar in individuals with and without GJH, thus not associated with GJH.

These findings support that orthotic use in asymptomatic children is not supported at this time by available evidence and may lead to unnecessary dependency, economic burden, and reduced intrinsic muscle activation *(Evans et al., 2022 [1a])*. For pediatric patients with HSD or hEDS and asymptomatic pes planus, a rehabilitative, alignment-focused approach may be more beneficial than orthotic use.

Dimensions: Care Recommendation 17

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden	☐ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective	☐ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☒ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯ ☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 18

Therapeutic management of pediatric patients with HSD or hEDS benefits from an individualized approach, especially in determining the frequency of therapeutic interventions. Symptoms present on wide spectrum of variability among these children and adolescents and can also impact functional ability and quality of life, reinforcing the need for a flexible and responsive therapeutic model *(Atwell et al., 2021 [5a]; Peterson et al., 2018 [1a])*. Increased physical demands or changes in activities *(e.g., sports participation, level of intensity, return to sports following injury)* can also exacerbate symptoms, necessitating changes in therapy frequency to manage pain and joint instability *(Hjalmarsson et al., 2023 [4a]; Lindholm et al., 2025 [4a])*.

The patient's readiness for therapy and engagement in self-management strategies enhances treatment efficacy *(Local Consensus, 2025 [5])*. Patients in early stages of readiness, who may experience fear of movement, or who have low confidence in movement, benefit from more frequent sessions focused on education and support *(Clark & Knight, 2017 [5a])*. As they progress, therapy can shift toward maintenance with less frequent visits.

To guide clinical decision-making, consensus-based frequency ranges have been outlined in Appendix 3. These ranges are not prescriptive but serve as flexible guidelines that should be adapted based on ongoing assessment of the patient's symptoms, activity level, and readiness. Individualizing therapy frequency for and effective management of pediatric patients with HSD or hEDS is supported by clinical evidence *(Palmer et. al., 2021 [1a])* and expert consensus *(Local Consensus, 2025 [5])*.

Dimensions: Care Recommendation 18

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden	☐ Moderate/Neutral Burden	☐ High Burden	
4. Cost *(Cost for organization and/or patient/family)*	☒ Cost–Effective	☐ Cost–Neutral	☐ Cost–Prohibitive	
5. Impact on quality of life, morbidity, or mortality	☒ Positive Impact	☐ Moderate/Neutral Impact	☐ Negative Impact	
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☒ High ⊕⊕⊕⊕	☐ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯ ☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Evidence Synthesis for Care Recommendation 19

While therapeutic interventions for patients with HSD and hEDS, such as physical therapy and lifestyle modifications, are recommended for most patients, these interventions are not universally effective. In cases where patients do not respond adequately to these interventions, or when additional symptoms interfere with therapeutic progress, it is both appropriate and necessary for therapists to encourage families to seek further care from primary care physicians or other relevant specialists *(Clark et al., 2024 [1a]; Kulas Soborg et al., [1a]; Palmer et al., 2020 [1a]; Local Consensus, 2025 [5])*.

Research consistently highlights the chronic and multifaceted nature of HSD and hEDS *(Celletti et al., 2013 [5a])*. Children with these conditions frequently experience pain, fatigue, coordination difficulties, and gastrointestinal or autonomic symptoms, all of which can hinder progress in therapy *(Atwell et al., 2021 [5a]; Bale et al., 2019 [2a])*. Symptoms change and fluctuate in severity or frequency, underscoring the importance of a multidisciplinary approach to care. Bale et al. *(2019 [2a])* and Dockrell et al. *(2021 [4a])* support that timely referrals to medical providers can facilitate more comprehensive assessments and access to pharmacological or adjunctive therapies. A randomized controlled trial *(Bale et al., 2019 [2a])* demonstrated that a multidisciplinary intervention strategy significantly improved outcomes in children with symptomatic joint hypermobility. Atwell et al. *(2021 [5a])* emphasized the role of primary care in managing these complex conditions.

Additional support for this approach is reported in systematic reviews. While exercise and conservative interventions can be beneficial, their success is highly individualized and often dependent on the integration of care across disciplines *(Buryk-Iggers et al., 2022 [1a]; Palmer et al. 2021 [1a])*. Integrated care models have been shown to improve patient outcomes and satisfaction. Rehabilitation alone can be insufficient due to the systemic nature of hEDS *(Corrado and Ciardi, 2018 [1a])*. There is a need for tailored interventions, such as those evaluated for lower limb symptoms in children with HSD or hEDS *(Peterson et al., 2018 [1a])*. Resistance training is emphasized for the importance of careful monitoring and individualized programming, particularly in pediatric populations *(Legerlotz, 2020 [1a]; Zabriskie, 2022 [1a])*. Adult patients with HSD or hEDS experience better healthcare outcomes when care is coordinated across disciplines *(Estrella and Frazier, 2023 [1a])*.

In summary, the recommendation to refer pediatric patients with HSD or hEDS to primary care or specialty providers when therapeutic progress is limited is strongly supported by current evidence. This approach ensures that the full spectrum of symptoms is addressed, facilitates individualized care planning, and enhances the overall healthcare experience for patients and families. Encouraging interdisciplinary collaboration is not only clinically sound but essential for managing the complexities of these conditions in pediatric populations.

Dimensions: Care Recommendation 19

1. Safety versus Harm	☒ Safety > Harm	☐ Balanced Safety & Harm	☐ Safety < Harm	
2. Clinically Effective / Benefits Patient	☐ Beneficial/Effective	☒ Neutral Effect or Benefit	☐ Ineffective/No Benefit	
3. Adherence *(Burden for staff/patient/family; Access to care)*	☒ Low Burden	☐ Moderate/Neutral Burden	☐ High Burden	
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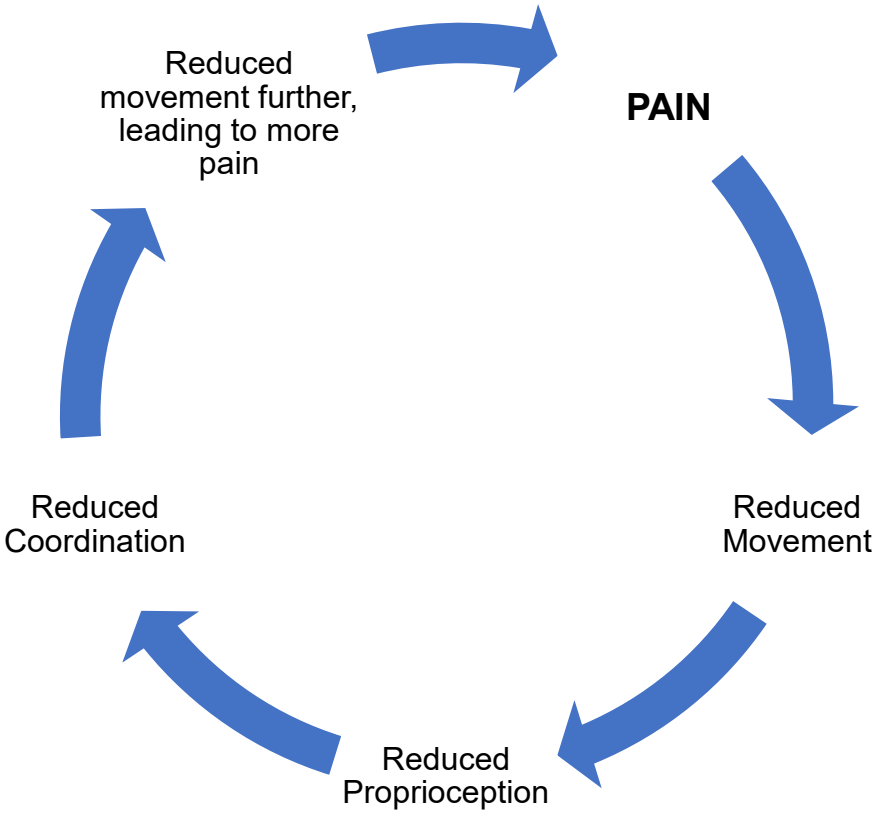
6. Directness of Evidence	☐ Directly Related	☒ Somewhat Related	☐ Indirectly Related	
7. Grade of the Body of Evidence	☐ High ⊕⊕⊕⊕	☒ Moderate ⊕⊕⊕◯	☐ Low ⊕⊕◯◯	☐ Very Low ⊕◯◯◯	☐ Consensus ◯◯◯◯
Overall Strength of the Recommendation:	☐ ***Strong***	☒ ***Moderate***	☐ ***Weak***	☐ ***Consensus***

Appendix 1

Proprioception & Pain Cycle



Appendix 2

Exercises *(and/or Activity Modification)* for a Patient with Joint Hypermobility

Breathing/Postural Control

Exercise	Tip	Progression
Diaphragmatic Breathing	Start in supine/hook-lying position and have hand on belly for feedback • Utilize resistive training to strengthen diaphragm and vocal folds/glottis for increased pressure regulation. • Teaching diaphragmatic breathing and strengthening both inspiratory and expiratory respiratory muscles can assist with deep core muscles.	• Supine/Hook-lying • Bridge Exercises • Side-lying • Sitting • Standing • Activity (such as walking, ADLs)
Parallel Alignment of Diaphragm and Pelvic Floor	Start in supine/hook-lying position • Use verbal cues to align ear, shoulder, and hip ***Note:*** If needed, use abdominal binder to assist with proprioception, positioning, and progression.	• Supine/Hook-lying • Bridge Exercises • Sitting • May use towel rolls to support small curve in back • Standing • Activity (such as walking, ADLs)
Slow and Controlled Return of the Diaphragm to its Resting Position	Start in supine/hook-lying position and inhale then perform one of the following actions to complete the slow exhale: • Humming or "ah" sound • Counting out loud • Mimic blowing up a balloon or blowing out candles ***Note:*** Aim to feel tightening of deep core muscles.	• Supine/Hook-lying • Bridge Exercises • Sitting • Standing • Activity (such as walking, ADLs)

Flexibility

Exercise	Tip	Progression
Cervical side bending and rotation	• May be done lying down if that improves comfort • Be mindful of potential cervical instability Other considerations: • A hypermobile TMJ may be stressed from tight cervical muscles	• Longer hold times with shortened repetitions
Pectoral/chest stretch	• Often started in supine if pain is present or if there is shoulder instability	• Start within pain tolerance and progress as tolerated
Hamstring	• Often started in longsit	• May need to change position and/or increase to 90 second hold based on tolerance
Gastrocs	• Often started with stretch on step	• May need to change position and/or increase to 90 second hold based on tolerance
Hip Flexors	• Often started with Thomas Test position or prone knee flexion	• May need to change position and/or increase to 90 second hold based on tolerance
Piriformis	• Often start with figure four with leg on wall	• May need to change position and/or increase to 90 second hold based on tolerance

Proprioception

Exercise	Tip	Progression
Scapular Stabilization	May be done in conjunction with exercises (such as breathing or seated hamstring stretch)	Work towards dynamic movement while engaging scapula Also addresses: • Strength • Neuro Re-education
Isometric Grip Strength	• Begin with very soft resistive putty or washcloth. ***Note:*** • Squeeze for 5 seconds and rest for 5-10 seconds to minimize fatigue • Overall length of time 2–5 minutes • Make sure DIP Joints do not hyperextend into putty.	• Increase repetition cycles • Increase putty resistance Also addresses: • Strength
Finger Thumb Opposition	• May also be done with resistive putty	• Can progress to strengthening once proprioception improves Also addresses: • Neuro Re-education
Bridges	• Can place towel or small ball between knees • Lift only until ears, shoulders, and hips are relatively in a straight line	• Add uneven surface under one foot (pillow, folded towel) • Add in dynamic movement (lift one leg at a time) Also addresses: • Strength • Neuro Re-education
Single Leg Stance	• Ensure ear, shoulder, and hip are relatively aligned (This should bring knees out of hyperextension.) • Utilize vocalization for eccentric control of diaphragm for core activation	• Perform on uneven surface (pillow, folded towel) • Perform with and without shoes • Perform with eyes closed Also addresses: • Strength • Neuro – re-education
Walk backwards	• Start with hands held for safety	• Increase distance or repetitions
Walk on heels	• Start with short distances with focus on upright posture (relative alignment of ears, shoulders, and hips) • Heelcord flexibility may impact ability to perform with good form. May need to focus on increasing flexibility prior to performing this exercise	• Increase distance or repetitions
Walk on toes	• Start with short distances with focus on upright posture (relative alignment of ears, shoulders, and hips)	• Increase distance or repetitions
Wall sits	• Start with mini squat and back against wall • Can place a towel or ball between knees for increased stability	• Progress to moving away from wall, keeping relative alignment of ears, shoulders, and hips • Increase time in mini squat or repetitions • Remove towel for increased work on control Also addresses: • Strength • Neuro – re-education

Strength

Exercise	Tip	Progression
Scapular stabilization	• Can be done in conjunction with breathing or seated hamstring stretch.	• Work towards dynamic movement while engaging scapula • Can also progress to wall push up Also addresses: • Proprioception • Neuro – re-education
Isometric Grip strength	• Make sure fingers do not hyperextend into putty. The focus is on wrist stabilization	• Begin with soft putty, even if strength is good. • Squeeze for 5 times then rest for 5-10 seconds so as not to fatigue hand Also addresses: • Proprioception
Lateral pinch & Palmar pinch	• CMC joint should be in abduction	Start with soft putty
Bridges	• Can place towel or small ball between knees • Lift only until ears, shoulders, and hips are relatively in a straight line	• Add uneven surface under one foot (pillow, folded towel) • Add in dynamic movement (lift one leg at a time) Also addresses: • Proprioception • Neuro – re-education
Wall sits	• Start with mini squat and back against wall • Can place a towel or ball between knees for increased stability	• Progress to moving away from wall, keeping relative alignment of ears, shoulders, and hips • Increase time in mini squat or repetitions • Remove towel for increased work on control Also addresses: • Proprioception • Neuro – re-education
Heel Raises	• Start with relative alignment of ears, shoulders, and hips • Place hands on surface for support • Both feet on ground	• Progress to no support from hands • Perform with single leg • Add in uneven surfaces • Close eyes Also addresses: • Proprioception
Clam Shells	• Start in supine hook-lying without resistance	• Progress by adding progressive resistance bands • Ensure there is relative alignment of ears, shoulders, and hips
Isometric quad sets	• May start with towel under knee • relative alignment of ears, shoulders, and hips • Verbal cues to keep heel on surface, to reduce knee hyperextension, and to avoid joint compensation	• Progress to sitting short arch quad set keeping knee in neutral Also addresses: • Neuro – re-education

Appendix 3

Models of Therapy

Models	*Frequency*	*Description*
Consultative	As needed visits	• Patient is managing their condition and comes in when needed (e.g., new onset of symptoms, symptoms exacerbated by growth or new activity). • Patient has established a regular maintenance level with home exercise program (HEP). • Patient no longer demonstrates significant functional limitations or only requires orthotic management for changes due to growth.
Periodic	Every 4 to 8 weeks	• Most frequently used model • Patient is completing HEP independently. • Home programming needs adjusting at each visit. • Symptoms require monitoring. • Patient is engaging in daily activities inside and outside of school. • Patient needs time to establish regular performance of HEP and demonstrate functional improvements.
Frequent	Weekly or Biweekly	• Patient's activities are impacted significantly by condition. • Patient requires closer monitoring of symptoms and HEP.
Intensive	More than one time per week	• Patient needs assistance with activities of daily living. • Attendance at school/extracurricular activities is interrupted or stopped due to pain. • Multiple disciplines are typically involved in this level of care including psychologists.