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Diagnosing a Hypermobility Syndrome

Who diagnoses hypermobility syndromes?

- In the US, formal medical diagnoses are generally established by physicians (MD or DO), physician's assistants (PA), or nurse practitioners (APNP). Although there are usually no limitations on which types of conditions they can diagnose, assessing patients for possible hypermobility spectrum disorder (HSD) or Ehlers-Danlos Syndrome (EDS) requires training and is a time-consuming process. Clinicians should only diagnose conditions that they are sufficiently knowledgeable about which makes raising awareness of these complex conditions critically important.

What does a clinical diagnosis entail for hypermobility spectrum disorder or Ehlers-Danlos syndrome?

- hEDS is the only type of EDS without a known molecular basis, therefore the diagnosis is based on clinical findings (signs and symptoms). The diagnosis is typically made by a medical professional with expertise in symptomatic joint hypermobility (SJH), such as a geneticist, pain management physician, or physical medicine and rehabilitation (PM&R) doctor.

What specific diagnostic tests may be used in the diagnosis process?

- Imaging studies mostly evaluate for structural abnormalities. Upright or dynamic imaging is sometimes necessary. Molecular (genetic) and other laboratory testing may be used to facilitate the diagnosis by ruling out other explanations for the person's symptoms.

How long does the diagnostic process take?

- Many different factors contribute to receiving a diagnosis. However, studies[1] have shown that it takes many years (sometimes ten or more) for some people to receive a diagnosis.

Source[1]:https://www.sciencedirect.com/science/article/pii/S0885392497000079