



Psychological Considerations in VEDS: A Guide for Mental Health Professionals

Introduction

This guide is designed to provide mental health professionals with a foundational understanding of Vascular Ehlers-Danlos syndrome (VEDS) and its profound psychological dimensions. Living with a rare, life-threatening genetic condition like VEDS presents unique and complex challenges, not only for the individuals diagnosed but also for their families and caregivers. This document will explore the medical realities of VEDS, the common psychological experiences encountered by those affected—including the intricate web of fear, grief, and identity shifts—and the significant impact on family systems, particularly given that VEDS is an inheritable condition often affecting multiple family members and potentially leading to complex grief and guilt. By equipping clinicians with insights into these areas, as well as specific therapeutic considerations and clinical recommendations, this guide aims to foster more informed, empathetic, and effective psychological support, reducing the need for clients to educate their providers and paving the way for a therapeutic relationship grounded in a comprehensive understanding of VEDS.

Understanding VEDS

Vascular Ehlers-Danlos syndrome (VEDS) is a rare, life-threatening genetic condition that affects the body's connective tissues, particularly blood vessels and organs. VEDS is caused by changes in a gene that produces an important type of collagen (a protein that provides strength and structure to tissues). This results in fragile blood vessels and organs that can rupture or tear unexpectedly, creating serious and potentially fatal complications that can occur even in childhood and young adulthood. Currently, there is no cure for VEDS and limited treatment options, as there have been few clinical trials specifically for this condition. This lack of curative or targeted treatments is a key source of frustration and anxiety for the VEDS community, in addition to the unpredictable timing of potential life-threatening events and the frequent lack of awareness among medical providers about the condition.

Key Medical Features:

- **Vascular fragility:** Risk of blood vessel tears (dissections), ruptures, and aneurysms
- **Organ fragility:** Risk of organ tears or ruptures, including intestines, uterus, and lungs
- **Thin, translucent skin:** Visible veins, easy bruising, and poor wound healing
- **Significant chronic symptoms:** Examples include widespread pain, persistent fatigue, and gastrointestinal issues, among others.

Note: VEDS is sometimes confused with other types of Ehlers-Danlos syndrome that are less medically serious. This

confusion can lead to misdiagnosis or delayed diagnosis, potentially resulting in individuals with VEDS being inappropriately dismissed from emergency departments without receiving necessary life-saving care.

Basic Information:

- VEDS is rare, affecting approximately 1 in 50,000 to 1 in 200,000 individuals.
- Life expectancy is reduced, with significant variability in outcomes.
- Inheritance pattern is autosomal dominant (50% chance of passing to offspring).
- Approximately 50% of cases arise from spontaneous genetic changes with no family history.

For more detailed medical information, see Supplemental Information, Section A.

Post-Diagnosis Experience

The post-diagnosis experience typically involves a complex interplay of emotions and adjustments that shape long-term psychological adaptation:

- **Relief:** For some, a diagnosis can bring relief, offering an explanation for symptoms and validation after potentially long periods of medical dismissal, and enabling access to specialized care.
- **Grief and Denial:** The recognition of the condition's life-threatening nature, the loss of a previously envisioned future or sense of normalcy, and the genetic implications can trigger profound grief. Denial may also be a part of this process, as individuals grapple with the weight of the diagnosis.
- **Adaptation:** This is an ongoing process of learning to live with uncertainty, frequently involving the development of coping mechanisms and the building of resilience. This process includes grappling with the inherent contradiction of daily life feeling profoundly altered by the diagnosis, even as many routines continue with a semblance of normalcy. As part of their grieving and adjustment journey, individuals may also dynamically engage with or withdraw from supportive communities.

Common Psychological Experiences in VEDS

Living with VEDS often involves navigating a complex landscape of emotional, cognitive, and social adjustments. Common experiences include:

Chronic Fear, Uncertainty, and Hypervigilance: The unpredictable nature of VEDS fosters ongoing anxiety. This often includes:

- **Health-Related Anxiety and Vigilance:** Persistent hypervigilance about physical sensations, where routine pains may be interpreted as potential emergencies, alongside the constant challenge of distinguishing normal sensations from serious warning signs. This can lead to developing rituals around emergency preparedness.
- **The Burden of Self-Monitoring:** The continuous mental and emotional effort of trying to discern between appropriate, necessary vigilance and potentially excessive hypervigilance, often leading to self-doubt and exhaustion.
- **Existential Distress:** Significant concerns about premature death, the condition's life-threatening potential, and the inability to make long-term plans due to profound uncertainty about the future and anticipatory anxiety.

Grief, Identity Shifts, and Body Image Issues: The diagnosis and lived reality of VEDS frequently trigger complex emotional responses related to selfhood and loss:

- **Grief, Identity Disruption, and Body Betrayal:** Profound grief over lost autonomy, altered career trajectories, and envisioned futures is common. Physical changes (e.g., surgical scars, thin skin, bruising, physical limitations, medical devices), along with repeated medical traumas or near-death experiences, can significantly impact self-image, disrupt professional identity, and foster feelings of the body being unreliable or betraying them ("strangers in their own bodies").
- **Survivor's Guilt:** Individuals may struggle with complex feelings of guilt, particularly when they survive longer than affected relatives or friends within the VEDS community, often intertwined with their own traumatic medical

experiences during emergencies or surgeries.

- **Genetic Concerns and Guilt of Transmission:** Persistent worry about potentially passing VEDS to children and anxiety about other at-risk or diagnosed family members. This often includes profound guilt experienced by parents or family members who unknowingly transmitted the condition. The weight of genetic responsibility and these complex emotions significantly compound daily stress and major life decisions.

Social and Relational Dynamics: VEDS significantly impacts interpersonal relationships and social functioning:

- **Family System Stress:** The condition can create intergenerational trauma, particularly from witnessing relatives' complications or deaths, managing guilt related to genetic transmission, and navigating complex decisions around family planning and prenatal testing (especially given high maternal risks and/or concerns about having a child with VEDS).
- **Relationship Strain, Isolation, and Invisibility:** Maintaining friendships and partnerships can be challenging, as peers may struggle to comprehend the condition's severity or its psychological implications. Individuals may hesitate to form deep commitments due to mortality concerns. Fatigue, self-consciousness, frustration with the illness's "invisible" nature (often leading to invalidating comments like "But you don't look sick"), and negotiating changing levels of dependency or roles can lead to social withdrawal and strained dynamics.

Adaptive Coping and Resilience: Despite the significant challenges, individuals with VEDS actively develop coping strategies and demonstrate resilience:

- **Developing Positive Strategies:** Many find strength and maintain quality of life through advocacy, creative expression, mindfulness, humor, or consciously reframing their narrative around living with VEDS.
- **Seeking Social Support:** Building strong support networks with family, friends, or VEDS-specific communities provides vital emotional and practical assistance, fostering belonging and reducing isolation.
- **Proactive Health Management:** Engaging in informed decision-making regarding medical care, lifestyle adjustments, and emergency preparedness empowers individuals, enhances control, and can help mitigate anxiety.
- **Protective Mechanisms:** It's also common for individuals to employ avoidant coping strategies (e.g., suppressing medical discussions) as a way to shield themselves from overwhelming emotions, which may be an area for therapeutic exploration.

For information on common mental health diagnoses seen in VEDS clients, see Supplemental Information, Section B.

Key Therapeutic Considerations

- **Avoid assumptions:** Do not presume familiarity with VEDS or equate it with hypermobility-spectrum disorders (HSDs), which are more commonly known to the general public but have substantially different medical implications.
- **Center client expertise:** Acknowledge their lived experience as equal to clinical knowledge.
- **Honor medical reality:** Balance hope with honesty, avoiding dismissive statements like "You just need to stay positive" or "Everyone has health challenges."
- **Distinguish Valid Worry from Disordered Anxiety:** Recognize that much of the anxiety in VEDS is an 'ecologically valid' response to real, life-threatening dangers, not necessarily disordered anxiety. Therapeutic goals should focus on managing distress and coping with reality, rather than solely trying to eliminate understandable fears.
- **Differentiate Physical and Psychological Symptoms:** Recognize that some physical symptoms of VEDS can mimic anxiety or panic attacks, requiring careful differential diagnosis.
- **Consider Neurodevelopmental Overlap:** Recognize potential symptom overlap between VEDS-related psychological impacts and conditions like ADHD. Collaborate with specialists to determine whether symptoms arise from living with VEDS or represent separate neurodivergent conditions.
- **Highlight Genetic Counseling:** Encourage individuals with VEDS and their families to seek genetic counseling for information on inheritance patterns, family planning, testing of at-risk family members, education, care coordination, and establishing specialized care teams.

Clinical Recommendations for Mental Health Professionals

1. Trauma-Informed and Validation-Focused Care

Many individuals with VEDS have experienced medical trauma from invasive procedures, near-death events, and emergency situations. Consider beginning sessions with consent-based inquiries like, "Would discussing your diagnosis feel helpful today?" Normalize the coexistence of resilience and exhaustion with validating statements such as, "It's understandable to feel both courageous and weary." Avoid dismissive positivity that doesn't acknowledge the realities of living with a serious chronic condition.

2. Therapeutic Considerations

When working with individuals with VEDS, consider how your existing therapeutic approaches might be adapted to address:

- Distinguishing between realistic health concerns and catastrophic thinking.
- Helping clients reconstruct identity beyond their medical condition.
- Addressing family communication about genetic concerns and health risks.
- Supporting adaptation to living with uncertainty and chronic health challenges.
- Managing hypervigilance and body-monitoring.
- Exploring existential concerns about mortality and meaning-making.

3. Collaborative Approaches and Resources

- Coordinate with medical teams to align therapeutic goals with physical limitations.
- Educate yourself about VEDS to avoid placing the burden of explanation on clients.
- Proactively discuss emergency plans and advance directives to reduce helplessness.
- Direct clients to VEDS-specific support networks, such as The VEDS Movement's virtual support groups.
- Suggest crisis planning to develop emergency protocols that can reduce anxiety. The VEDS Movement offers resources for emergency-preparedness: <https://thevedsmovement.org/what-to-expect/emergency-preparedness/>.

For detailed therapeutic strategies and approaches, see Supplemental Information, Section C.

Conclusion

Mental health professionals play a vital role in helping individuals with VEDS navigate the complex psychological terrain of living with a rare, life-threatening condition. By understanding both the medical realities and psychological challenges unique to VEDS, you can provide informed, compassionate care that acknowledges real medical concerns while supporting psychological well-being and quality of life.

This guide integrates clinical insights and lived experiences to support trauma-informed psychological care. Recognizing and honoring individuals' expertise about their own condition is essential for effective therapy, as is collaboration with medical specialists. By familiarizing yourself with these considerations before beginning work with clients who have VEDS, you create space for healing and growth without requiring them to be their own educators.

About The VEDS Movement

The VEDS Movement, a division of The Marfan Foundation, is dedicated to saving lives and improving the quality of life for individuals with Vascular Ehlers-Danlos syndrome (VEDS). We provide education, support, and resources for those living with VEDS and their families, while also creating a community to decrease the feelings of isolation that can come with rare conditions. Our website (<https://thevedsmovement.org>) offers comprehensive information on managing VEDS, emergency preparedness, and support resources.

For additional VEDS resources, see Supplemental Information, Section D.

Supplemental Information

Section A: Detailed Medical Information

Additional Medical Features:

- **Carotid-Cavernous Sinus Fistula (CCSF):** A potentially life-threatening complication involving an abnormal connection between arteries and veins in the brain, which can cause sudden and pronounced eye symptoms
- **Characteristic facial features:** Large/prominent eyes, thin nose and lips
- **Joint flexibility:** Often less pronounced than in other EDS types

Diagnostic Journey:

- Diagnosis often follows traumatic medical events or emergencies.
- The diagnostic journey may be long and frustrating, with possibly years of medical dismissal, requiring significant self-advocacy and overcoming barriers to genetic testing.
- Diagnostic criteria include a combination of major and minor features, with genetic testing confirming the diagnosis.
- Early diagnosis is vital for appropriate medical care and informed lifestyle choices.

Section B: Common Mental Health Presentations

Anxiety Disorders

- **Health anxiety:** Heightened and often rational concern about bodily sensations
- **Anticipatory anxiety:** Fear of medical emergencies and procedures
- **Post-traumatic stress responses:** Following medical emergencies or procedures

Mood Disorders

- **Depression:** Related to chronic condition management, grief over changed life circumstances and future prospects
- **Adjustment challenges:** During periods of health decline or after new limitations

Trauma Responses

- **Medical trauma:** From emergency events, surgeries, or negative healthcare experiences
- **Chronic pain management:** Many experience persistent musculoskeletal pain
- **Caregiver burden:** In family members and partners

Section C: Detailed Therapeutic Approaches

Practical Therapeutic Strategies

Balance Adaptive and Maladaptive Vigilance

- Acknowledge that some level of body monitoring is necessary and adaptive.
- Help identify when vigilance becomes excessive and counterproductive.
- Develop personalized strategies for managing health anxiety.

Crisis Planning

- Create concrete emergency protocols.
- Practice decision-making for different scenarios that might arise, such as those described here: <https://thevedsmovement.org/what-to-expect/emergency-situations/>.
- Establish communication plans with family members.

Communication Skills Development

- Role-play interactions with medical providers.

- Practice articulating needs and concerns effectively, especially during medical emergencies when clear communication can be life-saving.
- Empower individuals with VEDS to develop strategies for educating important people in their lives about the condition, including training close friends, family members, and coworkers to communicate effectively during medical emergencies if the client is unconscious or otherwise unable to effectively communicate.

Supporting Family Members

- Address genetic implications within the family.
- Help parents communicate with children about VEDS.
- Support siblings and partners through their own grief process.

Phrases to Foster Therapeutic Alliance

- "It's understandable to feel fearful given the uncertainties of VEDS. Let's explore ways to create a sense of safety and stability even when facing ongoing uncertainty."
- "How has VEDS impacted your sense of self, and what unexpected strengths have you discovered?"
- "We'll respect the realities of your medical situation and explore ways to enhance your emotional well-being."
- "I'm here to learn about your unique experience with VEDS and to support you through whatever comes next."

Collaborative and Educative Approaches

- For younger clients, collaborate with schools to implement accommodations for fatigue or pain.
- Develop basic familiarity with VEDS medical management.
- Consider consultation with genetic counselors for family planning discussions.

Resource Advocacy

- Provide templates for workplace or educational accommodations to mitigate stigma.
- Encourage creative outlets, like journaling or art, as tools for processing medical trauma.
- Help develop communication skills for effectively interacting with medical providers, especially first responders.

Section D: Additional Resources for VEDS Support

- **Annabelle's Challenge:** A UK-based charity offering support groups and resources for people with Vascular Ehlers-Danlos syndrome. www.annabelleschallenge.org
- **The Ehlers-Danlos Society:** Provides information on all types of Ehlers-Danlos syndromes. www.ehlers-danlos.com

Reviewed By

This content was reviewed in **2025** by the Chief Science Officer of The Marfan Foundation, the Director of The VEDS Movement, a social worker with The Marfan Foundation, and a mental health professional with the lived experience of VEDS