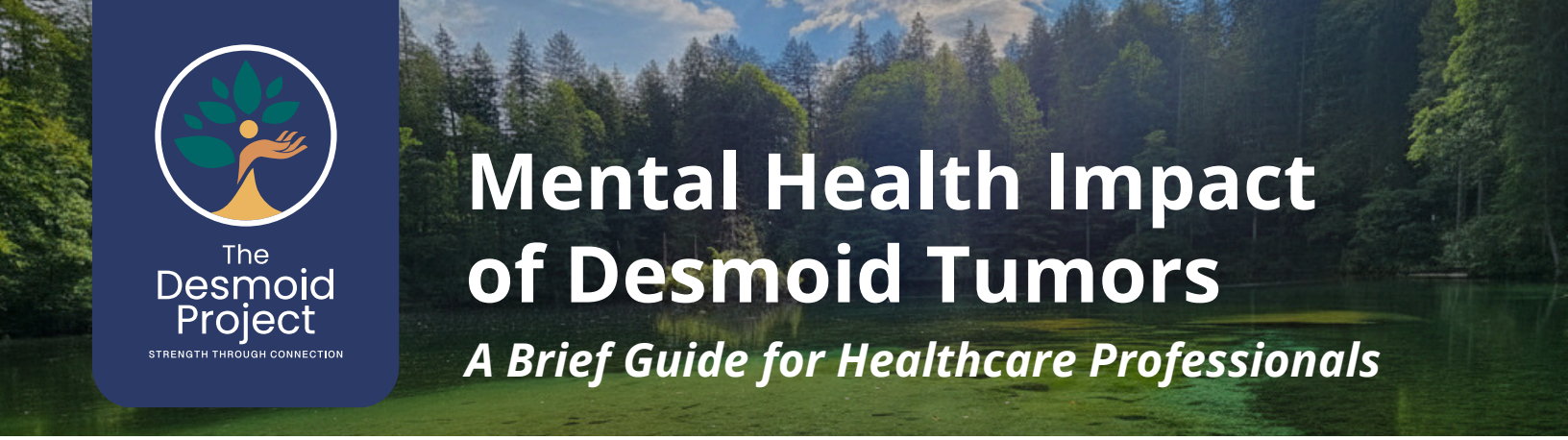

The Desmoid Project
STRENGTH THROUGH CONNECTION

Mental Health Impact of Desmoid Tumors

A Brief Guide for Healthcare Professionals

Desmoid tumor (DT) patients frequently report feeling dismissed, minimized, or misunderstood within healthcare settings, particularly as desmoid tumors are often inaccurately described as "benign" despite significant physical and psychological burden. Many patients report repeatedly having to explain, defend, or legitimize their experience throughout the medical system.

In a 2024 community needs assessment conducted by The Desmoid Project:

- 50% reported feeling dismissed by medical professionals
- 63% reported feeling misunderstood or isolated
- 66% reported minimizing their concerns out of fear others would think they were overreacting
- Nearly 20% reported suicidal thoughts

Despite this burden, referral to mental health support remains uncommon and often delayed, with 74% of patients reporting never being referred and those eventually referred waiting an average of 3.4 years.

These findings highlight that desmoid tumor care extends beyond disease management, with significant impact on psychological well-being and quality of life.

Mental Health Considerations in DT Care

Chronic Uncertainty

Uncertainty often becomes its own source of distress. Patients may spend years cycling through surveillance imaging, changing symptoms, treatment decisions, and unclear timelines while trying to make decisions about work, fertility, relationships, finances, and long-term quality of life.

Why This Matters: Chronic uncertainty may increase anxiety, hypervigilance, emotional exhaustion, and reduced quality of life.

Clinical Considerations: Acknowledging the emotional difficulty of prolonged uncertainty rather than unintentionally minimizing it may help improve trust, communication, and patient engagement within care.

Invisible Burden

Many DT patients experience significant pain, fatigue, functional limitation, or emotional distress that may not be externally visible or fully reflected by imaging findings alone.

Why This Matters: DT's are associated with significant physical, emotional, and functional burden, and stable imaging does not necessarily reflect stable quality of life.

Clinical Considerations: Assess quality of life and symptom burden alongside imaging to better understand disease impact. Consider desmoid-specific quality-of-life tools, such as the GODDESS and DTF-QoL.

Care Coordination Burden

DT patients describe significant administrative and emotional burden within the healthcare system, including coordinating care between specialists, educating providers about the disease, fighting for referrals or insurance approval, and traveling long distances for knowledgeable care.

Why This Matters: Fragmented care and limited disease familiarity may increase distress, reduce trust, and place additional responsibility on patients already navigating a complex condition.

Clinical Considerations: When unfamiliar with DTs, transparent communication and collaboration with sarcoma specialists may help reduce the burden placed on patients to coordinate their own care.

Isolation and Support Needs

Because DTs are rare and symptoms are not always externally visible, many report feeling misunderstood, emotionally isolated, or pressured to minimize their distress or appear "okay."

Why This Matters: Social isolation is associated with poorer psychological and physical health outcomes, while community support may improve coping, emotional well-being, and quality of life.

Clinical Considerations: Mental health support and community connection are meaningful parts of DT care. Referral to mental health or organizations like The Desmoid Project may help reduce isolation and improve coping.

Mental Health Matters

Supportive, validating, and collaborative care from medical professionals can meaningfully shape psychological well-being, trust, and the overall patient experience. The Desmoid Project is also here to help connect patients with mental health support, education, and community resources.