Miles 4 Hips

Connection, Community & Caution.

Navigating online Hip Dysplasia Communities

Why people love online support communities

You are not alone.

Support groups can provide:

- Emotional support
- Connection & validation
- Practical recovery tips
- Shared experiences
- Community during isolation

For many patients, support groups become an important source of comfort and belonging.

The hidden problem

Social media groups can unintentionally create bias.

Most groups include people with similar:

- diagnoses
- surgeries
- complications
- frustrations
- outcomes

That means the group may not represent all patients with hip dysplasia.

Online groups and patient peers often become "echo chambers" without realizing it.

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Who you hear online matters

The stories you hear may not represent everyone.

All people with hip dysplasia

People seeking support
People with strong experiences
People active online
People who stay engaged
People who post frequently

Voices that are most visible online

= “selection bias”

What you see (and don't see) online

Social media is not real-world outcome data

Online spaces may unintentionally overrepresent:

- Difficult recoveries
- Complications
- Revision experiences
- Strong treatment preferences
- Emotionally intense experiences

While underrepresenting:

- People quietly doing well
- Moderate/uneventful recoveries
- People who leave social media after improving
- Patients who choose different treatment paths
- Nuanced experiences

People doing well or who manage symptoms conservatively are often less active online.

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Experiences ≠ Medical advice

Sharing experiences is helpful. Replacing medical evaluation is not.

Helpful	Problematic
✅ “Here’s what recovery was like for me.”	⚠️ “You definitely need surgery.”
✅ “These questions helped me talk to my surgeon.”	⚠️ “Your surgeon is wrong.”
✅ “This is what helped emotionally.”	⚠️ “That procedure never works.”
	⚠️ “Everyone with dysplasia needs a PAO.”

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Great questions for online communities

Best uses for support groups and patient mentors:

- ✅ How did you prepare for surgery?
- ✅ What recovery items helped most?
- ✅ What has helped you manage emotionally?
- ✅ How did you handle work/school?
- ✅ What questions do you wish you asked?
- ✅ What surprised you during recovery?

Support groups are often strongest for emotional and practical support.

Questions that require caution

Questions that deserve individualized medical care:

- “Should I have a PAO or a THR?
- “When can I start running after surgery?”
- “Do I need a scope with my PAO?”
- “Does my incision look okay?”
- “Who is the best hip surgeon?
- “I am 3 months post op. What exercises should I be doing?”

Even patients with years of experience cannot fully evaluate YOUR anatomy, imaging, instability, cartilage health, goals, and surgical risks.

How to use online support communities wisely

Before asking questions or taking advice online, ask yourself:

- Am I only hearing from one subgroup of patients? What biases or limited perspecives might they have?
- Is fear influencing my decisions?
- Am I comparing myself to strangers online?
- Have I discussed these concerns with my medical team?
- Is this experience-sharing... or medical advice?

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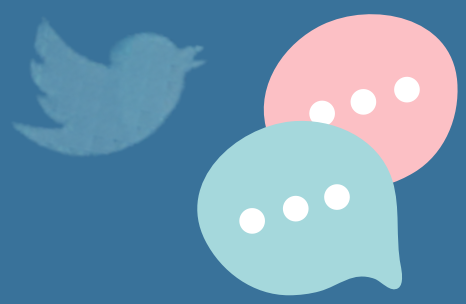
Remember

Your hip is not a poll

Other patients' experiences matter.
But they are not your anatomy, your goals,
or your future.



Use support groups for:
connection
encouragement
practical support
perspective

—not as your primary source for medical information or the sole driver of your medical decisions.

Save & share with someone navigating hip dysplasia