

# Twitter Chat: **Diabetes Peer Support Communities: What Healthcare Professionals Need to Know**

## **Let's Define Peer Support**

Peer support is the **ability to connect with another person with similar circumstances** to obtain support and knowledge. This can be active or passive (@MichLitch)

How you define #peersupport. **A group of friends/acquaintances can call themselves a peer support group**, but a trained mental health professional would lead a "process group" aka "group therapy." (@DrNBereolos)

The support I first found at diabetes camp ... is now **available all year long and in the comfort of our homes** (or wherever we are)! (@JaneKDickinson)

I would argue that #peersupport is the probably the **MOST important aspect of emotional support.** (@DiabeticPsych)

**You can get peer support anytime** and from those that understand the challenges that you live with, regardless of condition, same goes for other chronic conditions, MS, migraines, lupus, etc. (@DrNBereolos)

Keep #healthcare human. **#peersupport can be practical, engaging and constructive.** (@susangweiner)

Online peer support **removes the barrier of in-person access** in my rural area. (@zsquaredmama)

**Sharing skills, thoughts, emotions, solutions** all gained through life's day-to-day experience with #diabetes (@CharAHayes)

I also keep in mind that **#peersupport looks different to different people, and there's no 'right' way to get support.** Some ppl get a lot from in person support, others from interactive online support. Still others from passive support, like reading blogs. (@DiabeticPsych)

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## **Value of Peer Support in Diabetes Self-Care and Support**

Check out this **fantastic video on peer-to-peer health advice** by @susannahfox bit.ly/2JXm0Ys #peerhealthadvice (@AADEdiabetes)

New perspective, novel approaches, **out of the box thinking**. Resilience through difficult times or during a period of diabetes distress, that perseverance can prevail. (@DrNBereolos)

When I watch people discuss diabetes with their peers I see **camaraderie and relief**. Also lots and lots of questions and answers! (@JaneKDickinson)

It's always amazing to me that most PWD that I work with don't know any other PWD. They feel so alone and like no one else can understand their experience. **Connecting with others who 'get it' can take a big burden off**. (@DiabeticPsych)

I met a young person with type1 diabetes from Colombia, South America who had never met anyone in his city who had diabetes and a **#peersupport event allowed him the opportunity to meet others**. Magical! (@lorenadrigo)

**We would love to hear your stories on the value of peer support** so we can continue to shine a light on this amazing tool. Email us at [communications@aadenet.org](mailto:communications@aadenet.org). (@AADEdiabetes)

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## **HCPs' Concerns, Hesitancies & Barriers about Recommending Peer Support**

Concerns about encouraging #peersupport relate to people or communities that **go above and beyond support and into recommendations**. I like to see recommendations be evidence-based from trusted orgs/entities. (@HopeWarshaw)

There is also a sentiment out there - in people who don't join in - that "My blood glucose is not as well managed as theirs" or "**My A1C is higher**" etc. (@JaneKDickinson)

A lot of people I talk to are anxious about getting #peersupport. They **worry they won't fit in**, they'll be 'different' from others or they won't be able to relate. I always remind them that engaging is an experiment, not a commitment. (@DiabeticPsych)

I find that some #peersupport groups on **social media can become pretty negative**, which is not productive. I always encourage folks to be wary of this, and if they don't find it helpful, to leave. I also worry that these forums promote 'bad' medical advice. (@DiabeticPsych)

I worry about the **commiserating and complaining** that sometimes occurs. I warn people about it and encourage them to find #peersupport that fits their needs. But rarely do I see nagging or blaming, usually positive experiences for both parties (@JaneKDickinson)

The participants in AADE's peer support meeting last Oct. **identified several barriers to participation by HCPs**, many mentioned here. Read more about some here: [bit.ly/2H7lLv0](https://bit.ly/2H7lLv0). AADE is committed to addressing these. (@AADEdiabetes)

Recap from Oct 2017 AADE and #PeerSupport gathering and **collaboration captured in these two blogs: @DiabetesMine @AmyDBMine** (read here: [bit.ly/2HKX85M](https://bit.ly/2HKX85M)) and **@diabetesdaily** (read here: [bit.ly/2He6euQ](https://bit.ly/2He6euQ)). (@AADEdiabetes)

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## **Ways to Assess Online Peer Support Resources**

**It helps for HCPs to engage #online** as a #HCP so we know the value of the various #DOC (@DebGreenwood)

There are so many now that I am more likely to encourage people to **do a search and some "lurking"** and then make their own choices or check in with me if they have questions/concerns. (@JaneKDickinson)

I read their blogs, subscribe to their newsletter, attend and participate in their radio blogs & twitter chats. I also **use AADE peer support resources tip sheet in English/Spanish** [bit.ly/2E03suK](https://bit.ly/2E03suK) (@lorenadrage)

I often recommend blogs of people that I know personally, **trying to match the PWD to the blog** that I believe they would benefit most, especially if new to peer support communities AKA #DOC (@DrNBereolos)

I personally **check out #peersupport for myself**, easier to do as a T1D, but dive in and see what the community is all about before you recommend to your patients. (@MollyMacT1D)

Some people feel that they don't/won't fit in, like it is a clique. They feel overwhelmed or it doesn't fit their personality style, in particular someone with significant anxiety. **Having a guide to walk them through** or an easy way to get started might help. (@DrNBereolos)

Comfort is key. If a person is shy, suggest they **start by "lurking"** in a chat or on a peer support community (@susangweiner)

I ask the question: is the community one of the #peersupport communities **listed on the @AADEdiabetes Learn-Connect-Engage handout:** [bit.ly/2E03suK](https://bit.ly/2E03suK) (@HopeWarshaw)

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## **Who Benefits from Peer Support?**

People who have **particular interests and needs tend to be attracted to #peersupport communities**. For example, women who are pregnant with #diabetes, parents of young children or those going off to college (@HopeWarshaw)

Newly diagnosed or **no other support system**. People who are interested in wearing a pump or CGM. Peer support can be helpful to share experiences. (@diabetesevryday)

I find that **people who are newly diagnosed** are like a sponge and are eager to learn, often their families/friends too (@DrNBereolos)

I observe having a good sense of humor, **being willing to contribute ideas**, new perspectives and practical advice are valued. (@HopeWarshaw)

Nail on head - keeping healthcare human, I think **the #DOC has really opened my eyes as an HCP** to other patient's experiences to remind me of the human side if I ever forget myself. #peersupport (@MollyMacT1D)

Over the years more people with type 1 #diabetes and their **caregivers** have engaged. And generally, more people with tech skills have engaged online within websites or on Twitter chats, sharing with Pinterest or other social networking venues. (@HopeWarshaw)

I've found that **most people benefit from #peersupport**, especially those who feel alone in their condition. Specific groups include people with T1 who are thinking of trying new therapy (e.g., pump or CGM) and folks diagnosed as adults (@DiabeticPsych)

There are the **people who want info about one thing** (i.e. tech or a med) and once they have that - they don't engage anymore. Then there are **people who want/need more social interaction** related to #diabetes, they stay in for the long haul. (@MichLitch)

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## **Assessing Need for Peer Support**

Part of my assessment is asking the question “**who is your support system for your diabetes?**” If self is the answer, I offer the suggestion of peer support. (@diabetesevryday)

Important to also help patients **find #peersupport for those who speak languages other than English.** (@lorenadrigo)

People **willing to really listen to others and offer support before advice.** Diabetes is not a one-size-fits-all box of solutions, but an “I’m so sorry that happened” can go a long way. (@MollyMacT1D)

There’s a need to “show-up”. You can lurk in #peersupport virtual or in-person groups, but you **first need to be willing to get there.** (@DiabeticPsych)

I recently worked with a person diagnosed with T2 diabetes and she let me know she **felt all alone.** I referred her to @diabetessisters. She was very thankful. (@diabetesevryday)

There are folks who are resistant, and therefore less willing to engage, including folks with T2 (b/c of guilt and shame) and some teens and young adults with T1. These groups of people could benefit, if they would be **willing to engage.** (@DiabeticPsych)

I can’t think of anyone who doesn’t benefit from peer support. **It’s finding a good fit.** And there really is something for everyone out there! (@JaneKDickinson)

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## **Recommending Peer Support**

I'd benefit to hear, have **real-life case studies/scenarios** from people who have found engaging with a #peersupport community helpful in their #diabetes care and life in general. (@HopeWarshaw)

**I keep a list at my desk** with general resources, then ones that are specific to groups such as pregnancy, celiac, LADA, etc that I can hand-out for quick reference (@DrNBereolos)

**The #dsma tweet chat**, local private Facebook groups, the @DiabetesMixer, and the @UofUHealth One-Day Diabetes Education and Care Program (which includes group and individual support). (@MichLitch)

Speaking of lurking, **the Wed eve 9pm EST #DSMA Twitter Chats are a great way to see people with #diabetes connect.** @SweeterCherise (@HopeWarshaw)

Check out the **peer support area of the AADE website** for additional resources: [bit.ly/2E03suK](https://bit.ly/2E03suK) (@AADEdiabetes)

**Search different #blogs** & FB to find groups to fit specific needs. #caregiver forums are avail too! (@susangweiner)

I'd like to get a better sense of the types of needs people with #diabetes and their caregivers have for #peersupport. **What support, practical advice, and other information do people find helpful?** (@HopeWarshaw)

I'd like to **know what #peersupport sites are moderated by HCP's** so that if a question that needs medical advice is asked, the answer can be vetted and person can be referred to HCP. (@MollyMacT1D)

I am always looking for new resources and **rely on recommendations from my colleagues and people with diabetes** for resources they've found helpful (@DiabeticPsych)

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## **Tips to Engage People with Diabetes in Peer Support**

I **talk about benefits**, I stress how helpful having a shared experience can be in dealing with difficult things in life. PWD often feel like they're the 'only one' and I ask them what it would be like if they found out that they aren't the only one? (@DiabeticPsych)

I'll ask if they have **ever met another person with their type of diabetes**. This question also helps me assess any negative thoughts they might have about diabetes. (@MichLitch)

Peer Support Groups will give an **extra level of personalized support** that I, as a person without diabetes, can't offer. (@MaureenSRN)

Encourage people to **look for positive, encouraging, helpful communities** and watch out for those where there is a lot of complaining (especially if they are brand new to diabetes!). Also be open minded – there are two sides to every story! (@JaneKDickinson)

Advise that **it may take them a few tries to check out different communities** to find their online community or social media venue that fits their needs & provides a comfortable environment. (@HopeWarshaw)

I talk about how even when you are feeling like your #diabetes has gotten the best of you, that there is someone out there who has been there and **might just be the inspiration you need**. (@zsquaredmama)

Connecting with others with #diabetes **can help them stay up to date** on the latest medications, technology and more. (@HopeWarshaw)

**I want to see WAY MORE MILLIONS of people** with type 2 #diabetes engage in #peersupport communities. I'd like to see us #diabetes educators and HCPs carry this message to more people (@HopeWarshaw)

Love this. Everyone's journey is different but we **can always learn from them**. Key is to listen! #OzDOC Ashley Ng (@HangryPancreas)

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## **Collaboration among Peer Support Communities and HCPs**

Encourage #PWD to **engage with a #CDE when they are facing new challenges** or when they change meds etc., or to learn about new #diabetes #technology #peersupport (@HopeWarshaw)

Provide more activities where there is open dialogue & conversations. **Create a town hall virtual meeting & invite HCP to participate.** Many PSC already extend invitations (@lorenadrage)

There needs to be a **more positive connection** between #peersupport communities and #diabetes HCPs. Leaders in #peersupport can be more vocal about the value of #diabetes HCPs and #diabetes HCPs can do more to promote #peersupport. Works both ways. (@JaneKDickinson)

I would really like to see us supporting each other's missions more. Reality is today **too few people see #diabetes educators and too few people know about #peersupport** and related communities. Lots of potential win/win. (@HopeWarshaw)

We would love to see **peer support communities sharing information about the value of diabetes educators/DSMES** and how to access a diabetes educator using the Find a Diabetes Educator tool [bit.ly/2HdhVO8](https://bit.ly/2HdhVO8) (@AADEdiabetes)

**Regularly give resources for #peersupport as a referral to patients** during appointments. #Peersupport can augment therapy and lend a hand or ear when you can't. (@MollyMacT1D)

Keep talking about #peersupport and make it a key **part of our assessment and treatment planning.** Whenever I meet a new patient, I always ask if they know others with diabetes, and I always give them resources to access peer support - both in person and online (@DiabeticPsych)

And I think this is a 2-way street. **We engage to learn the value of #peersupport and #peersupport learns the value of #HCP** (@zsquaredmama)

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## **Growth of Online Peer Support in Diabetes Care**

Many of us are familiar with in-person #diabetes support groups. Though in-person groups still go on, **social media and networking has transformed these forums** to offer support more widely to people with diabetes and their caregivers. (@HopeWarshaw)

Today we have #diabetes online communities, #peersupport communities that meet up online, in small in-person groups. There are **people connecting and sharing across all social media venues**, from Twitter to Pinterest, SnapChat, Instagram, Facebook. (@HopeWarshaw)

**People with #diabetes are connecting across the globe.** Then we meet up in person at meetings and experiences are even richer. Already on hugging basis. Very exciting and rewarding to observe! (@HopeWarshaw)

As a #diabetes educator I'm delighted that people with diabetes are, "**finding their tribe.**" They're able to give and get support, offer practical solutions to diabetes management challenges, share the upsides and downsides of having diabetes. (@HopeWarshaw)

One thing I like people with #diabetes and caregivers to know is that a significant number of #diabetes educators have diabetes. **They have that "lived-experience" as well as being educators.** (@HopeWarshaw)

Today there's a thriving group for women with diabetes, @diabetessisters; a group for college students going thru the transition to young adulthood @CollegeDiabetes and more. (@HopeWarshaw)

**HCPs in #diabetes care can be a link to encourage MANY more people to engage in #peersupport** and benefit greatly from it. Let's all help accomplish this goal. (@HopeWarshaw)

AADE recently launched an area of their website focused on #peersupport: [bit.ly/2E03suK](http://bit.ly/2E03suK). Peer support is now **emphasized in the National Standards for Diabetes Self-Management Education & Support**: [bit.ly/2H7FXxY](http://bit.ly/2H7FXxY). AADE has begun to incorporate/emphasize it in our education/training. (@AADEdiabetes)

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