



A GUIDE TO ONLINE PEER SUPPORT



**Developed in
consultation with
consumers.**

Peer Support Group – A Guide to Online
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Table of contents

What is online peer support?	2
Diabetes Victoria Peer Support program	2
What kind of peer support is right for me?	3
Connect with us	3
Facebook	4
Twitter	5
Instagram	7
Blogs	9
Podcasts	10
YouTube	11
Reddit	12
TikTok	13
Diabetes specific forums and websites	14
Author bio	15

WHAT IS ONLINE PEER SUPPORT?

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People living with diabetes have created a thriving online community as a way to come together, share their stories, support each other and advocate for change. Peer support is connecting with others who 'just get it'.

People might connect using a Facebook group, Twitter or by sharing a picture of their day on Instagram.

People who participate in diabetes peer support say that it makes them feel like they are not alone and provides access to information and resources¹.

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There are many ways to find the diabetes online community. This guide will help you decide which is best for you.

DIABETES VICTORIA PEER SUPPORT PROGRAM

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Diabetes Victoria recognises the value of lived experience of people living with diabetes. Diabetes Victoria has over 15 years' experience in connecting and supporting people affected by diabetes and health professionals across Victoria.

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The Diabetes Victoria Peer Support program supports more than 90 groups across Victoria online and in person.

- Groups are run by people living with diabetes and/or health professionals
- Groups might meet formally and informally; some have social gatherings and others host guest speakers
- There are groups for people living with type 1, type 2, mixed groups and groups for parents and carers
- The network includes culturally and linguistically diverse groups and groups for Aboriginal and Torres Strait Islander peoples

Groups that connect with Diabetes Victoria have access to support from staff, grant opportunities, training opportunities and a network of groups across the state.

Above all, we value and respect the lived experience of Victorians affected by diabetes. This is at the core of everything we do.



¹ Browne JL, Bennet A, Halliday JA, Holmes-Truscott E, Speight J (2016). *Diabetes peer support in Australia: A National Survey*. Diabetes Victoria, Melbourne.

WHAT KIND OF PEER SUPPORT IS RIGHT FOR ME?

There are lots of ways to access peer support. Online peer support is great for people who are busy, live in remote or rural locations or just want to see what is out there. It can be a great steppingstone to connecting with communities that meet face-to-face.

It's important to remember that online peer support might not be for everyone. You might need to try a few different options to find out which online group or community suits your age, type of diabetes, life stage and values.

CONNECT WITH US

For a full list of online and face-to-face groups within the Diabetes Victoria network head to diabetesvic.org.au/support-groups.

I wouldn't feel comfortable seeking peer support online because seeing information about diabetes in my online feeds would make me feel stressed. Being online is like an escape from everyday life.

- Evie



FACEBOOK



Facebook is the most popular network worldwide with over 1 billion active users daily.

- Facebook accounts display your full name and chosen profile image
- People ask to connect with others by sending 'friend requests'
- Approved 'friends' may post on each other's walls, send private messages and comment on or 'like' each other's posts.
- Only approved friends may see your full page and posts
- You can interact with people you don't know by searching Facebook for groups or commenting on public posts
- You can livestream video to connect with friends or followers
- Minimum age – 13 years old.

What does peer support look like on Facebook?

Groups: A person living with diabetes can search "diabetes support group" and request to join groups that are nearby or relevant to their interests. Private groups create a sense of belonging and Facebook helps people to feel comfortable sharing by using real names and photos. A person living with diabetes can share their experiences and build connection with others by commenting on posts in Facebook groups. In private groups, only members can see and participate in discussions.

Pages: You can connect with people living with diabetes by searching for public pages that discuss diabetes. You can follow these pages so that posts related to diabetes will appear in your newsfeed.

"Facebook peer support groups allow me to access support as and when I feel like I need it. Some days diabetes plays along but I am grateful to have somewhere to ask questions and learn from others when diabetes doesn't play nice The peer support groups keep me going in between clinical appointments in terms of motivation, support and information like getting ideas for different CGM sites that work for other people."

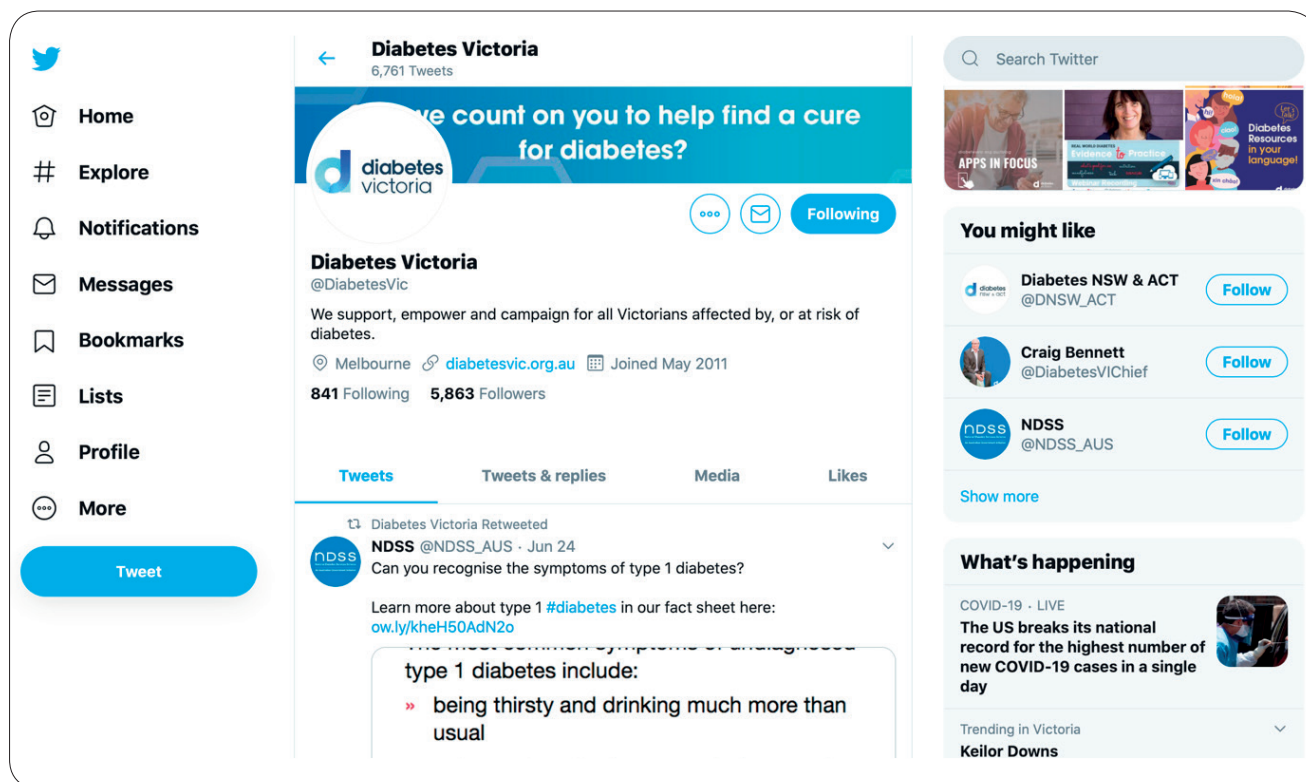
– Ashley

TWITTER



Twitter is a public microblogging website where people post short messages or 'tweets' up to 280 characters.

- Twitter is popular with journalists, politicians, professionals, and celebrities
- Users choose a searchable username, for example @DiabetesVic, and a profile image which appears next to their name when they post
- It is common to follow accounts of people you do not know in real life e.g. celebrities and politicians
- You can create your own tweets, reply to tweets, 'retweet' (share) and 'like' the tweets of others
- When you tweet in reply to others, you create a chat thread that others can read and reply to
- Hashtags are used to organise tweets into topics to make them easy to find e.g. #CGM
- You can follow accounts whose tweets will appear in your homepage or 'feed'
- Minimum age – 13 years old
- If your account is set to private, people who do not follow you won't be able to see or reply to your tweets.



What does peer support look like on Twitter?

On Twitter you can follow other people living with diabetes so their posts and conversation threads will appear in your newsfeed. Often members of the community will mention 'diabetes' in their bio, a short description of themselves that appears on their profile, to make them easier to find.

Twitter Chats: Diabetes specific tweets can be found on diabetes #hashtags. This is a good way to discover users you don't know who might be talking about diabetes.

Popular diabetes hashtags include:

#diabetes	#diabeteslife	#cgmforall
#type1diabetes	#CGM	#flashforall
#type2diabetes	#flash	#diabetessucks
#insulinpump	#DOC	#diabetesmanagement
#bgnow	#DEDOC	#makesenseifyouhavediabetes

A note on trolls

A troll is someone who posts inflammatory content online with the intention of upsetting others. Twitter is a place where people come to share opinions and attracts trolls. Sometimes this can be confronting and stigmatising for people living with diabetes. It's important to remember that this information is not always accurate or useful. Twitter allows people to 'mute' certain terms, block users and provide feedback on content to make their newsfeed a more friendly place. If online spaces become unsafe, it's a good idea to log off and reach out to a friend or loved one for support.

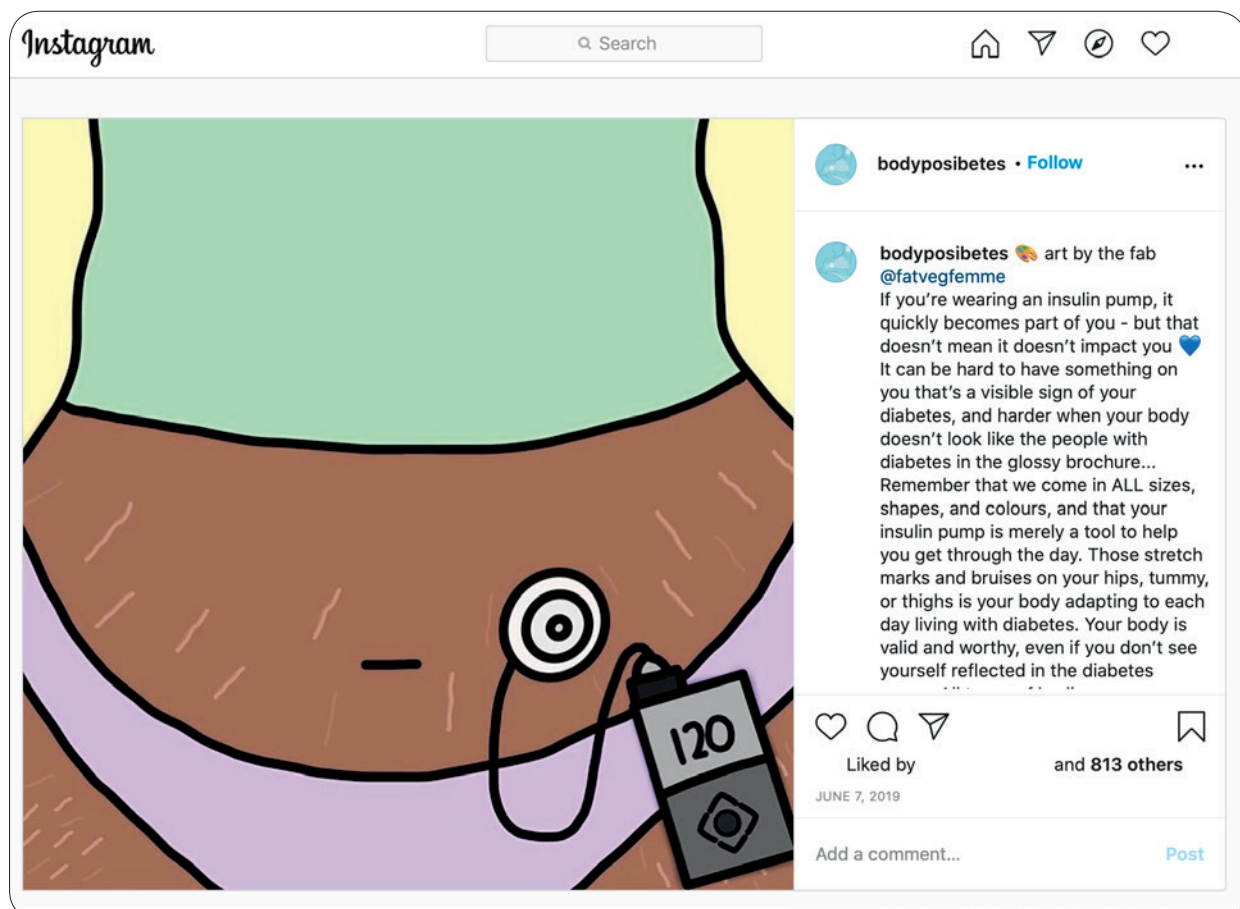
INSTAGRAM



Instagram is an image sharing platform with three key features - posting images or videos to the newsfeed, posting 'stories' that are visible for only 24 hours and private messaging.

- You can sign up through Facebook or with an email address
- You can follow accounts to see their posts and stories in your newsfeed
- You can follow celebrities, politicians, commercial brands etc.
- Accounts can be set to private so that only approved friends can see your posts
- You can interact with accounts by liking posts, commenting on posts, sharing posts with friends and private messaging
- Hashtags are used to organise posts, similar to Twitter
- Minimum age – 13 years old.

What does peer support look like on Instagram?



Diabetes accounts: Instagram is a popular way to connect with friends and peers. Instagram may reflect the thoughts of individuals, groups, or organisations. People share their experiences of living with diabetes and post about other everyday life topics. Some accounts are specifically dedicated to discussing diabetes related topics.

Instagram can be a platform that empowers and increases the visibility of people living with diabetes, particularly with its focus on image sharing. There are lots of diabetes accounts with large followings where people can follow and connect.

Using Instagram to access peer support has been a much needed visual complement to using other platforms such as Twitter or Facebook. On Instagram, I found my niche – people living in larger bodies with chronic illnesses. For all the posed and fake images in Instagram, you can find incredible and authentic conversations going on. It's a way to flood my social media feed with bodies and people that make me feel less alone! From there, I created @bodyposibetes because I wanted to create a space that went even further into that space...that is, people living with diabetes and body image concerns.

The diabetes space on Instagram is multi-faceted, yet is often not intersectional or diverse, and I wanted to make a movement where EVERYONE felt included, regardless of body shape, type of diabetes, ability, ethnicity, or sexuality. I've made amazing connections with people through this account, and that is why I use online spaces. You can find your people, discover that you are not alone in your experiences and struggles. There is such power in saying 'me too'.

- Georgie (@bodyposibetes)

BLOGS



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Blogs are websites where people can publish articles they have written.
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- Popular blog websites include Blogger (powered by Google) and WordPress
- Blogs can be customised with design and images
- Blogs give readers an option to join a mailing list for updates or “follow” to find out when there is a new post
- Readers can comment on blogs and start a conversation
- Blogs are public websites and there is no minimum age to access them
- To create a blog most websites have a minimum age of 13

How do people use blogs for peer support?

The diabetes blogging community is a vibrant and active online space. Blogging allows you to follow the journey of a person living with diabetes over a number of years and get to know them. Blogging is about sharing experiences and storytelling, making blogs the perfect platform for diabetes peer support.

How can I find diabetes blogs?

To find blogs, searching key terms in Google can help! You might like to google ‘diabetes blog’ ‘Australian diabetes blog’ or more specific terms like ‘type 1 diabetes blog’, ‘type 2 diabetes blog’ or ‘diabetes in pregnancy blog’. Once you find a blog you like, it’s often easy to find other like-minded bloggers in the comments or through a ‘blogroll’ where bloggers will link to other blogs they like to read.

Blogging has become a less popular platform and many have moved to Instagram as a ‘microblogging’ platform to connect. People may use both platforms to share with the same community of bloggers.

PODCASTS



Podcasts are recorded episodes of radio/audio and can range in length from a few minutes to multiple hours.

- Increasingly popular online medium
- Free to access with an Apple ID or Spotify account
- Accessible on a variety of platforms and websites
- You can subscribe to a podcast to receive notifications when a new episode is available
- There are many diabetes related podcasts available online
- Some podcasts will have age ratings based on content.

‘One of my favourite ways to access peer support is through listening to podcasts or taped interviews. It’s a way of accessing support on specific topics that interest me, but I don’t need anyone else to be available to participate. I really like that I can listen to podcasts at any time. Mamabetes was started because I found that when I first started listening to pregnancy podcasts for support, they didn’t fully meet my needs as a woman living with type 1 diabetes in Australia. I wanted to listen to the journeys of other women with Type 1 Diabetes in more depth. Podcasts are a great way to hear a more complete story from other women. I think they complement the snippets of people’s stories you see in online groups.’

– Ash

A screenshot of the 'MamaBetes' podcast page on a mobile app. The title 'MamaBetes' is at the top, followed by the hosts' names: 'Ashleigh Ricardo, Rachel Hicks, Carleigh...'. Below that, it says 'Subscribed'. There is a 5.0 star rating with '4 Ratings' underneath. A '2020 Parenting' badge is visible on the right. A description at the bottom reads: 'MamaBetes is a podcast created by 3 Australian women with type 1 diabetes for other women with type 1 diabetes. Mamabetes brings lived experiences backed by evidenced based practice on what it's like to plan pregnancy, be pregnant and be a mum with type 1 diabetes.'

Diabetes Victoria hosts their own podcast “Living Well with Diabetes”. Each podcast episode features an interview with a guest, often someone who is living with diabetes themselves. Living Well with Diabetes podcast discusses a variety of issues and experiences that you may share and find helpful. To listen to the Diabetes Victoria Podcast search ‘Diabetes Victoria’ in your preferred podcast app.

diabetesvic.org.au/podcasts

YOUTUBE



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YouTube is a video streaming platform where users can upload their own video content.
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- Youtube is a public platform where anyone can watch videos
- Creators have a “channel” or homepage where their videos are uploaded
- You can follow other channels to receive updates when the channel uploads a new video
- The average YouTube video is 11.7 minutes in length
- YouTube has a unique culture of user generated content. This ranges from creators who record themselves in daily life to creators who record themselves playing popular video games
- Minimum age – 13 years old

What does peer support look like on YouTube?

People living with diabetes use YouTube in a variety of ways. Their videos can provide support to others through sharing of experiences. People living with diabetes can look up tutorials on how to use certain technology or to practise self-management through watching another person.

Videos also exist as a public archive of diabetes resources, as videos don't expire unless removed by their author.



REDDIT



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Reddit is an online community of forums where users post content, comment on and rate posts on a variety of topics.

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- Users vote content up and down to determine its importance, relevance or popularity
- Information can be shared, questions can be asked and comments can be made
- Users do not have display images, instead they are identified by a plain text username that is commonly an alias or nickname.

What does peer support look like on Reddit?

On Reddit there are three main diabetes related forums where users can post about living with diabetes. Posts vary depending on type of diabetes but generally refer to technology, diet and the social experiences of living with diabetes.

The r/diabetes thread has 47.7k members, the r/type 1 thread has 14.8k members while the r/type 2 thread has 5.9k members.

“ My partner has type 1 diabetes. Sometimes I use Reddit to monitor information and news about diabetes. I also read some people’s experiences to see if there are any similar patterns to what my partner goes through.

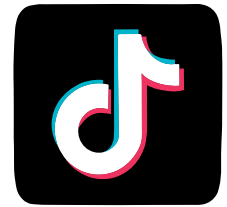
Whilst there is often some good information it is important to verify it through other means as there are a couple of key issues with using this form of social media. It is highly Americanised. The experiences talked about frequently on these forums are likely to be different to what we experience in Australia given our different health care systems.

Trolling is also second to none. Whilst the administrators are often on top of it, diabetes shaming can be present. Always be wary of what people are posting.

I find it useful as a place to seek out information and then move to a more verifiable news source or experiences. It can be a good starting point for information but should be used with an open mind.”

– Ryan

TIKTOK



TikTok is an app for making and sharing short videos up to a minute in length. Users navigate by scrolling up and down to go to the next video, like a feed.

- TikTok users make short videos with their phone
- Popular with a younger age group
- Content is organised with hashtags to make it easier to search content
- Dance/music videos are popular
- You can like and follow other accounts to see their content
- 'For you' feed shows users videos they might like based on who they follow and other posts they have liked
- 'Challenges' are popular on the platform (recreating the same video of another user, copying a dance someone else posted etc.)
- It is a popular trend to use the audio from another user's video and recreate it as your own

What does peer support look like on TikTok?

Recreating videos from others is a popular trend on TikTok such as learning a dance. One video that has been re-created by users living with diabetes involves a dance that shows off the user's continuous glucose monitor. Re-creating someone's video is a way to connect with them. Other videos demonstrate the application or removal of devices, blood glucose checks or videos where the user speaks to the camera about an experience.

TikTok is generally used by young people with type 1 and is still emerging. TikTok is a great platform for raising awareness of diabetes as it promotes original content through the 'For You' feed so that videos are viewed more widely. TikTok is a fun way to see what other people living with diabetes are up to without spending too much time or energy online!

DIABETES FORUMS AND WEBSITES



There are a variety of diabetes specific websites and forums that provide a space for people living with diabetes to come and ask and answer questions.

- They may include a newsfeed for diabetes related updates
- You may create a new thread to ask a question
- You may reply to threads on topics you have interest in
- Some forums require users to create an account to participate
- Forums are moderated

What does peer support look like on forums?

Those looking for information about their diabetes may find webpages that share news about diabetes and/or have a forum function useful. The platform does not have posts about topics other than diabetes making it simpler to find relevant information. People living with diabetes can make comments, ask questions, sometimes respond to the questions of others and receive professional advice.

Diabetes website and forums include:

- diatribe.org/
- beyondtype1.org/
- diabetesdaily.com/forum/
- diabetes.co.uk/forum/
- diabetessisters.org/forums
- type2diabetes.com/forums/



AUTHOR BIO

Megan Higgs is the Type 1 Peer Support Engagement Officer at Diabetes Victoria. Megan holds a Bachelor of Communication (Public Relations) from Deakin University and completed the Global Health and Social Justice Summer School Programme at King's College London. Megan is passionate about using her background in digital communications to create access to support and health services for people living with diabetes.

Megan first became aware of diabetes as a young person when a close family member was diagnosed with type 1. She remembers learning how to do finger pricks and check blood glucose levels as a 12 year old. She has developed this guide in consultation with the Diabetes Victoria consumer community and peer support group convenors, as well as those close to her who have generously shared their lived experience of diabetes.

The following Diabetes Victoria staff need to be acknowledged for their invaluable contributions to this resource:

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