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# Peer support in Australia: empowering people to live well with diabetes

Feature Article

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connect

Peer Support

type 1

type 2

## Introduction

Peer support enables people with diabetes to connect with each other. Feedback from peer support group members suggests this is a beneficial complement to their mainstream care for diabetes. So what is peer support, what is the evidence surrounding it, and what enables a valuable and sustainable model of peer support for people living with diabetes?

# What is peer support?

Peer support is defined as the help, assistance and encouragement that people with lived experience of a condition (e.g. diabetes) can offer to one another. It is based on the sharing of mutual experiences, emotional support and practical assistance to optimise self-management to fit with their lifestyle. <sup>1</sup>

The Victorian Department of Human Services' (2012) guide to peer support states that peer support is when people share what they have learned from their experiences with someone on a similar journey. <sup>2</sup>It acknowledges that peer support can include a range of activities, from informal conversations between peers, through to formal programs that might involve trained and paid peer support workers.

Various models of peer support exist, differing in both method and intensity of contact, time commitment, extent of training peer leaders receive, and whether they have volunteer or paid positions to support them. The American Academy of Family Physicians program '*Peers for Progress*' identifies seven models of peer support, and outlines the advantages and disadvantages of each on its website ([www.peersforprogress.org](http://www.peersforprogress.org)):

1. Professional-led groups with peer exchange
2. Peer-led structured groups
3. Peer-led support groups
4. Peer mentors/coaches
5. Community health workers
6. Telephone-based support
7. Internet-enabled support

The models are not always mutually exclusive, as different programs can include elements from multiple models. Given the variety of models available, it is evident that peer support needs to be defined and evaluated by its functions, not by who delivers it or how it is implemented. Thus, '*Peers for Progress*' identifies four key functions of peer support:

1. Assistance with daily management – peer supporters share their experiences and help each other to problem solve.
2. Social and emotional support – peer supporters offer an empathetic, non-judgmental 'ear', and encouragement to overcome any social and emotional burdens of living with and/or managing diabetes.
3. Linkages to clinical care and community resources – peer supporters can connect others with various resources, programs and services.
4. Ongoing support over time – peer supporters are there, providing ongoing follow-up that is proactive, responsive and flexible.

## The evidence for peer support

Despite numerous reviews of peer support intervention studies <sup>3, 4, 5</sup> the evidence does not always present a clear case for or against the effectiveness of diabetes peer support models. This is due to the high level of variability between studies in how diabetes peer support is defined, operationalised and evaluated. That is, studies vary in terms of which model of peer support is used, modes and duration of delivery, populations (type 1 (T1D) or type 2 diabetes (T2D), age group, ethnicity), and outcome measures used in the studies. This creates considerable challenges for trying to generate comparisons between studies.

Some studies have focused on clinical outcome measures, such as HbA1c, as the primary indicator of success. Two meta-analyses of randomised controlled trials identified small improvements in HbA1c following diabetes peer support. <sup>6, 7</sup> However, the expectation that HbA1c would improve due to peer support may not be appropriate, particularly for the type or duration of peer support offered; or it may be that baseline HbA1c was not sufficiently high to see an effect. Furthermore, it is clear that biomedical improvements may not be the primary advantage.

It appears that self-efficacy and other self-reported psychological outcomes (e.g. well-being) are often improved by peer support, though (again) effects are variable due to study designs. Furthermore, when meta-analyses are conducted, the effects cannot always be summarised quantitatively due to the use of different questionnaire measures. <sup>8</sup> However, it is clear that peer support can enable people to glean additional social support beyond their usual networks, and that this can result in greater feelings of social support, <sup>8</sup> reduced diabetes distress, <sup>9</sup> and improved self-care behaviours <sup>10</sup> and clinical outcomes (including blood pressure, lipids, BMI and HbA1c). <sup>10</sup>

## Diabetes peer support in Australia

A national audit of diabetes peer support initiatives in Australia identified 260 different diabetes peer support initiatives. Information about each initiative was collected through internet searches, structured interviews and program documents. The primary models available in Australia were community-based, face-to-face support groups (77%) and online forums or Facebook groups (12%), with each model having unique advantages, disadvantages and points of appeal. <sup>11</sup>

In contrast, a national online survey of National Diabetes Services Scheme registrants (N=2,342) found that the most commonly preferred model of peer support was online (38%), followed by group support (26%). Furthermore, only 11% of respondents were currently participating in peer support, while 38% expressed a wish to participate in future. <sup>1</sup> Given that no single model has been shown to be superior to any other, there may be cause to diversify the offering in Australia to enable greater choice for people with diabetes about when and how they can access peer support.

The findings of the national survey and the audit have informed the following recommendations <sup>11</sup> in relation to future directions for peer support in Australia:

- Ensure a range of peer support models are available.
- Invest in online and telephone-based peer support.

- Increase promotion of existing peer support programs.
- Increase engagement of the ‘hardly reached’ – the national survey identified these groups as: men, people with lower levels of formal education, people with T2D and people speaking a language other than English at home
- Improve awareness of peer support among healthcare professionals.
- Provide well-structured, expertly moderated/facilitated initiatives.
- Prioritise adequate funding, and assess funding priorities against best practice.

## Diabetes peer support in Victoria

Peer support groups have been operating across Victoria for decades, and Diabetes Victoria as the National Diabetes Services Scheme (NDSS) Agent in Victoria has been providing additional support to the diabetes specific consumer-led peer support groups through its Peer Support Program. In 2004, the program supported approximately 54 diabetes peer support groups across Victoria, and in 2017 this has increased to over 80 groups, with a rural and metropolitan reach of 63% and 37% respectively.

Key to the success and sustainability of the NDSS-funded peer support program in Victoria is the premise that consumers are the experts of their own lived experience, and that they benefit most from being assisted to lead and direct their own self-management. The program is an example of consumer engagement at the highest level of empowerment, where people with diabetes instigate and lead groups to support others living with diabetes, and maintain ownership of their support group.

A diverse range of peer support groups exist in Victoria, including those that are: specific for people living with T1D or T2D, or parents of children with T1D; for anyone with any type of diabetes; and others for people of specific cultural and linguistically diverse (CALD) backgrounds. Whilst a majority of the Victorian peer support groups are held face-to-face in suburbs or towns, there are several online groups that provide statewide access. Some of the face-to-face groups also have their own ‘member only’ Facebook groups or Twitter accounts, where members can communicate with each other between meetings.

Diabetes Victoria plays a facilitation role in supporting and connecting group convenors to the NDSS funded peer support program, and promoting local peer support groups to people living with diabetes. To be included in the NDSS funded peer support program, face-to-face groups are required to meet at least four times a year (unless the group operates exclusively online). However, the format, content, location, whether or not they invite guest speakers, and all other aspects that create the experience of the group meeting is left to the discretion and preferences of the convenor and the group members. Figure 1 illustrates how some convenors described their peer support groups.

"Different members come to different events - some just want social connection. Others repeatedly attend things. I think many of us have different needs."

"Our only requirement for participating is that there is a connection to diabetes."

"Some members have attended our group for over 30 years and formed close friendships and participate in all

our activities. We are a happy and caring group.”

“Our group’s top priority is making sure families feel as though they are not alone and have a safe place to vent their feelings.”

“We all have our good days and our bad days. Everyone has offered and received support. I think that's what keeps people coming back.”

Figure 1: Convenor comments about their diabetes peer support groups

When an individual contacts Diabetes Victoria and expresses an interest in becoming a peer support group leader they are offered one-to-one advice and support, and provided with a free copy of the Diabetes Victoria *Guide to Successful Peer Support Groups*. This handbook was created for people who are new to support groups, establishing a new group or taking on a new role in the group. Diabetes Victoria believes it is important that convenors have both the support and the autonomy to lead their peer support groups. Convenors are invited to attend an annual training and networking session, where they can explore strategies around consumer engagement and share their convenor experiences with others. Diabetes Victoria also promotes the group to prospective members through its website, social media, e-newsletters and educational events. It provides administrative support and funds to cover insurance costs and expenses related to operating the group (if required).

Dedicated staff assist the support groups and keep in regular contact with convenors through email or phone contact. This enables convenors to remain informed and pass information onto their group members about any news and developments happening across the organisation, such as research opportunities, diabetes education events or new diabetes resources.

## Evaluation of NDSS funded peer support groups in Victoria

In February 2017, peer support group convenors were asked to disseminate a feedback survey to their members as part of the NDSS National Evaluation Framework. Survey participation was encouraged but also voluntary, and dissemination was also at the discretion of the convenors with some opting for an online survey link, and others requesting paper-based versions of the survey for their members. This resulted in 310 peer support group members completing and returning surveys, with 75.6% in face-to-face groups, and 62.8% in regional or rural areas. Of these, 70% were aged 60-89 years, 20.8% aged 40-59 years, 38.6% had been a peer support member for 1-5 years, 28.4% for 5-10 years and 20.1% for 10 years or more.

Most respondents indicated that their support group had been helpful:

- to their emotional well-being (89.4%),
- in linking them to health care services (86%), and
- for their diabetes self-management (85.3%).

The feedback showed that most members were experiencing positive benefits from participating in peer support, with:

- 91.1% being able to share experiences with others,
- 92.0% gaining knowledge of how to live well with diabetes, and
- 82.5% feeling less isolated/alone in living with diabetes.

Peer support members also offered qualitative comments, which illustrate what being part of a peer support group means to them (Figure 2).

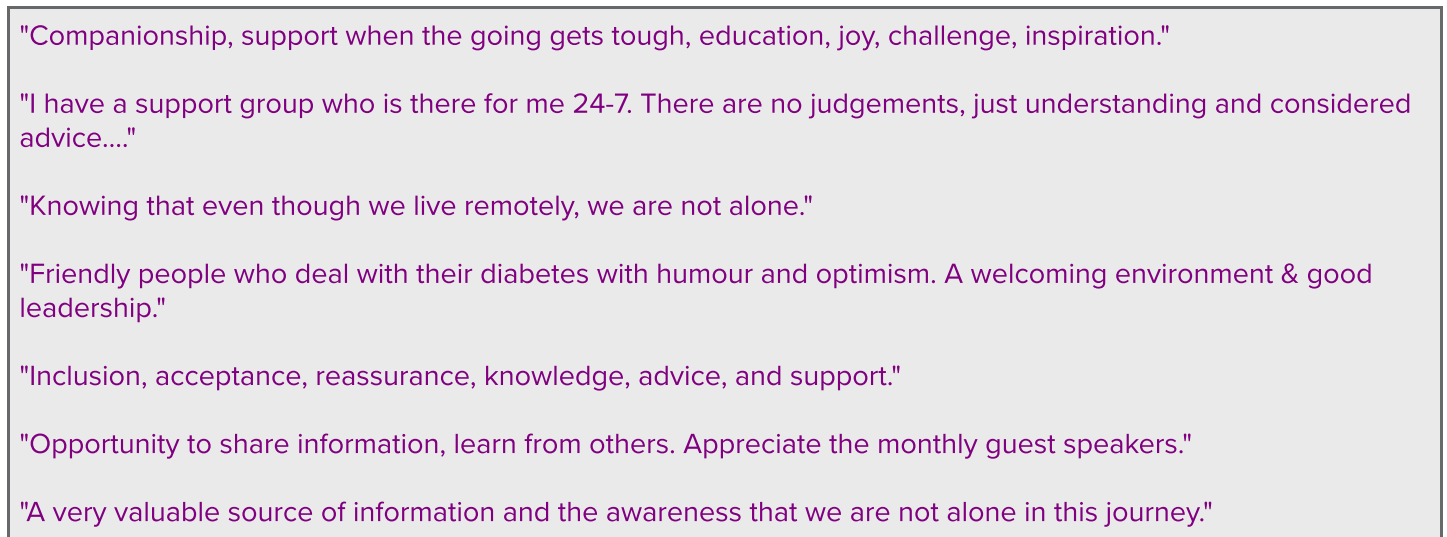


Figure 2: Comments from members on the value of being part of a diabetes support group

## Conclusion

Diabetes peer support enables people with diabetes to connect in order to support and empower each other to live well with diabetes. It does not replace mainstream diabetes care, but rather provides an opportunity to strengthen self-management and enhance linkages to health care services.

While the evidence for peer support appears mixed, this is largely due to the variation between studies, and there are plenty of examples of rigorous studies in which a range of important benefits have been demonstrated. Furthermore, the lived experiences reported by those participating in the Victorian peer support program demonstrate that it has significant value to those who choose to participate.

Thus, the authors believe that strengthening and expanding diabetes peer support models nationally should be a priority for government, health services and diabetes agencies. Improving awareness of, and access to, a variety of diabetes peer support models for people living with diabetes are relatively low cost options to increase the reach and effectiveness of peer support among the increasing proportion of our population affected by diabetes.

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