

Huntington's Disease Peer Support Group Kit



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Introduction

This kit outlines practical information that assists individuals in the running and engagement in a [Huntington's disease Peer Support Groups \(HD PSGs\)](#).

This kit includes information about:

- the purpose of the groups
- the management of the groups
- the role of a liaison person
- support from HV
- the HD SGs Code of Conduct
- practical examples
- Public Liability Insurance
- Frequently Asked Questions (FAQ)

Huntington's Victoria (HV) encourages all interested individuals affected by Huntington's disease (HD) to consider setting up HD PSGs wherever there are more than two people impacted on by HD. Once the need for the setting up of a group is established, please contact the [Community Engagement Coordinator \(CEC\)](#) at HV for further assistance.

The CEC is the contact person for the support groups.

The purpose of the groups

The general purpose of the HD PSGs is to provide safe environment, where people affected by or interested in HD can come together, share their experience, provide comfort and support to each other.

The group welcomes and supports new and existing members. By joining the group individuals affected by HD no longer feel like they are alone. They can talk about fears and concerns and learn practical ideas to better manage their condition from each other. The group can help them [reduce social isolation](#), offer a [sense of belonging](#) and provide [emotional support](#) and [access to information](#).

The management of groups

The HD PSGs are independent and self-sufficient. HV is not responsible for how the groups are established or operate.

The groups vary in size, membership and ways in which they operate. There is no one correct or prescribed way in which these groups should operate. There are some ground rules that should be adhered to by all members, if the groups are to fulfil their purpose. These are outlined in the group agreement, the HD SGs Code of Conduct.

The groups are voluntary. They are open to all members of the HD community. They are run for and by their members. That means that anyone from the HD community can put their hand up to organise or support the establishment of a new group. That also means that all members need to be prepared to share the workload for running and maintaining the group.

HV can provide some practical 'start-up' assistance, including a confirmation that another support group has not been already established in the area.

The role of the liaison person

Each group nominates one or, preferably, two liaison persons. This, ideally, is a self-nomination. The liaison persons can, but do not have to, be those individuals who were involved in organising the group. The responsibility for this role can be rotated on regular basis among other group members. This helps to share the load and empowers other group members to become involved and share new ideas.

The role of the liaison person is to:

- complete the HD PSGs induction training
- ensure all members are welcomed to the group and look after each other
- collect group members' names and contact details and provide these to the CEC at HV
- ensure all rules and guidelines provided by HV are followed
- contact other group members with meeting reminders
- receive information from HV and distribute it to the group
- contact the CEC after each meeting to report the attendance numbers at the meetings and any decisions regarding the direction of the group
- lead the planning for the consecutive meetings
- note the names and contact details of other group members
- notify HV of any safety concerns or other issues that cannot be solved by the group members themselves

It is not the role of the liaison persons to give personal advice to other group members.

Support from HV



The groups are run under the auspice of HV. HV aims to improve quality of life of all people impacted by HD. HV is a not-for-profit specialist statewide organisation established to support individuals and families living with HD to make choices about their care and needs.

HV, where possible, provides practical support to the groups. This includes assistance with:

- sourcing meeting venues, private and pleasant with easy access to parking, public transport and coffee/tea facilities
- organising guest speakers, as needs arise, by liaising with relevant external organisations
- updates, including on service improvements at HV, research developments in the HD area and other relevant issues
- the access to existing resources (information sheets etc.)
- the HD PSGs induction training
- notifying about and applying for grants to support the running of the group
- promoting the group to others in the HD community through the HV website, other social media and the community engagement newsletter
- referring other interested individuals to join the group
- evaluating the effectiveness of the group
- public liability insurance

From time to time, HV staff are happy to be invited to the group as guest speakers.

The HD SGs Code of Conduct

The members of the HD PSGs are expected to follow the ground rules included in this Code of Conduct. The adherence to these rules ensures a positive group environment without conflict between members. The Ten Ground Rules are as follows:

The HD SG fosters an environment that:

1. Protects group members' privacy and group's confidentiality
2. Encourages respect and cooperation
3. Is positive and advances the wellbeing of its members
4. Encourages everyone within the group to share the tasks and to celebrate group's successes

In the HD SG environment there is absolutely no place for:

1. Bad language directed at anyone
2. Abusive behaviour directed at anyone or physical violence
3. Bullying or imposing personal opinions on other members of the group
4. Breach of trust
5. Theft, inappropriate removal of property or any other criminal activity
6. Use of alcohol, illegal drugs or smoking

All members of the group are expected to sign a copy of the Code of Conduct when they join the group.



Ideas for different situations

Welcoming new people

There will be new people joining the group from time to time. This may create some anxiety among the old and new members of the group. Information about the group, including the Code of Conduct, should be provided to the new members before their first meeting to ensure they feel welcome.

When the new members are attend their first meeting the existing members should introduce themselves and share some of their stories.



The new members should be provided with the opportunity to introduce themselves as well. They may not take this opportunity at the first meeting and that is okay.



Welcoming new people

In a group environment it is quite likely people will have different views and opinions and may not agree with each other. It is normal to disagree.

It is the way in which the group decides to solve these disagreements that is important. If disagreements arise try to address them as soon as possible.

Remember you are a part of the group and need to try to get along with each other.

If this approach does not work and things escalate, please contact the HV CEC for support in solving this matter.

Frequently asked questions

Q: What are the groups for?

A: The aim of the HD SGs is to provide safe environment where people affected by or interested in HD can come together, share their experience, provide comfort and support to each other.

Q: Who can join the HD SGs?

A: Anyone who has HD or supports a person with HD.

Q: What benefits do I get from joining the group? Why should I join the group?

A: There are other people who may share similar experiences. Being around these people may give you some perspective on your experiences.

Q: Do staff from HV attend all the meetings?

A: No, the groups run independently. Staff from HV attends only to present relevant information or when other issues requiring attending arise.

Q: Are the groups run by staff from HV?

A: No, the groups are run by and for their members. HV and staff support the groups by assisting in organizational matters, such as liaising with venues for the meetings, organising guest speakers or applying for grants.

Q: Who is the group's contact person at HV?

A: The Community Engagement Coordinator at HV is the contact person for the groups.

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