

Setting up a Support Group



Support groups offer the opportunity for people dealing with similar challenges to share information, knowledge and support.

Benefits of a rare disorders support group

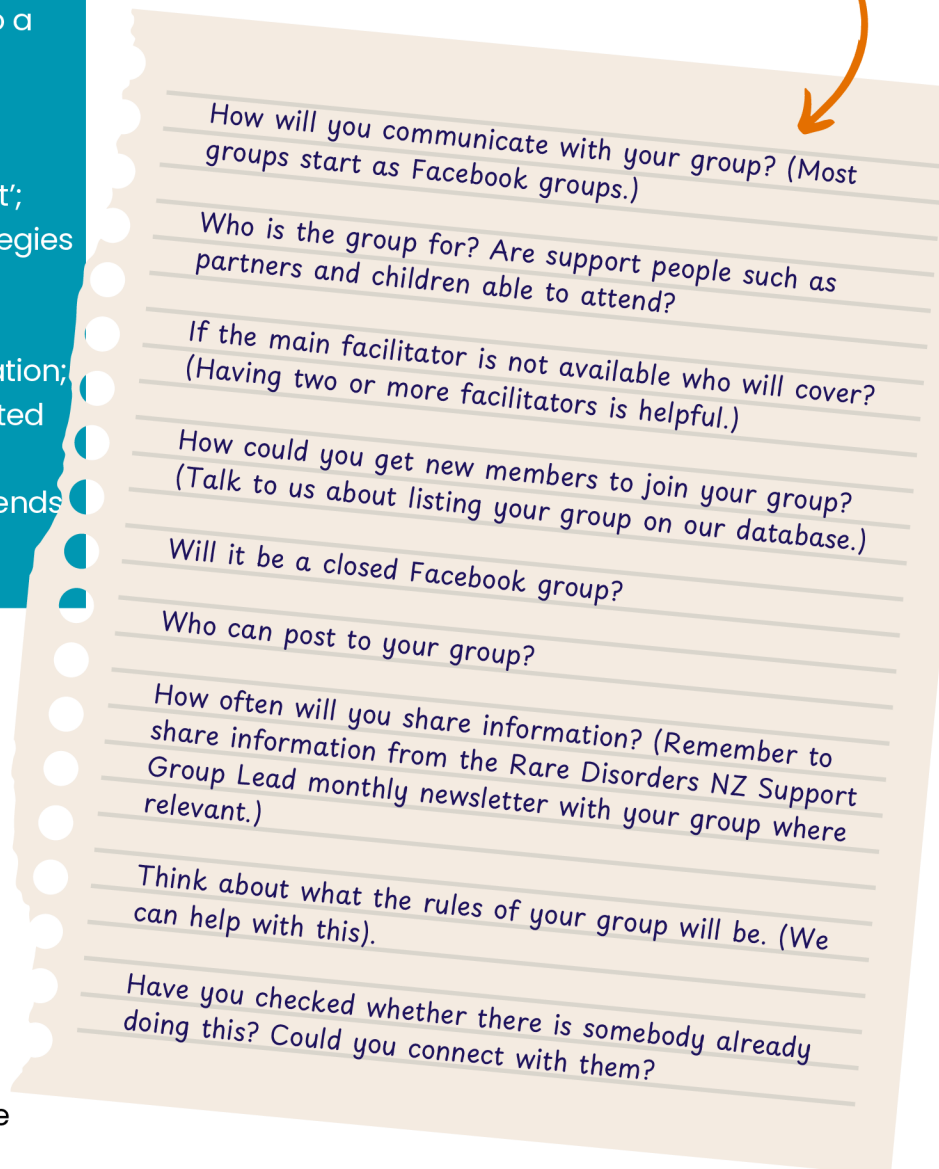
- Sense of connection and belonging to a community;
- Creating a central space to share experiences and information;
- Being understood by others who 'get it';
- Offering each other support and strategies for wellbeing;
- Sense of reward from helping others;
- Feeling more in control over your situation;
- Meeting new people, feeling less isolated and alone;
- Feeling better equipped to support friends or family with the condition.

Setting up and running a support group takes time and effort, so if you can partner with an established group this may make things simpler.

Check with RDNZ's directory of current rare disorder groups in NZ to see if there are other groups operating.

Once you have set up your group, we encourage you to join the RDNZ collective of over 160 rare disorder support groups. We provide a platform for groups to connect and learn from each other.

Are you interested in setting up a support group for a rare condition affecting you or someone close to you? Great! But before taking the first step, here are some important considerations:



Contact enquiries@raredisorders.org.nz for support or to learn more.

Helpful Links

If you would like to take your support group to the next level and register as a charity, you may find the below links useful:

CommunityNet Aotearoa is an online hub where you can find and share resources designed to strengthen organisations working with New Zealand communities. <https://community.net.nz/>

Starting a Support group. Health information and services. Available from <https://info.health.nz/assets/Locations/Starting-a-Health-Support-Group.pdf>

Choosing the right legal structure for your group. Community Law. Available at: <https://communitytoolkit.org.nz/choosing-the-right-legal-structure-for-your-group/>

Considering starting a new charity. Charities Services. <https://www.charities.govt.nz/ready-to-register/starting-a-new-charity/>

Fundraising Institute. FINZ. <https://www.finz.org.nz/about-us>

Charities Services | Personal liability. <https://www.charities.govt.nz/im-a-registered-charity/officer-information/officer-kit/personal-liability/>

Starting-a-Health-Support-Group_2016_C2244.pdf. Te Whatu Ora | Health NZ. <https://info.health.nz/services-support/support-services/health-based-support-groups>