



VIRTUAL PARENT SUPPORT GROUPS
GOOD PRACTICES GUIDE



VIRTUAL PARENT SUPPORT GROUPS

Purpose: *Create a safe online space for caregivers of children born with cleft to share experiences, seek advice and support one another.*

Good Practices:

- ❖ **Identify which caregivers would be interested** in participating in a virtual support group through a survey or phone call. Collect feedback on their preferred forum (WhatsApp, Facebook, local application). **Tip:** *reach out to parents are different stage of their cleft care journey. Caregivers who have been involved with your program for many years may be a great source of advice and comfort to those that are just starting the journey.*
Tip: *Once services resume at your centre, an invitation to this group can be included as part of your new patient registration process.*
- ❖ **Explain approach to privacy** to interested participants, making it clear that their name, phone number and any information or videos they post will be visible to members.
Tip: *Consider having participants sign a confidentiality waiver to ensure information shared through the group is kept private or add this to one of your existing waivers.*
- ❖ Based on participant feedback, **identify the best platform** for your group. TF partners have had a lot of success with WhatsApp. In some cases, Facebook Messenger or other local chat applications have worked well. **Tip:** *Consider having a separate discussion forum for male and female caregivers.*
- ❖ **Nominate a moderator** from your Comprehensive Cleft Care team to monitor the discussions and answer parents' questions. **Tip:** *Usually the patient coordinator is best positioned to administer the group and address a variety of caregiver questions. You could also decide to share this responsibility between two or more team members including the social worker and/or psychologist.*
- ❖ **Clarify any rules or guidelines** for how the support group forum should be used with participants. This may include making sure it is a safe space for everyone, using positive language, maintaining confidentiality outside of the forum and making sure the discussion topics remain focused on cleft care. **Tip:** *The moderator(s) can help ensure these rules/guidelines are followed and remove anyone who is not respectful of others.*
- ❖ **Encourage participants to share their experiences.** While the moderator(s) will play an important role, the group will be most successful if caregivers feel comfortable sharing their own cleft care experiences, and providing advice and support to each other.
Tip: *Participant phone numbers can change frequently. Encourage participants to let the moderator(s) know if they have a new number and check this information when families come in for appointments to help ensure the group contact list stays up-to-date.*