



Tourette Syndrome Association of Australia Inc.

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PARENT SUPPORT GROUPS IN AUSTRALIA

Starting a Group:

Support groups have a long history in Australia. For at least 30 years, there have been many types of support groups that developed to serve a common need. They can be as different as groups supporting sufferers of an illness to those supporting a type of service. Most have started with a handful of people together with some help from professionals and have grown from an informal beginning. Many have gone on to become incorporated associations with objectives and financial structures to assure their future. Some have remained small and informal because this better suited the needs of the members. There is no right way, but many ways.

There is no specific way to start a group except by going ahead. Organise a meeting, publicise it within the target audience and see what develops. For groups that have very few numbers, a telephone help line between the members is often a good beginning. Today, we have the internet to help this. The value of mutual support cannot be overestimated.

Some meetings start very informally, in a park or coffee shop, until the needs of the participants are made clear. It is often wise to start small whilst experience is gained. If one person can talk two or three others into a meeting, sometimes out of that small beginning will come growth as the value develops of the exchange of information and help. The starters can each develop new contacts so that growth continues.

In rural areas the needs will be different to groups formed in cities where there is likely to be more outside support and access to resources. Usually, however, each group does develop a cache of information, resources and even a library. Obviously, a database and list of members and their contact details is critical. Tangible records such as these need someone to maintain them. One of the first tasks of any meeting of like minds is to settle on the person(s) who will act as contact for the future. To prevent one person ending up doing it all, it is valuable to rotate the responsibility and in the beginning to have at least two people with this type of commitment so that they can help each other.

Once more than one meeting has occurred, it is often wise to develop a steering committee, where members receive specific tasks to accomplish. For example,

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- one person being the ‘secretary’, doing the written tasks such as membership lists or notices of next meeting,
- another person being the coordinator, that is, deciding upon the next meeting, its location, subject and date and publicising it.
- A third person could collect resources or organise a speaker.
- A fourth person could be in charge of reaching those members who don’t have email and need to be called.
- another person could act as contact in case new members ring for information or want details of venue, speaker, times etc.
- Someone else could organise tea and coffee if that were appropriate.
- Another person could coordinate a short newsletter or information sheet for members or new enquiry. This way, members feel included and the burdens do not get too great for any one person.
- And finally, someone should volunteer to facilitate the meeting so that there is a structure to it and everyone present gets a chance to speak and be heard.

Some groups never get any larger than this and rotate tasks amongst the membership so all have a chance at participation. This is fine – however, there is always the chance that the group will take off if a need is being met and many groups go to much larger platforms. The choice is for the members to make. Staying small and casual has its advantages as financial matters do not arise as there is no charge for anything and nothing to buy, the activity being entirely voluntary. If a group gets larger, it presents opportunities of another kind, such as more widespread help to others and a more permanent structure, however, then the group gets into the need for incorporation, a bank account, website, telephone number, insurance, and governmental compliance issues.

Conducting a Meeting:

Conducting a meeting can be as varied as the people attending. Again, there is no right way to do it, apart from some obvious things –

- The group needs to meet in a place where its members’ requirements are met. It would be inappropriate to meet in a coffee shop if 10 children were present as the obvious difficulty in management would arise. Safety should be important when selecting a venue. Likewise day or night meetings may make a difference to how many will attend.
- It is good to use ‘free’ venues as they do not put the meetings out of reach of anyone. There are many of these – i.e. community meeting rooms, libraries, some RSL clubs offer free use of rooms for non-profit or charitable groups. A park or a beach for a picnic is also possible. Using contacts in the member group may provide other alternatives. Everyone knows someone who may help. Some groups meet in private homes, but this can be awkward if that individual decides not to use their home any longer. So long as the venue is provided gratis, it encourages more to attend.
- An attendance book or register should be signed.

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- A contact list should be developed by asking people if they wish to be contacted for future meetings. If so, they need to offer their details. These are private, of course, and should not be offered to anyone else without consent.
- It is wise to stick to a time, say 1 or 2 hours depending upon what the group is doing. Showing a video is a good way for new groups to get acquainted. Information given this way always provides for lively discussion afterwards.
- A speaker also has the same effect and many professionals are quite willing to donate their time to a non-profit group. Don't overuse this, however, as teachers, doctors, psychologists or therapists are always very busy so their time may be limited. In general, if you get an hour from a professional that is long enough. You need to offer a topic for the person to develop and you need to leave time for questions afterwards. Many professionals have had to be 'rescued' from a barrage of anxious questions from group members if the topic is very contentious or interesting. Set the amount of time in consultation beforehand and have someone who is ready to end the session at that time so it doesn't drag on. Don't forget to send a thank you note/email or give a thank you gift afterwards. This is important.
- Round table discussions work well too, however, it is important again, to have a facilitator to ensure one person doesn't go on and on in a need to vent their own personal issues whilst holding the group hostage. Announcing in advance what you will do may help in this – i.e. *'each person will have 5 minutes to introduce themselves and relate their story if they wish. After that, the floor will be open to questions directed towho will moderate the discussion'* This person can be different each time so as to share this task.
- Children are the responsibility of their parents and this should be made clear, so that no one expects someone else to look after their child in a support group meeting. Sometimes breaking off into two groups, with adults in one and children in another can be very good in terms of enjoyment. However, the children's group will need someone to facilitate it so that each child gets a turn.
- Meetings should not go more than 1.5 - 2 hrs without a break. If refreshments are to be served, it is OK to charge a small gold coin donation for such. Be aware that this can become complex, so it is less work if none are served.
- Before the end of the meeting, ask members what topics they would like to cover in any future meetings. Sometimes the use of a form makes this easier and it can be analysed later. Some groups have a minute taker to ensure important issues are jotted down. If the response to this is good, asking individuals to research a particular topic, (say, natural therapies, food intolerances, OCD, ODD, Conduct Disorder, PANDAS, deep brain stimulation, relaxation therapies, acupuncture, Botox, etc.) often works well and that person can report back at the next meeting, either in written or spoken form. This adds to member's knowledge and gives them confidence.

Publicising a Meeting:

There are many ways to do this –

- Flyers created on a home computer and photocopied. Take to –
- Doctors' surgeries for notice boards

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- Community Health Centres
- Library notice boards
- Schools, churches, local councils
- Local news papers Community News Sections – usually free
- Radio stations have community news times – also free
- Shopping centre notice boards
- Other support groups with overlapping interests/concerns, i.e. ADHD, Anxiety, Aspergers etc
- Internet has community notice boards, too, and lots of self-help groups who may publicise your group.
- One note of caution – make sure you do not give out your contact's home telephone number on any flyer or publicity. A mobile is much better as it can be turned off and privacy ensured. An email address often works well too for contact point.

Collecting Information and Resources:

TSAA will help your group get started by providing resources for you to use. Our services can always be called upon for information you need as we have a medical advisor we can consult. We are happy to help by providing some of our videos and resources on loan to any group. Once your group acquires some resources of its own, you will need someone to keep track of them and a system for that. A card system rather like the library uses is probably the easiest. Eventually these resources may represent value to the group, so should be cared for properly. Members of TSAA get value for their membership in the form of newsletters and access to resources. We encourage any person staying in the group to take out membership. Most of our groups run independently of TSAA but we can provide varying types of assistance. Once the group has a name and contact, a rubber stamp should be gotten to overstamp the resources we send to you with the local contact name and number.

Other Sources of Support for a Group:

New groups forming could investigate support from the following in their community:

- District Offices of the Department of Education, incl. Disability Section
- Catholic and Independent School Education Offices
- Child Health Teams, Mental Health Teams, etc who may provide occupational therapist, speech therapists, psychologists, etc. as speaker or consultants
- Pre-schools, family centres
- Local Information Services/Community Directory
- Council Social Workers
- Local MP's for support also often provide photocopying for free
- TAFEs and Universities may also provide support
- Centrelink Offices for info about Carer's allowance
- Department of Disability – Disability Services Queensland
- Private philanthropic organisations and other charities

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All these outlets are worthwhile to investigate. Any group that does so will need to ensure their requests are sensible and their groups have credibility. Approaches should be made on a generic basis not an individual one, that is, support is being sought for the 'group'. Word often spreads quickly once these support services are advised so be prepared for an increase in enquiry. Having a structure to the group makes it more likely that the group can cope with an increase in numbers.

Remember, this activity of supporting others and thereby oneself is highly rewarding. There is no substitute for the sharing of concerns and helping others. Enjoy it!!

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