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# Starting a Support Group

Starting a food allergy support group may be one of the most rewarding experiences you'll have. In addition to sharing valuable information, support groups help people connect with others experiencing similar situations. All it takes to form a support group is a little bit of determination and organisation. Allergy & Anaphylaxis Australia is here to help you get started.

Remember, we're all in this together. If you have any questions or need any help, let us know.

## NEW SUPPORT GROUP LEADERS

- ▲ We thank you for your interest trying to form a support group. The role that you fulfil will benefit individuals like yourself who are living with anaphylaxis. Post diagnosis assistance is very much in demand for individuals at risk of anaphylaxis and their families, especially as we witness a rise in the number of Australians with food and insect sting allergy.
- ▲ While A&AA encourages the development of support groups, it is not possible to monitor the activities of each group or provide intensive training to the leaders. The success of each group will largely depend on the leadership ability and experience of the chair. In the context of this discussion, a support group is defined as a "supportive and caring environment where individuals with common needs come together to share strategies for managing the risk of anaphylaxis".

## GETTING STARTED

### Advice

We encourage sharing of science based, credible information from parent to parent in an effort to make living with the risk of anaphylaxis easier but this should never replace any advice that has been given by the treating doctor or allergist given specifically to that person regarding their diagnosis.

Information shared is from parent to parent. If anyone, for example, says 'A&AA's stance on XXXX is XXXXXX' - they must be sure that this is actually the case. If unsure, say you don't know and get back to [coordinator@allergyfacts.org.au](mailto:coordinator@allergyfacts.org.au) for clarification or suggest they email A&AA directly for further information. Support groups are encouraged by A&AA but they do not fall under our governance. Your group will have its own identity and independence.

A&AA cannot be responsible for information given out under the umbrella of a support group meeting.

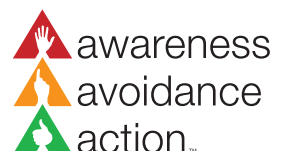
### MONEY COLLECTION

We suggest gold coins be collected to cover tea, coffee, cake and hire of meeting venue if the venue has not been donated. Most people have meetings in a school, scout or church hall, their own home, a coffee shop, park etc where there is no payment required. This is strongly encouraged as the person organising the event may have limited attendees and be left with a bill to cover venue hire and refreshments. A&AA cannot fund support groups.

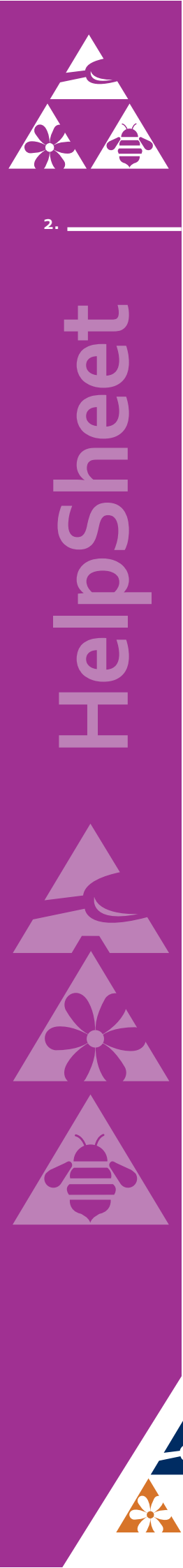


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## GUEST SPEAKERS

Inviting guest speakers helps build attendance at meetings. Local allergists, GPs with a special interest in food and severe allergy, registered dietitians, school food service professionals; school nurses, psychologists, or high school/uni students with food allergies will enhance any meeting. Parents usually attend support meetings and share information and knowledge at no cost. If a group leader has invited a guest speaker it is appropriate to get them a gift to show appreciation e.g bunch flowers, bottle of wine, bookshop voucher etc

Money from the tea /coffee kitty may be used.

## BEFORE YOUR FIRST MEETING

Create a flyer announcing your first meeting date, place, time, and the general focus of the new group. Post the flyer in the offices of GPs, allergists, paediatricians, dietitians, school nurses, as well as health food stores and other locations (with permission). Ask people to let others who are living with food allergies know you are starting a group. You might also like to contact your local newspaper and place an article.

## FIRST MEETING

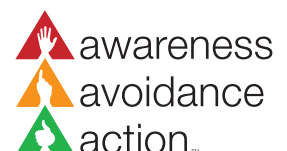
At the first meeting, the group should decide on a name, create a general mission or purpose statement, establish meeting times and places, and assign tasks. To create a mission or purpose statement, begin with a group discussion of common needs and goals, and let these direct the focus of the statement. Your group might be happy to meet once every few weeks for coffee and a chat whilst another group might want a more formal set up with particular topics being discussed at a given meeting. Whether you decide on improving the lives of members and their families, educating the community, or some combination of goals, a mission statement is a good way to keep your group focused and inform others of the group's purpose. Once these details are decided, update your flyer with the new information, and be sure to replace the first ones you posted.

Establish some general guidelines for how the meetings will go, though they may change along the way. Designate someone to record any questions or controversies if medical advice is needed so that they can be cleared up before the next meeting. Collect email addresses and other contact information so you can communicate between meetings if important issues arise.



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## ONCE THE GROUP IS ESTABLISHED

Plan meetings in advance and set out the topics to be discussed. It is important to stick to an agenda so that people know what to expect at each meeting. Publish a list of topics to be discussed at future meetings. Popular topics include:

- Cooking the Food Allergy Way
- Coping with the Stress of Raising a Child Who Has Food Allergies
- Anaphylaxis: What Is It, and What Can You Do About It?

Inviting guest speakers helps build attendance at meetings but this does require a few people to help organise the event. As most people attending meetings are parents with young children it is important to not over commit yourself unless you can see it through with back up help if needed. Most people are time poor these days and whilst health professionals are willing to donate their time, they appreciate a professional approach and a respect of their time.

Build on the individual strengths of group members as you get to know them better. Delegate tasks to others and provide them an opportunity to share in the pride of developing a thriving and vital community resource.

Enlist volunteers to assist in areas where they feel comfortable, such as preparing food and refreshments or keeping track of the mailing list. Enthusiastic people can help distribute materials to members and the local community with little added cost.

Consider some basic publicity to expand membership if you think your group could benefit from additional participants. Keep in mind, however, that support group success is about quality – better individual learning and empathy – not quantity. Once your group is up and running, others in your area with similar needs and concerns will be able to find you and join. Local newspapers are always looking for stories and many would be happy to come and interview you and your group. Many groups contact their local newspaper around Food Allergy Awareness Week which A&AA hold during May of each year.

Starting a food allergy support group brings many rewards. You'll make a real difference in the lives of families managing food allergies.

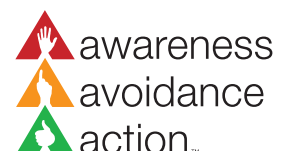
Members /attendees to the group

- ▲ Sometimes we have people in groups who are very needy or who dominate the group. This can put others off from attending.
- ▲ Your role as a founder/group leader/ coordinator does not mean you take on the issues of members in your group. Some people can be very demanding.
- ▲ Be sure not to over commit or become too involved in others problems.
- ▲ The group can be as active or non active as you want it to be. If people want more meetings, get togethers etc, share the load and get them to help with organisation.



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# Starting a Support Group

Membership to your group is voluntary however we strongly encourage your members to obtain their own membership to Allergy & Anaphylaxis Australia.

The sharing or photocopying of A&AA's member's only benefits i.e. newsletters, access to discount prices on resources etc. reduces the valuable income that supports the advocacy role A&AA plays in Australia for the allergic individual.

We are a small self funded non-profit organisation supported mainly by annual membership fees, sales of our resources and your donations. We deeply appreciate your help in raising awareness of food allergies and assisting all who may benefit from our information.

Please remember by encouraging support of A&AA you will be assisting us to continue the valuable work we do as well as the practice of generosity that has supported A&AA for the past 15 years.

Thank you, and good luck!



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