

Setting up a local APD support group

A guide for parents of children with APD and adults with APD wishing to set up a support group

WHAT IS A SUPPORT GROUP?

A support group is a collective with common goals or similar concerns. The purpose of a support group is to offer members the opportunity to make contact with others in a similar situation. Being part of a group can help individuals to gain support and know that they are not alone. Support can come in the form of conversation and sharing experiences and resources or by simply listening to others.

APD Support UK is the only organisation that currently provides information for families and individuals affected by APD in the UK and we also provide online support groups for parents and adults which you can access here. <https://apdsupportuk.yolasite.com/support.php>

However, you may also want to set up a local, in-person group, and this guide can help with that. There are several things to consider when setting up a local support group and this guide will help you work through them.

BEFORE YOU START

It might be worth considering this:

- Do you have the time and energy to commit running a support group?
- Do you have the backing of your family?
- Do you have enough help?

RESEARCH

You cannot do this alone. You should ask others for help set up the group as this will take a lot of time and effort. They can also help with research, suggesting ideas and decision-making. Find two or three other people (or even one person) interested in starting a support group with you. You can ask in the APD Support UK groups if there is someone else interested on your area, or speak to other local parents. Eventually you may need to identify a committee from within that group to help you manage it as it grows, possibly the founding members. It is advisable to do so sooner rather than later, especially if you intend to before setting up a “not-for-profit” organisation. (Once the group is up and running it will take a few more volunteers to manage it).

Solid research is invaluable. It is worth speaking to your local council for advice on setting up a support group early on. There may be certain procedures or rules you may need to follow. You may also find that you might need to register with the council first if you want to make it official e.g., in order to gain access to funds from the council for a community venture, gain information on/access to a hall or other venue to rent when the group becomes larger.

You should also consider the following.

NAME

You will need to decide on a group name. You will not be able to use “APD Support UK” as your group name as this is the name of the formal organisation for the whole of the UK. Keep it simple and to the point. When considering the name, give some thought to how it will attract other members – does the name clearly state who it is aimed and what you do? Remember to make it as local as possible e.g., “APD Parents – Coventry” or “APD Adults - York.” Parents might also want to take the name of your local authority, e.g., “APD Parents – Blackpool” to share support in your LA area. Make sure to keep it as localised as possible or you might eventually be inundated with members.

FOCUS

There is no right or wrong way to run a group. How formal your group will be depends on the wishes of the people involved and the aims and function of the group. Many groups change their structure as they develop, so there's no need to get tied down before you've even got off the ground. The support group could offer a “drop-in” session such as a coffee morning/evening, or be a more formal meeting with an agenda, or anywhere in between.

It helps to have a focus for your group from the start; you might choose one or all of these or another focus. You can always change it as the group grows, or you find it is developing in another direction.

- Decide who your group is for:
 - Parents of children with APD only (without children)
 - Parents of children with APD and their children
 - Adults with APD.
- Decide what your group will do. You might want a group where you can meet other parents of children with APD to share issues and seek advice and solutions, just chat. It might be a place to find other local families with children with APD for your child to socialise with, find friends, and know that they are not alone in having APD. A group for adults with APD might be just to meet like-

mindful others in the same situation, share strategies and make new friends. Your group might also want to also arrange social events, outings and activities.

- Your group can also share information on APD, online support, diagnosis etc. by passing on information from the APD Support UK website (please see suggested useful documents at the end of this guide) <https://apdsupportuk.yolasite.com/>
- You might instead want to set up a group with others to campaign on issues relating to promoting APD, seeking more local support at school, in work, or further education, or lobby local hospitals, MPs and health boards etc. for provision of full APD testing centres in your area. (If so, APD Support UK can help with information and template letters).
- Whatever focus or format you choose, you can identify what information you need and invite professional, speakers, organisations etc., to help you access this information and further your aims.

SETTING RULES

- Ground rules set out the behaviour that is expected of the group and are useful to ensure the group runs smoothly and will help to avoid problems or conflict. The ground rules are likely to be respected more if the group has been involved in drawing them up and they can be changed or added to as you gain members. You may want to display the ground rules during the meeting, or give each member a copy to sign, as a form of group contract. Ground rules can be added to or altered as the group progresses. Don't forget to let new members know about the ground rules and ask if they have anything to add. Some simple ground rules may include:
 - Listen to and respect each other
 - Respect confidentiality of all members
 - Be patient towards group members
 - Have constructive discussion
 - Group ownership: remember it belongs to all of you
 - Share responsibilities: rotate tasks and responsibilities among group members
 - Contribute to group discussions, if you feel able

LOCATION

- You will need a suitable location for your support group meetings. You may choose to hold meetings in your home at first, then rotate between homes of other members then move to a larger regular location as your support group grows. You could also meet outside, in a park for example, but this will depend on the weather.

- When choosing a location, consider size, a central location, accessibility, parking, transportation, suitability for those less able and those with prams/buggies, or with mobility issues; also access to toilets and baby changing facilities. It will also need to be secure and safe for children.
- You could consider schools, libraries, church halls etc. and community centres and leisure centres that rent out small rooms. But be careful that the space isn't too large or echoey and has little background noise etc. due to attendees having APD and the potential communication issues that come with it. If you have a regular room, it is easier then to decorate it with posters and rugs etc. that can help to minimise noise.
- If you do choose to rent a space, you will need to consider how this will be paid for. Some locations offer meeting spaces free of charge, or you may need to pay a fee which has to be recouped from members (or you will end up paying it yourself). Members of the support group can contribute to the hire, or you may prefer fundraising, but this is extra work and time-consuming, so a minimal fee per meeting is preferable. You might also consider council or other grants for voluntary community groups. If you decide to opt for fundraising, you should consider setting your group up as a *‘not-for-profit’ organisation (which will require a committee, proper accounts, a bank account and a treasurer).
- Will you provide refreshments like tea, coffee, cold drinks and snacks or will members bring their own? If meeting in rotation at home, the host could provide this when it is their turn. Or you could choose a venue near a café/shop.

FREQUENCY/TIMES

- Give some thought to how regularly you think the group will meet. Many groups meet on a monthly basis. It's worth considering meeting on the same day every month, such as, the first Monday or Saturday of the month, rather than specific dates, as this makes it easier for members to remember. You can always make this more frequent as needed.
- The day and time of meetings will depend on the availability of parents/adults with APD who may be working or have other commitments, or maybe on the weekend for those with school-age children who want to meet up.
- It might be good to get an idea from prospective members on their preferred day and time for the meetings.

MAKE IT APD-FRIENDLY

As this is a group for supporting APD, if there are parents, children and adults with APD present, you will need to make your group meetings as APD-friendly as possible.

- Encourage members to speak one at a time and allow extra time for those with APD to process and respond.

- Be aware of minimising background noise.
- Ask your members how they prefer information to be presented – repeated, rephrased or in writing etc.
- Always provide members with a pack of handouts with rules, aims, and important information.
- Send information about meeting times, dates and changes via email or text. Post this information up at the meeting venue.
- Ask members if there are any other adjustments that they need to support their APD and any other conditions or difficulties, as APD never usually exists alone.

N.B. There may be miscommunication due to the very nature of APD itself so be prepared to intervene discreetly to settle minor disputes (amongst children and adults).

AFTER THE PLANNING MEETING

Make sure someone writes down what the planning meeting has agreed about rules and aims etc. and check that everyone present is happy with the wording. For a formal organisation, this will make up your Constitution. Give a finalised copy to all members present at the planning meeting. If the group wants it to be a more formal one (e.g., for lobbying purposes) it is recommended to minute each meeting.

PUBLICITY

When you are ready to receive members, publicise the group well in advance with a reminder closer to the time, and in appropriate places suited to its potential members. E.g., you could put up a notice at your child's school, in the library, council offices, local shops, GP surgery etc. asking for other interested parents/adults with APD to contact you, also publicise in the APD Support UK online groups. You can also ask to list your group on the APD Support UK website when it is ready to receive members. apd.support.uk@aol.co.uk

It might take a while for people to realise the group is there, so be patient. Word of mouth is often the best form of publicity. Ask group members to advertise your group on other APD and disability online and in-person groups, but make sure new members have a diagnosis of APD, or suspect it and are seeking one (so you don't end up with a general disabilities support group rather than one specific to APD). You might even want to set up a Facebook page or group just for your local group members, where you can publicise meetings, events etc. There are instructions here. <https://edu.gcfglobal.org/en/facebook101/creating-a-facebook-page/1/> and <https://www.facebook.com/help/167970719931213>

REMEMBER

When you first meet up, or new members join, you will probably want to spend time getting to know each other and talk about your experiences. It can help to make it informal, e.g., not asking everyone to introduce themselves, say why they're there etc. You should allow members time to get to know each other and find out initial information from each other. It is worthwhile saying that if anyone prefers not to speak at this stage, they don't have to.

Not everyone will want to come back: be prepared for that. It isn't your fault. It may be that they were looking for something more/less formal, more/less about APD or more/less about socialising, or just not what you offer. Not everyone will get on with each other. But don't take it personally if the group doesn't work out. All you can do is provide the opportunity.

ADDITIONAL INFORMATION AND SUPPORT

If you need any further information on APD please visit the APD support UK website: <https://apdsupportuk.yolasite.com> or email: apd.support.uk@aol.co.uk

USEFUL DOCUMENTS to share with members

About APD <https://apdsupportuk.yolasite.com/about-apd.php>

APD testing centres October 2021 <https://apdsupportuk.yolasite.com/about-apd.php>

APD in the classroom <https://apdsupportuk.yolasite.com/information.php>

Adults with APD and Employment <https://apdsupportuk.yolasite.com/information.php>