

# **How to find safe and appropriate support**

## **A guide for parents and carers of PDA children**

Co-produced by professionals and PDA adults  
with the support of the PDA Society

This resource has been created by PDA adults, professionals and carers of PDA people, with the support of PDA Society. It's aims are to help PDA people find safe & appropriate support.

As a community that can be misunderstood, PDA people struggle to find helpful and appropriate services. This can often result in choosing services which may not meet their needs.

We believe that our community should be able to access support that helps us and doesn't harm us. It is our hope that this resource will help our community to identify safe practice and know what to do if services seem unsafe.

This guide has been created for parents and carers. A supplementary resource exists for PDA adults, and another will shortly be produced for professionals.

# Contents

Letter from the Safer PDA Panel .....	4
Identifying the type of support your child needs.....	5
Understanding professional titles.....	6
How professionals can adapt to the needs of a PDA person.....	7
Finding a professional.....	8
Making a shortlist.....	10
Initiating contact with a professional.....	11
Starting a professional relationship safely .....	12
Attending appointments .....	14
Assessing an existing professional relationship.....	15
Concerning behaviour in a professional relationship .....	17
Taking action following inappropriate behaviour .....	19
Ending a professional relationship .....	22
Moving on.....	24
A final note from PDA Society CEO - Elizabeth Archer .....	26

## **Letter from the Safer PDA Panel**

Hello,

If you're reading this guide, it's likely that you're looking for support, or are unsure about support you're already receiving for your child. PDA people can be vulnerable to putting up with harmful professional relationships for several reasons.

### **PDA people:**

- Tend to avoid mainstream ways of doing things.
- May miss social cues.
- May have learnt to doubt their own judgement (after all, if everyone: teachers, peers and bosses, etc have kept telling us our inner experience can't be real, it can be hard to trust our own perception).
- Are likely to have intense, roller-coaster emotions.
- May mask true feelings, making it hard for professionals to see their needs.
- May think of self-care as an irrelevant demand to avoid.

There are a wide range of professionals with different specialisms and skills who can offer support to your child. However, it can often be hard to identify who's the best fit. This guidance is designed to support you as you navigate the whole process: from the point of deciding help is needed, to ending a professional relationship safely.

We hope it's helpful.

***The Safer PDA Panel***

## **Identifying the type of support your child needs**

Once you have decided or your child has indicated they would benefit from some additional support, it helps to have clear expectations about the outcome you are looking for.

It's important for your child to feel included in the process, so it can be helpful to start with an open conversation about what your child would find helpful, if they are able to. It might help to consider the following questions:

- ♦ What does my child need help with?
- ♦ What outcome am I hoping for, and how would I like my child to feel about the support they are receiving?
- ♦ What professionals or services am I already engaging with on behalf of my child, and what impact is this having?
- ♦ What is important to me about the professional I'm seeking help from on behalf of my child?
- ♦ Do I need to seek a professional with specific knowledge, experience, values, or characteristics?

The answers to these questions will help you decide the type of professional you need to look for. You can also refer to your answers later to reflect on whether the support your child is receiving is meeting your expectations.

If your child wants or needs support in more than one area, it might be useful to consider whether you wish to prioritise engaging one service to begin with, before involving multiple agencies.

## **Understanding professional titles**

Once you have identified your child's needs, you can begin to research the types of professionals who are available to support them.

Professions vary greatly in terms of their training and monitoring standards which can make it difficult to understand whether a professional has the right qualifications and experience. There are three broad categories of professional titles:

### **Regulated titles:**

Some titles, such as "psychologist" or "speech and language therapist", are protected by law and can only be used if the practitioner has specific qualifications. In this case they must be registered with, and accountable to, a regulatory body. They will likely advertise this on their website or social media, and you can confirm this on the regulatory body's website. You can also verify some professionals on the [Health & Care Professionals register](#).

### **Self-regulatory titles:**

Some professionals work in a non-regulated industry but have undertaken a standard of training which enables them to elect to join a self-regulatory professional body. Counsellors and psychologists fall into this category. In this situation many professionals will choose to advertise the organisation(s) to which they belong by adding the logo or seal to their profile or website. This demonstrates that they have met a particular standard and are willing to practice in line with a code of conduct.

### **Unregulated titles:**

Unregulated professionals are not accountable to any external body. It's their responsibility to define their own role, what they are (and are not) competent to do, and how they ensure that the support they offer is safe and helpful.

**If you are seeking support around diagnosis, PDA Society have a helpful guide which can be found [here](#).**

## **How professionals can adapt to the needs of a PDA person**

Professional bodies may provide their own guidelines for best practice. However, as PDA is not universally recognised and understood, this may not always be suitable for PDA people. Whatever the case, it is always okay to ask a professional to adapt their practice to your child's needs or direct them to PDA resources.

### **Professionals working with PDA people should try to:**

- ♦ Be person centred and focus their work with your child around their needs and preferences where possible.
- ♦ Communicate in a non-directive way.
- ♦ Be flexible around your child's changing needs.
- ♦ Take account of your child's sensory needs.
- ♦ Offer creative and playful ways to approach things that must be done.

Be aware that many PDA people have co-occurring conditions and adjust around these too.

The clearer you can be about what adjustments are helpful for your child, the easier it will be for professionals to meet their needs.

## **Finding a professional**

If you're using your own money, have a personal budget or are using Right to Choose, you can decide who to work with. If you're looking for someone who's part of a regulated or self-regulated profession, their professional body will often be able to signpost you to their register.

You may also receive a referral from another professional. If neither of these are the case, it's perfectly fine to find a professional through an internet search engine, making sure you check their professional status using the guidance above.

If services are paid for by your local authority or health provider there may be no choice about who you work with. However, you can ask the referrer if they're confident the professional has experience working with PDA people. You can also work with the professional you've been allocated to set up their service in a way that's safe and adapted to meet your child's needs. (This is covered in the section called Starting professional relationships safely.)

The person signposting you may think a professional is appropriate and safe, but you and your child may think differently. It is worth doing your own research and looking at a few options, so you know you're making an informed choice.



## **What is a personal budget?**

This is money provided by your local authority (council) to pay for the social care or educational needs of your child. This may include support to help with day to day living tasks, different therapies or educational services. Depending on your finances, you might have to pay some of the cost of care or support. Useful information and guidance about personal budgets can be found [here](#) or by contacting your local authority.

## **What is Right to Choose?**

In England, the NHS will pay for a private specialist, provided they have a contract with any NHS Integrated Care Board and the cost is comparable to the NHS's usual provision. It can be useful if you live in an area that's short of resources, lacks a diagnostic pathway for neurodivergence, or applies outdated criteria. In order to apply you will need a referral from your GP. Right to Choose doesn't give you a right to demand a referral, but you can seek a second opinion if your regular GP has decided not to refer you. There are some exceptions and limitations, which are explained in guidance [here](#).

## **Making a shortlist**

Due diligence means assessing whether a professional meets your needs. The amount of diligence needed by you will depend on whether a regulatory body has already checked a provider's fitness to practice.

If the professional isn't regulated, it might be worth finding out:

- ♦ What qualifications and experience do they have, and does this meet your child's needs?
- ♦ How much will their services cost you, and what will you get for your money.
- ♦ Whether they talk about PDA in a way that leads you to believe they'll be helpful.
- ♦ If they have a DBS (Disclosure & Barring Service) check (or Scottish/Welsh equivalent) and insurance and registration with the ICO (Information Commissioners Office).
- ♦ Do they offer an introductory session so you can see if they're right for your child.
- ♦ What their terms and conditions are, including cancellation policies.
- ♦ Practical information like location, frequency and timings.

A well trained, experienced, and trustworthy professional might not meet all of these criteria. However, anyone who has your best interests at heart will be happy to answer any of these questions to the best of their ability.

## **Initiating contact with a professional**

To help you choose a professional who is a good fit for your child, it can help to get a feel for how they interact prior to arranging your child's first appointment. Contacting at least a couple of different service providers before you decide who to employ is a good way to do this.

A person-centred professional or organisation will try to prioritise your child's unique needs. You can get a sense of how person-centred someone is by getting in touch, using whichever method you are most comfortable with, and asking how they'll adjust to your child's needs. You might want to know if they are available at the times your child is able to attend, if they can they be flexible about changes to plans, and whether their venue is a sensory friendly environment or if they can conduct their support online.

It shouldn't feel uncomfortable to ask a professional if they can meet your child's needs. Appropriate and safe providers will be honest about their ability to meet specific needs, such as a quiet waiting space or public transport links.

### **Taster sessions**

A trustworthy professional won't put pressure on you to decide straight away, and some might even offer a taster session. This may or may not be free, but it's unlikely to involve a large upfront cost. Taster sessions can clarify if a service feels like a good fit for your child. It might be helpful to try sessions with more than one provider before making a decision, if that is something your child can tolerate.

## Starting a professional relationship safely

To start safely, it's best to have a written agreement. This might be a formal contract or a summary which they email to you. If your provider doesn't offer a written agreement, it's worth asking for one. This could be a simple email, covering the terms of engagement, so both sides have clear expectations of one another.

### **A written agreement might include:**

**Practical information:** Will meetings be in person, online, via phone, or a mixture? Is there a waiting room? Is there parking? What software will be used for online sessions? What happens if the connection drops? How can you make contact between sessions if you need to?

**Goals and outcomes:** What are you working towards? How long do they expect the working relationship to continue, and are there check in points as part of the review process?

**Fees and payments:** Is there a clear schedule of fees? How and when are payments to be made? Do they charge for any additional services or cancelled appointments?

**Cancellation process:** How to advise them if you need to cancel, what they charge for non-attendance and how to rebook. Last minute cancellations, or terminations of relationships, may incur costs for them.

**Ending the relationship:** Is there a final review session? How can either party terminate the relationship early? (This might need to be in writing with a period of notice).

**Complaints process:** They may have separate policy or document which explains how to raise concerns about their service, or they might signpost you to a regulatory body or professional association they're a member of.

**Confidentiality and safeguarding:** You can ask for confirmation that they're registered with the ICO, and information on how they keep your data safe and secure. In what circumstances would they need to break confidentiality if they have significant safeguarding concerns?

**Supervision and reflective practice:** How do they ensure they have their own needs supported so that, in sessions, their client's needs are central to the work and process? How do they keep their skills up to date?

## Attending appointments

Depending on the type of appointment, and the age of your child, you may want you to attend with them. It's useful to discuss this with your child, as well as the professional concerned. You may also wish to consider the following reflections:

If you feel strongly that you want to attend, what are your reasons?

- Would your presence impact the usefulness of the appointment? (This may be case with talking therapies for example)
- Is your child able to process and retain any important information that may be given to them without you present?
- If they don't wish you to attend the appointment, could a compromise be made that allows you to share information as needed – attending for a part of the session for example? Or could you attend the first session and then revisit the arrangement?
- What is the professional's reason for wishing you to be present, or not?

If you are not present and your child is under 12 years of age, then you can request to see a professional's notes. However, if your child is 12 or over then consent to share the notes may be requested from your child by the professional. Further guidance can be found [here](#).

Gillick competency and Fraser guidelines can be used to help people who work with children decide whether a child is mature enough to make decisions about things that affect them. Gillick competency applies to medical and other support/therapeutic type practice, whereas Fraser guidelines apply specifically to matters regarding contraception and sexual health. Further information can be found [here](#).

## **Assessing an existing professional relationship**

These guidelines can also be talked through with children and young people if their appointments are not attended by a parent or guardian.

What makes a relationship safe?

### **Person centred:**

- The sessions are focused on your child's needs and outcomes which have been agreed, and they won't use the time to work through their own issues.
- The professional will have thought about how they have their own needs met outside sessions, so they maintain focus on their client.
- They'll consider how to be approachable without sharing inappropriate personal information or being over friendly.
- Their behaviour won't give the impression that their approval must be earned.

### **Professional:**

- The sessions will be delivered as agreed.
- Clear, written boundaries are provided from the start, and the professional works within these boundaries for the length of the relationship and beyond to keep all parties safe.
- Contact is about professional matters and conducted at appropriate times and places. If contact happens at either your home or theirs, then it's important they can show you that they've considered all the risks.

### **Respectful:**

- The provider will prioritise your child's autonomy, privacy and personal space.
- The provider will regularly check your child's feelings of safety and confirm consent for anything done to them (even if it's been done before).

- Consent should be sought for any physical contact (with an explanation of why it is appropriate); for changes in the venue or the style of sessions; and for sharing or using any personal information about your child in any way.
- It will be clear that your child has a choice, and that there will be no negative repercussions of consent being withheld.

### **Transparent:**

- There is space for your child to share thoughts, feelings and ideas. Records are timely, accurate and available to you as appropriate. No professional should ask your child not to talk about what they do in sessions, or suggest they're being given "special treatment" which must not be mentioned.
- Your child should feel able to talk to their parent/guardian or any other trusted adult about anything that happens in a session with a professional.

### **Your child's PDA traits may also have an impact on their professional relationship:**

- If your child is masking during an appointment, the professional may not get an accurate view of how they are feeling.
- Demand avoidance may cause the professional to feel disrespected. For example, if appointments are repeatedly cancelled.
- Your child might avoid suggestions made by the professional, such as keeping a journal.
- A professional may assume that PDA traits – such as demand avoidance and anxiety – can and should be fixed. However, this might not be appropriate or desired as part of that relationship or session.



If you feel that there are misunderstandings as a result of your child's PDA traits, it might be worth explaining why your child reacted as they did, and exploring whether this understanding can enable the professional relationship to continue. Alternatively, one of you may decide that the relationship isn't able to meet your child's needs.

There's additional guidance on ending relationships safely in section 7.

## Concerning behaviour in a professional relationship

Below is a list of some unacceptable behaviours. If any of the following are observed or reported by you or your child you should end the professional relationship immediately and follow the relevant complaints process if you feel able to.

- ◆ Consuming alcohol or illegal substances in, or before, a session, or suggesting a client consume them.
- ◆ Seeking to connect their personal social media profiles with their client's or parent/guardian.
- ◆ Making sexual propositions, talking about their own sexual conduct or asking about that of a client or parent/guardian.
- ◆ Touching a client without consent, or when unnecessary for service being offered.
- ◆ Repeated and/or personal contact with client or parent/guardian between sessions.
- ◆ Suggesting socialising with client or parent/guardian outside of the work you're doing.
- ◆ 'Diagnosing' a client with conditions unless they are a diagnostic professional working within NICE guidelines.
- ◆ Sharing personal information without consent.
- ◆ Abusive or violent language or behaviour.

## **Evaluating potentially inappropriate behaviour**

At times you might be unsure whether a professional's behaviour is inappropriate. For example, if a professional tags or messages you or your child via social media about something outside of the scope of the professional relationship.

If something happens with a service provider which makes you or your child feel confused or unsafe, it could be a good idea to talk it through with someone you trust and ask for their perspective. It's OK to end a working relationship based on a gut feeling (you don't have to wait for something bad to happen). It's also important to note that some PDA people don't notice, or don't value their own discomfort. If you are unsure, it's always okay to ask for advice. The next section covers how you could do this.

## **Taking action following inappropriate behaviour**

Once you've realised that someone is working in an unsafe way you may decide to take action. If you believe someone is at immediate risk of significant harm, you could consider going straight to social services or the police.

If you don't think anyone is at immediate risk, but you still want to take action, you could consider the following:

### **1. Seeking support for your child and/or yourself.**

You might wish to speak privately to someone you trust. You could also contact the PDA Society's enquiry line to get support and discuss what steps to take next.

Some people use social media to get peer support quickly, or to flag untrustworthy behaviour. However, when sharing content publicly it's important to consider the privacy settings on your account, and whether you want to control who can view your post or reply in the comments. You are more in control of the outcome if you message people you trust directly, rather than posting to a public page.

If you do choose to post publicly, consider whether you can talk about your experiences and the support you need without naming the person you have concerns about. Talking publicly waives your rights to anonymity and, in some cases, could expose you to further negative experiences, such as being trolled online. A safe provider will not talk negatively about you or others online or tolerate others doing so.

Should you choose to use names you might also be at risk of being accused of libel or slander. If you're making a formal complaint to a professional body or the police, it might be worth asking whether talking publicly will impact their ability to act.

## **2. Take steps to ensure unsafe behaviour is recognised and addressed.**

Review sites offer you the opportunity to give feedback about how a service was for you. If a service has the facility to leave a review, this can be a safer way of sharing your experiences.

If the person or organisation you're working with has a complaints process, and you feel safe using it, you may also want to make a complaint. Safe people and organisations welcome complaints as ways to help them reflect upon, and improve, their practice. Their complaints procedure should also let you know what you can expect to happen next.

You may have the option to make a complaint directly to the organisation or individual you've been working with. A sole trader will normally respond to complaints themselves, whilst a complaint to an organisation might be shared with other employees to make them aware of the actions that made you uncomfortable.

If you are working with someone from a regulated profession, then their regulatory body will be able to decide if they are working in line with that profession's standards and can also take action to investigate further. Regulatory bodies typically publish their complaints process on their website, and this will inform you of the first step to take.

If you are concerned that the person you are working with is acting in a way that is unsafe, you can also seek advice from your local authority safeguarding team. The person you speak to might be called a LADO (Local Authority Designated Officer) or a MASH team (Multi Agency Safeguarding Hub). Different areas use their own terms – you can find your local safeguarding service and how to contact them using the [NHS Safeguarding App](#).

Making contact with a safeguarding team will allow you to tell someone what has happened. They will let you know what action they will take, if any, and can make suggestions about what you can do next. If you want to talk in general terms about your experience without using names this is usually OK.

It is always useful to follow up a telephone conversation with an email outlining your concerns. However, some safeguarding teams don't accept emails and may ask you to fill in an online form. Where this is the case, they should email you a link to this form. If you think a criminal act has taken place then you can also consider contacting the police about your concerns. They will explain to you what information they need from you and what you can expect to happen next.

## **Ending a professional relationship**

Ending a professional relationship early can be a difficult and sensitive matter. The approach you take will depend on the nature of the relationship and the reasons for ending it. Planned endings will likely have been covered in the working agreement you put together at the beginning of the relationship.

Unplanned endings are ones which don't happen in the way you agreed at the beginning of your work together. These could happen because of a change in your circumstances or because your child no longer wants to work with a person. Unplanned endings caused by the provider should have been set out in your working agreement. If you're not the one ending the relationship the content of this section is unlikely to be relevant for you. The next section, 'how to move on', may be more helpful.

### **Communicating that you want the relationship to end**

If you feel it's safe to do so, it can be helpful to let the person know that you are going to stop working with them (particularly if you are hoping to get a refund). You don't have to give a reason, but it can be helpful to communicate this in writing via email so you have a record. You may also want to request a receipt that the email has been received and read. If you don't feel safe and the professional has a reasonable expectation you will continue working together you may want to ask someone to get in touch on your behalf to let them know you will not be returning.

If you wish to have no further contact with this person, you can state this clearly in your email. If you want to share why you are ending the relationship, it's helpful to use factual, non-emotive language to describe why the service isn't right for your child. You don't need to do this unless you or your child wishes to.

## **What if they owe me money?**

If you are ending a professional relationship because they did not do what was agreed, then you can ask for some, or all, of your money back. This might be because the work was not done at all, or because it was very different from your initial agreement.

At this stage this is a commercial dispute, and the first step is to ask the person or organisation for a refund and give them a reasonable amount of time (normally up to 30 days) to respond. If they don't respond with what you believe to be a fair offer, you could choose to pursue a case through the small claims court. Information about this can be found [here](#).



## **Moving on**

When a professional relationship ends, it's a change for both your child and the professional they have been working with. In the case of planned endings, your child should have had an opportunity to prepare for and discuss this transition. There might also be an opportunity for you to work together to put a plan in place, which might include:

- How to help your child identify what they've learned.
- What your child can do to hold onto positive gains from this experience.
- What to do if your child needs this person's help again.

## **Can we be friends?**

A safe professional will recognise the likelihood of a power imbalance in any relationship, so moving from a professional relationship into friendship is unwise, both for the child and the parent or guardian. Some regulated professionals also have guidelines about this. It's possible to become friendly with people you've worked alongside, but safe professionals will discourage it unless a significant amount of time has passed and you have social connections outside of the work you did together.

## **Unplanned endings**

If the ending was unplanned because something went wrong, or your child felt unsafe, then it might be helpful to take time to process and understand what happened. It's important to discuss what you've both learnt and what you can do to minimise any long-term impact for your child.

You might choose to go through this reflection process with your child directly, or with someone else you both trust. You may also have reported your experiences to other organisations who can help, and it can be valuable to reflect on whether you are satisfied with any actions taken.

When your child feels ready, you can consider starting the process again to find the right support to meet their needs.

Once your work with a professional is completed, whether it ended because you had reached your goals together or for another reason, it can be helpful to reflect on the process you've been through. If you've used this guidance for the whole process, it might be worth going back and reflecting on your answers to the questions in section one.

- Did your child achieve what they hoped to?
- What have you learnt about what works for your child?
- Is there a way that this learning can serve you in the future?

Hopefully what you've learnt will be useful the next time you seek support from a professional and are going through this process again.

We hope you've found this guidance useful.

***The Safer PDA Panel***

## **A final note from PDA Society CEO - Elizabeth Archer**

I'd like to finish this guidance with a note of thanks.

Firstly, thank you to you for reading this guidance. I hope it's helpful.

Secondly, a big thank you to the volunteer members of the Safer PDA Panel who have worked on this document unpaid over the last 6 months because they want it to be easier for PDA people to access support that is appropriate and safe.

The panel came about after PDA Society noticed a trend; we were being asked regularly about how trustworthy different providers were – and it was difficult for us to give an answer. We are a small charity with limited capacity, and we realised that we couldn't responsibly answer these enquiries without redirecting resources away from other types of support, training and information which is desperately needed.

But we also knew we couldn't do nothing. PDA people are already misunderstood and underserved, and so it is vital that the support services which are available can meet their needs.

We put a call out for PDA adults, parents & carers of PDA people, and professionals with knowledge of safeguarding, and asked them to volunteer to join a panel. With PDA Society acting as Secretariat, these volunteers have worked collectively to put together this practical and accessible resource. We hope this makes it a little easier for PDA people and their carers to find safe services, and to know how to respond if something goes wrong.

This guidance represents 6 months of work by a group of committed volunteers with a shared purpose – to make accessing services easier and safer for PDA people.

Thank you to all the members.