

## Health & Behaviour Journal: For Suspected or Previously Confirmed PANS/PANDAS

For Parents, Carers & Families

### Purpose

This tool helps you track and organise concerns about your young person's health and daily functioning. PANS and PANDAS can involve changes across many areas of life from mood and behaviour to sleep, learning, eating, toileting and fine and gross motor skills. Recording these changes can help you notice patterns, give clearer information to health professionals, and support ongoing care.

Key words to keep in mind when recording are *spikes*, *intensity*, and *changes to baseline*. These highlight when symptoms appear suddenly, how strong they are, and how they differ from what is typical for the young person.

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### Important Note

This is an information gathering template intended for use in the home setting. It is not a diagnostic tool and should not be used to confirm a diagnosis of PANS or PANDAS. These conditions are diagnosed by exclusion and require assessment by a qualified medical professional.

The template may help identify traits or concerns that could be consistent with PANS or PANDAS, but it must be

considered alongside a broader range of clinical, and contextual information. Its purpose is to support awareness and guide further investigation, not to provide a diagnosis.

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## How to Use This Document

- **Keep it simple at first:** You don't need to complete every section immediately. Start with what you know and add details over time.
  - **Update regularly and keep notes as you go:** Symptoms may flare and settle. Add details when you notice new changes.
  - **Focus on shifts:** Record when abilities, behaviours, or symptoms change suddenly (e.g., handwriting worsens, eating narrows, toileting changes)
  - **Use examples:** Short notes like “stopped eating crunchy foods” or “wakes at 2 am nightly since July” are useful.
  - **Use your own words:** You don't need to use medical terms, simple descriptions are enough.
  - **Note patterns, not just diagnoses:** Fatigue, chronic pain, digestive issues, migraines, and sensitivities may be important even if they weren't formally diagnosed.
  - **Bring to appointments:** Share a copy (or key sections) with healthcare professionals to add valuable context.
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### Individual's Information

- **Name:**
- **Date of Birth:**

**Neurodivergence / Neurotype:** *how my brain works (e.g., Dyslexic, Autistic, ADHD)*

**Known Health Diagnoses:**

**Current Concerns:** *(Brief overview of what feels most important right now)*

**What I Want You to Know:** *(A space for your young person to express their feelings, suggest what helps and what doesn't help, or things important to them.)*

## Medications

*(Current or past medications that may be relevant to your or your young person's health and wellbeing)*

Name of Medication	Purpose / Condition	Taking Currently / Past	Notes (e.g., side effects, effectiveness)

## Supplements & Other Therapies

*(Include anything you or your young person is currently taking or has tried, such as vitamins, herbal remedies, probiotics, or alternative/complementary therapies. This can help health professionals see the full picture.)*

Supplement / Therapy	Purpose / Reason	Taking Currently / Past	Notes (e.g., effects, changes noticed)

## Health & Support Professionals

*(List any doctors, therapists, or other health professionals you or your young person has seen. Include past or current appointments that are relevant to their health and wellbeing.)*

Professional / Service	Reason / Health Area of Care	Dates Seen	Notes / Key Takeaways

### Additional Support Professionals

*(List any school staff, support workers that are involved in the care of your young person.)*

Professional / Service	Reason / Area of Care	Dates Seen	Notes / Key Takeaways



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## Notes Section

*(For anything that doesn't fit neatly into the tables above, questions for professionals or for reflections you want to keep for yourself.)*

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## Areas to Observe & Record

Use these sections to log changes or new difficulties. Each area is important and should be given equal weight by care professionals when discussing patterns and concerns.

Area	Things to Look For / Examples	Notes / Examples
<b>1. Sleep</b>	<ul style="list-style-type: none"> <li>• Trouble falling asleep / waking often</li> <li>• Nightmares / night terrors</li> <li>• Changes in sleep pattern (later bedtime, very early waking)</li> </ul>	
<b>2. Eating &amp; Drinking</b>	<ul style="list-style-type: none"> <li>• Food refusal or restriction</li> <li>• Sudden food fads or aversions (textures, smells, colours)</li> <li>• Changes in appetite or weight</li> <li>• Fear of choking, contamination, or vomiting</li> </ul>	

<b>3. Toileting</b>	<ul style="list-style-type: none"> <li>• Daytime accidents</li> <li>• Night-time wetting</li> <li>• Urgency or frequency changes</li> <li>• Withholding poo or urine</li> <li>• Urinating or pooing other than in the bathroom</li> <li>• Urine infections</li> </ul>	
<b>4. Schooling &amp; Learning</b>	<ul style="list-style-type: none"> <li>• Handwriting changes (smaller, less controlled)</li> <li>• Maths or other skill decline</li> <li>• School anxiety or reduced attendance</li> <li>• Trouble focusing or remembering</li> <li>• Executive function difficulties (organising work, routines)</li> </ul>	

<b>5. Emotional Well-being</b>	<ul style="list-style-type: none"> <li>• Sudden mood swings / irritability</li> <li>• Anxiety or panic attacks</li> <li>• Depression or withdrawal</li> <li>• Obsessive or compulsive behaviours (checking, washing, repeating)</li> <li>• Self-harm, suicide ideation</li> <li>• Psychosis (A loss of contact with reality, involving hallucinations or delusions)</li> </ul>	
<b>6. Social &amp; Daily Activities</b>	<ul style="list-style-type: none"> <li>• Unable to attend favourite clubs, sports, or groups</li> <li>• Separation anxiety from parent/carer</li> <li>• Loss of confidence in social situations, need for intense reassurance</li> </ul>	

<b>7. Physical Health</b>	<ul style="list-style-type: none"> <li>• Tics (motor or vocal)</li> <li>• Fatigue or sudden low energy</li> <li>• Pain (headaches, stomach aches, joint pain)</li> </ul>	
<b>8. Communication &amp; Language</b>	<ul style="list-style-type: none"> <li>• Loss of speech or reduced expression and understanding</li> <li>• Word-finding difficulties</li> <li>• May prefer to text/write to communicate versus speak</li> <li>• Fluctuations in communication ability</li> <li>• Changes in tone, pace, or repetition of speech</li> </ul>	

<b>9. Motor &amp; Skills Coordination</b>	<ul style="list-style-type: none"> <li>• Clumsiness or frequent dropping things</li> <li>• Changes in pencil grip/drawing ability</li> <li>• Difficulty with every day motor tasks (dressing, feeding, tying shoes, pouring drinks)</li> </ul>	
<b>10. Behaviour &amp; Routines</b>	<ul style="list-style-type: none"> <li>• Need or insistence on sameness</li> <li>• Meltdowns or shutdowns with routine changes</li> <li>• Reduction in independence (dressing, feeding, toileting, general hygiene)</li> </ul>	
<b>11.Sensory &amp; Perceptual Changes</b>	<ul style="list-style-type: none"> <li>• Increased or decreased pain tolerance</li> <li>• Hallucinations (seeing/hearing things not there)</li> <li>• Delusions (strongly held false beliefs)</li> </ul>	

	<ul style="list-style-type: none"> <li>Heightened or reduced responses to sensory input (touch, sound, taste, smell)</li> </ul>	
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## Notes Section

*(For anything that doesn't fit neatly into the tables above or questions for professionals)*

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## Timeline / Flare Tracking Log

Use this space to note when symptom flare-ups begin, improve, or repeat. Dates are especially helpful for spotting patterns if you can. The table is designed so you can record both the facts (dates, duration, possible triggers like illness/life transitions) and the impact on your young person's mental wellbeing, physical health, and everyday skills.

Date	Length of Flare	Possible Attributing Factor(s)	Notes / Observations



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## Signposting

To learn more about PANS / PANDAS and receive support, please contact PANS / PANDAS UK at <https://panspandasuk.org>