Themed Session 3

Monitoring and Review

Dr Ashley Liew
Professor Rajat Gupta
Professor Ming Lim
Chair: Dr Tim Ubhi

Perspectives on PANS

8 - 10 October 2026

Monitoring & Review

Dr Ashley Liew
Consultant Paediatric Neuropsychiatrist
South London & Maudsley NHS FT

Ongoing reviews for a child/young person with PANS

Who needs to be involved and how do they coordinate care?

How often should reviews occur?

How to monitor the clinical presentation?

Symptom profiles inform staffing for reviews

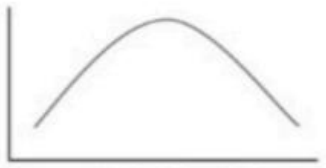
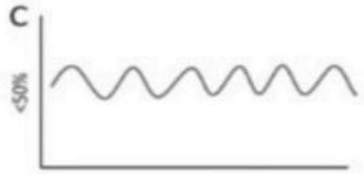
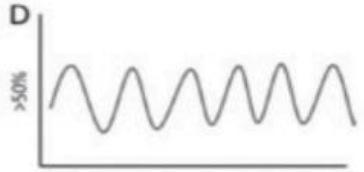
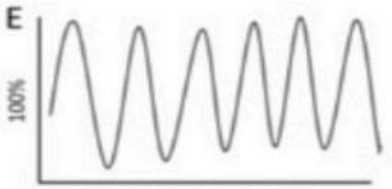
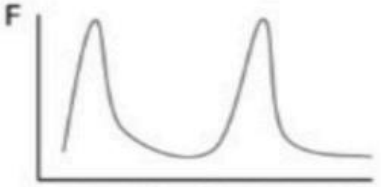
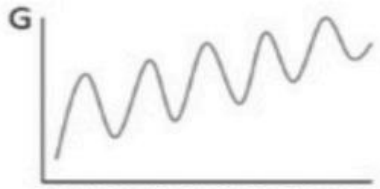
Neuropsychiatric symptoms at the initial clinic presentation, No. (%)	
Obsessive-compulsive symptoms	174 (90.2)
Anxiety	172 (89.1)
Irritability, aggression, and/or severely oppositional behaviors	156 (80.8)
Mood dysregulation	153 (79.3)
Sensory dysregulation or amplification[c]	147 (76.2)
Cognitive impairment	145 (75.1)
Sleep disturbances[d]	137 (71.0)
Eating restriction	107 (55.4)
Motor and/or phonic tics	88 (45.6)
Behavioral or developmental regression	86 (44.6)
Urinary symptoms[e]	79 (40.9)
Suicidal ideation or behavior	33 (17.1)

Ma, M., et al (2024) JAMA Network Open. 7 (7), e2421688.

Treatment/Support plan informs staffing for reviews

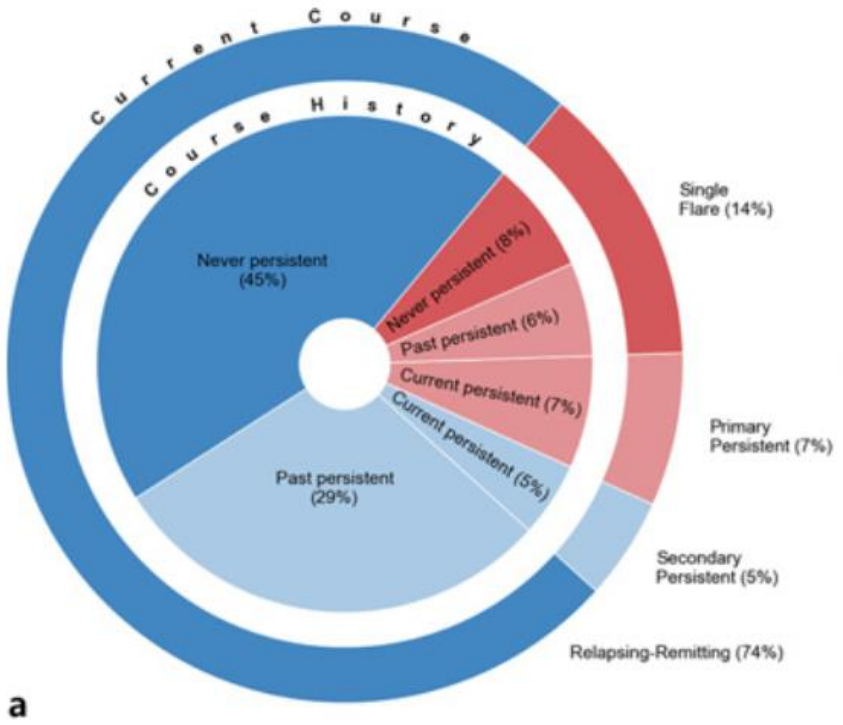
- Antimicrobial Treatments
- Immunomodulatory Treatments
- Anti-Inflammatory Treatments
- Targeted Immunomodulation
- Mental Health / Sleep Treatments
- Education Support / Carer & Family Support

Clinical trajectories inform review frequency

Clinical trajectories	PANS (%) (n=53)	Non-PANS (%) (n=106)
A  MONOPHASIC Single episode with or without complete resolution	4.3	0
C  MILD FLUCTUATIONS Change in symptoms, preserved function	6.5	14.9
D  MODERATE FLUCTUATIONS Change in symptoms and altered function	**13**	**44.6**
E  SEVERE FLUCTUATIONS Change in symptoms, incapacitated	**54.3**	**28.7**
F  RELAPSING REMITTING >3 months of complete recovery between episodes	**10.9**	**1**
G  CHRONIC PROGRESSIVE Incomplete recovery between episodes	8.7	8.9

Nishida, H., et al (2026) *European Journal of Paediatric Neurology*. 63, 60-68.

Clinical trajectories inform review frequency



Single Flare	**Primary persistent** a sub-classification of the Single Flare course
characterized by one recorded flare to date	*characterized by an initial flare* (isolated or flare series) *that lasts* >12 months without an unequivocal recovery
Relapsing-Remitting	**Secondary persistent** a sub-classification of the Relapsing-Remitting course
characterized by intermittent flare and recovery intervals; has had at least one unequivocal recovery and subsequent flare start	*characterized by a subsequent flare* (isolated or flare series) *that lasts* >12 months without an unequivocal recovery

Masterson EE et al. (2025).Dev Neurosci. 47(4):270–286.

Monitoring

Besides careful clinical reviews, collecting validated outcome measures help with monitoring disease course and treatment effects (Frankovich et al, 2017)

General[a]	Achenbach System of Empirically Based Assessment (ASEBA),[19] Mini international neuropsychiatric interview (M.I.N.I.-KID)[36] or equivalent
	Child and Adolescent Trauma Screen (CATS)[37]
	Children's Global Assessment Scale (C-GAS)[38]
	Clinical Global Impression- Severity Scale (CGI-S)[39]
	Paediatric Quality of Life Inventory (PedsQL)[40]
	Optional: Work and Social Adjustment Scale (WSAS)[26]
	Optional: KIDSCREEN[41]
Symptom-specific[a]	Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS)[42]
	The Screen for Child Anxiety Related Disorders (SCARED)[43]
	Yale Global Tic Severity Scale (YGTSS)[44]
	Kiddie Schedule for Affective Disorders and Schizophrenia (Kiddie-SADS)[45]
	ADHD rating scale (ADHD-RS) [46]
	Behaviour Rating Inventory of Executive Function (BRIEF)[47]

Pfeiffer HCV et al. (2021) Acta Paediatrica. 110(12):3153–3160.

Clinician-rated scales:
CGAS[a]
CGI-S/I[b]
CY-BOCS[c]
YGTSS[d]
Parent-rated scales:
CGI-S
KIDSCREEN-10
SMFQ-P[e]
SAAI-P[f]
AQ-10[g]
SNAP-IV[h]
Child-rated scales:
CGI-S
KIDSCREEN-10
SMFQ-C
ISI-C[i]

[a]*CGAS* Children's Global Assessment Scale
[b]*CGI-S* Clinical Global Impression – Severity scale
[c]*CY-BOCS* Children's Yale-Brown Obsessive Compulsive Scale
[d]*YGTSS* Yale Global Tic Severity Scale
[e]*SMFQ-P/C* Short Moods and Feelings Questionnaire-Parent/Child version
[f]*SAAI-P* Separation Anxiety Avoidance Inventory-Parent version
[g]*AQ-10* Autism Spectrum Quotient Child/Adolescent version-10
[h]*SNAP-IV* Swanson, Nolan and Pelham scale-IV
[i]*ISI-C* Insomnia Severity Index Child/Adolescent version

De Visscher C et al. (2021) BMC Psychiatry. 21(1):484.

Bespoke Questionnaires

PANS 31-Item Symptom Rating Scale

Obsessions
Compulsions
Hoarding
Food refusal/avoidance
Urge to overeat, thinking about eating all the time
Fluid refusal/avoidance
Separation anxiety
Other anxiety/fears/phobias/panic attacks
Mood swings/moodiness
Emotional lability (inappropriate crying or laughing spells)

Bernstein GA et al. (2024). Journal of Child and Adolescent Psychopharmacology. 34(3):157–162.

Bespoke Questionnaires

PANDAS/PANS Questionnaire	When symptoms were at their worst during the current episode of illness	Before the current episode of illness
0=not at all, 1=a bit, 2=little, 3=significant, 4=very, 5=very much		
Influence on your child's mental state and personality		
• Lability	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Depression	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Irritability or aggressivity	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Difficulties getting to school	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Separation anxiety	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• General anxiety	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Panic attacks	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Regressive behaviour	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Concentration difficulties	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Impulsivity	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Obsessions	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5
• Compulsions	0 – 1 – 2 – 3 – 4 – 5	0 – 1 – 2 – 3 – 4 – 5

Impairment in daily life – select the statement that best aligns with your experience (1-5)		
1. Minimal impairment: functional and social capabilities within the range of normal or minimally below normal. 2. Mild impairment: more difficulties with daily activities. Family may notice difficulties. 3. Moderate impairment: definite decrease in ability to function on their own. Symptoms need psychiatric treatment and service. 4. Severe impairment: the child is not able to function without substantial help. 5. Very severe impairment: the child requires 1:1 supervision at all times and for all self-care (brushing teeth, eating, dressing etc).		

Bleibach, A., et al. (2024) European Journal of Paediatric Neurology. 52, 109–130.

Bespoke Questionnaires



Behavior/Mood *

Rages

- Not a problem
- Minor problem
- Moderate problem
- Serious problem

School refusal

- Not a problem
- Minor problem
- Moderate problem
- Serious problem

Uncooperative or resistant

- Not a problem
- Minor problem
- Moderate problem
- Serious problem

Compared with the person's best level of functioning before they became ill (or their best-ever level of functioning), how well are they functioning today? (100% = Functioning completely at their best. 0% = At their worst level of functioning / unable to function) *

0 of 3 max characters

Please enter a whole number between 0 and 100%.

Compared with the previous PTEC©, has this individual's overall quality of life: *

- Improved a lot
- Improved a litte
- Stayed the same
- Worsened a little
- Worsened a lot

Overall, how well do you think the current treatment plan is working? *

- Extremely well
- Moderately well
- Slightly well
- Not at all well
- Not receiving treatment
- Unsure/too soon to tell

neuroimmune.org/pans-pandas-treatment-evaluation-checklist/

Monitoring

CORC
Child Outcomes Research Consortium

An Anna Freud project

NHS England

NHS Digital Mental Health Services Data Set (MHSDS)

GIRFT
GETTING IT RIGHT FIRST TIME



Considering the real-life and practical significance of the change for the group Expand +



Generalisability Expand +



Statistics Expand +

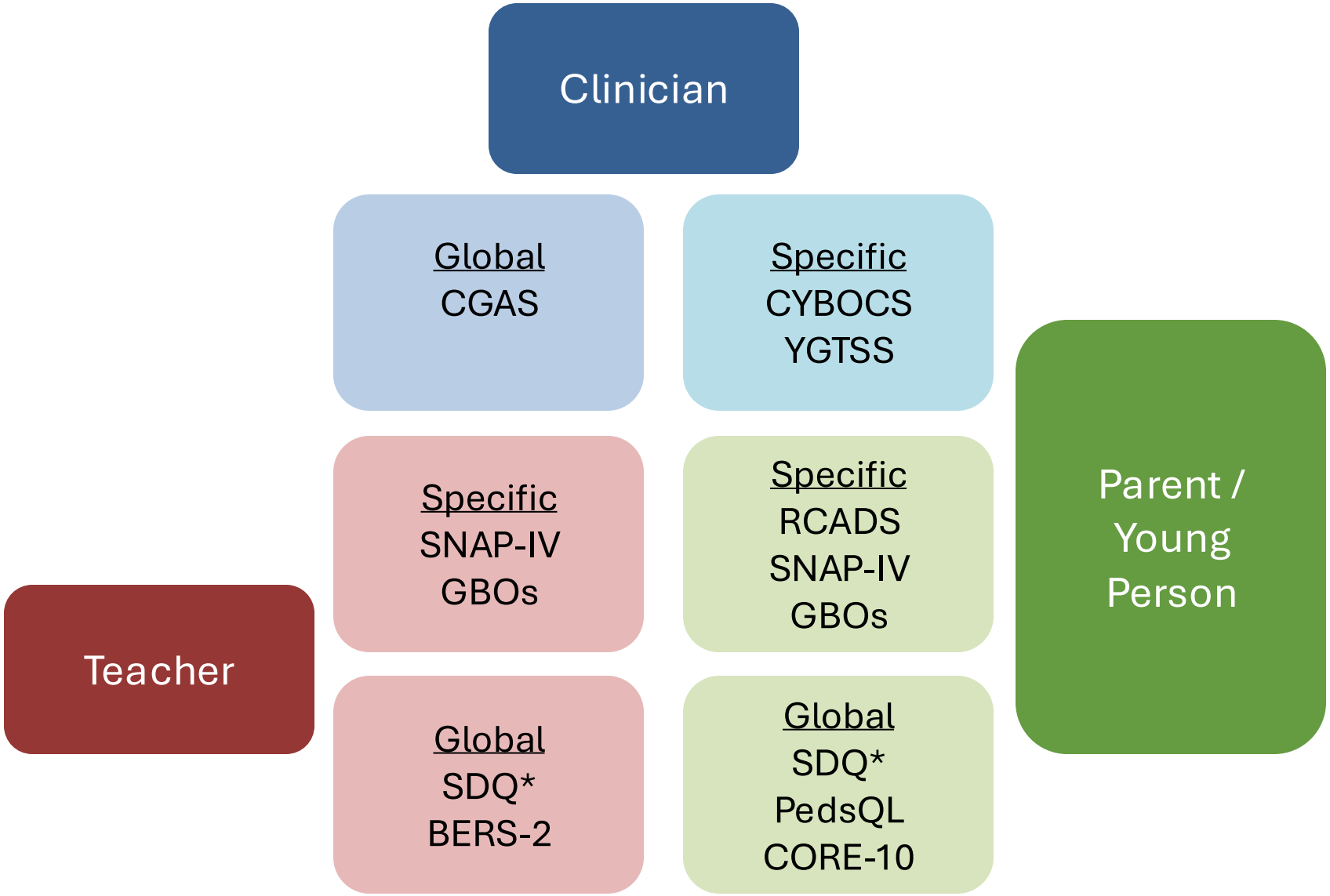


CORC comparators: do you know how change in your service compares to other services? Expand +

Monitoring

CORC
Child Outcomes Research Consortium

An Anna Freud project



Who needs to be involved?

Paediatric Neurologist

Paediatric Liaison / Neuropsychiatrist

Paediatric ID / Immunologist

Paediatric Rheumatologist

Medical Complexities Team

Nurse (Paediatric, School, Specialist, etc)

SLT, OT, Physio, Psychologist, etc

Paediatrician

Child & Adolescent Psychiatrist

Mental Health Nurse

Clinical Psychologist

Psychotherapist, Dietician, OT, SLT, etc

Education

GP

Social Care

Who needs to be involved?

GP

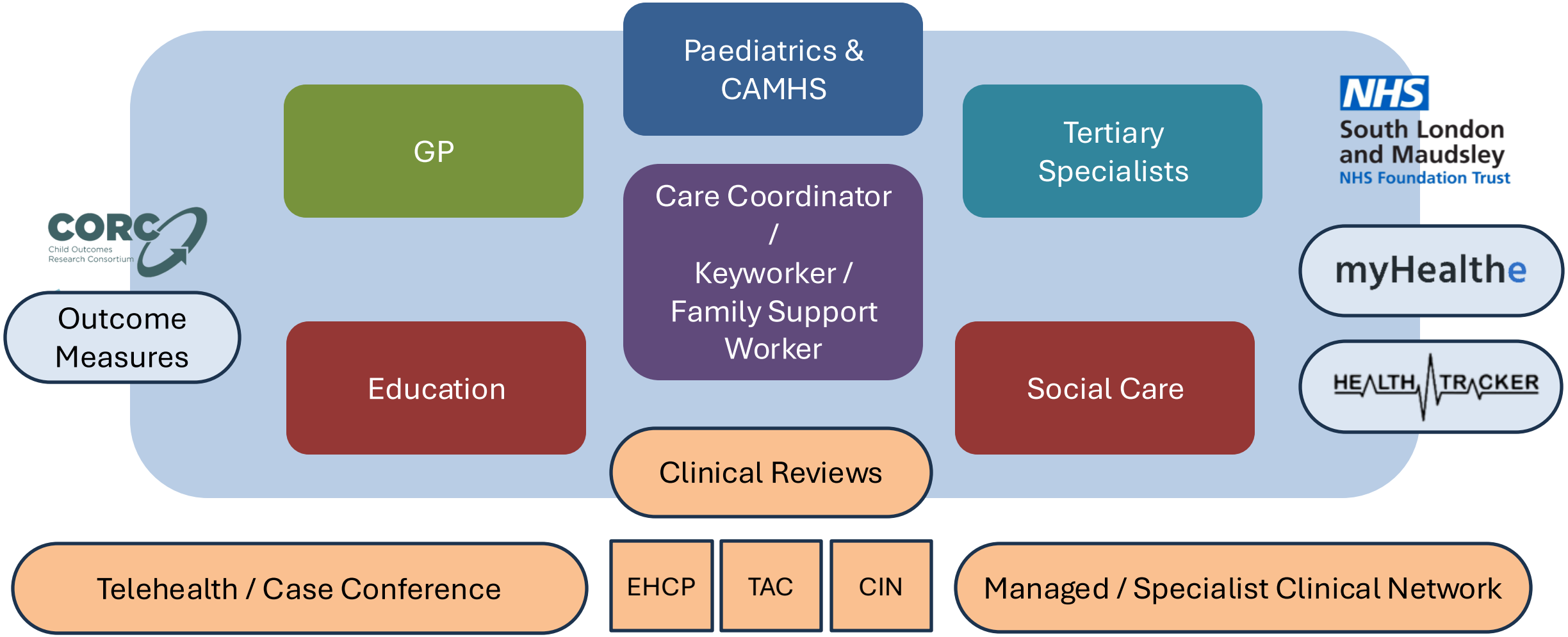
Paediatrics & CAMHS

Tertiary Specialists

Education

Social Care

How to coordinate reviews / monitoring effectively



Summary

Reviews are best coordinated by a multidisciplinary and multiagency care network, with an identified care coordinator

Use well-validated and CORC approved outcome measures of both global and symptom-specific functioning, completed in triangulation

Use existing multiagency meetings and leverage telehealth

New digital platforms allow regular symptom and function tracking to match the varied clinical courses of PANS

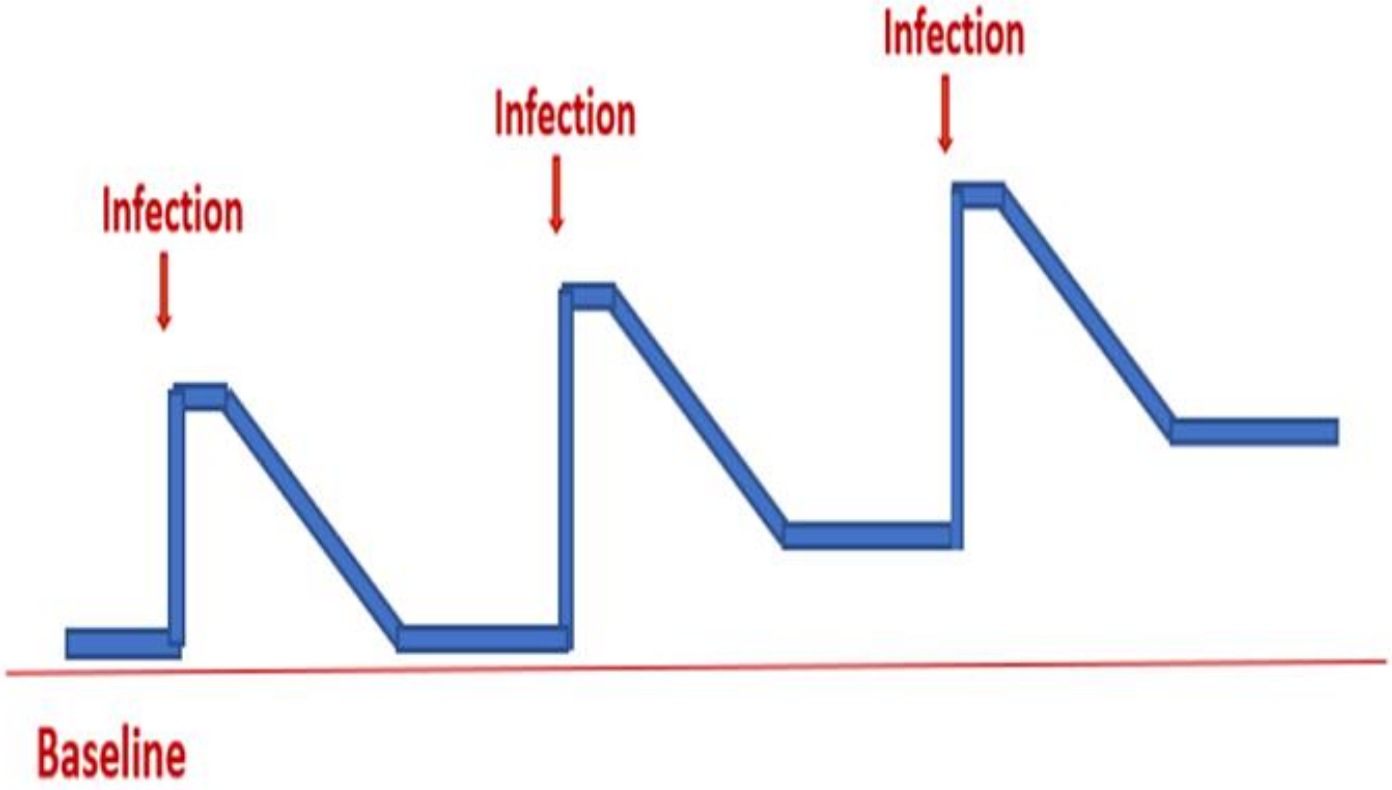
Flare protocols

Professor Rajat Gupta
Consultant Paediatric Neurologist
Birmingham Children's Hospital

Flares

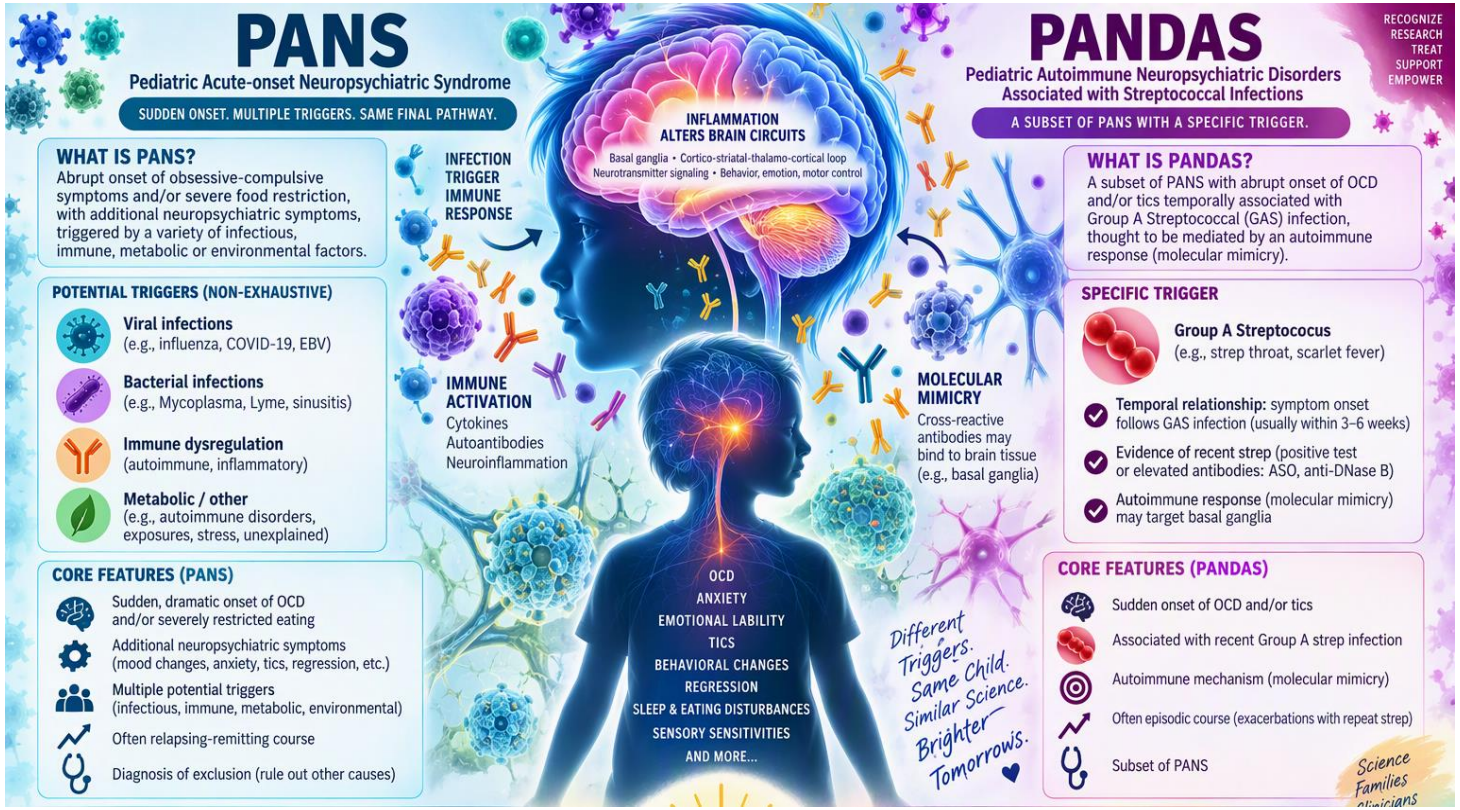
- Flares with recurrence or worsening of neuropsychiatric symptoms in PANS PANDAS are common

- Some patients follow a relapsing-remitting flare pattern



What Causes a Flare?

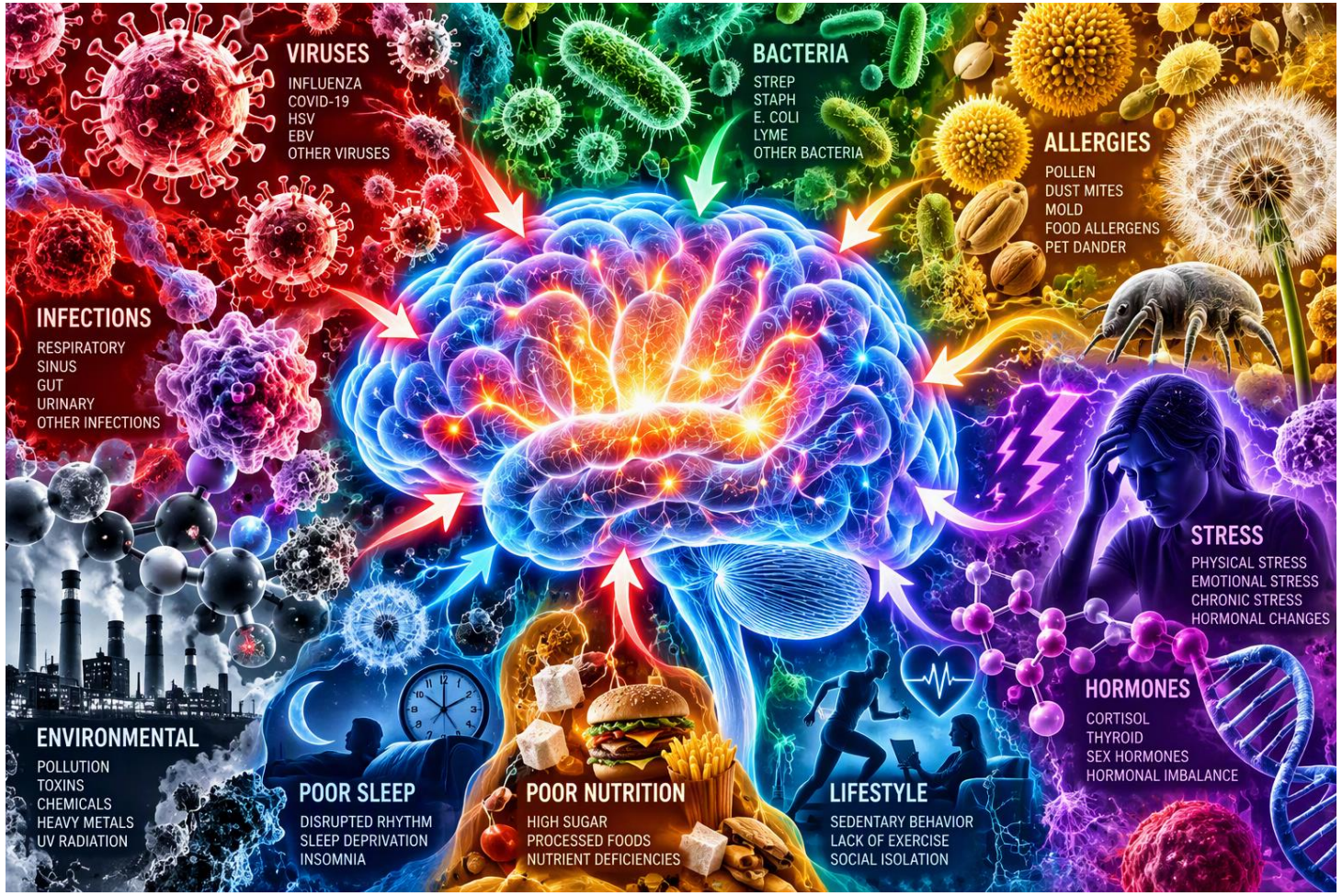
- Infections: Strep, influenza, EBV, HSV
- Atypical bacteria: Mycoplasma, Bartonella, Lyme
- Allergies, mold and inflammation
- Stress, illness and household exposure



Three-Pillar Treatment Protocol

1. Infection Control
2. Immunomodulatory / Anti-inflammatory
3. Symptom Management

All pillars should be addressed simultaneously



Pillar 1: Antimicrobial & Infection Control

- Treat active infection if present
- Targeted antibiotics
- Consider prophylaxis in recurrent cases
- Household screening and hygiene



Pillar 2: Immunomodulatory Support

NSAIDs for mild-moderate flares

- I advise usual dose of ibuprofen for age, 3 times daily with food – 5 doses. To stop if any GI symptoms. If GI symptoms persist, may then add in omeprazole or similar.
- Use ibuprofen with caution in individuals with asthma

Short steroid bursts may be considered when appropriate

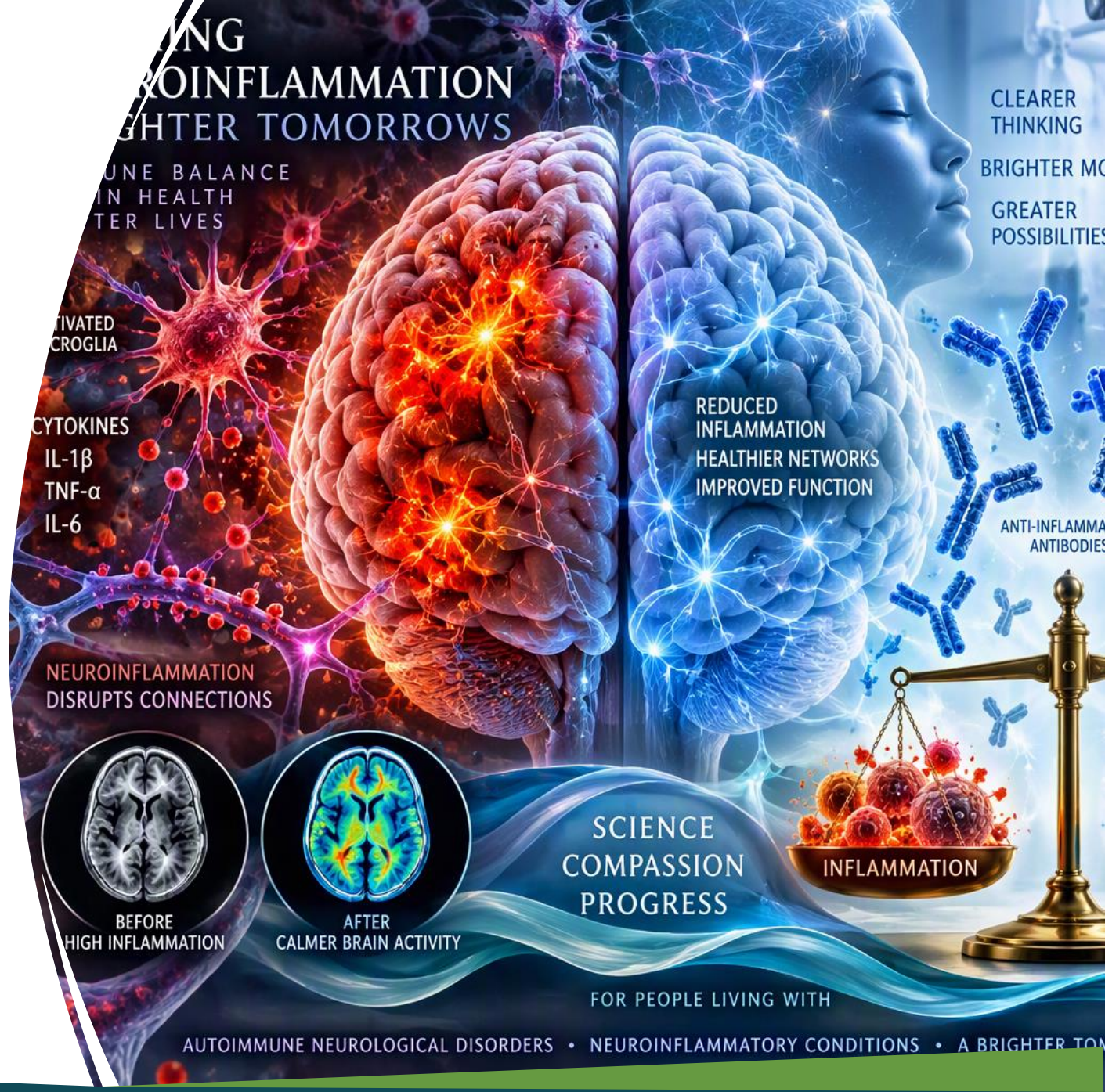
- IVIG in severe/refractory cases
- Plasmapheresis for selected patients



IVIG and TPE are not routinely available in the NHS for the treatment of PANS PANDAS

Pillar 3: Symptom Management

- CBT and ERP
- Careful psychotropic medication use
- School accommodations
- Reduce sensory overload



Emergency Flare Protocol



- Tailored to each child or young person
- 5-day course of three times daily ibuprofen

  (particularly if they have responded to this previously)
- If concerns seek medical advice
- If infection considered or identified, commence a 10-14 day course of antibiotics
- Alternatively, if on prophylactic antibiotics the dose can be increased to treatment dose for 10-14 days
- May consider a 5-day course of oral prednisolone
- Ensure safety and support throughout

Summary & Key Takeaways

- Identify triggers early
- Use all three treatment pillars
  - infection control
  - immunomodulatory/anti-inflammatory support
  - symptom management
- Individualised management
- Specialist care input as needed



References

Frankovich et al. (2017) JCAP Part II
Cooperstock et al. (2017) JCAP Part III
Thienemann et al. (2017) JCAP Part I
PANDAS Physicians Network Clinical Resources

Paediatric to adult transition

Passing the baton without dropping it



Professor Ming Lim
Consultant Paediatric Neurologist
Evelina London Research Lead
Associate Director GSTT NIHR Clinical Research Facility
Children's Neurosciences, Evelina London Children's Hospital
Faculty of Life Sciences and Medicine, Kings College London
Ming.lim3@nhs.net

Passing the baton without dropping it



Transition is a process

1. **Purposeful and planned** — addresses medical, psychosocial and educational/vocational needs, not just the referral letter
2. **Start early, go at the young person's pace** — driven by readiness, not a birthday
3. **Young-person-centred** — seen alone for part of the visit, confidentiality, shared decisions
4. **Parents move from manager to supporter**
5. **Coordinated handover** — named worker, overlap or joint clinic, written summary; support continues after transfer

Self-advocacy
Independent health care behaviour
Psycho-social support
Education and vocation
Health and lifestyle issues

Mulder et al., 2016, ***Eur J Cancer*** PMID 26735352; Blum et al., 1993, ***J Adolesc Health*** PMID 8312295; **NICE NG43, 2016**

Ready Steady Go — and Hello to adult services

Ready

from ~11 years

Transition introduced; first questionnaire; start seeing the young person alone

Steady

from ~14 years

Build skills: medicines, appointments, speaking up; goals reviewed each clinic

Go

from ~16 years

Timing agreed, adult team met, transfer summary written

Hello

adult service

Same format restarted after transfer, so the adult team picks up where paediatrics left off

Questionnaire domains: Knowledge | Self-advocacy | Health & lifestyle | Daily living | School, work & future

> **Generic, condition-agnostic, free to use** — built in Southampton paediatric nephrology, now used across NHS specialties. Fits **NICE NG43**: plan from 13–14 at the latest, a named worker, meet the adult team before transfer.

Nagra A et al., 2015, ***Arch Dis Child Educ Pract Ed*** PMID 26063244

Renal: a dropped baton costs a kidney

35%

of young adults in a UK cohort **lost a functioning transplant within 36 months** of moving to adult services

Why

Non-adherence to immunosuppression at a developmentally vulnerable age, often after a single-letter handover

What helped

An integrated paediatric–young adult clinic with youth workers improved medication adherence and engagement

Legacy

Ready Steady Go itself grew out of paediatric nephrology

Watson 2000, ***Pediatr Nephrol*** PMID 10872185; Harden et al., 2012, ***BMJ*** PMID 22661725

Diabetes: the patients who most need care are the ones who drop out

21–35%

lost to follow-up within 5 years of transition at two Scottish centres — those lost had the highest HbA1c

36%

had retinopathy by year 5 of adult follow-up in the same cohort

72%→4%

DKA admissions and readmissions after a dedicated young adult service (Sydney, 2001–14); only 8.6% lost to follow-up

Kyle et al., 2015, ***Br J Diabetes*** 15:70–4; Farrell et al., 2018, ***Diabetes Res Clin Pract*** PMID 29534994; Lyons et al., 2014, ***Pediatr Diabetes*** PMID 2430767

Epilepsy: more than seizures changes hands

Syndromes evolve

Dravet, Lennox–Gastaut and other DEEs look different in adults; revisit the diagnosis, including genetics

Comorbidity & capacity

Intellectual disability, autism, mental health; Mental Capacity Act applies from 16

Valproate

Review before puberty; Pregnancy Prevention Programme and current MHRA safety measures

Adult life

Driving, alcohol, sleep, contraception interactions, work and study

Safety

SUDEP and safety counselling owned by the young person, not only parents

Therapy continuity

Ketogenic diet, VNS and specialist drugs need a receiving adult service

Evidence: systematic review of 36 studies — only 4 rated good quality. Interventions tested: joint/MDT clinics, education, extended services (e.g. Saturday clinics, peer groups).

Goselink et al., 2022, ***Seizure*** PMID 35901664; **NICE NG217, 2022**

EM: 15-year-old boy with XP

JUNE 2017 · AGE 6

Acute onset

Tic-like eye rolling after intercurrent illness, with anxiety. Months later: stopped stopped drinking milk overnight.

OCTOBER 2017

Penicillin started

Much better within 48 hours. hours.

NOVEMBER 2017

Exacerbation with tonsillitis

Cycles of penicillin and azithromycin; ibuprofen as needed.

2017 → PRESENT

Relapses, then remission

Two major relapses. Asymptomatic for the past 5 years.

EM: 15-year-old boy with XP

June 2026 Resurgence of symptoms

Recent diagnosis of axonal neuropathy
Stop professional cycling

Improvement after Azithromycin

How do we begin to plan transition?

Self-advocacy
Independent health care behaviour
Psycho-social support
Education and vocation
Health and lifestyle issues

Which HCP we need to involve?

Very responsive GP

Excellent XP team that provides wrap around care that will continue

Looking to find adult expertise?

https://panspandasuk.org/support-resources/for-adults-with-pans-or-pandas/

Round up

Dr Tim Ubhi