NHS
North East and North Cumbria
Mental Health, Learning Disability and Autism Partnership

# PERVASIVE AROUSAL WITHDRAWAL SYNDROME (PAWS)

## - *Practice considerations for the management of PAWS*

**Please note that this is a collective opinion piece and is not clinical guideline. It has been developed using a Conference Consensus methodology utilising an expert multi-disciplinary cohort of clinicians and informed by current practice, the limited evidence base and by those with lived experience. It is intended to inform clinical management for patients presenting with PAWS. It is not intended to replace the expert multi-disciplinary team (MDT) roles or clinical judgement.**

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# Purpose

This working group initiative arose from recognising that there was a poor understanding of Pervasive Arousal Withdrawal Syndrome (PAWS) across clinical settings. This therefore led to unintended unhelpful clinical practice, which exacerbated the presentation and led to prolonged admission stays. These admissions were typically within only a few national specialist centres and were therefore typically a significant distance away from a patients home. This document therefore seeks to collate expert consensus together with published literature to:

- Improve the clinical understanding of PAWS
- Share findings of best practice (as defined by the clinical consensus) in the treatment of PAWS for consideration and/or application across a range of care settings

# Defining PAWS

Pervasive Arousal Withdrawal Syndrome (PAWS) was formerly understood as Pervasive Refusal Syndrome (PRS), and much of the available literature uses this term (Otasowie *et al*., 2020). However, as ‘pervasive refusal’ implies behavioural controllability it is now commonly understood and referred to as PAWS (Nunn *et al*., 2013). This is experienced as less blaming and is therefore more clinically helpful.

PAWS is a syndrome of extreme severity, to such an extent that it is often life threatening. Although not a diagnostic classification, PAWS is a complex condition that leads to social withdrawal (and school disengagement for young people) with a worsening function or no function in various domains. These include but are not limited to: eating, drinking, mobility and communication. The affected individual regresses and does not demonstrate functioning in relation to self-care. They will characteristically struggle to participate in rehabilitation and may remain entirely passive or actively resist help. Response to praise may be atypical, which further impacts the recovery journey. Affected individuals are withdrawn but remain fully conscious. They may sometimes sleep in the day as well as at night but are rousable. Even for those who are not mute, it is difficult to gauge their cognitions. On recovery, they may struggle to clearly recall how they felt or what they were thinking during this time. In typical cases, they may show distress when attempts towards rehabilitation are made.

## *Core syndrome features*

Although dated, Jaspers *et al.* (2009) have the most recent recommended characterisation criterion for PAWS, noting:

- Partial or complete refusal in three or more of the following domains: (1) eating, (2) mobilisation, (3) speech, (4) attention to personal care
- Active and angry resistance to acts of help and encouragement
- Social withdrawal and school disengagement
- No organic condition accounts for the severity or the degree of symptoms
- No other psychiatric disorder could better account for the symptoms
- The endangered state of the patient requires hospitalisation

## *Co-morbidities and differential*

Field experts continue to debate the specific identity of the condition. This is due to the conditions resembling chronic fatigue syndrome, catatonia/catatonic-response (fig.1 below), depression, anxiety, a variety of functional disorders and/or persistent physical symptoms including chronic pain, selective mutism, autism, post traumatic symptoms and eating disorders. These should all be routinely considered for differential explanation in patients presenting with the symptoms of PAWS.

Jaspers *et al* (2009) noted at the time of their review that the most common differential diagnoses were depression (54%), somatoform disorder (42%), anxiety disorder (29%), and eating disorder (17%). Similarly, Otasowie *et al* (2021) found depression (32%), selective mutism (19%), eating disorder (15%) and chronic fatigue syndrome / catatonia (both 11%) as the most common differentials. However, none of these diagnoses account for the full range of PAWS symptoms. Within the context of autism, it is also important to remember that psychiatric disorders may present atypically. With that said, given that PAWS is non-diagnostic, in contexts where medical diagnoses are required (such as detention under the Mental Health Act (MHA)) the clinical consensus was that PAWS is more broadly akin to Complex Somatoform Disorder.

Autistic burnout is a syndrome conceptualised as resulting from chronic life stress and a mismatch of expectations and abilities without adequate support. However, it is important to note that autistic burnout and depression symptoms can overlap and can influence each other. Autistic burnout is characterised by pervasive, long-term exhaustion (typically 3+ months), loss of function, and reduced tolerance to stimulus (Raymaker et al., 2020). It can include a withdrawal from oral intake.

We recognise a frequent correlation between PAWS presentations and a neurodivergent diagnosis (or suspected diagnosis) and related withdrawal or burnout, which may include pathological demand avoidance. At the time of writing, there is no clinical consensus about the links between these, nor a formalised clinical diagnosis for PAWS. More information and research are required to develop further understanding of this.

**Figure.1**

Catatonia can occur in association with another medical or physical diagnosis (F06.1 (DSM-5, 2013). These include:

***Psychiatric conditions** such as:*

- *schizophrenia*
- *mood disorders (including bipolar disorder and depression)*
- *obsessive-compulsive disorder (OCD)*
- *post-traumatic stress disorder (PTSD) or experiences of past trauma*
- *psychosis*
- *dissociative disorders*

***Physical conditions** such as:*

- *infections*
- *brain injury*
- *drug and alcohol use*
- *metabolic disorders, e.g., diabetes – these are where the body uses too much or too little of the essential chemicals that keep you healthy.*
- *autoimmune disorders – these are where the body's immune system, which normally fights off illness, attacks healthy cells by mistake.*

*If someone has catatonia, their medical team should always investigate whether there is a physical cause.*

(Table taken from RCP, 2022).

**Note:** Catatonia is a syndrome, often associated with mood disturbance and psychiatric diagnoses. It presents with behavioural and motor disturbance (under- or over- activity), a lack of responsiveness and mutism. It is assessed by a psychiatrist or other medical doctor who can differentiate it from PAWS.

## *Prevalence and prognosis*

A clinical presentation of PAWS is rare and therefore data is limited. Jaspers *et al* (2009) and Otasowie *et al* (2020) suggest that PAWS most often affects girls aged between 7 and 15 years, with a mean age 10.5 years.

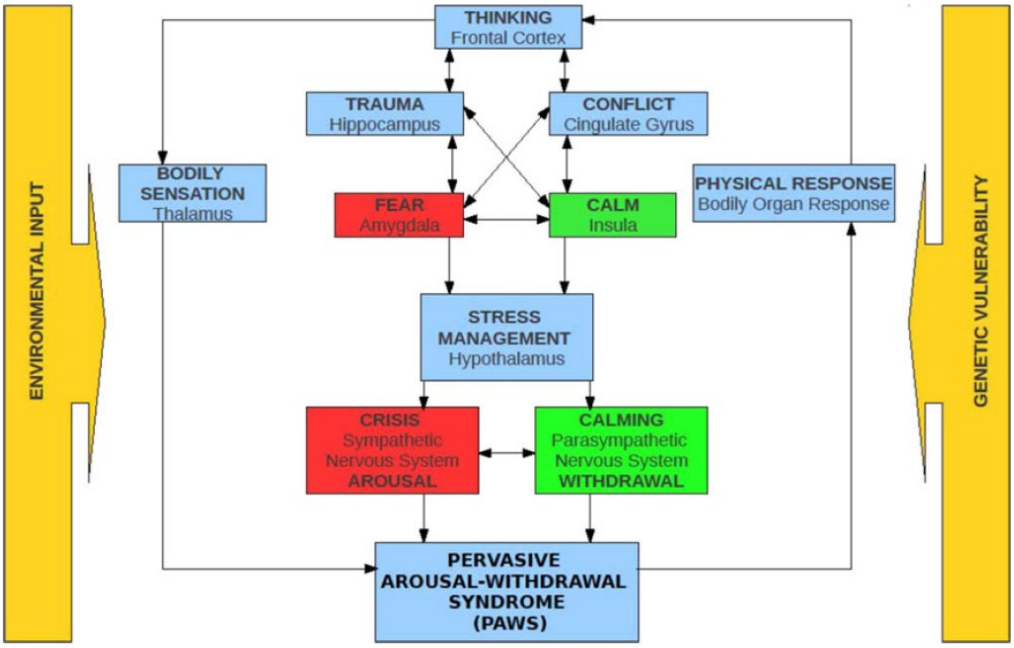
Thompson *et al* (2021) recognise that the treatment journey is typically long and complex. Otasowie *et al* (2021) concur, though cite a recovery rate of 78% if the condition is diagnosed and treated early, citing a compassionate, transparent and inclusive multi-modal rehabilitative strategy as central to improved prognosis.

# Proposed theoretical models

## *Autonomic Functioning*

Figure 2 (below) provides a simplified model of autonomic functioning. It demonstrates the lead roles of the amygdala in fear conditioning, and the parahippocampal structures, especially the insula, in parasympathetic regulation.

**Figure.2**



Model taken from: Nunn *et al* (2013)

This model (Fig.2) accounts for the observed behavioural variability including withdrawal, regression and active and angry resistance, as well as the intense anxiety and helplessness. It visually demonstrates an important movement from the states of Stress Management to Calm and to Conflict before Thinking (Thinking could be said to include expression).

A visual infographic of withdrawal regressions can also be found in Appendix 1. This infographic helpfully depicts two sources of regression: (1) helplessness (2) praise induced (which can alternatively also be considered as demand induced).

## *Polyvagal Theory*

Polyvagal Theory provides a neurobiological framework for understanding how the autonomic nervous system (ANS) responds to stress and safety cues. It emphasises the role of the vagus nerve in regulating heart rate, digestion, and social engagement. It describes how the body shifts between different states of arousal and engagement based on perceived safety or threat (Kozlowska *et al*., 2021).

To explain PAWS through the lens of Polyvagal Theory, we can consider the following key points (Polyvagal Institute, 2024):

### 1. *Hierarchical Organization of the Autonomic Nervous System*

Polyvagal Theory posits a hierarchical organisation of the ANS with three primary states:

- **Social Engagement System (Ventral Vagal Complex):** This is the most evolved system, promoting calm and social interaction. It is active when an individual feels safe.
- **Sympathetic Nervous System:** This system is responsible for the "fight or flight" response, becoming active when there is a perceived threat.
- **Dorsal Vagal Complex:** This is the most primitive system, responsible for immobilisation or "shutdown" responses, such as freezing or fainting, activated during extreme threats when fight or flight is not possible.

### 2. *PAWS and Autonomic States*

- PAWS, characterised by withdrawal from social and environmental interaction, can be viewed as a state where the dorsal vagal complex predominates. This system is activated in response to overwhelming stress or trauma, leading to behaviours associated with withdrawal and shutdown.

### **3.** *Adaptive responses to threat*

- In individuals with PAWS, there may be a history of chronic or severe stress or trauma, causing the nervous system to default to the dorsal vagal response. This is an adaptive mechanism to conserve energy and protect the individual when fight or flight responses are ineffective or impossible.

### **4.** *Neuroception and safety*

- Polyvagal Theory introduces the concept of *neuroception*. Neuroception is the unconscious detection of safety and threat. In PAWS, the neuroception mechanism may be dysregulated, causing the individual to perceive a threat even in safe environments, perpetuating a state of withdrawal and disengagement.

A graphic of the ANS states can be found in Appendix 2 (Polyvagal Theory, 2023).

A further conceptual model used to understand PAWS was proposed through the working group. Although unidentified in published literature, it draws upon Polyvagal Theory and combines it with psychoanalysis theory (Bion, 1962), systems theory (Bion, 1961) and organisational thinking (Trist and Murray, 1990). This proposed model convenes an understanding in a way that is similar to Jones' (2010) work which explores how various factors have combined to create the PAWS condition. In this way, this conceptual model, moves away from thinking about an individual with PAWS to thinking about a PAWS system involving an individual, their family, and then by extension their care team. This conceptual model requires consideration of the complex interdependence between the neurobiology of PAWS, the environment and the systems capacity to adapt to PAWS (rather than be dominated by it). It seeks to recognise the psychological strain on the whole system.

# Understanding PAWS

## *Predisposing vulnerability factors*

Literature (Otasowie *et al*., 2021) and clinical consensus determined that most individuals with PAWS will have multiple vulnerability factors which may include:

- Diagnosed or suspected autistic spectrum conditions which can predispose individuals to the intense impact of physical and/or emotional pain
- Systemic factors such as experiencing perceived family responsibility and/or experiences of highly competitive sibling rivalry
- Premorbid personality characteristics, most often described as: anxious, sensitive, rigid and routine focused, perfectionist, conscientious, high achieving with high self-expectation, and having difficulties coping with perceived failure
- Experiencing significant difficulty at times of transition and/or difficulty with social environments (including school)
- Experiencing domestic vulnerability / unsafe domestic environment (these include perceived threats owning to heightened sensitivities)
- Experiencing a comorbid mental health disorder (The following comorbid conditions were described in Otasowie *et al* (2009): PTSD (30% of cases), Depression (25%), anxiety (12%), anorexia (6%), autism (4%), chronic fatigue syndrome (4%), specific learning disability (2%), conversion disorder (2%) and emerging personality disorder (2%).
- Systemic-associated parental mental health disorder / intergenerational trauma
- Experiencing adverse childhood experiences or significant psychosocial stressors. Examples of this include parental conflict; sexual / physical / emotional abuse; witnessing violence; bereavement or other significant losses; relocation / refugee status; bullying episodes.
- Enduring normative stressors
- Experiencing physical illness, viral illness and/or infection
- Experiencing a difficult social environment

## *Clinical features of PAWS*

The clinical presentation of PAWS may include:

- An acute or insidious onset of malaise
- Lethargy
- Appearing subdued or withdrawn

- Significant problems with oral intake (both food and fluids) that may necessitate enteral feeding
- Withdrawing from managing continence as per their pre-illness functioning e.g. may need continence aids
- Gradual, progressive or sudden loss of communication (including speech which may lead to mutism)
- Other persistent physical symptoms (otherwise known as medically unexplained symptoms and functional physical symptoms)

### *Response to usual treatment*

Whilst each patient is an individual there are central characteristic responses to usual treatment that you would typically observe in patients with (or with developing) PAWS. These include:

- Difficulty in being able to accept support, care and treatment. It is important to note however that this is not universal. *There may be aspects of care which are accepted concurrently with aspects which are rejected.* This observation can extend to acceptance/rejection from specific individuals. For example, care that is accepted may only be accepted from certain staff and/or family, but not others.
- Actively, or passively, rejecting care. At its most severe, this can present as total passivity. Conversely it may present as an angry, hostile or violent opposition to treatment.
- Patients with PAWS may experience therapeutic support as coercive. For example, this may present as a notable difficulty to accept goal setting, functional rehab, education input or psychological therapy.
- Active clinical attempts to treat with increased restrictive practice typically leads to increased patient withdrawal and resistance. Examples of such precipitating treatments may include admission to hospital, or restrictive practice within hospital (e.g. the use of restraint holds for enteral feeds or for the provision of basic care).
- Those on the PAWS continuum often experience praise or talk of progress / recovery as difficult. Basic functioning can often worsen with praise.

**Carer quote:** *“When they are being positive - be positive back. But do so without praise. This can be very difficult, because it is counter-intuitive. An example is the occasion when [...] picked up her own toothbrush in an attempt to clean her teeth. We responded by saying: ‘we can leave your brush by the basin now’. In other words, we acknowledged that she had taken control of that particular action. Another example was her using the commode for the first time in her room. Again, we gave her no praise, just observed: “that will make your bed more comfortable not having to use a bed-pan or plastic sheeting”.*

- Best practice suggests that *graded, gradual, consistent, predictable, empathetic and compassionate boundaries are associated with better outcomes.*

## Practice considerations along the treatment journey

PAWS is a severe syndrome, and typical responses to treatment include a perceived experience of coercion with a resultant exacerbation of the difficulties. However, there are ways that treating teams can support patients with PAWS, and their families. Modifying the team approach in response to these challenges and framing their understanding through a compassion-informed-care lens is central. This section includes practice considerations and suggested adaptations along the patient treatment journey.

Polyvagal theory explains PAWS as a state of pervasive withdrawal driven by a dominant dorsal vagal response due to chronic or severe stress or trauma. Using a Polyvagal Theory lens, treatment should focus on restoring a sense of safety and engaging the social system to help individuals move out of the withdrawal state.

In view of all proposed theoretical models, these practice suggestions all use a trauma-informed care lens. This view acts compassionately to empower patients throughout their care journey. *At each stage, and at every opportunity possible, patients should be supported to participate in their care and treatment.*

## *Identification and differential considerations*

- ✓ There is usually a delay in the diagnosis of PAWS owing to its overlap with multiple psychiatric and medical conditions. Diagnostic uncertainty, multiple diagnoses from various professionals and the family's frustration with clinical management may contribute to the prolonged course of the condition. *Early identification and prompt treatment typically leads to shorter admissions* (Otasowie *et al*., 2021). This may extend to successful early intervention management in the community setting (see section: clinical advice for managing developing PAWS)
- ✓ Whilst extensive physical investigations are important to rule out any differential physical cause, the trauma-perpetuating, physical and systemic impact on the family's understanding of these investigations should be very carefully considered. Any investigative procedures should be carefully assessed for their benefits alongside any potential iatrogenic harm, and should include assurances that it is the correct clinical time to investigate. *Sound clinical rationale and close liaison with medical colleagues should be exercised.* Iatrogenic harm caused by perpetual physical investigations can be a prerequisite for the syndrome and/or can require additional psychological treatment. In both cases, this can prolong the hospital stay / treatment episode. There can be instances of family objections to a PAWS formulation alongside pressure to continue physical investigations. In these cases, *careful consideration of these views should be undertaken with the empathetic sharing of risk. This should include the risks of investigating versus risks of not.*
- ✓ There are several anecdotal cases where it has been possible, post acute illness, to make an assessment of neurodiversity or where these features may have been present pre illness. The collective clinical experience of these features has included selective mutism, social withdrawal, self-care withdrawal and executive functioning withdrawal. *It would therefore be sensible for clinicians to routinely consider / screen for autism.* A detailed developmental history may help you to formulate an understanding of neurodiversity which informs the holistic care plan. In most cases, *formal assessment of autism is unlikely to be appropriate during an exacerbation of PAWS*. However, you can work with presenting symptoms and apply helpful treatment adaptations without diagnosis. In this way, responding to *needs-led care is central*.

## The Multi-Disciplinary Team (MDT)

- ✓ *A comprehensive MDT is essential.* The team should include (or include access to): psychiatry, a paediatrician or adult physician (internal medicine), nursing, occupational therapy, physiotherapy, psychology, systemic/family therapy, dietetics, healthcare assistants, and (where applicable) social work and speech and language therapy. The MDT should have skills in considering all potential differential / co-occurring diagnoses, specifically autism, or have access to specialist teams to support this need. This is due to the reported higher prevalence of PAWS in girls and a lack of recognition of autism amongst females (Gould and Ashton-Smith, 2011).
- ✓ *In most cases family/systemic therapy can play a key role.*
- ✓ Where family/systemic therapy is offered, *consideration should be given to an additional and appropriate individual therapeutic space.*
- ✓ *Supplementary therapies such as music, art and play therapy should be considered* as part of the expanded MDT for those patients with low / no engagement in routine clinical therapies. Research has demonstrated that offering these supplementary therapies has not been shown to add additional burden to the patient (Otasowie *et al*., 2020) and they are therefore considered to be of low iatrogenic risk. Recent clinical experience has also found these same associated benefits from the use of therapeutic animals. These include informal family pets as well as formalised therapy dogs and equine therapy. Carer experience also found positive outcomes from hydrotherapy pools and sensory rooms when the patient was ready for this stimulus.

**Carer quote:** *"A number of times someone came through the ward with a therapy dog - there was a glimmer of engagement each time. On returning home, a kitten and then later a puppy, really made a difference".*

- ✓ *The MDT should offer a consistent, supportive and compassionate rehabilitation*. Lask (2004) noted that a safe, structured and consistent environment was important. This applies to all care settings as, although hospital admission is often essential, the high number of staff and the nature of the environment does not lend itself well to being safe, structured and consistent. As such, emphasis should be given to the role of early intervention and prevention in community settings (*see section*: clinical advice for managing developing PAWS).
- ✓ Healthcare practitioners looking after patients with PAWS may be susceptible to compassion fatigue. Therefore, *access to adequate and appropriate peer support and clinical supervision is essential* for continued safe practice.
- ✓ The intensity of suffering that results in PAWS can be a significant challenge for care teams to imagine, tolerate, and have empathy for.

One proposed conceptual model from the working group for clinicians working with individuals with PAWS was the 'Triad of Attitudes'. The Triad of Attitudes is proposed as a helpful way to maintain positive interactions and includes:

- *Compassion* and respect for their patients suffering
- *Discipline* and a willingness to endure professionally difficult and uncertain interactions whilst offering continual respectful observations of behaviours and/or non-verbal interactions
- *Curiosity* and a genuine desire to understand the patient's experience

## *Lessening the impact of systemic resistance and supporting families*

- ✓ An unwillingness to accept the formulation of PAWS can exacerbate a lack of engagement and increase passive or angry resistance. This applies to both patients and to their families. A considered awareness of this is helpful. To reduce the arising potential impact, *teams should ensure that adequate time is given to developing and understanding the shared and collaborative psychological formulation*. This time should include careful and sensitive communication.
- ✓ Adequate time should be given to *ensure that PAWS is understood correctly as non-blaming and non-intentional*. *Language used should be non-assumptive and non-judgemental.*
- ✓ PAWS places a significant strain on the family. This includes family relationships, the disruption of family life, emotional stress and financial impact. There may also be historic experiences of abuse across the whole family system. Families and carers may therefore appear defensive in their interactions with professionals. They may feel scrutinised and judged. *Professional acknowledgement of these emotional challenges and compassionate attention to them is essential.*

**Carer quote:** *"For the child, their parents (providing there has been no abuse) are their lifeline to the outside world. At times [....] was very angry with us, but that is part of the illness. It was safe for [....] to vent her despair and anger with the people who are the least threatening to her in the world".*

- ✓ *The treating team must validate the families experience through their challenging journey*. Clinicians should have a strong understanding of how family systems may have become realigned and reorganised. Such re-organisation should be understood as being a non-deliberate response to the challenges presented to them from caring for an individual with PAWS. It could be contributing to the maintenance of the disorder, but it should not be treated with hostility, judgement or blame. *Considered observation of the systemic behaviour patterns and a skilful, empathetic approach to challenge the ways in which these patterns can hinder recovery progress should be undertaken by the team*. Doing so is much more likely to lead to a positive outcome. This includes the utilisation of appropriate family therapy. Both directly within therapy sessions and indirectly with systemic supervision used for team reflections. Skilled family therapy can apply strategies to contain parental anxiety and provide a safe space for the family unit to work through their understanding and distress.
- ✓ Similarly, high anxiety from the patient or family can lead to misunderstanding medical input. This misunderstanding can lead to perceptions of medical treatment as a further threat or lead to experiencing treatment as coercive. Both are more likely to increase the withdrawal. A m*ulti-professional systemic understanding of anxiety and how to supportively work with this will be important.*
- ✓ Due to the length of time necessary to arrive at a diagnosis of PAWS, families can be left with a degree of uncertainty and mistrust of professionals. Consequently, therapeutic relationships may become strained. Therefore, *professionals must validate, empathise and build trust.* To improve this, it is important that treating clinicians *ensure transparency and honesty with the process and their explorations.* They should offer considered explanations and listen to reported symptoms. Safeguarding must also be robustly considered (see page 20).

- ✓ The possibility of neurodivergence within families should also be accounted for. Therefore, *knowing when communication with families and carers may need reasonable adjustments is essential*. This helps to ensure communication is well understood, reduces barriers and improves collaboration.
- ✓ *It is important to remain hopeful when the family and/or MDT are feeling helpless and overwhelmed.* Acknowledging that PAWS has been previously successfully treated can offer an important source of hope (Otasowie *et al*., 2021).

**Carer quote:** *"Given the ginormous withdrawal and length of illness, it is so important for us to hold on to hope. The feeling of helplessness for her entire team is very real. Reading about and talking with other PAWS families is a huge help. Also tracking any tiny progress with every member of the team, and reminding everyone of every single baby step forward. They may seem tiny, yet they are each huge!'*

## Supporting treatment progress

**Carer quote:** *"With the cooperation of nursing staff, we adopted a policy of counter-coercion. What this meant was that everyone accepted [...] in her pervasively withdrawn state. This is* ***very important.*** *We did not coerce or pressure her to do anything. The only exceptions to this were feeding, physical safety and basic hygiene. She was nourished through a nasogastric tube; washing and toileting was in bed, by means of bed pans or pads; if she was pulling out her hair, or scratching and biting, we gave her things to tear and rip as alternatives. Remember that in these very limited instances where coercing is unavoidable, there must be some other outlet to allow feelings to be expressed"*

- ✓ New PAWS symptoms typically manifest as the illness progresses. This requires modification of the treatment strategy depending upon the clinical urgency of the emerging symptom. The last set of symptoms can be among the first set to resolve. Therefore, *a dynamic, regularly reviewed MDT care plan is integral.*
- ✓ As demonstrated in Figure.1, the presence of PAWS is not a choice on the patients' part. Rather, it is a behavioural 'paralysis' formed from extreme emotional arousal or a 'frozen' response. Attempts to pressure or coerce PAWS patients is often counterproductive. Such well-meaning attempts simply intensify the sympathetic arousal. Literature notes that a contrary approach is required. This involves reducing pressure to recover which in turn reduces sympathetic arousal (Nunn *et al*., 2013). However, this should not be confused with inaction. It is instead about changing how suggestions and information are presented to patients and families. Working in this way means to *present suggestions collaboratively and in a non-blaming way.* Using this approach, clinicians should also *work on specified, achievable objectives in a slow, graded and every-day way*. This is different from working on treatment objectives in a way which is intensive, or which has fixed and rule-bound consequences.
- ✓ If symptoms are not consistently presented or observed, then clinicians should avoid drawing overt attention to this. This is known as attempting to 'catch out' incongruences in reported or observed behaviours (Nunn *et al*., 1998). Instead, *acknowledge that function inconsistency is part of the syndrome and enable any such observations of differences to support your multi-disciplinary formulation and care-plan.* Teams should see inconsistencies as potential opportunities to move forwards.

*__As an example__: the patient reports / presents with total oral refusal, but a nurse has noticed that a glass of water in the room is now half empty when it was full. Instead of seeking to find out the truth about this, see it as a potential building block for change. Ensure there are many opportunities to drink if or when the patient wants without any expectation or pressure and monitor hydration status accordingly. This is much more likely to lead to changes that can be built upon.*

This carer experience enhances this understanding and gives a further practice consideration example:

***Carer quote:*** *"We made sure that [she] had opportunities to practice her actions without anybody around. Part of her daily timetable was what we called her "own time". Knowing that she would not be disturbed, it was then possible to move around, pick things up, sit up, perhaps play with things. Later in [her] recovery, this is how she first experimented with food again. We left cups of ice by her bed which she started putting in her mouth and crunching when no one was around. We gave her the opportunities to experiment, and it was then up to her to show us when she was ready to take a step forward. Again, it is essential to acknowledge but not praise when this is happening.*

✓ *Further understanding that change can take a long time is essential*. Adapting to support any attempted efforts at change, even if a full goal is not reached, is more beneficial.

*__As an example__: (assuming the physical risk level is safe to do so) this may mean accepting that breakfast has been eaten even if this is 20% of the prescribed calories rather than replacing the rest of the missed nutrition with a nasogastric feed (NGF). Doing so recognises efforts, enables small successes to be built on, and avoids punitive punishments which could take away the progress made.*

✓ *Clinicians should remain within any agreed plan with consistency*. This offers predictability and containment. Using visual timetables on a wall can also be helpful with visual daily structure offering a key source of security. Initially, these may include only a few daily tasks and are built upon over time. Anything unusual that might occur during a day should be discussed with the patient before it happens and as much choice and control given to them regarding what happens next.

*__As an example__: if the agreed goal is to walk two steps each day for a week this shouldn't be deviated from or hurried, unless the change of pace is expressly initiated by the patient.*

**Carer quote:** *"As progress takes place – the return of speech, eating and movement, for example, it is fundamentally important to allow them to set the pace. Our instincts are to increase the pace of recovery. But we must go against these instincts and 'press the brake rather than the accelerator' of progress. If we do not, we can expect a reversal".*

✓ **Lived experience suggestion:** wherever possible, *keeping the clinicians / support workers as consistent as possible* is incredibly helpful for reducing arousal and improving trust.

- ✓ Clinicians can often find themselves in a situation where there are no ‘good’ options to present to a patient. This means that there are no options that they would find preferable or which do not cause distress. Teams should stick with changes made in the care plan for an appropriate length of time, and work at the patient’s tolerance level for this. *Teams should avoid changing too much too quickly* as this is less likely to help the patient to feel safe.
- ✓ Working with PAWS patients often lends itself to high expectations for clinicians to problem solve and find new answers. *Teams need to be helpful but persevere with changes and review the consequences of these over a pace-appropriate period.*
- ✓ *Maintaining therapeutic optimism for the long haul is important*. Where specialist inpatient treatment is required, Nunn and Thompson (1998) suggest that most young people with PAWS will require psychiatric hospital admission for more than a year, whilst Jaspers *et al* (2009) found an average duration of therapy to be 12.8 months and a further case series noted an average duration of 15.25 months (Guirguis *et al*., 2011).

> **Carer quote**: *“Acknowledge their illness. This will provide them with the security of knowing that they aren’t expected to recover fast. Remember they are in a state of intense fear. Don't give them a timescale of how long they are likely to be ill. It is essential to create a safe environment, removed from the normal pressures of everyday life, where they feel secure. Remember that, regardless of what triggered the illness, there is some aspect of their life which has become, quite literally, intolerable”*

- ✓ *Treatment methods used should be individualised and tailored to the presenting / evolving needs.* This includes working on goals or ambitions which are important to the patient and not just to the treating team.
- ✓ *Clinicians should consider delivering any appropriate therapies in stages.* This means progressing from passive involvement to active mobilisation / engagement at the pace dictated by the patients’ degree of motivation or participation. Understanding the patients’ tolerance and their current degree of emotional overwhelm is central to this process and should be skilfully assessed at each interaction.
- ✓ As with most clinical interventions, applied blanket actions are unlikely to be helpful and care must be individualised to the individual and their needs. The two carer quotes below expand on the helpfulness of care-team flexibility and agility, alongside understanding when agreed routines are most helpful:

> **Carer quotes:** *“Everyone [working with her] tries to look for her "window of tolerance" of what she can or will handle in the moment and look for "windows of opportunity". Her biggest steps forward in progress have been made spontaneously when the therapist has been open to any possibility in the moment, versus a set plan/goal for the day.”*
>
> *“We are all committed to going forward vs. pushing forward. We have an open space for what is happening in the moment vs. needing to make things happen”.*

## The role of medication

There is a very limited and low-level research base into the use of medication with PAWS. It is therefore *not possible to generalise the use of medication across the presenting symptoms of PAWS.*

There is limited research around the efficacy of psychotropic medications in the treatment of PAWS (Otasowie *et al*., 2020). Literature and clinical consensus recommend using Selective Serotonin Reuptake Inhibitors (SSRI) medications when depression or anxiety is prominent in the presentation.

As such, the collective consensus would suggest treating the associated co-morbidities appropriately and accordingly.

# Managing nutrition

Supporting effective hydration and nutrition for a patient with PAWS should be a creative and progressive process. Clinical considerations should include:

- ✓ Supporting an oral intake using *preferred foods* including types, textures and brands.
- ✓ Supporting *flexibility of the eating routine* including the times meals are eaten.
- ✓ Maximising the eating environment by *considering ways in which the eating environment can be adapted / supported to reduce sensory and demand input*. This may include adjustments to the dining space, considering alternative locations or supporting alternative mealtimes.
- ✓ *Having preferred foods and fluids freely available without any attached demand or expectation.* This may include having snack options or a cup of water in the patient's bedroom. In doing so, you should avoid any pressure or expectation to consume them and notice progress without any praise by using neutral statements only, or alternatively avoid praise or direct observation of any intake altogether.
    - Where at all possible, this should be an approach used on any feeding plan. Enabling free access to preferred foods and fluids may precipitate an autonomous change in feeding behaviour. This is because it maximises the opportunity for a patient-initiated change moment to occur simultaneously with the access required to facilitate change. The individual will then share and expand on this progress when they feel ready. Clinician preference for a strictly controlled nutritional plan should not come before opportunities which may maximise helpful change for the individual.
- ✓ If further nutrition support is needed, consider how oral nutritional supplements could be used as part of a nutritional care plan which may help to avoid more restrictive practices (such as nasogastric feeding)

# Nasogastric feeding (NGF) advice

## *Using NGF as a therapeutic tool*

*NGF can be considered as a life-saving treatment, but it can equally be used as a therapeutic intervention alongside a holistic treatment plan*. When used in this way, NGF is an enabling tool. This means that it can enable wider aspects of therapeutic participation and functional rehabilitation to take place / priority. By providing low-demand nutritional therapy, NGF can enable therapeutic aims and treatment goals to be achieved.

The decision to use NGF will not be appropriate for all. It should therefore be an MDT formulation-driven decision which robustly accounts for physical health and psychological functioning.

Where NGF is required, clinicians and teams should be encouraged to be safely creative with feeding practices.

***Examples*** *of this include:*

- *Encouraging the maintenance of oral feeding skills of any kind in combination with enteral feeding regimens.*
- *Offering flexibility between continuous or bolus feeding.*
- *Offering flexibility regarding the times of nutrition to facilitate preference and minimize distress.*
- *Considering different frequencies. It may be appropriate (depending on physical risk, feed tolerance, the level of distress and patient choice) to consolidate feeds by feeding only once per day (Fuller and Philpot, 2020) or feeding every-other day. This should be discussed by the full MDT and led by an appropriately skilled and experienced dietitian.*

Clinicians should be aware of the broader impacts from NGF feeding plans and where possible, find creative solutions for these.

***For example****: a 24-hour feeding program will limit the patients' ability to engage in their therapeutic rehabilitation program.*

## *Managing refeeding risk in patients with PAWS*

Medical Emergencies in Eating Disorders (MEED) Guidance (RCP, 2022) should be used to assess re-feeding risk and to determine the safe re-introduction of nutrition.

It can be very challenging to get regular and accurate physical health measurements in patients with PAWS. This is likely to include blood-pressure, pulse, weight, height, mid upper-arm circumference or biochemistry. Obtaining an echocardiogram (ECG) can be very difficult. There are also associated challenges with optimal positioning of the patient. In most cases, pushing for such indices will increase distress which is more likely to be harmful than helpful. Where you are limited in the information required to make a full clinical assessment, suitably skilled dietitians and medical professionals (e.g. psychiatrist) should be involved in the decision making around nutritional management.

## *Feeding challenges*

The physical symptoms of PAWS can include abdominal pain, nausea, and rumination-vomiting. These can make feeding very challenging as it can be difficult to differentiate between nasogastric tolerance issues and functional physical symptoms. It may be appropriate to consider other modalities of enteral feeding to manage some of these feeding challenges.

Dietitians and treating teams should be careful about the formulation and the role that the nutritional care plan has within that. Moving away from focusing on the physical symptoms can help to reduce impact, however, this requires a suitably skilled balance between validating the physical symptoms and distress, whilst not drawing overt focus to them. To best manage this balance, clinicians should acknowledge and normalize the symptoms and experiences without reinforcing them. This involves meeting the patient / family where they are and demonstrating listening using a biopsychosocial approach.

### *Feeding under restraint*

In some cases, NGF reduces self-efficacy and agency which can mimic abuse or become abusive. This in turn exacerbates trauma. NGF under restraint should always be the last resort after all other least-restrictive practices have been considered (Fuller *et al*., 2023).

For further practical considerations for feeding under restraint, see Appendix 3.

### *Supporting the family through NGF*

Consideration, care and attention must also be paid to supporting parents or carers through the process of NGF and any associated distress / iatrogenic harm that can result from these feeding challenges. Clinicians should ensure that they give adequate therapeutic space for this support, offer explanations and reassurance, and ensure that all / any concerns are heard, regarded respectfully and are considered as part of the collaborative care plan.

## Treatment settings

Treatment can be considered in community settings, acute inpatient settings and specialist inpatient settings (local or specialist treatment centres) depending on the severity of the presentation.

*An awareness of predisposing factors, early identification and implementation of helpful treatment approaches could help to enable patients to be treated in a home/community setting. Such settings can be considered before the presentation escalates to the severe end of the spectrum.*

With clinical PAWS, the most common feature is an acute and total refusal of both food and fluids. Given this, physical health risks are such that they can almost certainly only be managed in an appropriate inpatient setting. At present, treatment is typically carried out in one of a few specialist treatment centres (in the UK). It is rarely treated in local mental health units as clinicians in those sites often feel that they lack the expertise to successfully manage the condition. Specialist centres offer excellent care but are frequently located a long distance away from a patients' home which can present treatment challenges. *The factors involved in a case example of a successful local admission for PAWS are outlined in Appendix 4.*

Providing sufficient support within the community is often extremely challenging. Variable community resources and specialist knowledge can contribute to these difficulties. However, there is a consensus in recognising the potential harm from prolonged admissions, particularly those located long distances from a patients' home. Further exploration about how to effectively support individuals (and their families) with PAWS in the community is needed, however *this document brought together by specialist professionals and those with lived experience, can be used to support community teams to optimise care.*

## Transitions advice for admission and discharge from in-patients

Detailed preparation for a planned inpatient stay, or admission to a specialist centre, can help everyone know what to expect. It can support individuals to mentally prepare for what is involved and get ready for a significant change in routine. Preparation can include meetings between key staff, carers and the individual; visiting the ward / unit or seeing photos or a short film about it, and starting to implement plans and strategies at home prior to admission. These actions can help build trust and rapport. They can also help improve communication and contribute towards developing mutual understanding, meaningful goals, and assess readiness for change. This helps to optimise working relationships and support a successful admission.

Similarly, it helps to prepare for transition to discharge. Relationships with community professionals are key to supporting ongoing progress and reducing the risk of deterioration. This involves setting up regular meetings within the network across all relevant sectors including education, paediatrics / acute medicine, community mental health teams, crisis services and social care. The specialist inpatient staff should aim to support community professionals who may have less experience, ensuring that these professionals understand the presentation, clinical features and are armed with knowledge to support and maximise ongoing treatment.

A collaborative wellbeing passport can help communicate supportive strategies and help the individual and family feel cared for and prepared to know what to do and who to contact if issues arise.

## Clinical advice for managing developing PAWS (prior to the onset of the clinical syndrome)

- ✓ The most usual emerging symptoms of PAWS are a presentation of persistent physical symptoms without an organic cause. It has also been noted that an Anorexia Nervosa misdiagnosis is high amongst presentations. In such cases, *earlier consideration by clinical teams of a psychosomatic understanding as a differential to the physical symptoms would be useful*. This requires a thorough and detailed clinical and holistic history.
- ✓ *Presenting symptoms should be considered systemically*. This means thinking about the symptom function within a family system and not just in isolation, avoiding focusing on the individual symptom(s).
- ✓ *The developmental history should be completed skilfully and with adequate detail.* Indications of neurodivergence should be held in mind when proceeding with appropriate clinical action. This includes an understanding of the challenges to variations in Autism presentation - particularly amongst females.
- ✓ *A skilled, expert MDT should be convened at an early opportunity and should continue to support* the ongoing clinical intervention as indicated. Clinicians skilled to do this should be identified locally and should be operationally enabled to offer their clinical expertise.
- ✓ *The treating aim should be to maintain function as much as possible for as long as possible*. To support this, aim to maintain protective factors as much as possible.

***Examples*** *of protective factors include: maintaining school attendance / participation; maintaining active friendships; maintaining usual routines; and maintaining participation in sports as much as possible.*

- ✓ *Teams may need to be flexible and creative to support the maintenance of protective factors.*

***Examples*** *of protective factors include: flexible input in their favourite school subjects at a time and pace which better suits them; using a flexible attendance time-table; participating in only part of a sports session; or adapting routines to make them more consistently manageable.*

Where possible, teams should *aim to avoid prolonged acute admissions. This can be achieved by:*

- ○ *Utilising regular MDT reviews*
- ○ *Routinely evaluating the aims of admission and admission progress*
- ○ *Acquiring funding for expert complex case reviews or second opinions*
- ○ *Utilising multi-agency working*

✓ *Maintaining education in any tolerated form (being as flexible as possible including innovative or virtual technology to enable participation)*

✓ *Non-specialist treating teams should be enabled to access appropriately skilled clinical supervision support.* This can aid in re-formulating early assumptions, prevent the incidence of working in isolation, and improve reflective practice for continued safe clinical working. It will also support restorative supervision, which should be a high priority with complex cases as this maintains mental fitness to practice (HCPC, 2024). Through their local policies, *clinical teams should be able to access advice from specialist teams*. This includes arrangements for case discussions, consultation, scaffolding, and co-working arrangements for complex cases.

## Communication

*It is essential that all clinicians are compassionate and non-judgemental* in their communication with those experiencing PAWS. Clinicians should be engaged in actively listening to the patient's (and family's) needs and challenges, alongside maintaining strong professional boundaries.

Appearing directive, confrontational, dismissive, judgemental, controlling or critical would be significantly detrimental to relationship forming, hindering positive therapeutic engagement.

It is essential to remember that families know their loved one best but owing to the challenges of complex and chronic illness, may be stressed, exhausted, worried or frightened. Families and carers may need help to understand and need to be welcomed and listened to as well as involved (where appropriate) by providing family centred care concurrently with person centred communication. *Families need to be supported too.*

> **Carer quote:** *"I found the illness consumed my thoughts and energy. I was constantly thinking of my daughter and trying to do my very best for her. I was also worried about getting any little thing wrong, saying the wrong thing, thinking I should have handled a situation better and then beating myself up over it. I was fearful that I or anyone could hamper her recovery."*

### *Impact of communication and interpersonal skills*

**The bullet point reflections below are shared from a carer with lived experience of a PAWS admission. They outline the qualities of the care team which had the biggest impact on the young person's recovery and outcomes. These qualities are predominantly examples of communication and interpersonal skills, highlighting the invaluable contributions of these qualities.** The text below has been made gender neutral.

- From the very beginning, I was shown genuine compassion and commitment towards my child's wellbeing.
- The team's ability to connect, understand, and respond to my child's complex needs has made a significant difference in their recovery journey.

- I’m especially thankful for the way the team has been there for me as a parent. They helped me make sense of my own thoughts and feelings, during what has been an emotionally overwhelming time.
- The team’s calm approach, patient listening, and thoughtful explanations have helped me to rationalise my worries and fears, and to find clarity and reassurance when I needed it most.
- The team’s skills have given me the tools to better support my child and the confidence to trust the process.
- I always felt heard, respected, and genuinely included in my child’s care.
- The team’s empathy and expertise have been a true anchor for me and my family, and I will always be grateful for the role the team played.

## *Supporting progress with non-verbal communication*

Talking to a patient who does not speak can be very difficult, so it is important to pay attention to non-verbal communications.

**Carer example:** *“We slowly learnt that [....] was using her body to communicate. For example, she would rub her tummy when she needed the toilet. Picking up these sorts of clues are important and need to be shared with all those involved in their care”.*

***Carer quote:*** *“In all interactions we hold the mantra: the emotions are greater than the task. We visualise an "emotional bridge" to her every time we walk into her room - and take 1-3min to see where she is at emotionally before we attempt any hands-on task with her (such as medications or feeding tube). Given her non-verbal state, it is hugely important to just observe. Nothing is ever forced, as that can cause upset and protest. We meet her where she is at emotionally, and give her time if needed before we do the required task. We set the expectation that we still need to do the task - yet are recognizing she might not be ready just yet.”*

✓ *Clinicians must remain mindful of the ongoing importance of their communication with, and around, the patient*. They must constantly ensure this is inclusive, empathetic, non-judgemental and respectful.

**Carer quote: “***However ‘out of it’ they appear to be, they continue to see and hear people around them. So, it is essential to consider how the patient is spoken to, and how those in their vicinity speak about them. Do not talk about them as if they are uncomprehending. On the contrary, they hear and take in everything”.*

## *Creative practice strategies to support developing communication and engagement*

**Shared by those with lived experience of supporting both adults and children living with PAWS.**

- *“We found sometimes talking to them indirectly was a better way to calm the stress. [she] had a beloved teddy bear, so we would talk to the bear instead so that she could hear what we were saying, but not be expected to respond. [she] eventually started putting the bear under her sheet with her and may well have used it as a prop to practice with, possibly talking to it when no one was around”.*
- *“We would sometimes have a conversation in [her] presence and thereby communicate with her without her needing to engage with us.* Telling light-hearted

*stories of what might be happening at home or just general everyday trivia seemed to be relaxing. She would follow sometimes by watching us, or from under a sheet. Eventually she made a hole in the sheet so that she could look out while still feeling the protection of its covering".*

- *"In whatever way communication is taking place, understanding their feelings is key. Whatever they express, there will be lots of raw emotion and this needs to be acknowledged. If they are upset, acknowledge and empathise. In their extreme emotional state they can feel very vulnerable to any comment".*
- *"When talking to them it is also important to try and help them let go of the illness. Doing this in ways that help them advance rather than retreat, is very delicate and requires a fine balance. On the one hand we need to help [them] understand that there is a life outside waiting for them which is more attractive than being ill; on the other, the illness does bring sympathy and protection, so they need to be reassured that they will not lose these if they move away from the illness".*
- *"We found it very useful in recovery, to play in a no pressure way. To play with things that did not require her to perform or to produce anything - fuzzy felt, threading beads, blowing bubbles, play dough – anything that was sensory and uncompetitive and helped develop the use of her hands again".*
- *"The most interaction we get is with passive/sensory engagement. Telling her stories of a PAWS patient that recovered and fun notes she sends us always calms her and she sneaks a smile. Any story we tell her about someone else - anything silly or funny - helps her to think of something else. Sensory "play", or sensory engagement, is the best thing to help her use her body and make progress physically.*
- *"They may be shockingly zombie-like or quite feral, but that is not their usual self. I made a poster that had many happy photos of my son with positive words displaying who he is - displayed in his room. This was a good reminder to us as parents, and all staff (and I think himself too, when he looked through his 'closed' eyes)".*

## Safeguarding

Highly complex cases where there is no organic cause for physical symptoms can precipitate professional anxiety and concerns about safeguarding. Every team must:

- ✓ *Maintain staunch safeguarding vigilance* together with meeting fully compliant training requirements
- ✓ *Fully understanding their local safeguarding processes*
- ✓ *Be supported to raise any safeguarding concerns appropriately* if needed.

Additionally, teams should also seek to understand an alternative rationale. To do this, they should:

- ✓ *Use appropriately skilled clinical supervision.*
- ✓ *Explore the presenting challenges and the psychological formulation from different perspectives.*
- ✓ *Understand the patterns of systemic reorganisation* that families face when caring for an individual with PAWS
- ✓ *Consider early access to social care.* Early social care referral can support teams in thinking through options and differentials, particularly in highly complex cases. With any referral to social care, you should ensure that the rationale for the referral is well understood by the patient and family to avoid any assumptive stressors and a breakdown of the trusting therapeutic relationship.

## Disclaimer

**This document has been written and produced expressly with the care systems of the United Kingdom (UK) in mind**, though insights and clinical consensus has included practice in the United States (US) and the lived experience representation spans the UK, US, France and New Zealand. The working group is aware of interest in this paper from clinicians working with individuals with PAWS from outside the UK, such as in America, New Zealand, Australia and France. Applying advice from this document within other countries should be skilfully interpreted according to those healthcare systems, practices and legal frameworks.

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If you wish to share any comments or feedback about this document, or suggest any ways that the project could be expanded upon, please contact: clare.ellison@cntw.nhs.uk

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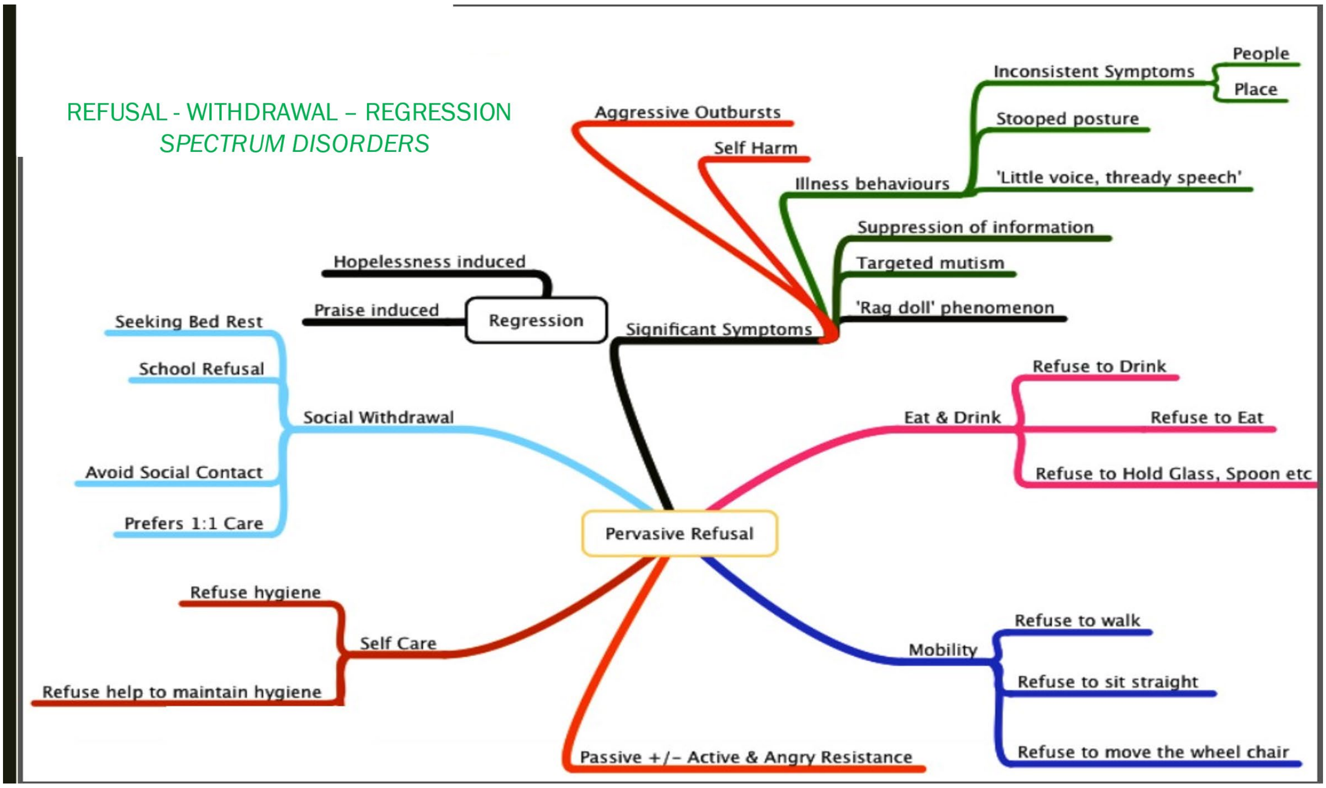
## Glossary of terms

| | |
|---|---|
| ANS | Autonomic Nervous System |
| ECG | EchoCardiogram |
| MDT | Multidisciplinary Team |
| MEED | Medical Emergencies in Eating Disorders |
| NGF | Nasogastric Feeding |
| OCD | Obsessive Compulsive Disorder |
| PAWS | Pervasive Arousal Withdrawal Syndrome |
| PRS | Pervasive Refusal Syndrome |
| PTSD | Post Traumatic Stress Disorder |
| SSRI | Selective serotonin reuptake inhibitors |

# Appendices

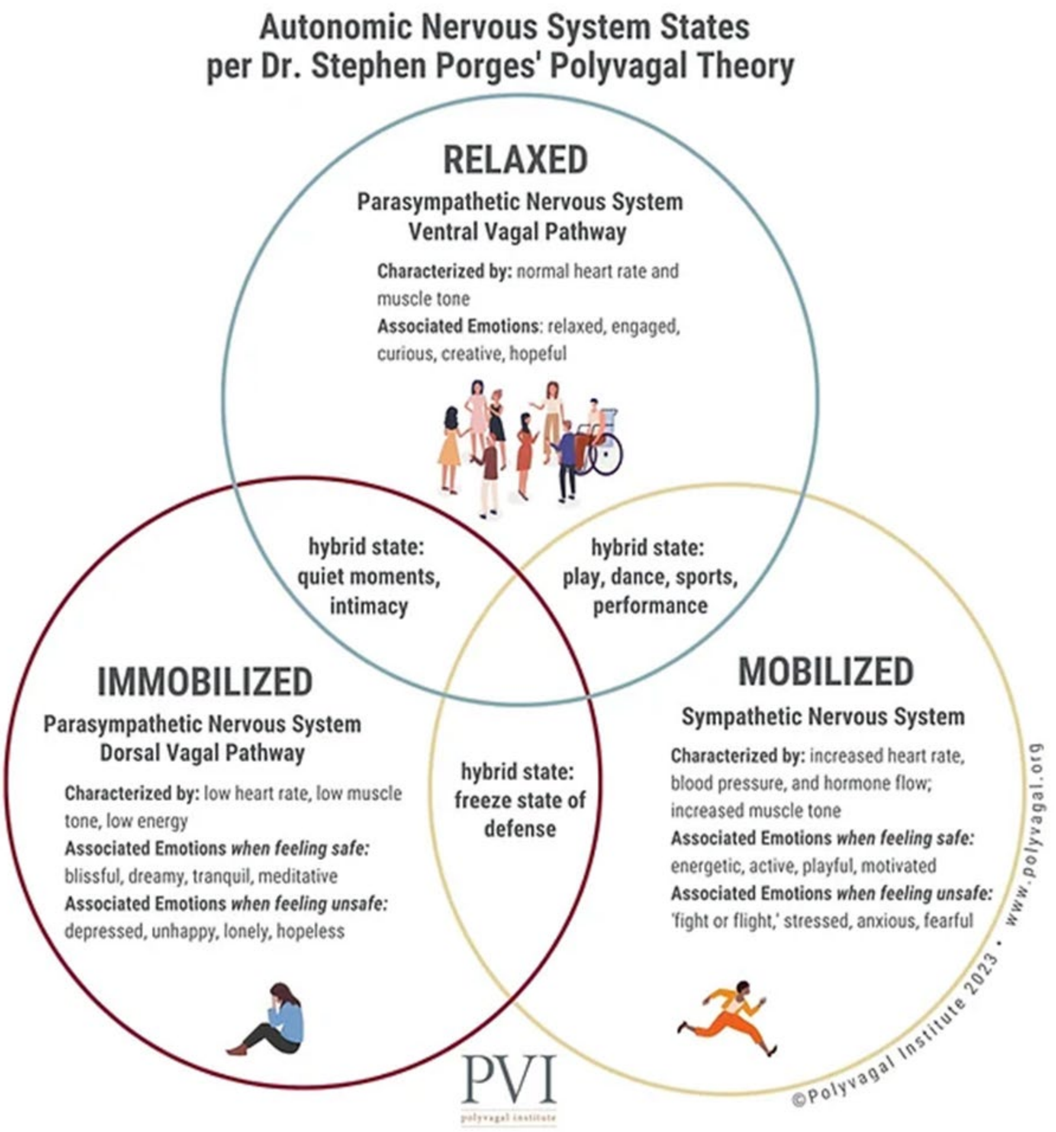
## Appendix 1

**Dr S Krishnan's illustrative model of the PAWS regression spectrum** (using Nunn et al, 1998)



# Appendix 2

**Autonomic nervous system states graphic** (Polyvagal Institute, 2023)



# Appendix 3

**Further considerations of feeding under restraint**

Where NGF is a consideration, anticipatory and / or mitigating measures could be of benefit (Fuller *et al*., 2023).

> ***For example:*** *discuss the possibility of NGF intervention with the patient at the beginning of their admission in anticipation of the need for emergency intervention.*

Before an NGF plan is put in place the following should be checked:

- Has the patient been encouraged to follow an oral diet? – ensuring that *all* reasonable and flexible adaptations have been considered first (including the use of oral nutritional supplements)

Where NGF is considered essential as part of life-saving requirement, the following should be discussed with the patient:

- Is the patient able to consent to the NGF and accept it with hand support only?

The use of restraint for NGF should be given careful, context specific consideration with the involvement of the full MDT, and in conjunction with your local policy and guidelines. If NGF necessitates the use of physical interventions (restraint), this should only be carried out under the appropriate legal framework according to the age, developmental stage and understanding of the patient or young person. The following should then be carefully considered:

- It is essential that the least restrictive method is always used when possible and this may change on a daily basis. Therefore, all least restrictive options should continue to be explored daily with the patient.
- Staff should explain the holds used during the NGF and the patient should be able to choose which they would prefer (if safe for patient and staff to do so).
- You should always be asking the question: *‘is the use of physical interventions proportionate for the level of risk the patient is at physically and/or mentally?’*
- NGF under physical intervention must be agreed and led by a consultant psychiatrist or Consultant Approved Clinician supported by an MDT.
- There should be a collaborative approach where the patient and treating team should try and work towards an ‘exit plan’ (supporting the patient to return to / start oral nutrition).

If NGF is medically necessary then facilitating a sensory-safe environment (e.g., dimmed lighting, quiet, as few people present as possible and ideally individuals with whom the person is familiar) during the procedure may be beneficial and reduce distress / iatrogenic trauma. This is particularly important for neurodivergent individuals. The insertion of a nasogastric tube can be extremely overwhelming from a sensory perspective (e.g., touch, taste, interoceptive discomfort and / or pain) and minimising environmental stressors may mitigate its anxiogenic nature for the neurodivergent patient (Cobbaert and Rose, 2023).

# Appendix 4

**Factors that supported a positive local (General Adolescent Unit) admission for a young person with PAWS**

The below points make up the contributing factors that supported a local acute admission for a young person (YP) presenting with PAWS. This treatment took place in a general adolescent unit which had previously transferred patients with PAWS to specialist national centres (at least 3 hours away).

The patients' treatment included NGF under the MHA. At their most pronounced stage of illness their presentation included violence and aggression towards their parent, complete communication shut-down, complete social withdrawal and partial withdrawal from self-care. The YP was not diagnosed as autistic although Autism was suspected by the clinical care team. There were no social care issues. The total admission duration was less than 1 year (significantly less than a typical PAWS specialist admission length). At discharge the YP was accepting NGF from their parent, communicating with their parent, reconnecting with other family members (previous significant relationships which had been shut down), and re-started social engagements including attending shopping centres, leisure parks and social centres.

**Local leadership and Care Team:**

- ✓ *The Responsible Clinician (RC) was skilled and experienced in treating patients with Autism.* They had an excellent understanding of the requirements needed for making reasonable adjustments and adapting care plans accordingly.
- ✓ *The local leadership addressed culture issues on the ward which may have negatively impacted recovery.* The leadership set care team expectations about how long and slow progress may be. They facilitated open dialogue about how frustrated the care team would feel when it seemed like care was making little progress. The leadership also persisted in supporting that it was the right clinical decision to keep the YP on the ward. Through supervision and healthy team dialogue, the leadership supported the care team to collectively process and sit through this discomfort.
- ✓ *The care team heavily invested in parent engagement from the very start, including at the point of pre-admission.* They practised significant openness and transparency to support the parental understanding of treatment expectations:
  - ○ The care team were clear with the parent about potential admission duration and cited (as according to previous research) that could mean an admission of up to 2 years
  - ○ The care team explained that treatment was likely to include aspects which seemed 'counterintuitive'. Within this, they ensured that there was always space given to supporting the parental understanding of any care plan recommendations and ensured that any questions were answered in a way that was acceptable for the parent.
  - ○ They explained that the YP's inpatient stay would form part of the treatment journey but would not represent treatment in full. This formed the expectation of hard work, including from the point of discharge, and also supported community team understanding and expectations.
- ✓ The care team ensured that they instilled hope with parents and within the team. They would describe successful recoveries from PAWS. They ensured that the care team and parent shared joy in the small steps of progress (this was not shared with the patient themselves as it would not have been helpful).

- ✓ *The care team leadership gave permission to think outside the box* and *ensured that formulation was an ongoing and dynamic process* which fully integrated the YP and their parent.
- ✓ The care team invested in getting to know their patient and *looking for patterns and insights into their behaviour*. They noted that curiosity often came before change. For example, that the YP would (non-verbally) communicate: ‘I’m not going to do this, but if I did (what would it look like). This behaviour allowed the YP to build up predictable details, without expectation and demand. It supported them in retaining their own autonomy for change. Following this pattern of behaviour in a way that supported autonomy was a powerful tool and allowed the care team to better predict opportunities for change.
- ✓ *The care team externalised PAWS.* This helped to create a dialogue which separated the YP from their difficulties and gave a shared focus towards recovery. This reduced frustration from being unintentionally targeted at the YP.
- ✓ The care team had well founded reasons to presume the YP was Autistic, though it was not appropriate to formally assess this. They therefore *facilitated all reasonable adjustments accordingly, in view of this assumption.,* A lack of diagnosis was not a barrier to making the adjustments that were necessary to support the YP.
- ✓ *The leadership team supported positive risk taking.*

**As an example:** the YP was permitted 2 days of home-leave where it was acknowledged that they would not accept NGF administration (food or fluid) from their parent nor consume this orally. It was deemed clinically safe to take this positive risk and there was a robust plan in place that enabled access to support and nutrition/hydration if needed during this time. This included an open door to return to the ward at any time and without any warning. The result of taking this risk was that the YP stayed at home for the full allocated 2 days without nutrition/hydration but had a significantly positive experience. On returning to the ward, they asked to access more of this. The care team acknowledged the conflict and discomfort they felt about potentially giving the YP the message that they could have time at home without nutrition, and they weighed this against the wishes of the YP. They chose to take this risk, tolerate the discomfort and facilitated more time at home without feeding expectations. This was a significant turning point and is when progress significantly sped up, resulting in accepting NGF from their parent. Full discharge home followed in less than 2 months.

### Systemic Strengths

- ✓ *The YP had a parent who was engaged and played an active part in the YP recovery.* Their skills, which were constantly supported and enhanced by the skilled clinicians, included:
    - *An ability to tolerate initial extreme and hostile rejection:* despite the distressing nature of this, the parent could see this as part of the illness process and avoided a transference of over-internalised self-criticism.
    - *A willingness to accept failure:* plans and aims were seen as trials. If a plan, for example spending some time off ward with the parent, was unsuccessful the parent simply accepted that the task was unsuccessful and calmly returned to the place of safety (ward). There was no attached criticism, blame, panic, pressure or other high expressed emotion.
    - *A high tolerance to keep trying*: despite repeated rejections, withdrawal, disengagement, hostility and plan-failures, the parent kept listening to the care team and to the signals from their child. They were ready and willing to participate in the next suggested engagement steps.

    - *A willingness to be guided by the care team: matching treatment pace*, avoiding pressure, tolerating resistance and accepting periods of slow/little progress.

**Geographical Factors**

- ✓ *The YP was able to be supported close to home. This meant that the admission was able to utilise, regularly, all of the strengths of the parent.*
    - In instances where a YP is placed far from home, parents may only be able to visit and engage in treatment and recovery at weekends. This can inadvertently create an infrequent, high pressure period of time that is focused on change. It may also not match the YP's emotional readiness at that time point and misses the opportunity to change-match at times when they may feel more open and able to engage. This could therefore inadvertently reinforce that 'admission without parents' (monday-friday) is the 'place of safety': perpetuating the challenges/admission duration. *Systemic strengths and skills are most useful and effective when they are in a close enough proximity to be utilised and integrated into the patient-led recovery pace.*
- ✓ *The parent was integrated into patient care 7 times per week,* either on the ward or at home
    - For the YP, fixed days and plans worked better as this avoided uncertainty and improved predictability and preparation.
    - In total, the YP was able to spend 6 months building up overnight leave very slowly. Initially, this started with facilitating leave which did not interrupt the 'safe' pattern of care (e.g. nutrition and hydration remained at the ward where there was least resistance). Being close to home meant the YP could spend time in their home environment without care demands. This supported pace matching and a low demand approach.

**Clinical Education**

- ✓ *Clinical practice suggestions defined in this document supported the local understanding of PAWS and informed strategies, approaches and principles that could be applied in a local care setting.* This educative understanding helped to support confidence in managing the care and treatment of a young person with PAWS in a local treatment setting and supported adopting a slow-pace low-demand approach.

The above points highlight the reflections that contributed to a positive admission outcome. Below, are additional reflections and learning points that the care team observed, which will support future admissions:

**Further learning points:**

- The care team notes that, in hindsight, they made too many care-plan changes too quickly at the beginning of the admission. This resulted in some probable early missed opportunities to support change. As a result, the care team acknowledge that, for future admissions, it would be more helpful to have more initial early confidence in their treatment plan. As this was their first non-transferred PAWS patient, it is acknowledged that this confidence will likely come from future admissions and exposure.
- In hindsight, the care team felt that they needed to better mirror their early communications with the YP's parent and have more confidence in sitting with the recognised slow pace of recovery and with not forcing change. They reflected that when they settled into a low pace of change, with fewer changes to the care plan, clinical improvements were much more regular and forthcoming.