# Pervasive Refusal Syndrome-
## A Rare Case of Complexity and Hope

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## Introduction

▪ Pervasive Refusal Syndrome (PRS) is a rare and life-threatening child psychiatric condition characterized by pervasive refusal to eat, drink, talk, walk and engage in self-care- in the absence of other psychiatric disorder or organic conditions to account for symptoms.

▪ Causes are unclear but likely complex, multiple and associated with learned helplessness paradigm with underlying vulnerable premorbid personality. Seen mostly in females, from age 8-15.

▪ Management involves a Multidisciplinary team approach to manage physical health risks and mental health complications with modified styles of communication- usually in a hospital setting.
A willful resistance to treatment is a hallmark of the condition.

▪Most children with pervasive refusal syndrome make a complete recovery with the correct treatment over a time period of 1-2 years on average.

## Case

Young female presented with several week's history of low mood, marked social withdrawal, refusal to eat or drink and reduced self-care shortly after transitioning to a new school and a recent viral illness. Premorbid personality of high-achiever and perfectionist.

Seen by local GP, who diagnosed depression of moderate severity and was started on SSRI antidepressant medication. This showed no improvement, and an alternative SSRI was tried followed by an SNRI, with no effect.

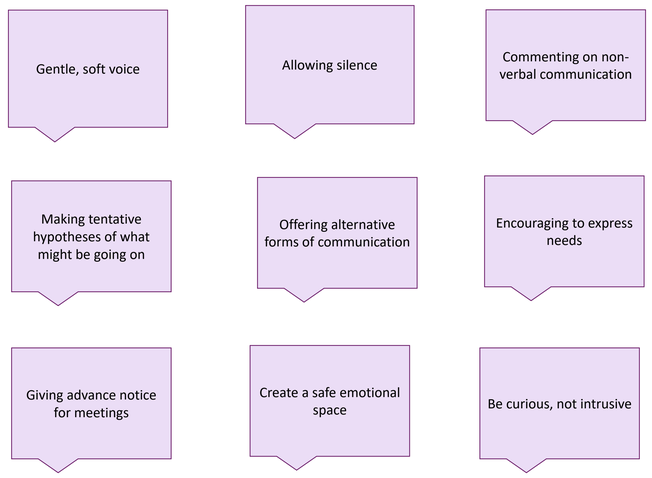
Admitted to paediatric hospital following collapse from food refusal, received NG feeding due to severely malnourished state for life-saving rehydration and refeeding. In hospital, remained largely under bed sheet, refusing to speak to anyone and not washing, declining to see parents.

Diagnosis of Pervasive Refusal Syndrome made.
Treatment involved attempts to engage with psychologist, and CAMHS team to build therapeutic relationship. Dietician input to manage nutrition, physiotherapy to build back movement into day and nursing staff to encourage personal care and feeding.
Feedback of any progress led to significant regression of symptoms.

Referral was made to Tier 4 in-patient admission to allow patient to receive specialist treatment for both mental and physical symptoms to aid recovery. Transferred and received rehabilitation, with individual and family psychological support in addition.

**MDT Involvement**
-CAMHS Psychiatrist
-CAMHS Psychologist
-Family therapist
-Advanced mental health practitioners
-Paediatric doctor
-Dietician
-Occupational therapist
-Physiotherapist

## Communication styles




(Figure 1, speech bubbles of different communication styles)

## Formulation

| Predisposing | Precipitating | Perpetuating | Protective |
|---|---|---|---|
| Family history of Mental Health | Viral illness | Difficult family dynamics | Strong collaborative team |
| High achiever/ low self-esteem | Developmental transitions | Loss of hope in doctors | Good premorbid function |
| Sensitive temperament | Bullying | Halted stage in development | Parents caring |

(Table 1: Formulation of PRS case)

## Challenges of treatment

▪ Complex mental and physical health risks, and prevention of life- threatening complications crucial

▪ Lengthy recovery, 1-2 years, patient and family can lose hope

▪ Staff must support with a different approach to natural instincts of wanting to mobilize swift change

▪ Parallel working of medical and psychiatric teams, along with NHS and private CAMHS services used interchangeably

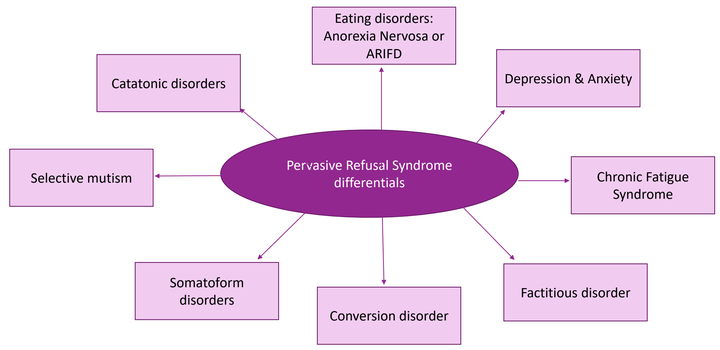
▪ Distinguishing symptoms of PRS from range of differential diagnosis, including depression and eating disorder

▪ Recognizing the link between mind and body, with the focus of treatment addressing both

▪ Issue of consent, in the context of refusal of treatment- ethical dilemmas

▪ *M*onitoring for co-morbid psychiatric diagnosis is important

## Differential Diagnosis




(Figure 2, mind map of differential diagnosis of PRS)

## Discussion- Psychological Aspects

▪ Children with pervasive refusal syndrome struggle to verbalize their distress, but communicate non-verbally through withdrawal, refusal and resistance to treatment. Encouragement and praise can trigger regression and relapse. Cause is linked to learned helplessness and pervasive retreat is used as protection against becoming part of healthy life encounters perceived to be uncontrollable.

▪For the treating team, this paradoxical way of providing care can engender feelings of frustration, demoralization and hopelessness, and cause us to question personal and institutional understandings of delivering care. Naming and recognizing countertransference responses is helpful to understand internalized relationships of the child. Interestingly, changes in the countertransference responses can be a pointer of development.

▪ The first steps include totally accepting the child's current state of withdrawal from life and providing complete comfort and safety for the child. Secondly, minimising expectations placed on the child and bearing not-knowing. Lastly, creating clearly delineated, predictable and consistent non-negotiables.

▪Understanding psychological aspects of pervasive refusal syndrome can result in greater empathy, and solidity in treatment approach.
Instead of feeling overwhelmed, unskilled and at a loss, approaching with a flexible attentive tact bearing the confusion can offer insights into the child's inner world, shinning a light into the darkness previously experienced.

## Holding onto hope

*"Bearing uncertainty and confusion, whilst simultaneously holding onto and protecting a sense of hope and utility can feel at times like a tightrope act. But this attitude can provide the containment and space for a child who is not talking, walking, or eating, to slowly let down his defences and start contemplating health again"- The Silent Child*

## Conclusions

In the case of Pervasive Refusal Syndrome, it is multi-faceted in complexity from both physical and psychological aspects, requiring a very attuned compassionate holistic approach, holding onto hope for the patient to encourage recovery- which is certainly possible in most cases.

## References

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