

**Inverclyde Practitioner Guidance**

**Perplexing Presentation (also known as Fabricated or Induced Illness)**

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**Introduction**

Perplexing presentation (PP) is a condition whereby a child suffers harm through the deliberate action of her or his primary carer. This rare and potentially dangerous form of abuse has previously been known as *“Munchausen Syndrome by Proxy/ Fabricated Illness by Proxy/ Factitious Illness by Proxy/ Illness Induction Syndrome and Fabricated or Induced Illness.* The term medically unexplained symptoms (MUS) may also be used. While these variations in definition can seem confusing, they are also helpful in maintaining professional curiosity in what is a complex diagnostic landscape.

**Identifying Perplexing Presentations**

Identifying perplexing presentations is a complex process and identifying the carer patterns of behaviours will require a multi-agency approach, expertise and close observation.

There are three main ways in which a parent/carer may fabricate or induce illness in a child. These are not mutually exclusive and include:

* Fabrication of signs and symptoms – may include fabrication of past medical history.
* Fabrication of signs and symptoms and falsification of hospital charts and records, and specimens of bodily fluids – this may include falsification of letters and documents.
* Induction of illness by a variety of means.

**Prevalence**

The fabrication or induction of illness in a child by a carer is considered to be rare. However, its consequences can be extremely serious.

**Indicators of Harm**

All parents exhibit a range of behaviours in response to their child being ill or perceived as ill. Professionals are required to distinguish between an anxious parent/carer who may in fact be responding in a reasonable way to a sick child and those who are exhibiting abnormal behaviours. Some parents may be more anxious than others or have perceptions about illness and expectations or of the medical profession which impact on how they cope with situations. Others may need reassurance that their child is indeed well. Some parents can be assisted to interpret and respond appropriately to their child’s needs whilst others may not be able to alter their beliefs. **It is this group of parents who are most likely to present their child for medical examination even though they are healthy.**

A list of indicators which may suggest concern regarding PP:

* Over time the child is repeatedly presented with a range of signs and symptoms of various illnesses.
* There tends to be no independent verification of reported symptoms.
* Signs found on examination are not explained by any medical condition from which the child is known to be suffering.
* Medical tests do not support and reported signs and symptoms.
* Claiming symptoms which are unverifiable unless observed directly.
* The response to prescribed medication and other treatment is inexplicably poor.
* New symptoms are reported on resolution of previous ones.
* Signs and symptoms do not begin in the absence of the carer.
* The child’s normal daily life becomes restricted in ways similar to those that might apply if they had a serious medical disorder from which they do not appear to suffer, or that is supported by medical evidence.
* There is a mismatch of evidence from the presenting parent usually, but not always the mother.
* The reaction of the parent or carer is disproportionate to the diagnosis or non diagnosis of the condition.

The characteristics of Perplexing Presentation are that there is lack of the usual corroboration of finding with signs and symptoms, or in circumstances of proven organic illness, lack of the usual response to proven effective treatments. It is this discrepancy that may alert the clinician to possible harm being suffered by the child.

**Parent/Caregiver motivation and behaviour to fabricate or induce illness (FII)**

Clinical experience and research indicate that the mother is nearly always involved or is the instigator of FII. The involvement of fathers is variable – they may be unaware, suspicious but side-lined or may be actively involved. Rarely, fathers are solely involved. They may be actively supported by grandparents and an intergenerational pattern. Rarely, foster carers have been known to be involved in FII. There is currently no data on same sex parental couples.

FII is based on the parent’s underlying need for their child to be recognised and treated as ill or more unwell/more disabled than the child actually is. FII may involve physical, and/or psychological health, neurodevelopmental disorders and cognitive disabilities. There are two possible motivations underpinning the parent’s need: the parent experiencing a gain and their erroneous beliefs. A parent themselves may not be conscious of the motivation behind their behaviour. Both motivations may be present although usually one predominates.

In FII, parents’ needs are primarily fulfilled by the involvement of doctors and other health professionals. The parent’s actions and behaviours are intended to convince health professionals about the child’s state of health. The parent is not usually ill-intentioned towards their child. Nonetheless, they may cause their child direct harm, unintentionally or in order to have their assertions reinforced and believed. Parents engage health professionals, in the following ways:

• The most common form is by presenting and erroneously reporting the child’s symptoms, history, results of investigations, medical opinions, interventions and diagnoses. There may be exaggeration, distortion, misconstruing of innocent phenomena in the child, or invention and deception. The parents may not be actually intending to deceive, such as when they hold incorrect beliefs and are over-anxious, to the child’s detriment.

• A less common way of engaging health professionals is by the parent’s physical actions which nearly always include an element of deception. They range from falsifying documents, through interfering with investigations and specimens such as putting sugar or blood in the child’s urine specimen, interfering with lines and drainage bags, withholding food or medication from the child and, at the extreme end, illness induction in the child. All of these are carried out in order to convince health professionals, especially paediatricians, about the child’s poor state of health or illness.

 Support groups and social media provide an important source of support for parents and families. Paediatricians and parents should, however, be aware that some support groups also exist for a number of conditions about which there is divided medical opinion. Furthermore, some social media / support groups may post inaccurate information, discuss diagnoses and how to obtain them, which can lead to harm.

Parental mental ill-health is not a prerequisite for FII, but if present it may help to explain the motivations and behaviours of some of the parents as well as indicating prognosis for change. Personality disorders are most likely to be found in parents who derive a clear gain from having their child regarded as ill/more ill. Anxiety disorders may lead the parent to have unfounded anxieties about their child’s health, to an extent which is harmful to the child. Rarely a psychotic illness or autism spectrum disorder (ASD) in the parent may underpin fixed beliefs about the child’s ill-health.

Clinical evidence indicates that fabricated or induced illness is usually carried out by a female carer, usually the child’s mother. Fathers and woman other than the mothers have also been known to be responsible. It is common in these latter cases for the adult to have undertaken significant responsibility for providing much of the child’s daily care.

There is no evidence to support a unique profile of carers who fabricate or induce illness in their children. There is, however, evidence that as with many parents who abuse or neglect their children, specific aspects of their histories are likely to have been troubled. A careful assessment is required to understand the contribution which their past experiences have made to the child’s illness fabrication or induction and the impact that past events may be having on their current ability to care for their child.

**Harm to the child**

Harm to the child takes several forms. Some of these are caused directly by the parent, intentionally or unintentionally; others are brought about by the doctor’s actions, the harm being caused inadvertently. FII is not a category of maltreatment in itself, harm may be expressed as emotional abuse, medical or other neglect, or physical abuse. There is also often a confirmed co-existing physical or mental health condition. When it is felt that a child is at risk of significant harm and a referral to Children’s Social care is required it is necessary to ensure that the harm or potential harm to the child is clearly indicated within the referral.

**Severity**

Severity of FII can be considered in two ways: a) severity of the parent’s actions, b) severity of the harm to the child.

a) Severity of the parent’s actions

This can be placed on a continuum of increasing severity which ranges from anxiety and belief-related erroneous reports to deception by fabricating false reports, to interfering with samples through to illness induction. However, there is no evidence about the likelihood or factors associated with a parent moving from one point on this continuum to another.

b) Severity of harm to the child

The different aspects of harm to the child may coexist. Severity of the harm to the child needs to be assessed according to both the intensity of each aspect of the harm, and by the cumulative effect of all the aspects.

It is important to focus on the harmful effects on the child, rather than gauge severity by what the parent is saying or doing. However, if there are clear deceptive parental actions or illness induction, it is likely that the harm to the child will be more severe.

**Child’s health and experience of healthcare**

• The child undergoes repeated (unnecessary) medical appointments, examinations, investigations, procedures & treatments, which are often experienced by the child as physically and psychologically uncomfortable or distressing

• Genuine illness may be overlooked by doctors due to repeated presentations

• Illness may be induced by the parent (e.g., poisoning, suffocation, withholding food or medication) potentially or actually threatening the child’s health or life.

 **Effects on child’s development and daily life**

• The child has limited / interrupted school attendance and education

• The child’s normal daily life activities are limited

• The child assumes a sick role (e.g., with the use of unnecessary aids, such as wheelchairs)

• The child is socially isolated.

**Child’s psychological and health-related wellbeing**

• The child may be confused or very anxious about their state of health

• The child may develop a false self-view of being sick and vulnerable and adolescents may actively embrace this view and then may become the main driver of erroneous beliefs about their own sickness. Increasingly young people caught up in sickness roles are themselves obtaining information from social media and from their own peer group which encourage each other to remain ‘ill’

• There may be active collusion with the parent’s illness deception

• The child may be silently trapped in falsification of illness

• The child may later develop one of a number of psychiatric disorders and psychosocial difficulties.

**Siblings**

In some families, only one child is subject to FII or has a Perplexing Presentation and this child may initially have had a genuine illness which began the relationship between the parent and health professionals. In other families, several children may be affected by FII or have a PP simultaneously or sequentially. Siblings who are not subject to FII or have a PP may become very concerned and distressed by the apparent ill-health of their affected sibling or may feel and be neglected.

**Other victims**

There have been reports of FII perpetrators also abusing spouses or animals. There may need to be consideration of referral to Adult Safeguarding or the RSPCA.

**Adverse Childhood Experiences**

Adverse childhood experiences, or ACEs, are potentially traumatic events that occur in childhood (0-17 years). For example:

• experiencing violence, abuse, or neglect

• witnessing violence in the home or community

• having a family member attempt or die by suicide

Also included are aspects of the child’s environment that can undermine their sense of safety, stability, and bonding, such as growing up in a household with:

• substance use problems

• mental health problems

• instability due to parental separation or household members being in jail or prison

ACEs can have lasting, negative effects on health, well-being, as well as life opportunities such as education and job potential. These experiences can increase the risks of injury, sexually transmitted infections, maternal and child health problems (including teen pregnancy, pregnancy complications, and foetal death), involvement in sex trafficking, and a wide range of chronic diseases and leading causes of death such as cancer, diabetes, heart disease, and suicide.

ACEs and associated social determinants of health, such as living in under-resourced or racially segregated neighbourhoods, frequently moving, and experiencing food insecurity, can cause toxic stress (extended or prolonged stress). Toxic stress from ACEs can change brain development and affect such things as attention, decision-making, learning, and response to stress.

Children growing up with toxic stress may have difficulty forming healthy and stable relationships. They may also have unstable work histories as adults and struggle with finances, jobs, and depression throughout life. These effects can also be passed on to their own children. Some children may face further exposure to toxic stress from historical and ongoing traumas due to systemic racism or the impacts of poverty resulting from limited educational and economic opportunities.

In summary ACEs are linked to chronic health problems, mental illness, and substance use problems in adulthood. ACEs can also negatively impact education, job opportunities, and earning potential. **It is however important to note that exposure to ACE’s are an indicator of possible negative outcomes, and not a prediction and preventative strategies can build resilience.**

**A Trauma-informed Approach**

A trauma-informed approach promotes understanding and care and shifts the focus from “What’s wrong with you?” to “What happened to you?” It acknowledges the importance of having a complete picture of somebody’s life situation – past and present. Adopting trauma-informed practices can potentially improve engagement, promote treatment adherence and health outcomes. A Trauma-informed care seeks to:

• Realise the widespread impact of trauma and understand paths for recovery;

• Recognise the signs and symptoms of trauma in patients, families, and staff;

• Integrate knowledge about trauma into policies, procedures, and practices; and

• Actively avoid re-traumatisation.

A trauma-informed approach can be implemented in any type of service setting or organisation and is distinct from trauma-specific interventions or treatments that are designed specifically to address the consequences of trauma and to facilitate healing. It is critical to promote the linkage to recovery and resilience for those individuals and families impacted by trauma. Consistent with this definition of recovery, services and supports that are trauma-informed build on the best evidence available and consumer and family engagement, empowerment, and collaboration

**Action to be taken when Perplexing Presentation is suspected**

Where perplexing presentation is suspected this should be considered as a child protection concern and a referral should be made to social work or the police in accordance with Inverclyde’s Multiagency Child Protection Procedures.

As perplexing presentation may involve the commission of a crime the Police should be involved as early as possible to share information as appropriate and determine the next steps.

The response to a referral about PP should be the same as for any other referral regarding the welfare of a child and child protection procedures should be followed.

Decisions about what the parents are told, by whom and when must be made in agreement with all agencies involved and as part of any enquiries made regarding the child’s welfare held under child protection procedures. All professionals must be aware of the importance of confidentiality in keeping the child safe. However a decision not to inform the parents should be kept under review to ensure that they are informed when necessary of the concerns regarding their child.

**Chronology**

Preparing a detailed multiagency chronology in cases of suspected PP is most important and will often confirm whether or not concerns about possible PP require further evaluation and the urgency with which these should be undertaken. It can also help identify undiagnosed medical conditions. In drawing up a detailed chronology it is important to distinguish between signs and symptoms that have been reported by a carer and those which have been independently observed/ witnessed by a health professional or another person.

* Those professionals involved in the child’s care should be identified as such to enable a coherent chronology to be prepared. This includes Education/ Health/ Police/ Social Work.
* A chronology of health involvement with the child, including access to all health services should be prepared to provide comprehensive information. This includes information from A&E/ GP/ Hospital admissions/ School Nurse/ Health Visitor etc.
* Any relevant information relating to the parents or siblings should be included.
* The medical/ psychiatric history should be shared as appropriate and proportionate.

**If at any point there is evidence to indicate the child’s life is at risk or there is likelihood of serious immediate harm, child protection procedures should be used to secure the immediate safety of the child.**

Where there are concerns about possible fabricated or induced illness those undertaking enquiries may need to seek medical advice about signs and symptoms. This may require evaluation by a paediatrician. For children who are not already under the care of a paediatrician the child’s GP should be contacted to facilitate a referral. It may also be important to consider seeking advice from a medical professional with expertise in the particular area of medicine related to the child’s symptoms. In emergency situations advice/signposting can be sought from the NHS GGC on call Paediatrician for Child Protection.

Other professionals involved with the child such as Education, Health Visitor and GP should also be involved as appropriate. Legal advice may also need to be sought from the Local Authority’s Solicitor.

**Guidance for Health staff**

All health professionals in the NHS or private sector may come across perplexing presentations in a child. Personnel in these services are well-placed to note the number of presentations of a child, and the manner and circumstances in which these children present. It is essential that health professionals, whether working with children or adults, should familiarise themselves with the various presentations of this type of child abuse. Health professionals may also identify a carer who is fabricating or inducing illness in themselves. In these circumstances, they should consider whether any child(ren) of this adult is/ are having their health or development impaired.

Once a health practitioner has suspicions that fabricated or induced illness is being presented, he or she should consult the clinical manager (who has lead responsibility for contacting the social work department or the police) and / or the named or designated doctor or nurse for child protection. This will be clarified by the Child Protection Advisor, Child Protection Unit. The named doctor or nurse should be contacted for support and advice. All health professionals should keep detailed notes of these discussions.

**Health practitioners should not normally discuss their concerns with the parents/ carers at this stage.**

Inverclyde Multiagency Child Protection Procedures should be followed via the submission of a Notification of Concern to the social work department. Social Work has lead responsibility for undertaking an initial assessment and if appropriate and in conjunction with the police and health, and Interagency Referral Discussion potentially leading to a child protection investigation.

**For all children, it is necessary that careful and complete notes are kept at every stage, together with the reasons why decisions are taken, for example, not to inform parents of concerns during particular periods in time in order to prevent the child suffering harm.**

**Effective Support and Supervision**

Working with children and families where it is suspected or confirmed that illness is being fabricated or induced in a child requires sound professional judgements to be made. It is demanding work that can be distressing and stressful. Practitioners are likely to need support to enable them to deal with the feelings, the suspicion or identification of this type of abuse can raise. It can be very distressing to a professional person, who has come to know a family well and trusted them, to have to deal with their feelings when they learn a child’s illness has been caused by actions of the child’s primary carer.

Possible known emotional responses to fabrication or induced illness by staff involved include:

* Self-doubt
* Fear leading to inaction
* Failure/ didn’t recognise the signs/ symptoms
* Feelings of failing the child
* Feeling of being manipulated
* Fear of litigation/ misdiagnosis
* Misdiagnosis
* Disbelief
* Denial
* Reluctance or unwillingness to pass on/ share information
* Fear of being criticised
* Fear of challenging more senior colleagues/ professionals and dealing with the power differential
* Helplessness
* Feeling unable to prepare a statement of evidence and / or giving evidence in court
* Fear of becoming frozen, unable to make decisions
* Becoming defensive
* Inability to treat the parents in a professional manner
* Knowing I was wrong / right

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| **Appendix 1 Characteristics of the child subject to PP/FII**The following features can be associated with this form of abuse, though none is indicative in itself: * The child’s medical, especially hospital treatment begins at an early stage of their “illness.”
* Children in this group often present with, or have a past history of both genuine and perceived feeding difficulties, faltering growth and reported allergies.
* Non-organic failure to thrive (physical neglect)
* They may develop a feeding disorder as a result of unpleasant feeding interactions. This is different from an eating disorder which is abnormal feeding habits associated with psychological factors, including anorexia, bulimia nervosa, pica, and rumination disorder.
* This may also apply to toileting disorders.
* The child develops an abnormal attitude to his / her own health.
* Poor school attendance. Including both the under achievement and deliberate underachievement by the child.
* There is professional perception that the parent or carer is deliberately “coaching” the child to underachieve.
* The child attends for treatment at various hospitals and other healthcare settings in different geographical areas. They may also have been seen in centres for alternative medicine or by private practitioners.
* Incongruity between the seriousness of the story and the actions of the parents.
* The child may already have suffered other forms of abuse.
* History of unexplained death, illness or multiple surgeries in parents and / or siblings.
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| **Appendix 2 Characteristics of Alleged Abuser:** The following may also be noticed: * The child’s parent or carer may have a history of childhood abuse. There may also be false or known allegations of physical or sexual abuse, self harm and / or psychiatric disorder, especially personality disorder or psychotic illness.
* Consideration must be given to the history and relevance of any previous mental ill health in the parent or carer.
* Parent or carer may have some medical knowledge and may try to imitate Health/ Educational professionals.
* Erroneous or misleading information provided by the parent or carer.
* Parent or carer refuses to allow professionals to “share” information regarding the child’s presentation/ illness.
* Parent or carer may threaten law suits too readily.
* Tends to be over friendly with health/ educational staff but may be abusive if practitioners do not comply with their wishes.
* Often shows inappropriate behaviour, e.g. being over-anxious or even less attentive than you would expect.
* May have mental health problems.
* Parent or carer is not always present when the victim has alleged or real symptoms or sights of illness, as presentation of symptoms may be deliberately delayed.
* Parent or carer may be motivated by financial gain; this can be through the receipt of benefits or educational
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