

# **Children's MARS Protocol**

**Management of Perplexing Presentations (including Fabricated and Induced Illness)** 

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## Introduction

This guidance is not intended as a detailed practice guide. It does, however, set out clear expectations about the ways in which agencies should work together in the interest of children's safety and wellbeing.

This guidance is based upon, and should be read in conjunction with, Working Together to Safeguard Children 2018, the supplementary guidance Safeguarding Children in Whom Illness is Fabricated or Induced (DCSF 2008) and the Children's Multi Agency Resilience Safeguarding (MARS) Board policies and procedures. Further guidance is available from the Royal College of Paediatricians and Child Health (RCPCH 2021).

## Context

Although child maltreatment due to abuse or neglect is pervasive within our society, less is known about fabricated or induced illness (FII) which is considered to be a rare form of child abuse (Lazenbatt and Taylor 2011). Although relatively rare this should not undermine or minimise its serious nature or the need for practitioners to be able to identify when parents or carers are fabricating or inducing illness in children (Davis 2009)

# Spectrum of harm including perplexing presentations/ medically unexplained symptoms

Some children may be presented for medical examination by their parent/carers when they are well. This can be due to over-anxious parents/carers, or a lack of understanding. Support may be required in order that the parents/carers are able to interpret and respond appropriately to childhood illness.

A key professional task is to distinguish between the over-anxious parent/carer who may be responding in an understandable way to a very sick child and those parent/carers who exhibit abnormal behaviour or have an unexpected response to a diagnosis.

There will be occasions where a child or young person may present for medical attention/appointments with unusual or puzzling symptoms (medically unexplained symptoms or perplexing presentations) which are not attributable to any organic disease, and do not involve deliberate fabrication or deception but may also be indicators of FII.

The spectrum of cases may include:

- An over-anxious parent/carer
- Parent/carer may genuinely believe the child is ill due to misinformation or misinterpretation
- The parent/carer may have mental health problems or difficulties with learning and understanding of clinical health information
- Familial or cultural styles of 'illness behaviour' may affect how children are presented to health professionals

Often the concerns for FII arise due to the child or young person being presented without adequate explanation by confirmed clinical signs, symptoms, or investigations. The situation will raise concerns for the adverse effect on the child/young persons' health, emotional or social well-being. Whilst FII may be initially suspected; unless there is immediate evidence of deception (confirmed or witnessed inducing of illness or tampering) the starting point for such cases should be considered under 'perplexing presentations'. Cases of FII will start out as perplexing presentations; **however**, not all perplexing presentations are confirmed as FII.

A 7-minute briefing on medically unexplained symptoms, perplexing presentations and FII can be found in Appendices 1-3

# Terminology and definitions

We acknowledge that there is ongoing debate regarding the terminology but currently recommend the use of Medically Unexplained Symptoms, Perplexing Presentations and Fabricated or Induced Illness respectively as defined below.

There is often a confirmed co-existing physical or mental health condition in the child.

## **Medically Unexplained Symptoms**

In Medically Unexplained Symptoms (MUS), a child's symptoms, of which the child complains and which are presumed to be genuinely experienced, are not fully explained by any known pathology. The symptoms are likely based on underlying factors in the child (usually of a psychosocial nature) and this is acknowledged by both clinicians and parents. MUS can also be described as 'functional disorders' and are abnormal bodily sensations which cause pain and disability by affecting the normal functioning of the body. The health professionals and parents work collaboratively to achieve evidence-based therapeutic work in the best interests of the child or young person. In 2018, the Royal College of Psychiatrists and the Paediatric Mental Health Association (PMHA) developed a guide to assessing and managing medically unexplained symptoms (MUS) in children and young people and a recent editorial is very helpful. Experienced clinicians report that, on occasion, MUS may also include PP or FII.

Synonyms include non-organic symptoms, functional illness, psychosomatic symptoms.

#### **Perplexing Presentations (PP)**

The term Perplexing Presentations (PP) has been introduced to describe the commonly encountered situation when there are alerting signs of possible FII (not yet amounting to likely or actual significant harm), when the actual state of the child's physical, mental health and neurodevelopment is not yet clear, but there is no perceived risk of immediate serious harm to the child's physical health or life. The essence of alerting signs is the presence of discrepancies between reports, presentations of the child and independent observations of the child, implausible descriptions and unexplained findings or parental behaviour.

#### Fabricated or Induced Illness (FII)

FII is a clinical situation in which a child is, or is very likely to be, harmed due to parent(s) behaviour and action, carried out in order to convince doctors that the child's state of physical and/or mental health and neurodevelopment is impaired (or more impaired than is actually the case). FII results in physical and emotional abuse and neglect, as a result of parental actions,

behaviours or beliefs and from doctors' responses to these. The parent does not necessarily intend to deceive, and their motivations may not be initially evident<sup>1</sup>

It is important to distinguish the relationship between FII and physical abuse / non-accidental injury (NAI). In practice, illness induction is a form of physical abuse (in Working Together, fabrication of symptoms or deliberate induction of illness in a child is included under physical abuse). In order for this physical abuse to be considered under FII, evidence will be required that the parent's motivation for harming the child is to convince doctors about the purported illness in the child and whether or not there are recurrent presentations to health and other professionals. This particularly applies in the cases of suffocation or poisoning.

# Identifying fabricated or induced illness

Identifying FII is not a swift or easy process and identifying the carer's pattern of behaviour will require a multi-agency approach, experience and observation.

There are three main ways that a parent /carer or professional may fabricate or induce illness in a child, these are not mutually exclusive

- 1. **Fabrication** of signs and symptoms. This may also include fabrication of past medical history
- 2. **Falsification** of hospital charts, letters, documents and records including falsification of specimens of bodily fluids
- 3. **Induction** of illness by a variety of means, this includes poisoning and the giving of inappropriate medication

Often symptom occurrence is linked to one setting only (child symptoms are seen within the home, whilst not observed within educational or clinical settings). Often cases will present on parental/carer verbal accounts although may include photographic evidence that cannot be confirmed as the child in question.

There is a lack of the usual corroboration of findings with signs and symptoms or in circumstances of proven organic illness, a lack of usual response to proven effective treatments. It is this puzzling discrepancy that normally alerts the clinician to possible harm.

There may be a number of explanations for the circumstances that lead to FII. Each requires careful consideration.

# NICE clinical guideline 89, 2009

The National Institute for Health and Clinical Excellence (NICE) identify that FII should be **CONSIDERED** in all circumstances where a child's history, physical or psychological presentation or findings of assessments, examinations or investigations leads to a

<sup>&</sup>lt;sup>1</sup> Blake, L., Davies, V., Conn, R. & Davie, M. (2018) Medically Unexplained Symptoms (MUS) in Children and Young People. A Guide to Assessing and Managing Patients Under the Age of 18 who are Referred to Secondary Care. August 18) and Heyman, I (2019) 'Mind the Gap: Integrating Physical and Mental Healthcare for Children with Functional Symptoms, Archives of Disease in Childhood, 104(12),pp 1127-1128

**DISCREPANCY** with a recognised clinical picture. FII is a possible explanation even if the child has a past or concurrent physical or psychological condition.

The same guideline identifies that FII should be **SUSPECTED** if a child's history, physical or psychological presentation or findings of assessments, examinations or investigations leads to a **DISCREPANCY** with a recognised clinical picture and one or more of the following is present:

- Reported symptoms and signs only appear or reappear when the parent or carer is present
- Reported symptoms are only observed by the parent or carer
- An inexplicably poor response to prescribed medication or other treatment.
- New symptoms are reported as soon as previous ones have resolved
- There is a history of events that are biologically unlikely (for example, infants with a repeated history of very large blood losses who do not become unwell or anaemic)
- Despite a definitive clinical opinion being reached, multiple opinions from both primary and secondary care are sought and disputed by the parent or carer and the child continues to be presented for investigation and treatment with a range of signs and symptoms
- The child's normal daily activities (for example, school attendance) are being compromised, or the child is using aids to daily living (for example, wheelchairs) more than would be expected for any medical condition that the child has

# Child presentation in fabricated or induced illness

The following features can be associated with FII although none is indicative itself, and this is not an exhaustive list.

- The child's medical (especially hospital) treatment begins at an early stage of their illnesses
- Children 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
- They may develop a feeding disorder as a result of unpleasant feeding interactions. This
  is not the same as an eating disorder which is associated with psychological factors for
  example anorexia nervosa or bulimia
- This may also apply to toileting disorders
- The child develops an abnormal attitude to his or her own health
- Poor school attendance, including under achievement and deliberate underachievement by the child and there is a professional perception that the parent or carer is deliberately 'coaching the child to underachieve
- The child attends for treatment at various hospitals and other health care settings in different geographical areas. The child 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/carers
- The child may already have suffered other forms of abuse
- History of unexplained death, illness multiple surgical episodes in parents and siblings

- The parent or carer is observed to be intensely involved with the child for example not allowing anyone else to take over the child's care, medical tests, taking temperatures or measuring bodily fluids
- The parent/carer may be unusually concerned about the results of investigations that may indicate physical illness in the child, although conversely they may appear not at all concerned
- If age appropriate the child is perceived as not being allowed to speak for themselves

# Possible characteristics of parents/carers

The essence of FII is the parents focus on engaging and convincing health professionals about their erroneous (mistaken) view of the child's state of health, parental behaviour may or may not include deception, it may be motivated by anxiety, attention seeking and/or by gain for the parents. (RCPCH 2021).

The following characteristics/behaviours may be noticed or identified:

- 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 (Eminson and Postlethwaite 1992)
  (Lazenbatt and Taylor 2011)
- 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 intimidate health /educational professionals
- Inaccurate or misleading information may be provided by the parent or carer
- Parent or carer may refuse to allow professionals to share information regarding the child's presentation/illness
- Parent or carer may threaten lawsuits too readily
- Tends to be over friendly with health /educational professionals but may be abusive if practitioners do not comply with their wishes
- Often shows inappropriate behaviour, for example 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 signs of illness, as presentation of symptoms may be deliberately delayed
- Parents or carers may be motivated by material/financial gain; this can be through receipt of benefits or compensation following an accident

# Harm and impact on the child

Harm to the child takes several forms. The following three aspects need to be considered when assessing potential harm to the child. As FII is not a category of maltreatment in itself, these forms of 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.

#### 1. Child's health and experience of healthcare (direct impact)

- The child undergoes repeated (unnecessary) medical appointments, examinations, investigations, procedures and 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 (eg. poisoning, suffocation, withholding food or medication) potentially or actually threatening the child's health or life

#### 2. Effects on child's development and daily life (indirect impact)

- 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

## 3. Child's psychological and health related wellbeing (emotional harm)

- 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

### Parent/carer motivation and behaviour

Both clinical experience and research indicate that the mother is nearly always involved or is the instigator of FII. The carer may be a single parent or may be acting alone unbeknown to the father. The involvement of father is variable. The father may be unaware, be suspicious but side-lined or may be actively involved. Rarely, fathers are solely involved. The parent may be actively supported by grandparents and there may be 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 (when the child has verified disorder, as many of the children do) FII may involve physical, and/or psychological health, neurodevelopmental disorders and cognitive disabilities. There are two possible, and very different, motivations underpinning the parent's need: the parent experiencing a gain and the parent's erroneous beliefs. It is also recognised that a parent themselves may not be conscious of the motivation behind their behaviours. Both motivations may be present although usually one predominates.

In the first, the parent experiences a gain (not necessarily material) from the recognition and treatment of their child as unwell. The parent is thus using the child to fulfil their needs, disregarding the effects on the child. There are a number of different gains – some psychosocial and some material. Some parents benefit from the sympathetic attention which they receive; they may fulfil their dependency needs for support, which might include the continued physical closeness of their child. Parents who struggle with the management of their child may seek and inappropriate mental Health diagnostic justification in the child such as Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD) Material Gain includes financial support for care of the child, improved housing, holidays, assisted mobility and preferential car parking

The second motivation is based on the parent's erroneous beliefs, extreme concern and anxiety about their child's health (e.g. nutrition, allergies, treatments). This can include a mistaken belief that their child needs additional support at school and an Education Health and Care Plan (EHCP). The parent may be misinterpreting or misconstruing aspects of their child's presentation and behaviour. In pursuit of an explanation, and the increasingly aided by the internet, the parent develops a belief about what is wrong with their child. In contrast to typical parental concern, the parent exhibiting such behaviour cannot be reassured by health professionals or negative investigations. More rarely, parents may develop fixed or delusional psychotic beliefs about a child's state of health. The parent's need here is to have their beliefs confirmed and acted upon, but to the detriment of the child

These two motivations appear to be in opposition to each other, the first putting the parent's needs before the child's needs and the second being disproportionately over-concerned about the child's health. However, both face health professionals with dilemmas and both lead to similar forms of harm to the child (with one notable exception, illness induction, which leads to direct physical harm to and, on extremely rare occasions, the death of the child). For these reasons, and illness induction notwithstanding, both motivations are included within FII. It is important to stress that understanding the parents' motivation is not essential to the paediatric diagnosis of FII in the child. This is important because a paediatrician is not expected to understand parental motivation, but simply to understand the cause of the child's presenting illness.

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, particularly paediatricians, about the child's state of health. It is important to note that, as is common in child neglect, the parent is not usually ill-intentioned towards the child per se. Nonetheless, they may cause their child direct harm, unintentionally or in order to have their assertions reinforced and believed.

Support groups and social media provide an important source of support for parents and families where there is a childhood illness. 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.

#### 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.

## • 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

#### Severity of harm to the child

The different aspects 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

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

# Managing emerging concerns

In situations where there are perplexing presentations of a child, often this may occur within education settings/community settings, early help processes should be initiated by the agency raising the concern. It is imperative that a health professional is included within the early help plan.

Where concerns are identified within the community, frontline/universal health professionals (may include health visitor/school nurse or GP) should take the lead role in liaising with wider health agencies, this may include tertiary care centres and targeted services, for example Child and Adolescent Mental Health Services (CAMHS). The identified health professional should ensure arrangements are in place for Consultant Paediatric oversight where appropriate.

Where concerns are identified by professionals within the acute provider, they **should take the lead role of liaising with wider health agencies**, this may include tertiary care centres and targeted services.

The involvement of the Designated Nurse should be sought when there is an identified problem by the agency attempting to liaise with wider health providers. The role of the North Lincolnshire Health and Care Partnership is set out on page 14.

Professionals should avoid discussing potential diagnosis or signposting parents/carers to websites for further information.

A flowchart setting out how to respond to emerging concerns is included in Appendix 4.

# Involvement of the family

A declined offer of the targeted formal early help assessment should not cease professional involvement; an informal approach may be required initially. Meetings should consist of early help support and include relevant family members. Access to wider health information should be adequately explained around the need to gain clarity and understand the context of the child's presentation, consent should be sought initially (the use of the conversation tool in <a href="Appendix 5">Appendix 5</a> may assist in such discussions). Wider family information, inclusive of social domains should attempt to be obtained from the relevant parent/carer. Parenting capacity including cognitive functioning should be considered and include the need for liaison with additional targeted services.

The safeguarding supervision aide memoire as per <u>Appendix 6</u> should be utilised to ensure consideration is given to information known by professionals involved.

If immediate harm is deemed likely, a referral should be made to Children's Services in line with the One Family Approach - Helping Children and Families in North Lincolnshire Document 2020/24.

While professionals should seek, in general, to discuss any concerns about a child's welfare with the family and, where possible, seek their agreement to sharing information or making referrals to other agencies, this should only be done where such discussion and agreement seeking will not place a child at increased risk of harm.

If no immediate harm is thought likely, ensure services are offered and/or provided as appropriate.

# Medical evaluation by Paediatrician: Practical application

The process for medical evaluation by a Paediatrician is set out below. A flowchart is also included within Appendix 7.

- 1. Emerging concerns by a Paediatrician or other service that clinically require Paediatric
- Engage family in early discussions to explore and clarify presentation. Seek consent to discuss, share information to and from other services. Paediatrician to contribute to any targeted informal / formal support
- 3. Full medical evaluation by Paediatrician to include completion of medical investigations. May include admission to ward for period of observation and / or referral to Specialist Tertiary Centre if clinically appropriate. If agreed medical explanation and diagnosis identified, treat and review as required. If no signs or symptoms from admission reassure parents and reduce any medications / treatments / interventions with Paediatric review as required. Review and revisit as required in response to any professional concerns
- 4. If parents refuse admission or investigations as recommended by Paediatrician which prevents full assessment and any progress within case discuss/refer to Children's Services
- If there is no agreed medical explanation from admission or investigations (medically unexplained symptoms). Meet with parents to discuss, reassure, and arrange Health and

- Education Rehabilitation Plans (See <u>Appendix 8</u>). For no further investigations and reduction of interventions.
- 6. Proceed with Health and Education Rehabilitation Plan approach to promote child achieving full potential within targeted informal / formal support process.
- Health and Education Rehabilitation Plan not proceeding or parents decline Health and Education Rehabilitation Plan and continue to request further investigations, seek further medical opinion, then refer to Children's Social Care under suspected FII

Paediatricians should follow the Royal College of Paediatrics and Child Health – Perplexing Presentations (PP) / Fabricated or Induced Illness (FII) in Children RCPCH guidance (2021).

Throughout the process, they should also discuss and liaise / seek supervision with Named Doctor and Northern Lincolnshire and Goole NHS Foundation Trust (NLaG) Safeguarding Children Team.

# Where FII is suspected

Where concerns are such that professionals feel that FII is suspected, if the child or young person is not currently under Paediatric Consultant, a referral should be made by the child/young person's GP. If the child or young person is already under the care of Paediatrics, the named Paediatrician and NLAG Safeguarding Children Team should be made aware of the presenting concerns. Where immediate harm is thought likely, such as evidence of inducing illness, urgent action should be taken by the identifying agency and referral made to Children's Services.

Where concerns are clear around FII and the Consultant Paediatrician view confirms this, procedures should include an immediate referral into Children's Services with a strategy discussion to follow. Agencies involved should ensure they have collated relevant and proportionate information. Efforts should be made to ensure mental health oversight is included within health information.

# Involvement of the family

While professionals should seek, in general, to discuss any concerns about a child's welfare with the family and, where possible, seek their agreement to making a referral to children's social care, this should only be done where such discussion and agreement-seeking will not place a child at increased risk of significant harm.

In the case of FII, unless it is clear that the parent/carer is not involved in the fabrication, falsification or induction of illness, parents or carer SHOULD NOT be informed of concerns or referral to Children's Services.

Careful thought should be given to what parents/carers are told, when and by whom. Children's Services should involve the police, the child's paediatric consultant and GP, senior nursing staff (named nurse or senior ward) and other relevant professionals in making these decisions.

# Expectations of professionals/ services identifying concerns, including in tertiary health settings

Where concerns in respect of perplexing presentations, or possible FII are identified, there is a responsibility on the professional/ service who identifies the concerns to be clear about the nature, rationale and evidence (including lack of evidence of carer reported signs or symptoms) for the concerns. Any referral to Children's Services, where FII is believed to be evidenced, must be confirmed in writing which clearly outlines the rationale for the professional opinion that FII is present, or a significant risk.

As in other forms of harm, where there are professional concerns in respect of perplexing presentations or FII, referral to another service or agency does not reduce the responsibility of the referrer to actively participate in activity to understand and reduce the risk posed to the child. Where concerns are identified within tertiary care settings, tertiary care safeguarding teams **should take the lead role in liaising with wider health agencies**, this may include targeted services, for example CAMHS.

Where any service/agency identifies that health services within or outside North Lincolnshire are not appropriately contributing to professional or safeguarding enquiries in these circumstances, issues can be escalated to the North Lincolnshire Health and Care Partnership Safeguarding Team. However, this should only be considered once all reasonable attempts to escalate within the relevant services/ organisations have been exhausted.

# Role of North Lincolnshire Health and Care Partnership

As commissioners of most local health services in North Lincolnshire, the Health and Care Partnership would expect local and tertiary provider organisations (irrespective of commissioner arrangements) to work together to provide coordinated care to North Lincolnshire resident children, or those registered with a North Lincolnshire Health and Care Partnership member practice, receiving health services.

North Lincolnshire Health and Care Partnership hosts the Head of Safeguarding (Designated Nurse), and a team of specialist nurses. The Safeguarding Team work as part of the health service offer to support the arrangements, within North Lincolnshire's health services, and across the multi-agency system.

Where there are medically unexplained symptoms/perplexing presentations, and health (or other agency) professionals are seeking clarification from other agency/ service professionals, best practice is for direct communication between services and organisations involved in the provision of services to the subject child(ren) and their family. This is to ensure timely and robust understanding of the issues by those who know the child and family best.

Where any difficulties in communication or receiving clarity are encountered by any agency with health services within or outside North Lincolnshire, issues can be escalated to the North Lincolnshire Health and Care Partnership Safeguarding Team. However, this should only be

considered once all reasonable attempts to escalate within the relevant services/ organisations have been exhausted.

# **Maintaining records**

- There is a need to ensure robust and holistic recording of concerns/carer behaviour/how carer behaviour may vary from expected behaviour
- Records should use clear, straightforward language, should be concise and should be accurate not only in fact, but differentiating between opinion, judgement and hypothesis (DCSF 2008)
- Detailed accurate and informative medical records are pivotal to the management of all cases (RCPCH 2021)
- Where the possibility of FII is present, all records for the child should be kept in a more secure location than usual, for example, in a hospital setting, not on ward trolleys. (RCPCH 2021)
- A single health case record for medical and nursing staff will help to promote effective clinical communication. (RCPCH 2021)
- If a child moves between organisations, it is best practice for the notes to follow the child.
   This may not always be possible and so a clinical summary should follow the child (RCPCH 2021)
- It is essential that records include a health chronology of the child's medical presentation including any aspects which may indicate FII (RCPCH 2021)
- It is essential that clinicians concerns about FII are documented in the records; where there is uncertainty, this should be expressed as a differential diagnosis<sup>2</sup>. (RCPCH 2021)
- Record in the child or young person's record exactly what is observed and heard from whom and when.
- Record why this is of concern

The process for responding to referrals, determining next steps, and actions required to safeguard the child should be in line with the <u>Children's MARS policy and procedure for assessing need and providing help</u>. However, the following should be considered:

### • Criminal considerations

Consideration needs to be given to the potential consequences of the loss of evidence, including the obtaining of and preservation of evidence. Advice should always be sought from the police

## • Preparation for a strategy discussion

All practitioners should be advised that this is confidential and parents/carers are **not to be informed**. The Consultant Paediatric opinion should inform the strategy discussion/meeting of diagnosis of FII

<sup>2</sup> Differential Diagnosis - the determination of which one of several diseases/circumstances may be producing the symptoms

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 powers should be used to secure the immediate safety of the child

#### Attendees at the strategy discussion

The following professionals should be included in /invited to the strategy discussion:

- Social Worker
- Consultant Paediatrician
- Police
- GP of both child and parent/carer (if different)
- Health visitor/ school nurse
- Education representative (if school aged child)
- All relevant professionals (especially for a child who has chronic medical condition or disability).
- Named or Designated Doctor

Consideration should also be given to including

- Adult Mental Health Service representative
- o Representative of the local authority legal service

#### • Within the strategy discussion

When a decision has been made that a concern has been reached around FII, a referral will be made into Children's Services by the relevant health professional (this will be decided and agreed within the health community with consideration for the lead professional) and strategy discussion will follow. The referral should include the information gathered by agencies involved; this will include any work around the parenting capacity/family and environmental factors in addition to Paediatric opinion that has taken place prior to the referral.

The <u>Children's MARS policy and procedure for assessing need and providing help</u> should be followed in respect of conducting a strategy discussion, however, the following should also be included:

- o Specific information to be collated and shared to inform decision making
- Clarification of the medical history, including details of any incidents that are reported to have occurred in the presence of people other than the suspected perpetrator
- Verify the personal, family and social history. This includes the parent's medical or psychiatric history
- Any other relevant agency/professional involvement
- Agree what, how and when parents/carers are informed of suspicions/ activity.
   Reference should be made to section above on Involvement of family
- Any relevant information relating to the parents or siblings
- Chronology to be considered if deemed necessary at this point and requested from all agencies

## Completion of chronologies

All agencies should use the chronology template included within <u>Appendix 9</u> to ensure compatibility when integrated. The integration of all chronologies will fall into the responsibility of statutory services.

All agencies involved with the care surrounding the child/young person deemed to be at risk or has suffered FII must provide a chronology of their involvement and frequency of contact with the child/parent. This includes education/ health/ police/ social care. Those professionals involved in the child's care should be identified as such to enable a coherent chronology.

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 appointments and admissions/ CAMHS/ School Nurse/ Health Visitor/ Community Paediatrics/ therapies etc. It should include any relevant information relating to the parents or siblings. The medical/ psychiatric history of parents should be shared as appropriate and proportionate.

# **Effective support and supervision**

Working with children and families where FII is suspected or confirmed requires sound professional judgements to be made. This demanding work can be distressing and stressful and practitioners will need regular support and supervision to enable them to deal with the feelings, the suspicion or identification of this type of abuse, and to maintain focus especially when coming to terms with the fact that a child's illness has been caused by another person often the primary carer. Where a professional has come to know a family well and trusted them, e.g. where the child has a chronic medical problem or disability, this can be particularly challenging. Operational managers and/or supervisors should recognise the stress experienced by frontline staff that may have had a close professional relationship with a family.

Recognised emotional responses to FII by staff involved include:

- Self-doubt
- Fear leading to inaction
- Loss of self-respect, self-esteem
- Failure / didn't recognise the signs / symptoms
- Feelings of failing the child
- Anger at colleagues who disbelieve / believe
- Loss of trust
- Anger at parents / how could they have used me?
- Feeling of being manipulated
- Feeling of being duped
- Fear of litigation / misdiagnosis
- Misdiagnosis
- Disbelief
- Denial
- Reluctance or unwillingness to pass on / share information

- Fear of being cruised
- 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

This is not an exhaustive list. (From Incredibly Caring, DCSF 2008)

# Allegations against staff or volunteers

If the parents/ carers are working with children in a professional capacity as either paid staff or volunteers, then appropriate action needs to be taken in respect of dealing with this situation. For further information, see the Children's MARS Policy and Procedure for Managing Allegations against people who work with children.

## References

- Blake, L., Davies, V., Conn, R. & Davie, M. (2018) Medically Unexplained Symptoms (MUS) in Children and Young People. A Guide to Assessing and Managing Patients Under the Age of 18 who are Referred to Secondary Care. August 18
- Department of Children, Schools and Families (2008) Incredibly Caring: A Training Resource for Professionals in Fabricated or Induced Illness (FII) in Children, HM Government
- Department of Children, Schools and Families (2008) Safeguarding Children in Whom illness is fabricated or induced, HM Government
- Eminson, M. D. and Postlethwaite, R. J. (1992) Factitious illness: recognition and management. *Archives of Disease in Childhood*. 67:1510-1516
- Eminson, M. D. and Postlethwaite, R. J. (eds.) (2000) Munchausen syndrome by proxy abuse: a practical approach. Boston: Butterworth- Heinemann.
- Heyman, I (2019) 'Mind the Gap: Integrating Physical and Mental Healthcare for Children with Functional Symptoms, Archives of Disease in Childhood, 104(12),pp 1127-1128
- Incredibly Caring, DCSF (2008)
- Lazenbatt A and Taylor J (2011) Fabricated or induced illness in children: a rare form of child abuse?, NSPCC Research Briefing
- McClure, R. J., Davis, P. M., Meadow, S. R. and Sibert, J. R. (1996) Epidemiology of Munchausen syndrome by proxy: non-accidental poisoning and non-accidental suffocation. *Archives of Disease in Childhood*. 75(1): 57-61.
- National Institute of Health and Care Excellence (NICE) (2009) CG89 When to suspect child maltreatment (last updated Jan 2014)
- Royal College of Paediatrics and Child Health (2021) Perplexing Presentations (PP) / Fabricated Induced Illness by Carers (FII) in Children RCPCH guidance.

•	Danya Glaser & Safeguarding Children Group (2014) Guidance on the managemer perplexing presentations at Great Ormond Street Hospital (GOSH)					

# Appendix 1 – 7 Minute Briefing on Medically Unexplained Symptoms

1

In Medically Unexplained Symptoms (MUS), a

child's symptoms, of which the child complains, and which are presumed to be genuinely experienced, are not fully explained by any known pathology. The symptoms are likely based on underlying factors in the child (usually of a psychosocial nature) and this is acknowledged by both clinicians and parents. MUS can also be described as 'functional disorders' and are abnormal bodily sensations which cause pain and disability by affecting the normal functioning of the body. The health professionals and parents work collaboratively to achieve evidence-based therapeutic work in the best interests of the child or young person

2

Fabricated or Induced Illness or Perplexing Presentations

Experienced clinicians report that on occasion MUS may also include Fabricated or Induced Illness or Perplexing Presentations

3

7

Health, Education and Rehabilitation Plan

A Health, Education Rehabilitation Plan (HERP) should be used where possible, encouraging children and families to 'live with/alongside' presenting symptoms. Professionals should work with families to promote the ability to achieve their full potential

Medically Unexplained Symptoms Include the Family

In the early stages where a professional is concerned that a child's presentation is unexplained, unless there are immediate concerns requiring medical intervention, professionals should seek to include families in early conversations and any meetings should include the family.

**Family Context** 

Within the early emergence of 'medically unexplained symptoms' it is helpful to gain an understanding of the family context, this will assist in trying to understand the presenting issues, parental anxiety, experiences of health services, and understanding of what has been explained to them about their child. Explore within the early help arena.

Consent

Consent should be sought to gather further information from parents to understand the presentation of the child and why this may be unexplained. Further health liaison such as GP, and paediatric involvement (including tertiary care) should be sought by the named health professional

Early Help

Ensure the most appropriate professional is engaged with the family (involve health professional such as Health Visitor or School Nurse initially). A family who declines the offer of an Early Help Assessment may still be supported and engaged without the formalised

6

5

4

# **Appendix 2: 7 Minute briefing on Perplexing Presentations**

#### What are Perplexing Presentations?

Perplexing presentations (PP) are situations where a child's presentation cannot be adequately explained by confirmed illness/diagnosis and the situation is impacting on the child's health, development and or social well-being

#### **Fabricated or Induced Illness**

Most children found to have fabricated or induced illness (FII) are initially recognised as perplexing presentations BUT, not all perplexing presentations are FII

#### 'Living with'

A 'living with' approach, inclusive of a Health, Education, Rehabilitation plan should be used where possible, encouraging children and families to live with/alongside presenting symptoms . Professionals should work with families to promote the ability to achieve their full potential

Perplexing Presentations

#### Include the Family

In the early stages where a professionals is concerned that a child's presentation is confusing, unless there are immediate concerns requiring medical intervention, professionals should seek to include families in early conversations. Meetings about the child should include the family

#### Family Context

Within the early emergence of 'perplexing presentations' it is helpful to gain an understanding of the family context, this will assist in trying to understand the presenting issues, parental anxiety, experiences of health services, and understanding of what has been explained to them about their child

Consent

Consent should be sought to gather further information from parents to understand the presentation of the child and why this may be confusing. Further health liaison such as GP, and paediatric involvement (including tertiary care) should be sought by the current health professional

#### **Early Help**

Ensure the appropriate professional is engaged with the family (involve health professional such as school nurse or health visitor initially) A family who declines the offer of an early help assessment may still be supported and engaged without the formalised tool

# **Appendix 3: 7 Minute Breifing on Fabricated or Induced Illness**

1

Fabricated or induced illness (FII) in a child is a spectrum of conditions where a child experiences or is likely to experience significant harm and impairment due to the health care seeking behaviour and actions of the caregiver(s), usually the mother. FII lies within the category of physical abuse

7

#### How it presents

ERRONEOUS: incorrect or misleading reporting of medical history, symptoms or signs, this may include false reporting or exaggeration.

DECEPTION: falsification of medical records, interference of investigations, specimens, intravenous lines or inducing illness such as adding salt to a baby's feed

3

7

Chronologies should be compiled by all relevant agencies, information should be relevant and proportionate to the concern and encompass all domains of the child's life and including family context/ significant events. Further action should be in accordance with Children's MARS policy and procedures

Fabricated or Induced Illness FII often presents as a perplexing presentation, when a professional feels that there is sufficient cause to suspect FII, they should ensure the correct professionals are involved, the Paediatrician shall assume the lead role (if no paediatrician involved, referral should be made after consulting with the GP) the current health professional should seek to liaise with partner health agencies

Following Paediatric view and referral to children's social care, a strategy discussion should follow, this should include the Police, Paediatrician, GP, Education, other relevant health professionals for child and parent/ carer Paediatric view will be made following relevant medical tests and seeking explanation for signs and symptoms, if FII is now suspected, this should be discussed with the Named/ Designated Doctor and referral into children's social care initiated Professionals should aim to work within an evidence based approach. Where concerns have substance around FII (and this view should be obtained from the appropriate professional involving a multi-agency approach), parents should not be informed of FII suspicions at this stage

6

5

4

# Appendix 4: Perplexing Presentations and emerging concerns regarding FII: Flowchart Any professional has a concern about medically unexplained symptoms Early help should be initiated by the agency raising the concern Where frontline health professionals identify concerns, (this might include health visitor/school nurse) they will take the lead role in liaising with wider health agencies Where acute sector is the agency identifying the concern, they need to take the lead role in liaising with wider health agencies Where concerns are identified by tertiary care, they should take the lead role in liaising with wider health agencies Discuss an Early Help Assessment with family and arrange early help meeting – if an early help assessment is declined by parents, the lead agency should make all efforts to invite family discussion around health concerns within informal, targeted approaches. Establish any Paediatric/ psychology/ CAMHS involvement and invite to a multiagency meeting If immediate harm is deemed likely, referral to be made to children's Gather information across all domains of the child's life using social care conversation tool if required) and include wider family relevent and proportionate information to gain context around the presenting concern within the early help arena Utilise the aide memoire (appendix 6) within supervision where perplexing presentations lead to concerns about FII. Supervision should be made available to practitioners managing FII concerns from a senior safeguarding lead within your own organisation

If concerns remain regarding perplexing presentations, proceed within

medical evaluation by Paediatrician (appendix 7)

# **Appendix 5: Conversation tool**

A copy of this tool can also be found on the Children's MARS website.



What are my beliefs and understanding of my illness?

What is it like to be ...?

What am I most worried about?

What would I like to be different?

Most children found to have fabricated or induced illness (FII) are initially recognised as perplexing presentations.

#### **BUT**

Not all perplexing presentations are fabricated or induced illness

Think about parental experience

- Confusion and anxiety in navigating health services and how conversations many be confusing
- Not all parents will understand what is being said about their child
- Parents/carers may feel a diagnosis will be beneficial to their child

#### Talking to me and my family

My presentation may confuse and concern you but there may be a reason for this

Support me and my family in early help and involve the right health professional (at first this might be my health visitor or school nurse) Gain my family's consent for more information

Include me and my family within early conversations

> If my parents don't want an early help assessment, you can still support us

#### When to consider FII

- New symptoms emerging and remain unexplained
- Repeated presentation to a variety of doctors with same of different health concerns
- Parents not wanting to engage in 'working alongside symptoms' model
- Concerns around falsification or interference to induce illness
- Child's voice indicates concerns (discloses they are told to report symptoms or behave in a certain manner)
- Once the carer's access to the child is restricted, signs and symptoms fade and eventually disappear

The above indicate significant or potential for significant harm





Supporting Children and Families

Talking to families when there are emerging concerns around the health of a child or young person

Rotherham Doncaster and South Humber

and South Humber

Northern Lincolnshire and Goole
NHS Foundation Trust

- Please tell my family that you want to help and support us
- Tell my family you need to understand a little more about my health and symptoms
- Tell my family about the importance of my education and meeting my full potential
- Tell my family you want to support them by working with other professionals, you need their consent
- Tell my family you all have the same goal, to ensure I am healthy, happy and meeting my full potential

- Ask about parental/carer anxiety relating to the child's health or their own health
- Ask about parental/carer experiences of poor health or health services
- Consider parental/carer understanding of health and factors that may affect this
- Consider social factors such as mental health/domestic abuse
- Explore parental/carer reasons for diagnosis—what would this mean

- Do not encourage parents/carers to explore symptoms (e.g. Google search)
- Do not attempt to diagnose unless medically qualified to do so
- Try not to name disorders that are actually descriptions (e.g. chronic pain syndrome)

Talk to families— Have a conversation Seek the right information and ask the right questions

AVOID...

# Appendix 6: Safeguarding supervision aide memoire

This aide memoire is designed to help you within safeguarding supervision throughout the process of perplexing presentations and possible FII concerns and liaising with partner agencies: it is not exhaustive. Use and consider all aspects of this as necessary. **This aide** memoire should be used in conjunction with Children's MARS Policies and Procedures.

## Questions and considerations for all agencies

- What are the significant issues? What is the perceived gain for the carer?
- Are the correct agencies involved at this point?
- Consider health/ police/ social care/ education
- Have agencies worked together. If not what were the barriers?
- Are there any professional issues or misunderstanding preventing agencies from working effectively?

## Questions and considerations for individual professionals/ agencies

#### Health

- Is there clear evidence of diagnoses?
- Are appointments made and kept?
- Are parents/carers health shopping? That is taking their child to different doctors/clinics and seeking numerous medical opinions
- Has anyone other than the parent or carer witnessed the problems?
- Does the parent have an extensive history of involvement with any health services, including GP, medical/ surgical or mental health?

#### **Police**

- Is there evidence to suggest that a crime has been committed?
- Are parents/carers known' to the police? If so in what capacity, is it relevant.

#### Children's Services

- Are the family known to social care?
- Are there any previous child protection concerns

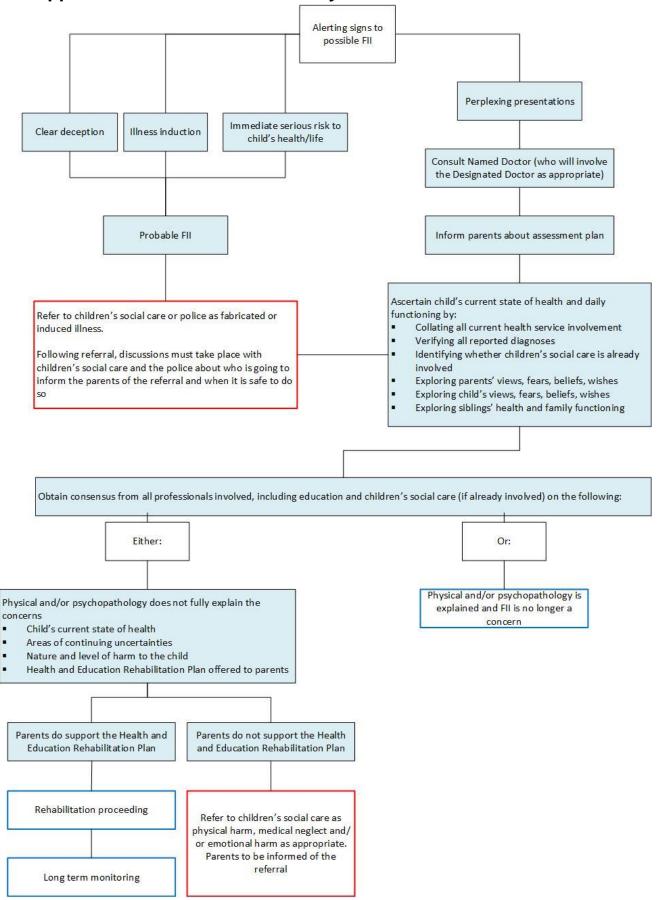
#### **Education**

- What is the school attendance like?
- Has this deteriorated?
- Is there evidence of repeated patterns of non-attendance?
- What are the reasons for non-school attendance?
- Are absences always explained by parents, or have medical certificates, letters or reports been made available to school?
- How does the child present at school?
- Have parents/carers reported health problems/symptoms which are never apparent in school?

#### **Next considerations**

- Is this child safe? What is the impact on the child/young person?
- Do you need to gather more information?
- Where the presentation is considered perplexing, proceed to offer early help. Please note
  the offer of early help may not necessarily involve an early help assessment but include
  informal/targeted approaches.
- Consideration for involvement of paediatric/targeted services
- Has the threshold for significant harm been reached?
- Does this need to be referred to Children's Services/ police?

# Appendix 7: Medical evaluation by Paediatrician: Flowchart



# Appendix 8: Health and Education Rehabilitation Plan (HERP Plan)

Paediatric Consultant (and specialist colleagues if appropriate) meets with the family, and child /young person if appropriate to explain:

- Investigation results / professional opinions to date and reasoning behind them
- That further investigations / specialist referrals are not warranted and are likely to do more harm than good
- That these results are not life threatening & child / young person will not come to harm as a result
- That you are unable to give diagnosis or define a problem (this is preferable to avoid naming disorders which are actually descriptions, e.g. chronic pain syndrome)
- That the child / young person needs to be helped to function alongside symptoms
- That the health team may recommend a Health and Education Rehabilitation Plan

Explore with parent & child / young person what changes in daily life are required to function optimally and improve health

- Parents / professionals to encourage child to continue their activities, physical and social instead of keeping them at home / declining activities
- Plan to wean and stop any current unnecessary medical treatments / aids / medication or treatment where side effects outweigh benefits (unnecessary aids may prolong and may worsen symptoms, i.e. wheelchairs)
- Basic symptom management for presenting symptoms, e.g. headaches, abdominal pain
- Provide general advice about importance of diet, sleep, graded exercise
- Aim for optional education to recommence if affected.
- Multi-agency early help plan to continue inclusive of the Health and Education Rehabilitation plan. Consultant paediatrician to contribute as appropriate.
- May require CAMHS intervention

# **Appendix 9: Chronology guidance and template**

#### Guidance

- All agencies to access the below chronology template to ensure compatibility when integrated
- The integration of all chronologies will fall into the responsibility of statutory services
- A chronology should be a succinct summary and overview of the significant dates and events in a child's life. This may include events relating to significant others, where they have an impact on the child
- Information included in a chronology should be relevant so as not to be lost in a mass of insignificant and irrelevant events
- The key purpose of a chronology is to provide an early or clear indication of an emerging pattern of concern
- A chronology, as the most robust mechanism of collating information, can reveal risks, concerns, themes and patterns, strengths and weaknesses within a family.
- However, chronologies should include, or be complemented by analysis of the available information
- The analysis should outline the impact,
  - · actual and potential, and
  - immediate and cumulative,
  - of events and changes on the child's developmental progress
- Professionals should draw on the expertise of professionals from other agencies when considering impact on child
- It is essential that the analysis, facts, emerging themes and patterns drawn out from the chronology are agreed

## **Chronology template**

Date:	Client The individual(s) involved in the event	Agency The agency sharing the information	Event The significant piece of information	Analysis To examine the event in detail establishing its meaning (include parent/ carer responses as relevant)	Outcome and Actions Any action taken in response to the event.