Fabricated or Induced Illness and Perplexing Presentations

Pathway Explainer

Red Pathway – Probable FII

Immediate Action

Ensure Safety

- If there is immediate or potential serious threat to the child (e.g. include tampering with medical equipment, administering harmful substances, withholding or switching treatments, evidence of smothering), take urgent steps to secure the child's safety and prevent further harm;
- If not already an in-patient, consider immediate admission via ambulance (not allowing carers to bring child in alone), or other action to ensure the child's safety;
- Consider whether the child is in need of immediate protection and measures to reduce immediate risk.

Escalate and Refer

- If in hospital, escalate to the most senior medical and nursing staff on site, call police immediately and secure any evidence (e.g. feed bottles, giving sets, nappies, blood/urine/vomit samples, clothing or bedding if they have suspicious material on them). Inform the consultant;
- An urgent referral should be made to Children's Social Care Services, who should make a rapid decision and respond immediately. The safety of siblings needs to be considered. Refer to the police. An emergency protection order or police protection powers may be needed;
- Usually an urgent strategy meeting will be arranged which must include the paediatrician with primary responsibility for the case.

Review Management

- Review medical management plans in the light of the new information. Some planned investigations, procedures or treatments may now be inappropriate;
- This may include stopping administration of a harmful substance or inappropriate treatment, replacing equipment, or taking specimens for toxicology.

Preserve evidence

- Keep any substances or equipment or clothes that might constitute evidence for a later police investigation in secure storage (such as a controlled drugs cabinet / lines / bedding);
- Ideally these should be locked away by two professionals working together to preserve chain of evidence or given to police.

Identify lead clinician

- Identify which clinician will take a lead for the health aspects of the process. For inpatients, this will be the lead consultant managing the patient.

Seek safeguarding advice

- Advice should be taken at the earliest opportunity from the Named or Designated doctor for children's safeguarding, and the relevant safeguarding team(s) should be alerted (this could be the hospital safeguarding team, or the area team, depending on setting).

Keep thorough records

- Events should be documented in detail, along with professional details of all staff involved. Document concerns in the child's health records e.g. 'this unusual constellation of symptoms, reported but not independently observed, is worrying to the extent that, in my opinion, there is potential for serious harm to the child'). This is important in case the child is seen by other clinicians who are not aware of the concerns.

Don't confront parents

- Confronting parents with concern about FII is best avoided at this point. It may sometimes increase risk to the child, or compromise any criminal or safeguarding process. Discussions must take place with children's social care/police about who is going to inform the parents and when it is safe to do so. This may be agreed at the strategy meeting.

Referral and Further Action

Referral

- FII is a form of child abuse so usual procedures apply. A referral should be made to Children's Social Care Services and the Police in accordance with local referral procedure. A rapid decision and response is required (same day). A strategy meeting should be convened involving appropriate professionals (health, social care, police, and consider legal and education).

Strategy Meeting

- The strategy meeting should also consider: level of risk to the child and any siblings; how the child might be given opportunity to share their story; need for further investigations, observations, management; need for a police investigation; information sharing with parents (what should be shared, when, and by whom); needs of carers, particularly after disclosure;

- If the strategy meeting identifies that a professional should talk to the child about what is going on for them, to try to understand the situation, the professional should seek guidance regarding safeguarding procedures first. If the red pathway is being followed, this should be undertaken by someone who is trained in Achieving Best Evidence, and the strategy discussion should plan who will talk to the child, and what questions they should ask, in order to help gather evidence and ensure that best practice guidelines are followed.

Chronologies

- A multi-agency chronology should be compiled as soon as possible, ideally for consideration at the first strategy meeting. This is normally led by the lead paediatrician for the child, or social care. If there is doubt about who will assemble the chronology, advice should be sought from the Named Doctor. A standard chronology template should be used (e.g. see LINK FOR CHRONOLOGY TEMPLATE). Compiling the chronology should not delay the process.

Observation

- A (further) period of admission may be helpful for closer observation and decisions about management. This should be planned carefully with clear instructions and understanding of issues by nursing and other staff involved. Significant improvement while under close observation may add to the concern about FII;

- Covert video surveillance is almost never necessary, since if indicated, then the threshold for care proceedings will already have been reached. Where it is under serious consideration, senior advice from within health, police and social care should be sought, including involving designated professionals. Any CVS would be carried out by police not health workers.

Outcome of Section 47 Enquiry and Single Assessment

Concerns Not Substantiated

- As with all Section 47 Enquiries, the outcome may be that concerns are not substantiated - e.g. tests may identify a medical condition, which explains the signs and symptoms;
- It may be that no protective action is required, but the assessment concludes that services should be provided to the child and family to support them and promote the child's welfare as a Child in Need, or through early help. In these circumstances, appropriate assessment should be completed and planning meetings held to discuss the conclusions, and plan any future support services with the family;
- It may be appropriate for further management to follow the Amber pathway, including consideration of a Health and Education Rehabilitation Plan

Concerns Substantiated and Continuing Risk of Significant Harm

- Where concerns are substantiated and the child judged to be suffering or likely to suffer Significant Harm, an Initial Child Protection Conference may be convened or the child may be made subject to orders e.g. an Interim Care Order.

Amber Pathway – Perplexing Presentations (PP)

This pathway should be followed where the child has presented in a perplexing or unusual way and the possibility of fabricated or induced illness is being considered, but the risk of serious harm is low. The key is to quickly establish the child's actual current state of physical and psychological health and functioning, and the family context. The parents are told about the current uncertainty regarding their child's state of health, the proposed assessment process and the fact that it will include obtaining information about the child from other caregivers, health providers, education and social care if already involved with the family, as well as likely professionals meetings. Wherever possible this should be done collaboratively with the parents.

- An early decision should be made about whether the Red Pathway would be more appropriate, and this should be kept under review throughout. If in doubt, escalate to the Red Pathway;
- The Amber Pathway is slower paced and may take weeks or months: the urgency and timescale is proportionate to the degree of risk and likelihood of FII;
- Regularly consider whether any of the spectrum of presentations outlined in Table 2 may apply.

Identify lead clinician for the child

- Where multiple professionals are involved, communication can become difficult and mixed messages are likely. It is best to agree one person who will take a lead, usually the responsible paediatrician most involved. They will be the main channel of communication with the parents and lead in decisions about further investigation;
- If the lead clinician is also the Named Doctor, then another clinician will need to undertake this consultative role, possibly the Designated Doctor. This means that safeguarding decisions can be made objectively, free from duress, threats and complaints and the responsible clinician has appropriate support in these challenging cases;
- The lead clinician could be the GP or Children and Young People's Mental Health Services (CYPMHS) consultant, but consider a paediatric referral for an opinion about the specific presenting symptoms. A discussion with Named or Designated Safeguarding professionals may be helpful, according to the nature of the problem and local arrangements. Concerns should be clearly summarized in the referral, including the possibility of FII.

Consult with Named Doctor for safeguarding children (who will inform Designated Doctor as appropriate)

Because these situations can be complex with potentially serious repercussions, the lead clinician should have an early discussion of concerns about Perplexing Presentations or possible FII with the Named Doctor. An opinion from a tertiary specialist may be necessary.

Establish current status

The lead clinician (usually the responsible paediatric consultant) should review the situation and establish the current status with regard to the child's health and wellbeing; the parents' views; and the child's view (if old enough). Provide signposting advice for children, young people and their parents on where to access more information or support.

Child's health and wellbeing

- Collate all current medical/health involvement in the child's investigations and treatment, including from GPs, other Consultants, and private doctors, with a request for clarification of what has been reported and what observed. (This is not usually a request for a full chronology, which would need to include all past details of health involvement and which is often not relevant at this point);
- Ascertain who has given reported diagnoses and the basis on which they have been made, whether based on parental reports or on professional observations and investigations;
- Consider inpatient admission for direct observations of the child, including where relevant the child's input and output (fluids, urine, stool, stoma fluid as applicable), observation chart recordings, feeding, administration of medication, mobility, pain level, sleep. If discrepant reports continue, this will require constant nurse observations. Overt video recording may be indicated for observation of seizures and is already in widespread use in tertiary neurology practice to assess seizures (which must be consented to by parents);
- Consider whether further definitive investigations or referrals for specialist opinions are warranted or required;
- Obtain information about the child's current functioning, including: school attendance, attainments, emotional and behavioural state, peer relationships, mobility, and any use of aids. It is appropriate to explain to the parents the need for this. If the child is being home schooled and there is therefore no independent information about important aspects of the child's daily functioning, it may be necessary to find an alternative setting for the child to be observed (e.g. hospital admission).

Parents' views

- Obtain history and observations from all caregivers, including mothers and fathers; and others if acting as significant caregivers;
- If a significant antenatal, perinatal or postnatal history regarding the child is given, verify this from the relevant clinician;
- Explore the parents' views, including their explanations, fears and hopes for their child's health difficulties;
- Explore family functioning including effects of the child's difficulties on the family (e.g. difficulties in parents continuing in paid employment);
- Explore sources of support which the parent is receiving and using, including social media and support groups;
- Ascertain whether there has been, or is currently, involvement of early help services or children's social care. If so, these professionals need to be involved in discussion about emerging health concerns;
- Ascertain siblings' health and wellbeing;

- Explore a need for early help and support and refer to children's social care on a Child in Need basis, where appropriate depending on the nature and type of concerns, with agreement from parents.

Child's view (if appropriate developmental level and age)

- Any professional seeking the views of a child should first familiarise themselves with safeguarding guidance to ensure this is considered;
- Explore the child's views with the child alone (if of an appropriate developmental level and age) to ascertain:
    - The child's own view of their symptoms;
    - The child's beliefs about the nature of their illness;
    - Worries and anxieties;
    - Mood;
    - Wishes.
- Observe any contrasts in verbal and non-verbal communication from the child during individual consultations with the child and during consultations when the parent is present;
- Some children's and adolescent's views may be influenced by and mirror the caregiver's views. The fact that the child is dependent on the parent may lead them to feel loyalty to their parents and they may feel unable to express their own views independently, especially if differing from the parents;
- Consider use of 'Being Me' and 'Me first' resources to help children and young people to share who they are, how they are feeling and what support they would like. These resources have been co-designed and developed with children and young people.

Reach a multi-professional consensus

Multi-professional meeting

- Ascertain child's current state of health and daily functioning:
    - Collate all current health service involvement;
    - Verify all reported diagnoses, who has given them, and on what basis;
    - Identify whether children's social care involved;
    - Explore parents' and child's views, fears, beliefs, wishes;
    - Explore siblings' health and family functioning.
- Obtain consensus from all professionals involved, including education and children's social care (if already involved) on the following:
    - Child's current state of health;
    - Areas of continuing uncertainties;
    - Nature and level of harm to child.

There may need to be one or more professionals' meetings to gather information. These can be virtual meetings. Where possible, families should be informed about these meetings and the outcome of discussions as long as doing so would not place the child at additional risk. Care should be given to ensure that notes from meetings are factual and agreed by all parties present. Notes from meetings may be made available to parents, on a case by case basis and are likely to be released to them anyway should there be a Subject Access Request for the health records.

Although this meeting can be chaired by the lead clinician, consider whether it might be better chaired by the Named Doctor (or a clinician experienced in safeguarding with no direct patient involvement) to ensure a degree of objectivity and to preserve the direct doctor-family relationship with the responsible clinician. Parents should be informed about the meeting and receive the consensus conclusions with an opportunity to discuss them and contribute to the proposed future plans (see below).

A consensus needs to be reached in a meeting between all professionals about the following issues:

Either

- That all the alerting signs and problems are explained by verified physical and/or psychiatric pathology or neurodevelopmental disorders in the child and there is no FII (false positives);
- Medically Unexplained Symptoms from the child free from parental suggestion;
- That there are perplexing elements but the child will not come to harm as a result;
  Or
- That any verified diagnoses do not explain all the alerting signs;
- The actual or likely harm to the child and or siblings;
  And agree all of the following:
- Whether further investigations and seeking of further medical opinions is warranted in the child's interests;
- How the child and the family need to be supported to function better alongside any remaining symptoms, using a Health and Education Rehabilitation Plan (see below for details);
- If the child does not have a secondary care paediatric Consultant involved in their care, consideration needs to be given to involving local services;
- The health needs of siblings;
- Next steps in the eventuality that parents disengage or request a change of paediatrician in response to the communication meeting with the responsible paediatric consultant about the consensus reached and the proposed Health and Education Rehabilitation Plan.

Detailed chronology and multi-professional working

- Professionals involved should compile their own chronologies and agree who is responsible for merging these. Advice can be sought from named professionals. Compiling a full chronology should not delay the process;
- The aim is to build up a clear understanding of all the child's health presentations, and who is involved. It is helpful to talk to the child about their own concerns, anxieties and beliefs about their symptoms. Reports and records of other professionals should be sought, including the child's GP, who may have important background knowledge. It may be appropriate to approach school or nursery. It is important to build up a full picture of the child's daily functioning including school, activities, aids etc.;
- All of this should be done openly with parents where possible unless this would put the child at risk. Parents will usually be pleased that their concerns are being taken seriously and information is being gathered together to make a thorough assessment. Lack of engagement with the process, or refusal for further information to be sought, would increase concern.

Consider involving social care

- Not always necessary at this point, but appropriate if FII thought quite likely, or other social issues have been identified, or a social care perspective might help towards understanding the child's problems;
- Consider carefully whether to inform parents at this stage, and if in doubt, take advice from Named professionals. The child's welfare and safety is the overriding priority;

- Early help approaches may be applicable and helpful.

Involve and Inform the GP

- Keep GPs fully informed and so they can support children and their families as appropriate as well as work in partnership with other professionals involved to ensure the best outcomes for children.

Agree a Health and Education Rehabilitation Plan

This plan should be developed and implemented, whatever the status of children's social care involvement is. It requires a coordinated multidisciplinary approach and negotiation with parents and children and usually will involve their attendance as appropriate at the relevant meetings. The Plan is led by one agency (usually health) but will also involve education and possibly children's social care. It should also be shared with an identified GP. It must specify timescales and intended outcomes.

- Agree who in the professional network will hold responsibility for coordinating and monitoring the Plan, and who will be the responsible lead clinician (usually a secondary care paediatrician). This person's employing organisation should ensure the clinician has adequate time and resources for this task to be fulfilled;
- Consider what support the family require to help them to work alongside professionals to implement the Plan (e.g. psychological support and / or referral to children's social care for additional support);
- The Plan requires health to rationalise and coordinate further medical care and may include:
    - Reducing/stopping unnecessary medication (e.g. analgesics, continuous antibiotics);
    - Resuming oral feeding;
    - Offering a graded return to normal activity (including school attendance).
- Psychological input may be helpful;
- Social care or other agencies may also be involved.

Avoid medical testing /treatment that is not clearly indicated, restore normality

- Harm to the child can be mainly through the excessive response of (usually health) professionals, in terms of over-investigation and treatment;
- Aim to draw a line and reach the point where parents can be told "We have investigated enough";
- This may need multi-professional or multi-speciality discussion. If a further opinion is sought, they need to be aware of the context, and investigations already done;
- Where possible, aim to restore the child's daily functioning to nearer normality.

A period of admission may be helpful for closer observation

- Occasionally in cases of medical uncertainty, a period of in-patient admission is helpful to observe in detail what is happening.
- This is arranged transparently with the family, explaining that this is part of good practice in these situations and the ward team will ideally be involved in all the details of the child's care and observation;
- All staff involved should be clear about the nature of the concerns, and the purpose of the admission, including what is to be particularly observed, and how this should be documented;
- Seek advice from Named professionals.

Support for parents

- Where excessive parental anxiety is part of the presentation, this should be contained through having a lead person, avoiding mixed messages, avoiding continued investigation, appropriate and repeated reassurance (including in writing) and having clear pathways of support (what to do and who to contact if…);
- Attention should be given to the parent(s)' own support networks and mental and physical health, if these are thought to be contributing to anxiety. A referral for mental health support may be appropriate.

Communication to parents and child

- Once health consensus has been achieved and a draft Health and Education Rehabilitation Plan formulated, a meeting should be held with the parents, the responsible clinician and a colleague (never a single professional). The meeting will explain to the parents that a diagnosis may or may not have implications for the child's functioning, and that genuine symptoms may have no diagnosis. It is preferable to acknowledge the child's symptoms rather than use descriptive 'diagnoses'. It is often useful to use the term 'issues/concerns' in clinical letters rather than 'diagnoses' in these circumstances;
- The current, as of now, consensus opinion is offered to the parents with the acknowledgment that this may well differ or depart from what they have previously been told and may diverge from their views and beliefs. The draft Health and Education Rehabilitation Plan is explained to the parents, including what to explain to the child, what rehabilitation is to be offered, and how this will be delivered. Negotiation about the plan details can take place with the parents at this stage, provided that the final Plan is consistent with the consensus reached by the multi-professional meeting;
- Often the process outlined above has led to clarity amongst all professional involved where they can say to parents "We are confident there is no serious underlying medical problem, and we want to work with you to enable your child to live as normally as possible despite any symptoms". This message should be given positively with constructive planning to limit the impact of on-going symptoms on the child's well-being.

Long term monitoring of progress and when to escalate

- The response to, and progress after, the meeting is key and may further clarify whether this is FII. Careful monitoring is needed for weeks and months afterwards, with an agreement regarding when escalation to a formal safeguarding pathway (the Red Pathway) would be needed. It is important to agree who will monitor progress;
- Outcomes that would increase concerns regarding FII would include: parents wishing to 'sack' the lead clinician and refusing to work with them; attempting to move the child out of area or to a different hospital; refusal to engage with any agreed process; increasing physical symptoms (still without any medical explanation); new or more dangerous symptoms.

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