

Guidance on management of Children & Young People presenting with perplexing presentations to secondary healthcare Sept 2017

Box 1: One or more of the following present (if one present always look for others)

- A carer reporting symptoms and observed signs that are not explained by any known medical condition
- Physical examination and results of investigations do not explain the symptoms or signs reported by the carer
- The Child/Young Person (C/YP) has an inexplicably poor response to prescribed medication or other treatment, or intolerance of treatment
- Acute symptoms and signs are exclusively observed by/in the presence of one carer
- On resolution of the C/YP's presenting problems, the carer reports new symptoms or reports symptoms in different children in sequence
- The C/YP's daily life and activities are limited beyond what is expected due to any disorder from which the C/YP is known to suffer, for example partial or no school attendance and the use of seemingly unnecessary special aids
- The carer seeks multiple opinions inappropriately

Actions to take / consider

- Nominate lead consultant if C/YP under more than one speciality
- Discuss with other specialities involved at same organisation, GP and any specialists at other health organisations. Ask about diagnoses given, evidence to support these, medications recommended and what is on repeat prescription by GP or other professional
- Compile chronology of involvement within organisation. Ask other health organisations to compile chronology (include contacts with ED, other services, social care). Named Doctor / Nurse should be asked for advise if FII considered likely.
- Obtain full account of C/YP's daily life & child's/family social history including talking to the C/YP alone to ascertain his/her views, experiences and possible anxieties about their health
- Consider if a period of overt, close or constant observation of the C/YP may be indicated if the history and reports cannot be relied upon. This needs to be discussed with the multi-disciplinary team to co-ordinate admission & ensure all aware of concerns
- Consider if there is a medical investigation / opinion that could confirm the presence or absence of an organic disease. This should be undertaken promptly, but the temptation to keep investigating must be resisted. Explain to the carers that you intend to conduct investigations as follows and then stop, because further investigations are likely to cause more harm than good

Agreed medical explanation

- If new or rare syndrome ensure clearly justified, described & ensure accounts for all concerns raised in box 1

Manage and treat as appropriate

Still no agreed medical explanation for child's presentation which accounts for all previous concerns described in box 1

Medically unexplained situation

- Parents refuse admission after recommended by professional's which makes progressing conservative plan of action towards rehabilitation impossible
- Information suggest evidence of 'true' FII (deliberate deception or illness induction) and / or the child is at risk of significant harm

Lead Consultant (+ specialist colleagues if appropriate) meets with family, & C /YP, if appropriate to explain:

- Unable to give diagnosis or define problem because does not know (preferable to avoid naming disorders which are actually descriptions e.g. chronic pain syndrome)
- These symptoms are not life threatening & C / YP will not come to harm as a result
- Investigation results / opinions to date and reasoning behind them
- That further investigations / specialist referrals are not warranted and are likely to do more harm than good
- Child /YP needs to be helped to function alongside symptoms
- **Health team recommends and will support rehabilitation / coping with symptoms approach and that evidence shows this improves quality of life even though actual symptoms may take longer to improve**

Parents and C/YP accept plan & engage in a multi - agency plan (e.g. EHAF) including appropriate professionals e.g. GP, Paediatrician, physiotherapy, school nursing, school and CAMHS

- Support C / YP & family to construct a credible narrative about the C/YP's 'recovery' or improvement in symptoms
- Explore with parent & C/YP what changes in daily life if functioning optimally and better state of health
- Parents to become coaches to encourage the children to continue their activities, instead of keeping them at home
- Plan to wean and stop any current unnecessary medical treatments / aids or treatment where side effects outweigh benefits (unnecessary aids will prolong and may worsen symptoms)
- Provide general advice about importance of diet, sleep, graded exercise
- Basic symptom management e.g. headaches, abdominal pain

Parents and/or C/YP:

- Decline plan
- Request further investigations or further opinion (where >1 has already been given)
- Initially agree plan but don't engage

Advice /support available from safeguarding team

Refer to Children's Social Care under concerns regarding FII (see NSCB policy & procedures)