

Learning Briefing

James

What were the circumstances that led to this Rapid SAR?



James is a 21-year-old white British young man with a learning disability, cerebral palsy, epilepsy and a Percutaneous Endoscopic Gastronomy (PEG) tube for medication and food. James is Continuing Healthcare (CHC) funded. James is non-verbal and does not have capacity to make decisions about his care. James's mother had been his main carer all his life. James was admitted to hospital in February 2023. And was found to be significantly underweight and malnourished and extremely poorly on admission. MDT meetings (whilst James was an inpatient) raised concerns around 'Perplexing Presentations/ Fabricated or Induced Illness'. Medical concerns were raised that since James had his PEG inserted, he had undergone multiple gastroscopies and has had the PEG replaced six times, due to the PEG being damaged. The Consultant advised that PEGs should last for years. The referral for the SAR indicated that James was in replacement residential care for a period of just over 12 months, and during this time did not require any endoscopies. On returning home the issues continued. A Section 42 enquiry was commenced. Following the section 42 enquiry and a Best Interests Decision, James was moved to a permanent residential placement where he is happy and thriving.

What should you do?

- If you are concerned about the behaviour of a family carer, discuss with other professionals who are involved.
- When there are concerns regarding perplexing presentations and complications over and above what you would expect, discuss with other agencies involved. Compile and compare chronologies.
- Consider the emotional and physical well-being of a family carer who is caring alone for their adult child. Provide information and signpost to accessing support and carers assessment.
- Ensure application of the Mental Capacity Act and especially where a parent has been used to making decisions for their child. Preparation for this change is required.
- Find out about Fabricated and Induced Illness in Adults. Consider if concerns remain the same on admission to hospital/respite/alternative provision.
- Discuss concerns in team huddles, ward rounds, MDT meetings, supervision etc.

Learning identified	What will help?
<p>History Informing Assessment</p> <ul style="list-style-type: none"> • SARs both regionally and nationally find that history often provides valuable information to the nature and context that a family/person functions within. • SARs consistently find that understanding history is key to the safe and effective delivery of care especially where trauma informed practice is required whether that be in the victim or carer. 	<p>Consider in team meetings and supervision, how you gather, understand and assimilate the history of a person and their family.</p> <p>What enables history sharing with other agencies?</p>
<p>Transition</p> <ul style="list-style-type: none"> • Transition is a difficult time for young people, families and professionals. • Seamless services and transitions pathways support all involved. • Transfer of the right information from children to adults' services ensures safe and effective transitions 	<p>Consider with your team and in self-reflection the pathways for transition in your service?</p> <p>Think what enables and hinders smooth transitions.</p> <p>Access your services transition policies (where applicable), this is as important for adult services receiving young people from services for children.</p> <p>Ensure safeguarding concerns for children are known and transferred with information at transition.</p> <p>The WSAB have produced two YouTube videos which provide information and guidance on application of the Mental Capacity Act and undertaking Best Interest Decisions during transition – these can be found via the below link: WSAB Mental Capacity Podcasts.</p>
<p>Carer needs</p> <ul style="list-style-type: none"> • Professionals should be curious about the refusal of help and support from a carer who is caring alone for an adult with complex needs. • There is a balance between home being the best place for a person, how effectively care can be delivered/received and the objective picture. 	<p>Where carers refuse help and support, consider why that might be? How can you engage with carers who decline support for an adult child they are caring for?</p> <p>Is the Mental Capacity Act being used in order to act in the person's best interest? Consider Escalation.</p> <p>Is home still the best place for the adult to be cared for where their needs are complex, and they may be isolated?</p> <p>Further details on support available to carers can be found at Worcestershire Association of Carers (WAC) Link to WAC website.</p>

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	<p>The WSAB also has a dedicated page for carers which can be found here: WSAB website family and carers page</p>
<p>The Voice of James (decision making and advocacy)</p> <ul style="list-style-type: none"> • Parents and professionals need to ensure they are prepared and that they prepare families for the changes in decision making at 18 and use of the Mental Capacity Act from 16-18 years. • Suitable and appropriate advocates should be appointed for those who cannot make decisions about their own safety and where the carer/family member is a person who concerns are being raised about. 	<p>What resources do you have access to prepare families for the legislative changes post 18.</p> <p>Remember the need for a suitable advocate for a person who does not have capacity to ensure their voice is heard. This is particularly the case where there may be concerns regarding a carer a voice.</p> <p>Remember different advocates provide different services: do you know who provides which advocacy services and how to access them?</p> <p>Details of advocacy services available in Worcestershire can be found by following this Link to Onside Advocacy services</p>
<p>Safeguarding</p> <ul style="list-style-type: none"> • FII in adult safeguarding is little researched. • A recent SAR in London has found similar learning to this SAR; national guidance is recommended but has not yet been agreed by DHSC. • Adult workforces are not skilled in FII in adults • Combined multiagency chronologies are required to provide evidence of trends and patterns in perplexing presentations. 	<p>Use this case as a time for reflection on your safeguarding knowledge and experience with your team and peers.</p> <p>How can you find out more about FII in adults? Discuss in clinical/reflective supervision meetings, or team meetings. Add learning to CPD records.</p> <p>Do you have any people were FII might be a concern? What can you do?</p> <p>Ensure you collate chronologies as it is the most important way of understanding the whole picture.</p> <p>Discuss with safeguarding leads and local authority if you are worried.</p>