Norfolk Safeguarding Adult Review (SAR): Joanna, Jon and Ben
Briefing paper on Carer Themes
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Background and context

The Norfolk Safeguarding Adults Board (NSAB) carried out a Safeguarding Adults Review (SAR) in 2020/21 into the deaths of three young adults with learning disabilities and complex needs, placed in a Norfolk private hospital. Joanna, Jon and Ben had learning disabilities and had been patients at Cawston Park Hospital for 11, 24 and 17 months respectively. They all died in a 27-month period between April 2018 and July 2020.

Please refer to the SAR report for detail, information, and wider recommendations.

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Key points from the report

Joanna and Jon were placed in Norfolk by separate Clinical Commissioning Groups (CCGs) and Ben was a Norfolk resident.

Joanna and Jon had been placed in several out of family placements throughout their lives. Ben had lived with his mother & main carer for most of his life.

In all cases, it is reported their behaviour had become challenging to manage for their families and services; Joanna had been declined by 38 placements prior to moving to the hospital. Their placements at Cawston Park resulted from personal and family crises.

The review found there was a lack of information recorded for all 3 individuals in relation to the day-to-day care provided by the hospital. Significantly, there were 179 days where there were no daily records concerning Joanna. This represents one third of her time as an inpatient. For 450 days, there was no information concerning Ben (it should be noted that this represents the information made available by the hospital to the SAR – additional records were provided to the Coroner for inquest). There was a single day missing for Jon.

Parents interviewed reported the following:

- indifferent & harmful practices
- staff ignored questions and distress
- unsafe grouping of patients
- excessive restraint & seclusion
- over medication
- high tolerance of inactivity.

There were also undocumented assumptions made about their Mental Capacity, where the responsibility for decisions was transferred to patients. For example, both Joanna and Ben used Continuous Positive Airway Pressure (CPAP) machines. Over the last 209 nights of her life, Joanna was recorded as using this 29 times; Ben declined to use his CPAP on 115 occasions. There is no evidence of staff attempting to encourage or desensitise them to use the machine.

Both Joanna and Ben were obese; the CPAP needed regular adjustment to accommodate weight gain, and there were concerns about their physical inactivity, which increased health issues. When accompanied to outpatient appointments, they were not well supported by Cawston Park staff to manage their anxieties; nor did the staff have up to date health information.

Families and carers were not consistently involved in key meetings, kept up to date with changes, or asked to use their experience / expert knowledge of the person to help Cawston Park Hospital to plan and deliver care.

**Key points relating to Carers**

The report found that there was no information sought about Joanna, Jon and Ben’s lives before they went into the hospital. Research consistently highlights that carers should always be consulted and are experts regarding the person they care for and support; this did not take place for any of them.

Parents / carers were not consulted by the setting, to find out about the patients’ hobbies or interests, which could have facilitated a more person-centred approach.

Two of the parents / carers were not informed that the placements at Cawston Park had been made. In Jon’s case, little was known about his early life; it is unclear why staff did not do more to engage with Jon’s mother to find out more.

Families were clearly not acknowledged or supported as equal partners in the care of their loved ones.

There was no evidence of Joanna and Ben’s parents being consulted about them not using their CPAP machines; this missed an opportunity to see if they could have provided advice and guidance on how to encourage use of the CPAP treatment.
There was no evidence of parents / carers being consulted about useful tips, strategies, and techniques on how to support Joanna, Jon or Ben to attend appointments and manage anxiety. There was no evidence of Cawston Park staff seeking information about their medical history.

Essential contact with families, with whom Joanna, Jon and Ben had formed attachments, was not valued, or supported; potentially affecting everyone’s wellbeing and mental health.

There was no evidence that, where appropriate, a Carer’s Assessment was offered to the parents / carers of Joanna, Jon and Ben; particularly if they were providing emotional support and reassurance.

**Recommendations for practice**

Ensure you utilise a ‘whole family approach’ and recognise carers and wider families as experts in the care and support of their loved one.

Ensure family members and carers are consulted at each step and include them in the care and support planning. They can support with information and creative ways to engage and support their loved one, enabling good quality and person-centred care.

Be aware of carers and their legal rights to a Carer’s Assessment, and access to good quality advice, information and support to aid them in their role. Just because their loved ones were in a different setting, the patients’ families’ caring roles did not simply cease; they could be considered to still be providing care at a distance and it is unclear whether they were signposted to relevant support, to help them deal with the situation they and their loved one were facing. Consider this and signpost accordingly.

END.