

Feedback from carers of people with learning disabilities, ADHD and ASD* in hospital

This paper is based on 10 interviews conducted with carers by Healthwatch North Tyneside in 2017.

The issues highlighted are from carers of people with multiple different needs who had been in general hospital wards. By definition they had medical needs, but also often profound and complex physical and mental health or learning disability needs.

The issues can be categorized as follows:

- Lack of adequate pre-planning for arranged admissions or predictable medical admissions.
- Often little ward staff awareness of existing care programmes and a need to co-ordinate ward staff to work with carers on a joint hospital programme.
- Some issues with specialist feeding needs and whether enough ward staff were trained to offer this specialist help.
- Communication issues are often a problem - they may be difficult to detect. for those with ASD, and alternatively some people had almost no easily interpreted communication ability for even their basic needs.
- Some people had behavioural issues when feeling stressed which affected others when they were on open wards - or vice versa.
- Some people were very afraid of being alone, even for very short periods, so cover was needed from staff when carers took a break.
- Sometimes a moving and handling assessment was not completed on admission to determine the best way to assist someone with their bathing and toileting needs.
- Many carers reported their own needs being seen as peripheral, so sleeping arrangements, food provision and washing arrangements could be a problem - as well as the considerable costs of parking that were sometimes mentioned.
- Discharge arrangements were not always discussed as early and fully as carers needed them to be.
- Carers in employment also mentioned the cost of lost wages.

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Having considered these comments, we are making the following suggestions as a checklist for all hospitals and wards:

1. A pre-admission, or immediately on admission, discussion between carers and ward staff to include the existing and likely care programme, including the need for a single room, carer sleeping arrangements if appropriate, feeding and moving issues, communication problems. This to be recorded so that all staff have access to this information when on shift.
2. A ward keyworker who helps co-ordinate all staff to ensure the care programme is followed as closely as is possible, and who liaises with staff and carers to get feedback on any problems
3. Specialist feeding advice, equipment and support available as appropriate
4. A visible reminder for all staff of special communication needs for relevant individuals
5. The Hospital Passport system understood by all staff.

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*ADHD Attention Deficit Hyperactivity Disorder

ASD Autism spectrum disorder