

## **Patient story relayed by the hospital Learning Disability Nurse - Diagnostic Pathway for People with a Learning Disability**

### **Introduction**

Ali is a 38-year-old man with a severe Learning Disability and complex behaviour issues, Ali lives at home with his parents and extended family. He has a very close relationship with his family especially his mother.

I first met Ali and his parents over 20 years ago in my role of community Learning Disability nurse and over the years I have been involved in supporting Ali's admissions to hospital for dental treatment under general anaesthetic.

Ali has a wonderful sense of humour, he likes watching his favourite TV programmes and films. He is severely needle phobic and very anxious about any invasive health interventions. I would not describe Ali as aggressive however his fear of needles is so extreme that he is likely to push people out of the way to escape putting his safety and the safety of others at risk.

Over the years, I have also supported Ali to come to the hospital for blood tests. In recent years despite a bespoke service that included experienced phlebotomists, arranging the blood test at a time that is quiet, with no members of the public present and allocation of a double slot, each attempt for a blood test was unsuccessful.

Ali's parents repeatedly expressed concerns to professionals and their GP that Ali's health and wellbeing was declining, convinced that the decline in behaviour and physical wellbeing was due to an undiagnosed health condition. They felt that if Ali could access blood tests and diagnostic tests we would have a clearer picture about cause and treatment – things that Ali wasn't able to tolerate.

With the involvement of Ali's community Learning Disability Nurse working closely with his GP and following the Mental Capacity Framework it was agreed that Ali would be referred a new hospital pathway that was launched in June 2021

### **Diagnostic Pathway for People with a Learning Disability**

The Pathway is central to supporting individuals with a Learning Disability in receiving equitable care and maximising the potential for positive health outcomes.

Some people with a learning disability, associated complex needs or challenging behaviour have severe anxiety about needles or health interventions. They struggle to access routine diagnostic tests such as blood tests, ECGs or X-rays.

Being unable to access diagnostic tests in a timely manner or in some cases not at all, can delay treatment and is detrimental to the individuals' health, wellbeing and a source of great distress for carers.

Using the pathway, if diagnostics cannot be undertaken at a GP practice or Health Centre then Community Learning Disability Nurse and GP are able to assess the need for diagnostic tests to be completed in hospital under sedation or general anaesthesia. The ability to refer patients on this pathway allows healthcare to progress, and it's a key step forward in supporting individuals to receive equitable care and maximise the potential for positive health outcomes.

Ali's referral to the diagnostic pathway was accepted and we were moving on to the next step, which was organising the Best Interest meeting, inviting all the relevant professionals and Ali's parents making sure all decisions are in the best interest of Ali.

Unfortunately, prior to this taking place Ali was involved in a serious accident which resulted in hospital admission and the need for treatment under a general anaesthetic. Therefore, instead of a planned admission we utilized the emergency admission to complete diagnostic tests, as described below.

After suffering an outside fall in July, his family became concerned about his injuries and his brother accompanied him to the ED (Emergency Department). Ali refused to enter the ED and he was taken home before any examination could take place.

The following morning it was clear to Ali's family that he had injured both of his arms and his knee and his GP advised a return to the ED department.

The hospital Learning Disability Nurse liaised directly with an Advanced Practitioner in ED, explaining that Ali could not tolerate waiting in the crowded ED Department.

Nick, the AP, implemented the following reasonable adjustments:

1/ Met Ali outside, offered Ali and his parents reassurance, developed a rapport with Ali, he was able to direct Ali and his parents directly to a side room (on that day the ED was extremely busy with 400 people attending throughout the day)

2/ Ali was given immediate priority and Nick remained his primary clinician. Ali responded well to Nick's calm and patient manner.

3/ The hospital Learning Disability nurses were present to support Ali, his parents and the ED staff. Our goal was to minimise distress to Ali, encourage him not to leave the hospital and offer support and advice to all the hospital staff caring for Ali.

The outcome of the x-rays was that Ali had fractures of both elbows and he would require surgery.

4/ The LD nurse liaised with the flow team and explained the need for a side room and how imperative it was for his parents to stay, to enable him to stay. Ali's mother was key to his compliance of treatment.

From the moment I was made aware that Ali required surgery under general anaesthesia, I highlighted the need to carry out all agreed diagnostic tests under the one anaesthetic as opposed to Ali requiring a further admission to undergo another general anaesthetic.

Also taking into consideration the trauma to Ali regarding health interventions, it was absolutely in Ali's best interests.

The diagnostic tests identified as follows:

1. CT brain scan
2. Blood tests
3. E.C.G
4. Dental examination and treatment

Co-ordinating all the above was a massive undertaking and only made possible in my opinion because of the intervention by the Consultant Anaesthetist.

There is consistent evidence that people with learning disabilities in England die much earlier than the rest of the population and a large proportion of these deaths are preventable. Increasing evidence suggests that the inequalities in health care experienced by people with learning disabilities could be considerably alleviated by making reasonable adjustments.

### **Update on Ali's progress**

I recently met Ali when he attended his orthopaedic outpatients' appointment with the orthopaedic consultant who carried out the surgery on his arms, and I am delighted to report Ali is continuing to make progress.

During the appointment, his parents reported how thrilled Ali was the first time he was able to raise both arms to wash his hair in the shower.

Ali is also due to start hydrotherapy to aid his recovery facilitated by specialist staff in the community learning disability team.