‘Know how better to care for people with learning disabilities’

People who have learning disabilities are an extremely vulnerable patient group, in particular when admitted to hospital. This is for many reasons: they are more likely to be underweight, lack independent mobility, have limited or no verbal communication capacity and are more likely to have one or more long-term conditions. In addition, GPs frequently fail to highlight a diagnosed learning disability when they refer a patient, hospital ‘flagging’ systems can be ineffective, and hospital staff don’t always understand the diagnosis and consequent needs. Patients who have learning disabilities manage better in those hospitals that have learning disability liaison nurses; however, more than 40% of NHS trusts do not provide this service.

Despite staff’s best efforts, a hospital visit is rarely a pleasant experience. We associate hospitals with pain, fear, illness and death. If we put aside, for a minute, a patient’s ill health, forget any expectation of investigations, treatment or bad news, a hospital visit should not, in itself, be too bad. But there are immediate expectations we have of our patients that make a difference.

Patients are generally expected to be able to read. Few hospitals have readily available pictorial information, and you cannot even order your food in most hospitals without having to read a menu. Patients are expected to be able to understand concepts such as ‘waiting’ and ‘getting better’. They need to be able to communicate symptoms, fears and frustrations, and to show empathy for others. If these are just the basic aspects of being in hospital, then you can see how a visit will undoubtedly be more difficult for someone who has a learning disability or autism.

Sadly, this has been documented time and time again in reports and papers such as Mencap’s Death by Indifference report of 2007 and the Confidential Inquiry into Premature Deaths of People with Learning Disabilities in 2013. If you currently, have ever or will ever work in a general hospital, I urge you to read these. They outline patient and family experiences, and quote facts and figures, which I’m sure will shock and disturb you, but that accurately reflect the experiences in hospital of many people who have learning disabilities.

All too often, premature deaths in patients who have learning disabilities are caused by delays in diagnosis or treatment, and difficulties providing appropriate care in response to identified needs. These issues often stem from a poor understanding of the law. For example, the Mental Capacity Act 2005 guides us in effectively obtaining consent and working with those who are unable to give it, and the Equality Act 2010 tells us we must make protocols flexible and our services adaptable for them to be accessible.

I know we are all busy. Far, far too busy. And I know we are all trying to do our best. But next time there is a patient who has been nil by mouth for days, let’s not mistake their silence for comfort. Perhaps they cannot talk. Next time there is a patient who is ‘challenging’, let’s not assume it’s because of a disability. Perhaps they are frightened or in pain. And next time we have a patient who is ‘non-compliant’, let’s not hastily discharge them. Perhaps they have not understood. What can you do to help overcome these inequalities?

Jane Iorizzo is a learning disability nurse