Why are people on the spectrum dying young?

Dr Carole Buckley, RCGP Clinical Champion

A recent paper from Scandinavia\(^1\) showed premature mortality was markedly increased in ASD owing to a multitude of medical conditions. The reasons for this are unclear. It is going to require significant investment in research and is likely to be multifactorial with both genetics and the environment implicated but it is well known that autistic individuals struggle to access healthcare services.

As GPs we can have a positive impact on the lives of these vulnerable patients by considering autism as a diagnosis irrespective of age. We can recognise that consultation skills may need to be modified when communicating with someone on the autism spectrum. We can acknowledge that the GP surgery is a confusing, noisy and sometimes frustrating place to visit.

We can act as advocates for our patients to access other health services, ensuring that the diagnosis is clearly marked and that we highlight the reasonable adjustments that secondary care services need to make to allow these patients access. We must also avoid diagnostic over shadowing, do not “blame” the autism for all symptoms and recognise the numerous co-morbid conditions that may occur. GPs have an important role in monitoring the physical health of those patients with an intellectual disability and autism by offering an annual health check. As many as 35% of those with ASD have epilepsy and this is the leading cause of premature death for those with intellectual disability. There is clear evidence that poor epileptic control is associated with excess morbidity and mortality. We must encourage compliance with medication and refer early for specialist support if control of seizures is poor.

There is also a need to monitor medication as the widespread use of anti-psychotic treatment to manage behaviour that challenges services is often devolved to general practice for repeat prescribing and NICE guidelines are clear that the specialist should communicate a clear plan for the treatment. The plan should include what behaviours are being targeted, how long the anti-psychotic is going to be used for and how it is going to be stopped. Chronic use of the medication is often due to the failure of appropriate positive behavioural support services and sometimes a failure to recognise physical health problems – particularly undiagnosed pain.

Finally a recent survey among 306 GPs (results to be formally published in Sept) showed a clear understanding about autism but a lack of confidence in our ability to support these patients and a woeful lack of specialist support services. Many commissioning areas do not have readily available diagnostic pathways, and no post-diagnostic support. The RCGP is working hard with all appropriate bodies to get better services for us to refer to for help with autism.

Carole Buckley is the RCGP Clinical Champion for ASD, and is running a series of workshops throughout April and May. Further details can be accessed here. A Facebook group for doctors with ASD is also managed by our Clinical Fellow, Dr Silvana Unigwe.