



# Supporting the carers of patients with autism

**Dr Silvana Unigwe, RCGP Clinical Fellow**

## **Supporting Carers of patients with Autism at GP visits**

If the needs of patients with autism are sometimes overlooked, the same fate is often even more likely for their parents and carers.

Sue Kirkman has a son with autism and sometimes has found visits to the GP surgery challenging. We asked for Sue's opinions on what can be changed to make the experience of carers more a positive one.

-----  
The first point Sue made was that carers can be treated as if they themselves have autism and/or learning disabilities. She describes a tendency of some health professionals to speak in unnecessarily slow or loud voices, which can inadvertently cause offence and damage rapport.

Another potential barrier is the supposition that symptoms in a carer are invariably stress related. Sue commented, "GPs [can]... assume that whatever symptoms you take to their surgery you are suffering from stress. I once asked a GP that if my leg had fallen off would he attribute that to stress?!" The concern here is that treatable physical illness may be missed.

Apart from being mindful about making assumptions, Sue says there are other things we as GPs can do to help. Consider:

- Offering carers a double appointment so they have enough time to air their concerns about their son/daughter as well as talk about their own health. Actively encourage them to talk about their symptoms, which they can be prone to neglecting.
- Flagging the records of carers so they can be easily identified. Making contact with a carer at regular intervals to check all is well would be greatly welcomed.
- Making available a quiet space/room onsite for the carer's child with autism. They may have to accompany their parents to the surgery and long stays in busy waiting rooms can cause undue agitation.

Sue's final plea is that we acknowledge the expertise of carers : "We probably understand the condition better than the typical GP does, and we are certainly more expert on its manifestations in our child."

## **Waiting for a Diagnosis**

As a GP you may also engage with patients who haven't been formally diagnosed but are awaiting assessment. This can be a trying time, not only for them but also their carers.

NICE guidance advises that the autism diagnostic assessment should start within 3 months of referral to the autism team.

In reality, many wait years from the time of initial contact with a healthcare professional to proper diagnosis. This is due to a number of factors including unclear referral pathways and the limited availability of diagnostic services in some areas of the UK.

Ultimately, it is the onus of the CCGs to fund appropriate services. However, GPs can help by:

- Familiarising themselves with existing local referral pathways. This can help prevent delays caused by sending referrals to the wrong places.
- Being as detailed as possible in their referral letters, so they convey the impact of the symptoms on the patient and their carers.
- Signposting patients and carers to organisations that can offer advice and support while they are waiting, such as the National Autistic Society (NAS). There will also be a wealth of information on the RCGP Autism Toolkit, due to be launched online this May.