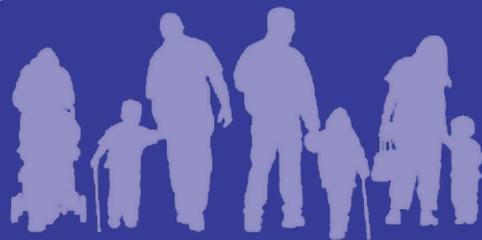


LIVING WITHOUT A DIAGNOSIS

This fact sheet has been written by parent carers for parent carers.
Clinical information has been approved by West Sussex practitioners.



When a child has difficulties but doctors are not able to give parent carers a firm diagnosis it can be very distressing and frustrating. Often, families say they feel alone; it is hard to access support and the future remains uncertain as they don't know how their child's condition will develop. The organisation 'Genetic Alliance UK' estimates that as many as half of children with learning disabilities do not have a definitive diagnosis.

For many parent carers, not having a firm diagnosis can feel very upsetting. One of the biggest concerns is that without one they will be unable to access support, but this is not the case – the support a child is entitled to is based on their needs rather than whether they have a diagnosis or not.

First signs

For many parents, the first signs that their child may have difficulties can be if you notice they seem different to their peers. It could be that they fail to meet developmental milestones at an appropriate age in one of the following areas:

- **Motor skills** – gross motor skills, such as sitting up, crawling and walking and fine motor skills, such as picking up objects.
- **Speech and language** – babbling, for example, and imitating sounds, as well as understanding what people are communicating.
- **Cognitive skills** – the ability to learn new things, to remember them, to process information and organise thoughts, for example.
- **Social and emotional skills** – interacting with others, controlling emotions, and understanding the needs and feelings of others.

When there are no answers

If your child is having difficulties, you will want to find out why. But it's not always this straightforward. Sometimes clinicians are unable to give you a reason and name for your child's condition. This can be very frustrating, as well as frightening. However, there are a number of reasons why this happens. Every child's features and symptoms will be different. Sometimes they may fit more than one condition.

Other children may be 'borderline' for conditions such as ADHD or Autism – they may have traits of the condition but not meet the criteria for a diagnosis or sometimes it is too early to make a diagnosis. For other children, their condition and set of symptoms may be so rare that clinicians are unable to put a name to it. Even with genetic testing, it is not always possible to get answers or a diagnosis (see our separate fact sheet, *Rare Syndromes*).

What happens next?

Not having a diagnosis can be upsetting and frustrating. You may feel that your child's difficulties are somehow your fault because you can't put them down to a recognised condition. Or you may feel that you aren't entitled to ask for support, but this is not the case. Your child should be able to access the same services as children with similar needs who have a diagnosis. It is also worth remembering that many strategies and techniques (such as those for communication) work for many different conditions, so these can be adapted to help your child, too.





LIVING WITHOUT A DIAGNOSIS

Types of therapy

Depending on your child's needs, you could get support from the following services:

- **Education** – your child is entitled to extra support and/or adaptations to help them at nursery, pre-school, school or college.
- **Occupational Therapy (OT)** – can help your child develop their hand skills and can identify solutions to help your child develop their independence with every day tasks such as dressing, eating and drinking.
- **Physiotherapy** – an important intervention to help a child develop and maximise their range of movement and posture.
- **Speech and Language Therapy (SALT)** – specialist support provided by a therapist to help build language and communications skills.

Ask About

- **Disability Living Allowance (DLA)** – your child may qualify for DLA, a state benefit that will help with their care. For further information visit: www.gov.uk/disability-living-allowance-children.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Crawley and East Grinstead: **01293 572480**, Chichester and Horsham: **01243 536182**, Mid Sussex: **01444 243150**, Worthing: **01903 242558**.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. We also offer benefits advice, peer support, a Facebook group & handbook (*see below*) for parent carers of children & young people with SEND in West Sussex: See: www.reachingfamilies.org.uk.
- **Sensory Toys** – sensory toys are available for loan through local family hubs and libraries. Go to: www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries.
- **Single Point of Access (SPoA) West Sussex** – a dedicated route to access specialist emotional wellbeing and mental health support for those aged 4-17. Anyone can refer to SPoA including children & parent carers. Referrals will be directed to the most appropriate help from Youth Emotional Support, YMCA Dialogue or Sussex Child and Adolescent Mental Health Services (CAMHS). Alternatively, signposting to other sources of support may be given. To make a referral, use the online form at: <https://e-wellbeing.co.uk/support> or Tel: **0300 304 0462**.
- **West Sussex Children's Services** – support from health and social care. If your child is under 18, contact the Integrated Front Door (IFD) for West Sussex Children's Services. Tel: **01403 229900** or email: WSChildrenservices@westsussex.gov.uk. The IFD is also an entry point for the Children with Disabilities (social care) service for children & young people with severe and/or complex disabilities. Eligibility criteria apply – See: <https://westsussex.local-offer.org/services/265>. For over 18s call the Adults' CarePoint: **01243 642121**, or email: socialcare@westsussex.gov.uk.

Further reading and useful links

- **Making Sense of it All: From Birth to Adulthood** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: www.reachingfamilies.org.uk/guides.html.
- **Contact** – for further information search for 'living without a diagnosis' on their website: <https://contact.org.uk> or call their helpline on **0808 808 3555**.
- **Syndromes Without a Name (SWAN UK)** – go to: www.undiagnosed.org.uk.
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org> for local services, support and details of Short Breaks providers for children & young people aged 0 - 25 years with SEND.

