

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.





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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.
- **Social Services** – contact the MASH (see below) to ask for an assessment of your child's needs and a Carer's Needs Assessment for you.
- **Speech and Language Therapy (SALT)** – specialist support provided by a therapist to help build language and communications skills.

Ask About

- **Child Disability Service** – a social work service for children and young people with severe and/or complex disabilities, it works with families and other agencies to ensure they get the right support. Information can be found via the local offer website: <https://westsussex.local-offer.org/services/265-child-disability-teams-lifelong-services-social-care> or families should call the Integrated Front Door (IFD) for West Sussex Children Services on **01403 229900** or complete the online referral: www.westsussex.gov.uk/Raiseaconcernaboutachild.
- **Compass Card West Sussex** – a free leisure discount card for 0 to 25 year olds with SEND, which is run by Amaze. Find out more at: www.compasscard.org.uk or by calling: **0300 123 9186**.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Chichester: **01243 536182**; Crawley and East Grinstead: **01293 572480**; Horsham: **01243 536182**; Mid-Sussex: **01444 243150**; Worthing: **01903 242558**.
- **Sensory Toys** – available to borrow from a number of children and family centres. See: www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries.
- **Short Breaks for Disabled Children** – commissions holiday clubs, after school clubs, buddy schemes and short breaks at home or in the community. Tel: **0330 222 2562** or email: SENDCommissioningTeam@westsussex.gov.uk.
- **West Sussex Children Services** – support from health and social care. If your child is under 18, call the Integrated Front Door (IFD) for West Sussex Children Services, tel: **01403 229888** or email: WSChildrenservices@westsussex.gov.uk. For over 18s call the Adults' CarePoint: **01243 642121**, or email: socialcare@westsussex.gov.uk.
- **Other resources** – the Ashdown club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Springboard Project, Horsham: **01403 218888**.

Further reading and useful links

- **Making Sense of it All** – our handy parent/carer guide contains information and advice on benefits, support for your child at school, getting help from social services and accessing social & leisure activities – www.reachingfamilies.org.uk.
- **Contact** – for further information search for 'living without a diagnosis' on their website: <https://contact.org.uk>.
- **Disability Living Allowance (DLA)** – your child may qualify for DLA, a state benefit that will help with their care. You don't need a specific diagnosis to claim – you just need to prove that your child's care or mobility needs are significantly greater than the needs of their peers. For further information visit www.gov.uk/dla-disability-living-allowance-benefit/overview.
- **Syndromes Without a Name (SWAN UK)** – go to: www.undiagnosed.org.uk.
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org>.

