Frequently asked questions

GENERAL DEFINITIONS

What is Developmental Coordination Disorder (DCD)?

Developmental Coordination Disorder (DCD) is a common neurodevelopmental condition, thought to affect between 2-6% of people. It is diagnosed when a person has severe difficulties in learning and executing everyday motor skills, which cannot be explained by physical, sensory or intellectual impairments. These motor difficulties can affect a range of activities such as dressing, using utensils and playing sports. These may also influence academic and vocational performance. The full criteria to receive a diagnosis of DCD are listed in a manual called DSM-5.

What is DSM-5?

DSM refers to the Diagnostic and Statistical Manual of Mental Disorders, which is a classification system published by the American Psychiatric Association. It is used internationally, by researchers and clinicians. It is based on the latest research evidence and describes a wide range of psychological and developmental conditions seen in childhood and adulthood, including Developmental Coordination Disorder (DCD). Importantly, it lists the central characteristics of each disorder, to help clinical professionals make accurate and consistent diagnoses. The latest version is the fifth edition, referred to as DSM-5 (published in May 2013).

What is dyspraxia?

The term 'dyspraxia' is used in many ways, by different people. Some people use the term dyspraxia interchangeably with DCD. Other people use the term dyspraxia to refer to something quite different. Unlike DCD, there is no internationally agreed definition or description of the term dyspraxia, and it is not included in DSM-5. In the UK, dyspraxia is used in a very broad way to refer to children who have motor difficulties as well as difficulties with speech, organization, planning, sequencing, and working memory, as well as various other psychological, emotional and social problems. There is, however, little evidence to support such a broad definition.

What is the difference between Developmental Coordination Disorder (DCD) and Dyspraxia?

Developmental Coordination Disorder (DCD) refers to a condition in which a person has severe difficulties in learning and executing everyday motor skills, which cannot be explained by physical, sensory or intellectual impairments. The main features of the condition are clearly described in DSM-5. The term 'dyspraxia' is used in many ways, by different people. Some people use the term dyspraxia interchangeably with DCD. Other people use the term dyspraxia to refer to something quite different. Unlike DCD, there is no internationally agreed definition or description of the term dyspraxia, and it is not included in DSM-5.

Is verbal dyspraxia the same as DCD?

No. Verbal dyspraxia falls under DSM-5's Communication Disorders category, as opposed to DSM-5's Motor Disorders category. A diagnosis of verbal dyspraxia is given when a child has difficulty making the precise movements needed to produce individual speech sounds and has problems putting these sounds together in the right order (to form words). Some children with communication disorders also have a diagnosis of DCD. In these cases, the two conditions are separate but co-occurring.

What is 'dysgraphia'?

The term 'dysgraphia' means different things in different countries. In Holland, for example, it is used to refer to those who perform poorly on a standardised test of handwriting (such as the BHK scale). In the USA, as in most of the developed world, the term is used synonymously with a 'handwriting difficulty' and there are subgroups of dysgraphia ('dyslexic', 'motor' and 'visuo-spatial'), depending on the main features. Although commonly used by researchers and practitioners, there is no internationally agreed definition or description of the term 'dysgraphia', and it is not included in DSM-5.

Some individuals have significant difficulties with handwriting. These might be associated with other problems (e.g., a sensory or physical impairment; a language, spelling or motor difficulty), or they might be isolated difficulties in those who are otherwise typically developing. In this context, we recommend that (rather than use the vague term 'dysgraphia') the nature of the handwriting difficulties should be described (e.g., whether the writing is slow and/or difficult to read). This should be in addition to any accompanying problems that might have an impact on this (e.g., reading/spelling difficulties or an intellectual impairment).

DIAGNOSIS OF DEVELOPMENTAL COORDINATION DISORDER (DCD)

Who can diagnose DCD?

A diagnosis of DCD is usually undertaken by a range of different professionals as part of a 'multidisciplinary team'. This team may include occupational therapists, paediatricians or psychologists, for example. A diagnosis of DCD is undertaken after gathering information from the child, their parents and their school, to see how the difficulties impact on their everyday life (to make a diagnosis in adulthood, information must be gathered from the person themselves, as well as others who know them well). To access an assessment for DCD, it is usually necessary to ask a GP for a referral to a diagnostic team. The team would consider the information about the person's coordination and conduct some assessments. They would also aim to rule our other reasons for these motor difficulties (e.g., cerebral palsy, muscular dystrophy).

Why are GPs not diagnosing DCD?

A diagnosis of DCD is usually undertaken by a team of multi-disciplinary professionals (e.g., a paediatrician, occupational therapist), after gathering information from the child, their parents and their school, to see how the difficulties impact on the person's everyday life (for a diagnosis in adulthood, information is gathered from the person themselves, as well as others who know them well). GPs have an important role to play in this process. GPs may undertake an initial examination of the child/adult and find out about their past development and current functioning. They may then refer the child/adult for a broader assessment. Some GPs have more experience of DCD than others.

At what age should a diagnosis of DCD be given?

It is not recommended that a formal diagnosis of DCD is given before 5 years of age. This is because there is a lot of variation in children's development before this age, as well as variations in the opportunities that children have to experience different motor skills. However, this does not mean that a child who appears to be delayed in motor skills before the age of 5 should not be closely monitored or should not receive some form of needs led support. The child can be informally noted as having movement difficulties and appropriate actions can be taken.

If you have a diagnosis of DCD in childhood, does it still apply later on?

Most children with motor coordination difficulties do not grow out of them, so it is likely that they will still experience problems in this area as they get older.. In some cases, motor difficulties do resolve, and a diagnosis would no longer apply. A childhood diagnosis only holds in adulthood if the diagnostic criteria are still met. To confirm this, a formal diagnosis in adulthood would involve a recent assessment of motor skill, to establish that all the DSM-5 criteria for DCD are met.

CHARACTERISTICS OF DEVELOPMENTAL COORDINATION DISORDER (DCD)

Are planning difficulties part of DCD?

The main characteristics of DCD is difficulty in the control and coordination of movement, which impacts negatively on everyday life skills. Many everyday tasks involve both the execution of actions (e.g., reaching for a cup) and planning sequences of actions (e.g., reaching for a cup, placing it under a tap, turning on the tap, holding the cup under the flow of water etc.). Indeed, many tasks involve quite complex movement sequences. Dressing is a common example. Putting on a jumper involves: ensuring the jumper is the right way around; finding the arm holes and pushing each arm through; finding the head hole and pushing the head through; pulling the jumper down to the waist, etc. To manage this task, we need to be able to execute each part accurately, but also plan and organise the sequence of movements. It is hard to separate the 'execution' and 'planning' element of such tasks but some children with DCD do seem to find it particularly difficult to cope with activities involving a string of movement sequences.

Other activities involve a different type of planning; to meet particular external demands. For example, when packing a lunch box or a suitcase, it is necessary to plan where to place items, to fit everything in a constrained space. Such tasks also require spatial and perceptual skills (to judge the size of objects) and this is an area of difficulty for some individuals with DCD.

Are organisational difficulties part of DCD?

The main feature of DCD is difficulty in the control and coordination of movement, which impacts negatively on everyday life skills. At a different level, it is sometimes reported that individuals with DCD have difficulties with daily organisation (e.g., planning ahead, time management, managing money). These more general organisational problems are difficult to assess formally but may have a significant impact on the person's ability to cope with everyday life. Although organisational difficulties may commonly co-occur with motor difficulties, they do not form a core part of the condition and are not considered when assessing a person for a formal diagnosis of DCD.

Are problems with executive functions seen in those with DCD?

Executive function (EF) is a broad term that encompasses a range of important skills such as: planning; inhibition; mental flexibility; and initiating/monitoring actions. Parents, teachers and individuals with DCD sometimes report difficulties with EF (e.g., poor planning, difficulties with remembering instructions, problems sequencing information). Researchers are considering whether EF difficulties are common in those with DCD, whether they might be a core part of the condition, or whether they may co-occur in some individuals. Different research studies have focused on different aspects of EF, with findings suggesting that there are large individual differences. This means that some people with DCD have difficulties with aspects of EF, while other do not.

Are sensory processing difficulties part of DCD?

The main feature of DCD is difficulty in the control and coordination of movement, which impacts negatively on everyday life skills. Skilled motor control involves processing and integrating information from our sensory systems (e.g., eyes, ears, skin, muscles, joints). This information is then used to form an appropriate action plan to control messages from the brain to the muscles, to initiate and coordinate movement. Many different parts of the brain are involved in processing and integrating the sensory inputs and motor outputs to make efficient movements. A range of specific assessment tools have been developed to evaluate a person's ability to process and integrate the range of sensory information available to the body. It is commonly reported that children with DCD have difficulties on such tests, and therapeutic interventions are often planned around improving skill in this area. Research evidence supports the notion that sensory and perceptual processing/integration is poor in many (but not all) children with DCD; however, the nature of the links to their motor difficulties are unclear. There is also little evidence to support the use of interventions that specifically target these difficulties. In fact, evidence suggests that interventions focusing on the learning of specific motor tasks (rather than the presumed underlying processes) are considerably more effective.

Is DCD associated with epilepsy?

Many children with DCD will have other developmental or medical conditions in addition to their DCD. As such, they may be at greater risk of epilepsy because of this association. Some work has looked at the associations between DCD and Benign Epilepsy with Centrotemporal Spikes (BECTS), also known as nocturnal or Rolandic epilepsy. Motor difficulties have been seen to be present with this form of childhood epilepsy, although more research is needed. There is no suggestion that most children with a diagnosis of DCD will have epilepsy.

I have or my child has DCD and is anxious, what can I do?

It is sometimes report that people with DCD become anxious. Anxiety has been recognised as an associated feature of DCD (from a young age through to adulthood). For some people, an early loss of confidence can lead to the avoidance of certain tasks, which can make gaining skills harder to achieve. Merely thinking about the activity may cause the child or adult to feel anxious. Anxiety may also be seen when doing activities that a child or adult is less familiar with, or when going into new situations (e.g., when going to play with other children).

Try to find out if there are specific triggers causing concern (e.g., difficulties in school or at work) that can be tackled (e.g., by practicing sufficiently to gain confidence; by adapting or – if necessary – avoiding tasks). Discuss ways to deal with feelings that may arise in childhood and adulthood. These could include talking to others, rehearsing skills that are difficult or worrying, or practicing relaxation techniques (e.g., using Mindfulness approaches).

I've heard that there might be a connection between the retention of primitive reflexes and DCD. Is there any evidence for this and can it be addressed by intervention?

Young infants have a range of reflex actions (these are involuntary movements made in response to a specific stimulus). Some reflex actions remain through our lives (e.g., the patellar or 'knee-jerk' reflex). Others, sometimes referred to as 'primitive reflexes', disappear over the first few months of life as the brain matures. One example is the 'palmar reflex' - a grasping movement made in response to touching the palm of the hand.

There are some complex issues surrounding primitive reflexes: when they appear, the timing of disappearance; non-appearance; strength; and the retention of some when they should have gone. There is evidence that for some infants, including those born prematurely, primitive reflexes may take longer to disappear. People have claimed that some primitive reflexes can be retained into later childhood and beyond, and that these can hinder the development of movement skills. Within this view, several approaches to intervention have been tried to reduce these reflex patterns through various techniques (e.g., doing exercises with your child, brushing the skin). Another viewpoint is that primitive reflexes are thought to be essential for typical development and if they have been absent in infancy then they need to be re-established, with work on 'patterning' (repeating set movements) being a prime example. Although there are individual reports of this type of intervention being effective, there is little (if any) scientific evidence to support any of these varying approaches.

Many different interventions have been used in the field of DCD and neurodevelopmental disorders more generally. It is usually found that most interventions will be helpful and this may be for a variety of reasons. However, the interventions that receive most support from scientific studies are those that work on everyday functional tasks with the person, teaching them in a manner that will allow them to be used in different ways across a range of settings.

TREATMENTS AND INTERVENTIONS

How will I know if an intervention is working?

Why an intervention is successful might relate directly to the nature of the intervention, but equally it could simply be the result of one to one time with a skilled teacher or therapist. To fully understand why an intervention might have positive results it is necessary to carry out carefully controlled studies to test the intervention against other approaches and against no intervention. Until these studies are undertaken, it is not possible to be certain about whether these approaches are effective, nor is it possible for approaches to be recommended.

When should early intervention start?

The first step is for someone to recognise that the child is not progressing in their motor skill development as one would expect. This can be the parent, a nursery nurse (or equivalent), a pre-school teacher, friends, or family. At this stage, it would be advisable to obtain some form of professional help, probably through health or education services. This may involve some form of assessment to help plan intervention that can be given by parents and others in the context of daily living. A diagnosis should not be given at this stage, but the child can be helped by providing appropriate activities that are geared to their needs. Some children improve quickly with this intervention, while others will need support throughout their childhood.

What can parents do to help in the early years?

Once the child has been recognised as having motor difficulties, their parents are in a unique position to support their needs. First, parents can provide their child with exposure to and experiences of activities that one would expect during daily living, and not as separate 'intervention' schedules. It is much better to participate in short activities on a regular basis, rather than having long, but infrequent, formal sessions. Help and guidance for parents can be obtained from health and education services. However, it may be that the child requires more than simply experience. In such cases, direct teaching of an essential activity is needed. For this, parents may require additional assistance in the form of more specific guidance from a professional (see our factsheet for parents).

Do all children with DCD need to have Occupational Therapy?

In the UK, it is common for children with DCD to see an Occupational Therapist (OT). The referral may be directly from the child's parent, from their school, or from a healthcare professional (e.g., a GP or Paediatrician). To begin, an OT will usually undertake an assessment to ascertain the nature and extent of a child's motor difficulties and their impact on the everyday activities they need and want to be able to do. The assessment commonly includes standardised tests of motor function, perceptual skills and everyday function (including self-care tasks and handwriting), but may also include a range of other measures. Sometimes the OT will work as part of a team of different professionals (referred to as a 'multi-disciplinary team') to obtain a broader assessment. This assessment process can provide useful information to plan to support a child with DCD. The OT may have helpful advice for parents, teachers and the child him/herself.

In addition to support at home and school, some children with DCD benefit from Occupational Therapy. This may take place individually or in a group and may take many forms, depending on the training of each OT. A range of different types of intervention are used in Occupational Therapy.

Can exercise programmes help to improve skills?

Many different exercise programmes are available, with claims that they improve motor coordination and other skills (e.g., attention and memory). Some go further, suggesting that the programmes can change the connections and/or structures of the brain. Many of these claims are unsupported by research evidence. However, there is evidence to suggest that physical exercise can be beneficial for physical/mental health and general well-being, if it is of sufficient frequency, duration and intensity.

If considering whether to engage in an exercise programme, you might consider the following: (1) If the programme involves very vigorous or sustained exercise you might check with your GP as to whether this is appropriate for you; (2) Consider what your personal priorities are and how these fit with the aims of the programme (are they designed to teach the skills that you want to learn?); and (3) How much time do you have available and what motivates you? This will help choose a programme that suits you and that you are most likely to engage with.

Many people do report that exercise programmes are beneficial. The mechanisms underlying these benefits are likely to be complex and could relate to the physiological effects of exercise, social participation, or skill practice. If you do start an exercise intervention, try to monitor and review any progress to check how effective it has been in relation to your individual goals.

Alternative therapies have been suggested to me. What should I consider?

The terms "alternative" or "complementary" are used to refer to non-traditional methods of diagnosing, preventing, or treating conditions. Many parents consider using alternative therapy either as an additional therapy alongside the mainstream treatments or because they are having difficulty accessing the local therapy services.

There are many different types of alternative therapies that have been developed and are practiced for the treatment of DCD. If you are considering a particular therapy, then gather as much information as possible: request details of the professional/recognised body of the therapist, and check their credentials.

DEVELOPMENTAL COORDINATION DISORDER (DCD) IN ADULTHOOD

If you have a diagnosis of DCD in childhood, does it still apply later on?

Most children with motor coordination difficulties do not grow out of them, so it is likely that they will still experience problems in this area as they get older. A formal diagnosis needs a recent assessment of motor skill to establish that all the DSM-5 criteria for DCD are met.

I am an adult and I think I have DCD, who can help me?

Many adults may have undiagnosed DCD, although there are few options for accessing a formal diagnosis of DCD in adults. Help and support for adults varies greatly from area to area, and according to what your specific concerns are at this time. For example, concerns may relate to home life, studies or work. Alternatively, you may just want to know whether you have DCD or not. If you have new concerns and seem to have deteriorating motor/co-ordination skills, then you should see your GP in the first instance (since other causes of this deterioration need to be ruled out before DCD can be considered, you may need to see a neurologist for this sort of assessment). In some areas, an Occupational Therapist may undertake the assessment and can give you practical guidance on your day-to-day functioning. In other cases, a workplace assessor can give you guidance for the workplace. However, they may not be able to diagnose DCD.

What is the Equality Act 2010 and how does it relate to me if I have DCD?

The UK's Equality Act 2010 consolidated previous discrimination and harassment law; to ensure uniformity in what employers and employees need to do to make the workplace a fair environment, and to obey the law. Through this Act, it is unlawful for employers to discriminate against disabled people in their selection and recruitment practices unless there is justification for such action. In this context, disability is defined as having a physical or mental impairment that has a "substantial" or "long term" negative effect on your ability to do normal daily activities. All workplace processes are covered through the Equality Act (from recruitment, through working arrangements to promotion, training and grievance procedures). DCD comes under the Act: if you have DCD, reasonable adjustments may need to be made by an employer for you to do your job. This does not mean that adjustments can be made; rather, the employer must consider whether it is possible and reasonable for adjustments to be made. It also means that you do still need to be appropriately qualified for a specific job.

Can I get reasonable adjustments for the workplace with DCD?

In the UK, there is a scheme called <u>Access to Work</u>, which will help fund the costs of workplace adjustments (if you meet the criteria). To access this, you (not your employer) need to apply for a workplace assessment. This may lead to guidance being provided to your employer in terms of reasonable adjustments for you in your workplace. This may include software and/or support. You and your employer can see examples of reasonable adjustments that have been made in the past here, for example.

What can individuals with DCD do to help employers understand their difficulties?

DCD is not as widely known as conditions such as dyslexia or autism. An employee with DCD should give their line manager, employer and Human Resources (HR) staff information about DCD, to help explain that it is a 'real' condition and help describe some of the key characteristics. It is also advisable to contact the HR department and ask for an appointment with Occupational Health, who can suggest reasonable adjustments. Employees could also contact Access to Work at JobCentrePlus, who can provide an assessment and specifically tailored support. They can also work with employers. Adjustments might include, but are not limited to, allowing employees to use the computer (rather than handwriting), or allowing employees to start work a little later than other staff members. People with DCD have varying needs, and different solutions will apply for different people.

What support is available for a student with DCD starting university?

Universities do not cater specifically for students with DCD but provide support for all students with additional learning needs, usually through student support services. However, if a student makes it known that they have experienced this type of difficulty in the past, they will be advised of any provision that they can take advantage of. It is always sensible to contact the University's Student Disability Team/Disability Office (see our <u>factsheet for people in further or higher education</u>).