

Dyskinetic Cerebral Palsy – Functional Impact Scale (D-FIS)

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Introduction

People with cerebral palsy frequently have difficulties with the activities they need to do on a daily basis due to their abnormal muscle tone. This can include increased tone or stiffness called spasticity, decreased tone or floppiness, or fluctuating tone called dyskinesia. Many children have a combination of these different types of tone. Children with dyskinesia have fluctuating tone which changes throughout each day, is usually involuntary and is frequently made worse by emotion, concentration, tiredness and pain.

This scale aims to measure the impact this fluctuating tone and involuntary movement has on your child's ability to perform daily activities or be cared for. The scale can provide doctors and therapists with valuable information about the impact your child's dyskinesia has on the activities they do on a daily basis such as moving around, dressing, play and school, accessing technology and sleep. This will help therapists and doctors to better target interventions to help your child participate in activities and reduce the impact of the dyskinesia.

There are many reasons why a child may have difficulty with a daily activity and your child's dyskinesia may be only one of the reasons. Please keep your child's developmental age and dyskinetic movements and postures in mind when answering the questions.

All the activities in the scale are an important part of a child's daily routine but the D-FIS asks you to rate how much of a priority the activities are to you and your child right now to help us set goals with you and to choose the best interventions. We may ask you to complete the D-FIS again, after intervention, to measure your child's response to treatments that aim to reduce dyskinesia.

Instructions

- This scale asks you to rate how much your child's dyskinesia affects their ability to do activities or your ability to complete the activities with them. It also asks how much of a priority each activity is to you and your child right now
- Please read all the questions and circle the number for the best response
- In all questions the word dyskinesia refers to fluctuating muscle tone
- Please consider how the dyskinesia has impacted on the following activities over the **past 2 weeks**

Scale explanations

Impact scale

These questions investigate the impact of dyskinesia on specific activities:

- | | |
|----|--|
| 0 | Dyskinesia may be present but has no impact on the named activity |
| 1 | Dyskinesia may be present but has only minimal impact on the named activity |
| 2 | Dyskinesia is present and interferes with the named activity, child requires some help |
| 3 | Dyskinesia is present and interferes with the named activity and child requires lots of help |
| 4 | Dyskinesia is present and prevents child doing named activity, even with help |
| NA | The activity is difficult but NOT due to dyskinesia |

Priority scale

These questions ask you to highlight how much of a priority each activity is to you/your child **right now** from an intervention perspective, that is, how important is it that your team focus on this activity?

- | | |
|---|------------------|
| 1 | Not a priority |
| 2 | Small priority |
| 3 | Medium priority |
| 4 | Highest priority |

Child's details

Child's name:

Child's date of birth:

Date:

Name of parent or caregiver completing form:

Thank you for taking the time to complete these questions

Sitting

Ability to sit			
0	No impact: able to sit independently without support with good balance		
1	Mild impact: dyskinesia has some impact on sitting ability and balance		
2	Moderate impact: dyskinesia interferes with ability to sit independently, minimal postural supports are required for sitting and balance		
3	Severe impact: dyskinesia interferes with sitting ability and balance, full postural supports are required		
4	Extreme impact: dyskinesia prevents ability to sit even with maximal support		
NA	Sitting is difficult but not due to dyskinesia		
What priority is sitting ability?			
1	2	3	4
Not a priority	Small priority	Medium priority	Highest priority

Standing

Ability to stand			
0	No impact: able to stand independently with good balance		
1	Mild impact: dyskinesia has some impact on standing and balance		
2	Moderate impact: dyskinesia interferes with ability to stand independently, minimal supports are required for balance		
3	Severe impact: dyskinesia interferes with ability to stand and balance, supportive standing equipment required		
4	Extreme impact: dyskinesia prevents standing even with maximal support		
NA	Standing is difficult but not due to dyskinesia		
What priority is standing ability?			
1	2	3	4
Not a priority	Small priority	Medium priority	Highest priority

Walking

Ability to step or walk

- 0 No impact:** able to independently walk on all surfaces
- 1 Mild impact:** dyskinesia has some impact on walking ability
- 2 Moderate impact:** dyskinesia interferes with ability to walk independently, use of walking aid/s required (e.g., walker, sticks)
- 3 Severe impact:** dyskinesia interferes with stepping and walking ability, fully supportive walking aid required
- 4 Extreme impact:** dyskinesia prevents stepping or walking

NA Walking is difficult but not due to dyskinesia

What priority is walking?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Positioning

Positioning in bed, wheelchair, stroller, equipment

- 0 No impact:** able to independently position and change position with ease
- 1 Mild impact:** dyskinesia has some impact on ability to independently position and change position, position changes are clumsy
- 2 Moderate impact:** dyskinesia interferes with ability to position or change positions, some postural supports or assistance may be required, change of position is slow
- 3 Severe impact:** dyskinesia interferes with positioning, assistance of carer required, full postural supports required in all equipment
- 4 Extreme impact:** dyskinesia either prevents positioning or requires maximal effort of carer to position correctly with use of full postural supports

NA Positioning is difficult but not due to dyskinesia

What priority is positioning?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Transfers

Ability to move from bed to chair/wheelchair, chair to toilet, be hoisted or do standing transfers

- 0 No impact:** able to independently transfer with ease
- 1 Mild impact:** dyskinesia has some impact on ability to independently transfer, transfers clumsy
- 2 Moderate impact:** dyskinesia interferes with ability to transfer, some assistance or balance aids may be required, transfers slow
- 3 Severe impact:** dyskinesia interferes with all transfers, assistance of carer and/or use of transfer aids required (e.g., hoist)
- 4 Extreme impact:** dyskinesia either prevents safe transfers or requires maximal effort of more than one carer and transfer aid (e.g., hoist)
- NA** Transfers are difficult but not due to dyskinesia

What priority are transfers?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Other gross motor activities

Ability to complete gross motor activities such as hopping, jumping, running, climbing stairs, bike riding, swimming

- 0 No impact:** able to complete age appropriate gross motor activities with ease
- 1 Mild impact:** dyskinesia has some impact on gross motor activities (e.g., uses rail to climb stairs), speed and coordination affected
- 2 Moderate impact:** dyskinesia interferes with gross motor activities, supports or aids required for improving ability (e.g., requires training wheels on bike)
- 3 Severe impact:** dyskinesia interferes with gross motor activities, full support or assistance required to attempt selected activities (e.g., may be able to swim with full carer assistance)
- 4 Extreme impact:** dyskinesia prevents attempting gross motor activities
- NA** Gross motor activities are difficult but not due to dyskinesia

What priority are gross motor activities?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Fine motor activities

Ability to complete fine motor activities, e.g., writing, typing, cutting, drawing, cutlery use, dressing (buttons, zips, laces), play with small toys or access a screen with fingers

0 No impact: able to complete age appropriate fine motor activities with ease

1 Mild impact: dyskinesia has some impact on fine motor activities, activity completion slower with reduced accuracy

2 Moderate impact: dyskinesia interferes with fine motor activities, modifications to activity required for completion (e.g., built up cutlery, keyboard with guard, alternative laces)

3 Severe impact: dyskinesia interferes with all fine motor activities, modifications required to attempt or partially complete activities (e.g., alternative technology access)

4 Extreme impact: dyskinesia prevents attempting any fine motor activities

NA Fine motor activities are difficult but not due to dyskinesia

What priority are fine motor activities?

1 Not a priority

2 Small priority

3 Medium priority

4 Highest priority

Reaching

Reach in any direction with purpose, e.g., reach towards bike handle, powerchair control, iPad, switches, help with dressing

0 No impact: able to reach purposefully in all directions with ease

1 Mild impact: dyskinesia has minor impact on purposeful reach, may not be able to reach fully in all directions

2 Moderate impact: dyskinesia interferes with purposeful reach, reach limited and not accurate

3 Severe impact: dyskinesia interferes with purposeful reaching, range limited and reach unsuccessful

4 Extreme impact: dyskinesia prevents reach in any direction

NA Reach is difficult but not due to dyskinesia

What priority is reaching?

1 Not a priority

2 Small priority

3 Medium priority

4 Highest priority

Use of technology

Ability to use, by whichever means, any technology device including: computer, iPad, mobile phone, switches, environmental control unit, eye-gaze technology, voice-activated technology

- 0 No impact:** able to access all technology and use with ease
- 1 Mild impact:** dyskinesia has minor impact on ability to use technology, access/use may be slower or less accurate
- 2 Moderate impact:** dyskinesia interferes with use of technology, access may be imprecise or alternative access required for success (e.g., key guard, switch access, eye-gaze, voice activation)
- 3 Severe impact:** dyskinesia interferes with ability to use technology, alternative access with maximum postural support required for full or partial success
- 4 Extreme impact:** dyskinesia prevents use of technology by any means
- NA** Using technology is difficult but not due to dyskinesia

What priority is use of technology?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Daily hygiene activities

Ability to complete daily hygiene routines, e.g., brushing teeth, bathing, toileting, nappy changes

- 0 No impact:** able to independently complete all daily hygiene activities
- 1 Mild impact:** dyskinesia has some impact on ability to independently complete daily hygiene activities, reduced accuracy and speed of completion may be evident
- 2 Moderate impact:** dyskinesia interferes with some or all daily hygiene routines, some assistance or activity modification may be required for some activities
- 3 Severe impact:** dyskinesia interferes with all daily hygiene routines, assistance to complete all activities required but carer able to complete activity
- 4 Extreme impact:** dyskinesia interferes with all daily hygiene activities, complete assistance is required and completion of hygiene activities by carer is difficult
- NA** Daily hygiene activities are difficult but not due to dyskinesia

What priority are daily hygiene activities?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Upper body dressing

Ability to dress the upper body, including underwear, t-shirts, tops, shirts, jumpers and jackets

- 0 No impact:** able to independently dress upper body
- 1 Mild impact:** dyskinesia has some impact on ability to independently dress upper body, reduced dressing accuracy and speed may be evident
- 2 Moderate impact:** dyskinesia interferes with upper body dressing, some assistance or clothing modification may be required for some garments
- 3 Severe impact:** dyskinesia interferes with upper body dressing, assistance to complete all dressing is required but carer able to complete activity
- 4 Extreme impact:** dyskinesia interferes with upper body dressing, complete assistance is required and completion of dressing by carer is difficult
- NA** Upper body dressing is difficult but not due to dyskinesia

What priority is upper body dressing?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Lower body dressing

Ability to dress the lower body including underwear, shorts, long pants, socks and shoes

- 0 No impact:** able to independently dress lower body
- 1 Mild impact:** dyskinesia has some impact on ability to independently dress lower body, reduced dressing accuracy and speed may be evident
- 2 Moderate impact:** dyskinesia interferes with lower body dressing, some assistance or activity modification may be required for some garments and for footwear
- 3 Severe impact:** dyskinesia interferes with lower body dressing, assistance to complete all dressing is required but carer able to complete activity
- 4 Extreme impact:** dyskinesia interferes with lower body dressing, complete assistance is required and completion of dressing by carer is difficult
- NA** Lower body dressing is difficult but not due to dyskinesia

What priority is lower body dressing?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Feeding

Ability to eat and drink

- 0 No impact:** able to eat and drink with ease
- 1 Mild impact:** dyskinesia has some impact on ability to eat and drink, meal times may be slower and messy
- 2 Moderate impact:** dyskinesia interferes with ability to eat and drink safely, some swallowing difficulties evident
- 3 Severe impact:** dyskinesia interferes with ability to eat and drink, unable to eat solid foods, gastrostomy feeds required to supplement nutrition
- 4 Extreme impact:** unable to eat or drink orally, fully dependent on gastrostomy feeding
- NA** Feeding is difficult but not due to dyskinesia

What priority is feeding?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Speech

Ability to communicate using spoken words

- 0 No impact:** speech is age appropriate
- 1 Mild impact:** dyskinesia has some impact on speech, speech is only sometimes difficult to understand
- 2 Moderate impact:** dyskinesia interferes with speech, speech cannot fully be understood by unfamiliar listeners
- 3 Severe impact:** dyskinesia interferes with speech, speech largely incomprehensible but able to make sounds or words that are understood by familiar listeners
- 4 Extreme impact:** dyskinesia prevents any understandable speech
- NA** Speech is difficult but not due to dyskinesia

What priority is speech?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Sleep

Ability to fall asleep and stay asleep

- 0 No impact:** able to rest in a safe and comfortable position in any bed to get to sleep, and go back to sleep during desired sleep period
- 1 Mild impact:** able to rest in a safe and comfortable position to get to sleep or go back to sleep, using appropriate positioning support (e.g., cushions/foam wedges), and/or brief assistance from carer to assume comfortable position
- 2 Moderate impact:** requires unique bed/positioning equipment, and/or attention from carer to rest in safe and comfortable position to fall asleep or go back to sleep (carer needs to stay with child for 5–15 minutes, or return to child 1–2 times, to assist with safe and comfortable positioning for sleep)
- 3 Severe impact:** with or without unique bed/ positioning equipment, requires repeated or sustained attention from carer to rest in safe and comfortable position to fall asleep or go back to sleep (carer needs to stay with child 15–60 minutes, return to child several times, or sleep in the same bed as child to assist with safe and comfortable positioning for sleep)
- 4 Extreme impact:** requires use of medication and appropriate equipment to ensure bed setting is safe, needs constant and firm physical support from carer to stay in a safe and comfortable position to get to sleep; dyskinesia causes child to be extremely unsafe, uncomfortable or in pain if they wake during the sleep period

NA Sleep is difficult but not due to dyskinesia

What priority is sleep?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Leisure activities

Ability to undertake preferred leisure activities in the community, at school or with family

- 0 No impact:** able to independently participate in all preferred leisure activities
- 1 Mild impact:** dyskinesia has some impact on participation in preferred leisure activities, may not be able to fully participate
- 2 Moderate impact:** dyskinesia interferes with participation in leisure activities, assistance or activity modifications required for participation
- 3 Severe impact:** dyskinesia interferes with participation in leisure activities, assistance and activity modifications required to partially participate in preferred activities
- 4 Extreme impact:** dyskinesia prevents attempting leisure activities

NA Leisure activities are difficult but not due to dyskinesia

What priority are leisure activities?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Pain

Any pain likely to be caused by dyskinetic movements and impacting on activities

- 0 No pain:** does not complain of any pain
- 1 Mild pain:** dyskinesia has some impact and pain is experienced on occasions, managed with/without pain medications, e.g., paracetamol
- 2 Moderate pain:** dyskinesia causes pain on frequent occasions, manageable with pain medications e.g., paracetamol
- 3 Severe pain:** dyskinesia causes pain with specific activities e.g., dressing, nappy changes, transfers or positioning, managed with prescription pain medications
- 4 Extreme pain:** dyskinesia causes daily pain and child is frequently unhappy due to pain and requires ongoing prescription medication
- NA** My child has pain but not due to dyskinesia

What priority is pain?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

Fatigue

How tired your child is on a daily basis due to dyskinetic movements

- 0 No fatigue:** no fatigue obvious
- 1 Mild fatigue:** dyskinesia causes little to no impact on fatigue levels during the day, e.g., may complain infrequently of feeling tired
- 2 Moderate fatigue:** dyskinesia causes fatigue and child complains of tiredness, some poor concentration or inattentiveness compared to peers is evident
- 3 Severe fatigue:** dyskinesia causes fatigue, difficulty concentrating and child needs frequent rests from activities that require thinking and concentration
- 4 Extreme fatigue:** dyskinesia causes high levels of fatigue, child may be unable to concentrate and sleepy during the day
- NA** Fatigue is a problem but is not due to dyskinesia

What priority is fatigue?

- | | | | |
|-------------------------|-------------------------|--------------------------|---------------------------|
| 1 Not a priority | 2 Small priority | 3 Medium priority | 4 Highest priority |
|-------------------------|-------------------------|--------------------------|---------------------------|

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Reference: Stewart K, Lewis J, Wallen M, Bear N, Harvey A. *The Dyskinetic Cerebral Palsy Functional Impact Scale: development and validation of a new tool*. *Developmental Medicine and Child Neurology*, 2021.