**HOSPITAL LABEL**

**(To be affixed by medical secretary prior to sending)**

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| **Name of individual completing form:** |  |
| **Relationship to Child:** | Self / Parent / Carer / Other:  ………………………………………………………………………….. |
| **Date completed:** |  |
| **School or nursery including whether extra support, EHCP or specialist provision** |  |

**Children and young people with epilepsy have an increased risk of difficulties with physical skills, learning, behaviour, mental health and/or development.**

**This checklist is intended to help us check for these kinds of difficulties.** **and to make referrals as needed**

**Please do look through the form carefully but leave blank any sections that you feel you cannot answer and feel free to add comments that reflect your concerns. Please return this form to the epilepsy team treating your child and discuss any queries with them.**

**Milestones:**

Do you/did you have concerns about delayed developmental milestones including regression (going backwards)? Please put ages when these were achieved if possible:

|  |  |  |
| --- | --- | --- |
| **Physical skills** | **Date achieved** | **Delayed?** |
| head control |  |  |
| sitting |  |  |
| standing |  |  |
| walking |  |  |
| running |  |  |
| **Hand skills** |  |  |
| spoon |  |  |
| cup |  |  |
| fastenings |  |  |
| games |  |  |
| writing |  |  |
| **Social skills** |  |  |
| sharing toys |  |  |
| turn taking |  |  |
| sitting in groups for short periods of time |  |  |
| **Communication** |  |  |
| Pointing |  |  |
| facial expression as well as speech |  |  |
| **Hearing concerns** |  | |
| **Vision concerns** |  | |

**General skills:** Current level *(please circle)*:

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| **Language:** | | | | | | | | |
| non-verbal | single word | short phrases (3-4 words | | | longer phrases | fluent - long sentences & conversation | | |
| **Self-care:** | | | | | | | | |
| Fully dependant for most needs | | | dependent on others; some self-care skills | | | | | Independent |
| **Mobility:** | | | | | | | | |
| Wheelchair | needs significant support e.g. walkers | | | some difficulty (orthotics) | | | completely mobile | |

**Neurodevelopmental or mental health**

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| **Are there any concerns about the conditions below/received a diagnosis of:** | **Yes** | **No** |
| Autism Spectrum Disorder (ASD) including Asperger’s Syndrome |  |  |
| Attention Deficit Hyperactivity Disorder (ADHD |  |  |
| Anxiety, *including as panic, phobia, separation anxiety disorder* |  |  |
| Depression |  |  |
| Non epileptic attacks/seizures (psychogenic non epileptic seizures/pseudo-seizures) |  |  |
| Other (please specify): |  |  |
|  | | |

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|  | **Yes** | **No** |
| If YES to any of the above have you had further evaluation or support for this? |  |  |
| Would you like to have further evaluation or support for it? |  |  |

***Please carefully look at the features below but Skip sections as appropriate/IFanswered yes to relevant questions above e.g autism for sdocial communication or adhd for Attention and Concentration***

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| **Behaviour** Have there been any difficulties with any of the following? | **Yes** | **No** |
| Anxiety |  |  |
| Depressed mood (including self-harm) |  |  |
| Mood swings |  |  |
| Aggressive outbursts or temper |  |  |
| Tantrums |  |  |
| Self-injury or, such as hitting self, biting self, scratching self |  |  |
| Are there any other behaviour or emotional difficulties causing concern to you or to other people, please specify: | | |
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| **Communication and social interaction concerns** | **Yes** | **No** |
| Speech and communication problems including lack of social chat |  |  |
| Unusual or reduced eye contact |  |  |
| Difficulties getting on with other people of similar age |  |  |
| Repetitive behaviours, *such as doing the same thing over and over again* |  |  |
| Very rigid about how to do things or not liking change |  |  |
| Unusual responses to light, sounds, smells, tastes, textures – e.g. seams on clothes, haircuts, nails, washing or tooth brushing routines |  |  |

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| **Attention, concentration** | **Yes** | **No** |
| Over activity/hyperactivity, *such as being constantly on the go* |  |  |
| Difficulty paying attention or concentrating |  |  |
| Restlessness or fidgetiness, *such as wriggling or squirming* |  |  |
| Acting as if not heard. Forgetting items or instructions |  |  |
| Impulsivity, *such as butting in, not waiting turn* |  |  |

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| **Eating** | **Yes** | **No** |
| Swallowing or chewing *such as drooling, choking or spluttering on food or drink* |  |  |
| Eating too much, too little |  |  |
| Limited range of foods such as tastes, textures, brands |  |  |
| Eating unusual things |  |  |

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| **Gut issues** | **Yes** | **No** |
| Constipation |  |  |
| Abdominal pain |  |  |
| Nausea or vomiting |  |  |

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| **Sleep issues** | **Yes** | **No** |
| Difficulty falling asleep |  |  |
| Frequent waking in the night |  |  |
| Difficulty waking in the morning |  |  |
| Other (please specify): |  |  |
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| **Learning/intellectual development** | **Yes** | | **No** |
| Have you ever been concerned about this |  | |  |
| Has there been formal evaluation of intelligence by a professional using IQ-type tests? |  | |  |
| If YES, and you have this information what did results show? | **Please tick one** | | |
| Normal Intellectual Ability (IQ > 80) |  | | |
| Borderline Intellectual Ability (IQ 70-80) |  | | |
| Mild Intellectual Disability (IQ 50-69) |  | | |
| Moderate Intellectual Disability (IQ 35-49), |  | | |
| Severe Intellectual Disability (IQ 21-34) |  | | |
| Profound Intellectual Disability (IQ <20) |  | | |
|  |  | | |
| What age equivalent intellectual ability would you say? | **Age in years** | | |
|  | **Yes** | **No** | |
| Have you discussed this with nursery, school or other professionals? |  |  | |
| Would you like to have further evaluation or support for it? |  |  | |

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| **Difficulties in nursery or school** | **Yes** | **No** |
| Reading |  |  |
| Writing |  |  |
| Spelling |  |  |
| Mathematics |  |  |
| Break times or Mealtimes |  | **NO** |
| Friendships/play |  |  |
| School arrival or leaving |  |  |
| **If you answered YES to any of the above** | **YES** | **NO** |
| Has there been further evaluation or support for this? |  |  |
| Has any additional support in school been considered (extra help or an Individual Educational Plan (IEP) or Education,Health and Care Plan (EHCP)? |  |  |
| Would you like to have further evaluation? |  |  |

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| **Difficulties in specific cognitive and learning skills** | **Yes** | **No** |
| Memory, *such as remembering things that have happened* |  |  |
| Attention, *such as concentrating well, not getting distracted* |  |  |
| Dual-tasking/ Multi-tasking, *such as doing 2 tasks at the same time* |  |  |
| Co-ordination/Visio-spatial tasks, *such as solving puzzles or using building blocks* |  |  |
| Executive skills, *such as planning, organizing, flexible thinking* |  |  |
| Getting disoriented, *such as not knowing the date or where you are* |  |  |
| Word finding difficulties |  |  |
| **If you answered YES to any of the above** |  |  |
| Has there been any further evaluation or support for it? |  |  |
| Would you like to have further evaluation or support for these difficulties |  |  |

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| **Emotional well-being** | **Yes** | **No** |
| Low self-esteem |  |  |
| Very high levels of stress in families, for instance between *siblings* |  |  |
| Very high levels of stress between *parents* leading to significant relationship difficulties (leave blank if you wish) |  |  |
| **If you answered YES to any of the above** |  |  |
| Have/has [subject] and/or your family had further evaluation or support for it? |  |  |
| Would you like to have further evaluation or support for it? |  |  |

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| **Safety** | **Yes** | **No** |
| Are you or other carer concerned about your child’s safety or risk? |  |  |
| Has it affected what they have been allowed to do e.g. sleep overs, school activities, trips |  |  |
| Do they have any additional safety support e.g. monitors or checks? |  |  |

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| **If not covered above have you got any concerns about side effects of treatment** | **Yes** | **No** |
| Physical health – growth, rashes |  |  |
| Learning/school |  |  |
| Mood, Mental health/behaviour |  |  |
| Fatigue |  |  |
| Other (please specify): | | |

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| **Transition** - should be completed by the young person or carer on behalf | **Yes** | **No** |
| Do you feel you know enough about your condition and treatment options? |  |  |
| Are you taking some responsibility for this, such as taking your medications, as agreed? |  |  |
| Are your aware of online resources e.g. Epilepsy action, Young Epilepsy/Epilepsy space? |  |  |
| Are there any lifestyle issues, alcohol, drugs, relationships, |  |  |
| Are there any specific issues you would like to raise e.g driving, employment, ocp, pregnancy? |  |  |
| Other (please specify): | | |

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| **Barriers to participation** | | | | | | | | |
| Taking together all the difficulties discussed above, how much have these bothered, troubled or distressed you/your child/family? (Please circle): | | | | | | | | |
| O (Not at all) | 1 | 2 | 3 | 4 | 5 | **6** | **7** | **8(Extremely)** |

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| **Goal-setting** |
| Of all the concerns listed above, what are your top priorities to work on next? |
| 1. |
| 2. |
| 3. |

**As this is a draft tool please comment on whether you found this checklist helpful and how?**

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**If you did not feel it was useful at this moment when do you feel is the best time to complete this?**

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|  |

**Was this about right or too short or too lengthy to complete?**

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**When do you think this questionnaire would be useful. For example before the clinic appointment, in the waiting room, after meetings with school, concerns in-between appointments?**

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**How would you like to complete this? E.g paper, website link, app?**

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**What are your expectations after completing this?**

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**Any other comments to help us develop this further.**

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**For clinicians/epilepsy team.**

**Do you think you will use this information? How?**

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**Do you think there will be useful outcomes as a result, such as signposting for further assessment or exploration or support of particular difficulties or conditions?**

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**For use by assessor:**

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| **Impact/burden on the individual/child/family – circle (map to DDCGAS if you wish)** | | | | | | | | |
| O (nil) | 1 | 2 | 3 | 4 | 5 | **6** | **7** | **8 (Extreme)** |