**ChECC –** Ch**ild and young person Epilepsy Concerns** C**hecklist**

**Parent/Carers version**

**HOSPITAL LABEL**

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

|  |  |
| --- | --- |
| **Name of individual completing form:** |  |
| **Relationship to Child:** | 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 and co-ordination 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.**

**Leave blank any sections that you feel you cannot or do not wish to answer and feel free to add comments reflecting 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 or age achieved** | **Any concerns?** |
| Head control |  |  |
| Sitting independently |  |  |
| Standing |  |  |
| Walking |  |  |
| Running |  |  |
| **Hand skills** |  |  |
| Spoon |  |  |
| Cup |  |  |
| Pencil and drawing skills |  |  |
| Dressing  |  |  |
| Ball games, puzzles |  |  |
| **Social skills** |  |  |
| Sharing toys |  |  |
| Taking turns |  |  |
| Joining or staying in groups  |  |  |
| **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 dependent 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/non -epileptic seizures  |  |  |
| Other (please specify): |

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

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

Have there been any difficulties with any of the following?

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| **Behaviour** | **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 or diarrhoea (hard or loose stool)  |  |  |
| Abdominal pain, bloating or discomfort |  |  |
| Nausea or vomiting |  |  |

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| **Sleep issues** | **Yes** | **No** |
| Difficulty falling asleep |  |  |
| Frequent waking in the night |  |  |
| Difficulty waking in the morning |  |  |
| Bed wetting |  |  |
| 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? |  |
|  |  |
| Have you discussed this with nursery, school or other professionals? | **Yes** | **No** |
| Would you like to have further evaluation or support for it? | **Yes** | **No** |
| Other comments? |

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| **Difficulties in nursery or school** | **Yes** | **No** |
| Reading |  |  |
| Writing |  |  |
| Spelling |  |  |
| Mathematics |  |  |
| Break times or mealtimes |  |  |
| Friendships/play |  |  |
| School arrival or leaving |  |  |
| **If you answered YES to any of the above;** |  |  |
| 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)? |  |  |

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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, organising, 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? |  |  |

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| **Emotional well-being** | **Yes** | **No** |
| Low self-esteem |  |  |
| High levels of stress in families, for instance between *siblings* |  |  |
| 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 this? |  |  |

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| **Safety** | **Yes** | **No** |
| Are you or other carer(s) 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? |  |  |
| Have you had an opportunity to discuss safety issues with your epilepsy team such as SUDEP |  |  |

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

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| **Transition** – is the child or young person able to complete the separate transition questionnaire? If yes please complete that. | **Yes** | **No** |
| Other comments or concerns about transition that you would like to discuss (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): |
| 0 (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 checklist? For example, on paper, using a website link or app?**

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

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**Do you have 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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**Please return completed form to:**

**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) |