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

**Young person version**

**HOSPITAL LABEL**

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

|  |  |
| --- | --- |
| **Name of individual completing form:** |  |
| **Any other support helping with this form** | Parent / Carer / Other:  ………………………………………………………………………….. |
| **Date completed:** |  |
|  |  |

**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.**

**Leave blank any sections that you feel you cannot answer and feel free to add comments reflecting your concerns.**

**Please return this form to the epilepsy team treating you and discuss any queries with them.**

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| **Have you ever wondered if you had** | **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 |  |  |
| 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? |  |  |  |
| Further comments | | | |

*\*here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

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| Are there any other behaviour or emotional difficulties causing concern to you or to other people? Please specify: |
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| **Have you ever, or felt you have ever struggled with** | **Yes** | **No** | **Comment** |
| Communication and social interaction concerns |  |  |  |
| Difficulties getting on with other people of similar age |  |  |  |
| Being 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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| **Have you ever, or felt you have ever struggled with** | **Yes** | **No** | **Comment** |
| Over activity/hyperactivity, *such as being constantly on the go* |  |  |  |
| Difficulty paying attention or concentrating |  |  |  |
| Restlessness or fidgetiness, *such as wriggling or squirming* |  |  |  |
| Forgetting items or instructions |  |  |  |
| Impulsivity, *such as butting in, not waiting turn* |  |  |  |

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| **Are you concerned about the following** | **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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| **Do you currently or regularly have any gut issues such as** | **Yes currently** | **Yes regularly** | **No** |
| Constipation – “hard poos” |  |  |  |
| Abdominal (tummy) pain |  |  |  |
| Feeling sick or vomiting |  |  |  |

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| **Do you currently or regularly have any sleep issues such as** | **Yes currently** | **Yes regularly** | **No** |
| Difficulty falling asleep |  |  |  |
| Frequent waking in the night |  |  |  |
| Difficulty waking in the morning |  |  |  |
| Other (please specify): | | | |

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| **Do you have difficulties in school or college with** | **Yes often** | **No** | **Sometimes** |
| 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? |  |  |  |
| Would you like to have further\* evaluation? |  |  |  |

*\*here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

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| **Have you ever, or felt you have ever struggled with difficulties in specific cognitive and learning skills, like:** | **Yes often** | **No** | **Sometimes** |
| 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? |  |  |  |
| Would you like to have further evaluation\* or support for these difficulties? |  |  |  |

*\*here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

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| **Have you ever, or felt you have ever struggled with** | **Yes** | **No** |
| Low self-esteem |  |  |
| Very high levels of stress in your family, for instance between *siblings* |  |  |
| Very high levels of stress between *parents* (leave blank if you wish) |  |  |
| **If you answered YES to any of the above** |  |  |
| Have you and/or your family had further evaluation\* or support for this? |  |  |
| Would you like to have further evaluation\* or support for it? |  |  |

*\*here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

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| **Safety** | **Yes** | **No** | **Don’t know** |
| Have you got a healthcare plan and emergency medication |  |  |  |
| Has your epilepsy affected what you have been allowed to do e.g. sleep overs, school activities, trips |  |  |  |
| Do you have any additional safety support e.g. monitors or checks? |  |  |  |

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| **If not covered above, have you any concerns about side effects of your epilepsy treatment** | **Yes** | **No** |  |
| Physical health – growth, rashes |  |  |  |
| Learning/school |  |  |  |
| Mood, Mental health/behaviour |  |  |  |
| Focus and mental processing |  |  |  |
| Fatigue/energy levels |  |  |  |
| Other, including treatment not relating specifically to epilepsy (please specify): | | | |

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| **Transition** | **Yes** | **No** |  |
| Do you feel you know enough about your condition, treatment options. SUDEP risk? |  |  |  |
| Are you taking some responsibility for your own care, such as taking your medications, as agreed?. |  |  |  |
| Are your aware of online resources e.g. Epilepsy action, Young Epilepsy, The Channel, Epilepsy space, SUDEP action. |  |  |  |
| Are there any lifestyle issues, alcohol, drugs, relationships, that affect your treatment? |  |  |  |
| Are there any specific issues you would like to raise e.g driving, employment, contraception, 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? (Please circle): | | | | | | | | |
| 0 (not at all) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 (Extremely) |
| Taking together all the difficulties discussed above, do you think these have stopped you from doing everything you want to do? f so, how much? (Please circle): | | | | | | | | |
| 0 (not at all) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 (Extremely) |
| Taking together all the difficulties discussed above, do you think these have stopped you joining in with your friends and peers? If so, how much? (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) |