CHild and Young Person **E**pilepsy **C**oncerns **C**hecklist - **CHECC**

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.

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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)*:

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

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):		

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?

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:		

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		

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*		

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		

Gut issues	**Yes**	**No**
Constipation or diarrhoea (hard or loose stool)		
Abdominal pain, bloating or discomfort		
Nausea or vomiting		

Sleep issues	**Yes**	**No**
Difficulty falling asleep		
Frequent waking in the night		
Difficulty waking in the morning		
Bed wetting		
Other (please specify):		

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)?		

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?		

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?		

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

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):		

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)

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?

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

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

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?

How would you like to complete this checklist? For example, on paper, using a website link or app?

What are your expectations after completing this?

Do you have any other comments to help us develop this further?

For clinicians/epilepsy team.

Do you think you will use this information? How?

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?

Please return completed form to:

For use by assessor:

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)