CARER-HEAD INJURY PARTICIPATION SCALE (C-HIPS)

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Reference: Deb S., Bryant E., Morris P.G., Prior L., Lewis G. & Haque S. (2007) Development and psychometric properties of the Carer-Head Injury Neurobehavioural Assessment Scale (C-HINAS) and the Carer-Head Injury Participation Scale (C-HIPS): patient and family determined scales. Neuropsychiatric Disease and Treatment 3, 3, 389-408.

Name of the patient:

Patient's date of birth:

Name of the carer completing the C-HIPS:

The relation of the carer with the patient:

Carer's date of birth:

Place where the scale was administered:

Name of the person administering the scale:

The role of the person administering the scale:

Date of completion:

The cause of brain injury:

The date of brain injury:

The initial severity of brain injury (e.g. length of coma, PTA or the lowest GCS score):

Current treatments:

Carer-Head Injury Participation Scale (C-HIPS)

We are interested in the things that cause problems in day-to-day life for individuals who have suffered brain injury.

Each question asks whether a particular symptom has been either 'not a problem', or a 'mild', 'moderate' or 'serious' problem in the day-to-day life of the person you care for during the past four weeks.

There are 56 questions in total and they all follow the same format. The first 48 questions ask about problems experienced by the brain injured person you care for during the past four weeks. The last 8 questions ask about how the consequences have affected you.

EXAMPLE QUESTION

One question asks whether the hearing of the person you care for has caused her/ him problems over the last four weeks.

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty hearing (loss of hearing)	☐	☐	☐	☐
	Either the symptom is not present or the symptom is present but does not cause difficulties	The symptom causes some mild problems with day-to-day life, but these are manageable	The symptom causes problems that have a moderate impact upon day-to-day life	The symptom causes problems that have a serious impact upon day-to-day life

Therefore for the 'Difficulty hearing' question:

If the person you care for does not have any difficulty hearing, then tick the 'Not a Problem' box. Or, if s/he does have difficulty hearing but this does not cause any problems for her/ him (even if it is a bit worse), then tick the 'Not a Problem' box

If it causes some mild problems, but these are manageable, then tick the 'Mild Problem' box

If it causes problems that have a moderate impact upon their life, then tick the 'Moderate Problem' box

If it causes problems that have a serious impact upon their life, then tick the 'Serious Problem' box

Please tick ☑ one box only

CARER–HEAD INJURY NEUROBEHAVIOURAL ASSESSMENT SCALE (C–HINAS)

(Please answer all questions)

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Temper / Irritable (e.g. loss of temper, more aggressive, irritable etc.)	☐	☐	☐	☐
Social behaviour (e.g. too loud, causing offence, acting childishly, saying the wrong thing etc.)	☐	☐	☐	☐
Lack of motivation (e.g. difficulty getting round to doing things, gives up too easily etc.)	☐	☐	☐	☐
Difficulty with feeling tired / fatigued (e.g. feeling tired, drained or exhausted, having less energy etc.)	☐	☐	☐	☐
Difficulty with sleep (e.g. sleeping a lot or not sleeping, having nightmares etc.)	☐	☐	☐	☐
Feeling scared (e.g. frightened, panic attacks etc.)	☐	☐	☐	☐
Paranoia (e.g. feeling more suspicious about people etc.)	☐	☐	☐	☐

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Feelings of loss (e.g. troubled by loss of previous life or how life could have been etc.)	☐	☐	☐	☐
Frustration (e.g. because of not being able to do things that they would like to do etc.)	☐	☐	☐	☐
Worrying about things (e.g. feeling anxious or worried etc.)	☐	☐	☐	☐
Crowds (e.g. feeling uneasy in large crowds or amongst strangers etc.)	☐	☐	☐	☐
Loss of confidence (e.g. less confident in unfamiliar situations or when doing things they used to do etc.)	☐	☐	☐	☐
Depression (e.g. feeling down or isolated, expressing suicidal thoughts etc.)	☐	☐	☐	☐
Arguments with close family (e.g. arguments with partner, children, parents etc.)	☐	☐	☐	☐

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Reduced interest in family (e.g. less loving, less caring, less affectionate etc.)	☐	☐	☐	☐
Strain on family (e.g. tension, stress or depression amongst family members etc.)	☐	☐	☐	☐
Don't see friends as often as would like	☐	☐	☐	☐
Lack of good friends (e.g. close friends etc.)	☐	☐	☐	☐
Lack of understanding from others (e.g. people don't understand their situation, people judge or label them etc.)	☐	☐	☐	☐
Lack of people to talk to (e.g. social interaction, people to confide in etc.)	☐	☐	☐	☐

CARER – HEAD INJURY COMMUNITY LIVING SCALE (C – HICLS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with mobility (e.g. getting around places, going up stairs, getting in and out of bed etc.)	☐	☐	☐	☐
Lack of independence (e.g. reliant upon help from others, unable to live by themselves etc.)	☐	☐	☐	☐
Sports (e.g. restrictions in playing sports etc.)	☐	☐	☐	☐
Leisure activities (e.g. restrictions in taking part in leisure activities e.g. going to pub, cinema, going out for meals etc.)	☐	☐	☐	☐
Preparing meals (e.g. preparing / cooking meals etc.)	☐	☐	☐	☐
Physical self-care (e.g. washing, dressing etc.)				
Travel (e.g. getting around local area, travelling to shops, visiting friends, going out etc.)	☐	☐	☐	☐

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Shopping (e.g. buying food, clothes, things for everyday needs etc.)	☐	☐	☐	☐
Local environment (e.g. restriction due to steps or kerbs in local area, lack of ramps, handrails etc.)	☐	☐	☐	☐
Difficulty with balance (e.g. loss of balance, standing/sitting upright, walking etc.)	☐	☐	☐	☐
Physical appearance (e.g. changes to physical looks due to paralysis or scars, weight change etc.)	☐	☐	☐	☐
Difficulty with eye-sight (e.g. limited or blurred vision, can't see things properly etc.)	☐	☐	☐	☐

CARER – HEAD INJURY COGNITIVE ASSESSMENT SCALE (C – HICAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Group conversations (e.g. difficulty following conversations when several people speak at the same time etc.)	☐	☐	☐	☐
Difficulty reading (e.g. difficulty reading letters, bills, newspapers, books etc.)	☐	☐	☐	☐
Difficulty speaking (e.g. words come out jumbled, they have to concentrate harder on speech, people can't understand them properly etc.)	☐	☐	☐	☐
Difficulty with recent memory (e.g. forgetting things e.g. what day it is, what happened yesterday etc.)	☐	☐	☐	☐
Difficulty with concentration (e.g. focusing on reading newspapers, watching TV, doing tasks, easily distracted etc.)	☐	☐	☐	☐

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with planning/ organisation (e.g. doing things in the right order, allowing enough time etc.)	☐	☐	☐	☐
Difficulty with multi-tasking (e.g. doing more than one thing at a time e.g. walking and talking etc.)				
Dealing with money (e.g. paying bills, knowing how much change they should get etc.)	☐	☐	☐	☐
Safety risks (e.g. leaving gas on, not safe crossing roads, using electrical goods etc.)	☐	☐	☐	☐
Difficulty hearing (e.g. loss of hearing etc.)	☐	☐	☐	☐

CARER – HEAD INJURY PHYSICAL ASSESSMENT SCALE (C – HIPAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/ his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with headaches	☐	☐	☐	☐
Difficulty with pain other than headaches (e.g. pain from body, legs, arms etc. not headaches)	☐	☐	☐	☐
Difficulty with epilepsy / fits (e.g. blackouts, seizures, absences etc.)	☐	☐	☐	☐
Difficulty with feeling dizzy / faint (e.g. feeling as if head is spinning, vertigo, dizziness, feeling giddy etc.)	☐	☐	☐	☐
Difficulty with buzzing noise in ear (e.g. tinnitus etc.)	☐	☐	☐	☐
Difficulty with sensitivity to noise / light (e.g. can't tolerate noise or light etc.)	☐	☐	☐	☐

How the injury has affected you:

The last few questions ask about how the consequences of the injury have affected you

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

Effect on You	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Increased responsibility (e.g. having to take decisions, dealing with finances etc.)	☐	☐	☐	☐
Reduced social life (e.g. not being able to go out as much or meet up with friends etc.)	☐	☐	☐	☐
Feelings of loss (e.g. of previous life, the way your life could have been etc.)	☐	☐	☐	☐
Depression (e.g. feeling down etc.)	☐	☐	☐	☐
Feeling alone (e.g. lack of support etc.)	☐	☐	☐	☐
Less money (e.g. lack of income etc.)	☐	☐	☐	☐
Stress or strain	☐	☐	☐	☐

How the injury has affected you

Were you working or studying before the person you care for had their brain injury?

Yes ☐ (please answer the question below)

No ☐ (please go to the next page)

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

	Not a Problem for work	Mild Problem for work	Moderate Problem for work	Serious Problem for work
Work (e.g has caring for the person with a brain injury caused you problems with work / employment)	☐	☐	☐	☐

ADDITIONAL COMMENTS

Thank you for taking the time to complete this questionnaire