

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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social behaviour (e.g. too loud, causing offence, acting childishly, saying the wrong thing etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of motivation (e.g. difficulty getting round to doing things, gives up too easily etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with feeling tired / fatigued (e.g. feeling tired, drained or exhausted, having less energy etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with sleep (e.g. sleeping a lot or not sleeping, having nightmares etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling scared (e.g. frightened, panic attacks etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paranoia (e.g. feeling more suspicious about people etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frustration (e.g. because of not being able to do things that they would like to do etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worrying about things (e.g. feeling anxious or worried etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crowds (e.g. feeling uneasy in large crowds or amongst strangers etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of confidence (e.g. less confident in unfamiliar situations or when doing things they used to do etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression (e.g. feeling down or isolated, expressing suicidal thoughts etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arguments with close family (e.g. arguments with partner, children, parents etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strain on family (e.g. tension, stress or depression amongst family members etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Don't see friends as often as would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of good friends (e.g. close friends etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding from others (e.g. people don't understand their situation, people judge or label them etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of people to talk to (e.g. social interaction, people to confide in etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of independence (e.g. reliant upon help from others, unable to live by themselves etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sports (e.g. restrictions in playing sports etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure activities (e.g. restrictions in taking part in leisure activities e.g. going to pub, cinema, going out for meals etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preparing meals (e.g. preparing / cooking meals etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical self-care (e.g. washing, dressing etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel (e.g. getting around local area, travelling to shops, visiting friends, going out etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Local environment (e.g. restriction due to steps or kerbs in local area, lack of ramps, handrails etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with balance (e.g. loss of balance, standing/sitting upright, walking etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical appearance (e.g. changes to physical looks due to paralysis or scars, weight change etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with eye-sight (e.g. limited or blurred vision, can't see things properly etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty reading (e.g. difficulty reading letters, bills, newspapers, books etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty speaking (e.g. words come out jumbled, they have to concentrate harder on speech, people can't understand them properly etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with recent memory (e.g. forgetting things e.g. what day it is, what happened yesterday etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with concentration (e.g. focusing on reading newspapers, watching TV, doing tasks, easily distracted etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Safety risks (e.g. leaving gas on, not safe crossing roads, using electrical goods etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty hearing (e.g. loss of hearing etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with pain other than headaches (e.g. pain from body, legs, arms etc. <u>not</u> headaches)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with epilepsy / fits (e.g. blackouts, seizures, absences etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with feeling dizzy / faint (e.g. feeling as if head is spinning, vertigo, dizziness, feeling giddy etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with buzzing noise in ear (e.g. tinnitus etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with sensitivity to noise / light (e.g. can't tolerate noise or light etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?

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

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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ADDITIONAL COMMENTS

Thank you for taking the time to complete this questionnaire