

Questionnaire about the impact of narcolepsy and idiopathic hypersomnia on daily life

PROM-CDH, original Dutch version (version 1, 2023)

The following questionnaire is about the complaints and impact of narcolepsy and idiopathic hypersomnia. You may also complete the questionnaire if you have not yet been diagnosed. Your answers will give us insight into how you are doing in daily life. You are asked to indicate how often a statement applies to you.

The following questions are about the <u>impact of narcolepsy and idiopathic hypersomnia on your daily life.</u> Please indicate how often in the past four weeks these statements have applied to you <u>because of your condition.</u>							
		<i>almost always</i>		<i>hardly ever</i>			
1.	I cannot keep my attention while working/studying/at school/during other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2.	I dislike having to keep myself occupied (e.g. fidgeting with something in my hands, or chewing on something) to avoid falling asleep in monotonous situations during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O n/a: I don't need to keep myself occupied
3.	It bothers me that after sleeping (at night or a daytime nap) it takes me some time to be fully awake and I do not function as I would if I felt fully awake (e.g. I feel groggy, clumsy or confused, or I have difficulty remembering things)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O n/a: I function well immediately after sleeping
4.	I cannot change my daily routine (e.g. keep to a nap schedule, or get enough rest/sleep when I need it)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O n/a: I don't need to change my daily routine (any more)
5.	I dislike taking daytime naps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O n/a: I don't need to take naps (any more)
6.	I am dependent on others in my daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
7.	My complaints (e.g. frequent yawning in social situations, falling asleep suddenly or experiencing cataplexy) embarrass me and prevent me from doing all the things I would like to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8.	My condition influences my daily eating habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
9.	I am not happy with my body weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
10.	I do not have enough energy left to do an evening activity (e.g. physical exercise)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
11.	I cannot do the things I want to do in life (e.g. social activities, fulfilling ambitions, travelling, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
12.	I am not confident about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
13.	I feel that my life does not matter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
14.	Because of my complaints I cannot (or dare not) drive myself for extended periods of time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O n/a: I have never had a driving licence or I am not allowed to drive
15.	Because of my complaints I avoid using public transport as much as possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O not applicable
16.	Because of my complaints I have difficulty with intimacy/engaging in sexual activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	O not applicable
17.	I have insufficient knowledge about my condition and its treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
18.	I am easily irritated/ I have a short fuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
19.	I feel down/gloomy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
20.	I dread the nights	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
21.	I don't have the feeling that those around me take my complaints seriously	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
22.	I don't trust my body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
23.	I have a negative frame of mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
The following questions are about <u>cataplexy</u> (sudden, brief episodes of muscle weakness, triggered by certain emotions)							
Do you have cataplexy?							
If yes							
<input type="radio"/> Yes							
<input type="radio"/> No							
		<i>almost always</i>		<i>hardly ever</i>			
24.	Cataplexy negatively affects my daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
25.	I avoid certain emotions so as not to trigger cataplexy attacks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Information on SCORING

- **Questionnaire structure:**
The questionnaire includes a total of 23 items. It includes a total of 25 items for patients suffering from cataplexy.
- **Questionnaire instructions:**
The patient completes closed questions about how often a statement applies to their condition/situation. The patient can indicate this on a five-point rating scale, from “almost always” to “hardly ever”. The complaints and the impact are evaluated over a period of four weeks.
- **Measurement scale:**
Item scoring is ordinal.
- **Scoring:**

The answers are scored as follows:

	<i>almost always</i>				<i>hardly ever</i>
	0	0	0	0	0
scoring	1	2	3	4	5

- **Subscales:**
Twenty of the 25 items are used for 5 subscales. The scores are calculated as follows:
 - 1. Outlook on life:**
 - Average of the four items: 12, 13, 19, 23
 - 2. Energy, attention and activities:**
 - Average of the five items: 1, 3, 10, 11, 18 (1x possibility n/a)
 - If item 3 is completed as “not applicable”, the average of items 1, 10, 11 and 18 is taken.
 - 3. Coping with my central disorder of hypersomnolence:**
 - Average of the six items: 4, 6, 7, 17, 20, 21 (1x possibility n/a)
 - If item 4 is completed as “not applicable”, the average of items 6, 7, 17, 20 and 21 is taken.
 - 4. Physical well-being:**
 - Average of the three items: 8, 9, 22
 - 5. Impact of cataplexy:**
 - Average of the two items: 24 and 25
- **Individual items:**
The following five items are not used for a subscale and are scored individually: **2, 5, 14, 15, 16**.
The following labels can be used:

<i>item</i>	<i>label</i>
2	Daytime sleepiness
5	Nap(s)
14	Driving a car
15	Public transport
16	Sexual activity

- **Interpretation:**
 - The score runs from 1 (poor quality of life) to 5 (good quality of life). In each domain, a higher score indicates a better quality of life.
 - The individual items can be useful in the consulting room.