



# Deriving lexicon from community word usage: A social listening analysis of “brain fog” in central disorders of hypersomnolence

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## Background

While not one of the hallmark symptoms that forms the “pentad of narcolepsy,” brain fog is a symptom that many people with narcolepsy and idiopathic hypersomnia struggle with. The term “brain fog” lacks clear definition and is likely interpreted differently across conditions and between patients and clinicians.

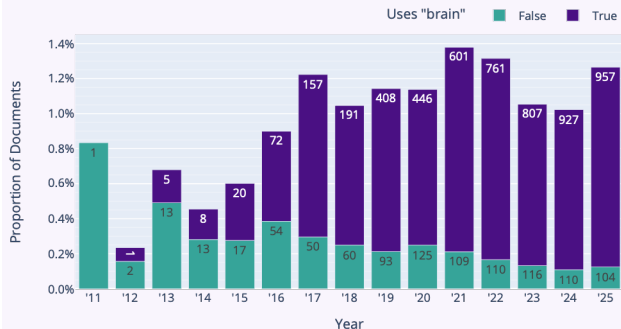
Social listening has proven to be a valuable tool to gain insights into patient experiences, especially when employed with social media groups devoted to discussion of specific medical conditions. We used social listening to analyze 14 years of central disorders of hypersomnolence (CDH) communities to reveal authentic patient experiences and evolving lexicon of brain fog for the sleep community.

## Methods

We analyzed 554,312 documents (posts/comments) from 2 subreddits (*r/narcolepsy* and *r/idiopathichypersomnia*) and a private Facebook group (PWN4PWN) using vector semantics to determine words often used in the context of “brain fog” as well as phrases used in a similar way to “brain fog”. The vectors for words/phrase were created using dimensionality reduction on a context-distribution smoothed Positive Pointwise Mutual Information (PPMI) matrix of n-grams and context words up to 7 words away. The counts of n-gram and context cooccurrences were based on the full corpus of CDH social media documents and nothing else. Two-proportion z-tests comparing documents from two timespans — historical (2011-2015) and recent (2017-2025) — were utilized to compare usage of “brain fog” and the 10 most semantically similar phrases (that satisfy the requirement of ≥10 documents using the phrase in both samples). Documents were also run through a proprietary analytics engine that recognizes mentions of clinical findings as well as their relation to the author (e.g., actually experienced, hypothetical) in social media text, to uncover clinical findings whose mentions are associated with mentions of “brain fog.”

## Results

**Figure 1: Yearly proportions and counts of documents mentioning brain fog (“brain fog”, “brainfog”, “fog”, “fogginess”, “mental fog”, “foggy brain”), colored by whether or not any mention contained the word “brain”**



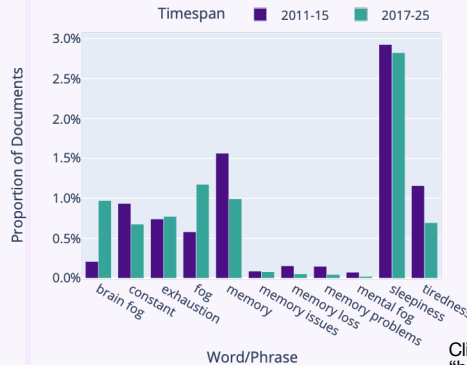
The yearly proportion of documents using “brain fog” and related “fog” words grew steadily until 2017 and has remained consistently over 1% of documents thereafter. Context words most associated with the phrase “brain fog”, as measured by smoothed PPMI, were “clears”, “forgetfulness”, “lifted”, “memory”, “fatigue”, “drunkenness”, “dissociation”, “concentration”, “cognitive”, and “constant”.

**Table 1: Words/phrases most semantically similar to “brain fog”**

Word/Phrase	Sim. Score	Word/Phrase	Sim. Score	Word/Phrase	Sim. Score
fog	0.993	forgetfulness	0.874	sleepiness brain fog	0.846
tiredness	0.909	fatigue brain	0.874	lack of motivation	0.845
mental fog	0.908	sleepiness brain	0.871	mental fatigue	0.842
fog etc	0.906	severe brain	0.864	extreme brain	0.842
difficulty concentrating	0.897	constant	0.861	memory problems	0.841
inability to focus	0.893	lethargy	0.858	exhaustion	0.84
brain fog etc	0.891	fog fatigue	0.855	like brain fog	0.839
fogginess	0.889	concentration issues	0.855	memory	0.838
poor memory	0.888	fatigue brain fog	0.854	like fatigue	0.834
memory issues	0.884	severe brain fog	0.852	intense brain	0.834
foggy brain	0.882	constant brain	0.851	brain fog fatigue	0.834
brainfog	0.88	lack of focus	0.85	sleepiness	0.832
memory loss	0.876	cognitive issues	0.846	general feeling	0.829

Phrases that were semantically similar to “brain fog”, as measured by cosine similarity, included synonyms (e.g., “fog”, “mental fog”, “fogginess”) and descriptions like “difficulty concentrating”, “inability to focus”, “poor memory”, “forgetfulness”, and “lethargy”.

**Figure 2: Proportions of documents using “brain fog” and semantically similar phrases by timespan**



N-gram	z	p-value
brain fog	18.74	< 0.001
constant	-3.32	< 0.001
exhaustion	0.34	0.734
fog	9.12	< 0.001
memory	-5.61	< 0.001
memory issues	-0.52	0.606
memory loss	-3.23	0.001
memory problems	-3.38	< 0.001
mental fog	-2.49	0.013
sleepiness	-0.77	0.443
tiredness	-5.30	<0.001

**Table 2: Results from two-proportion z-tests comparing proportions of documents mentioning “brain fog” and semantically similar phrases across the two timespans. Statistically significant results (p<0.05) are bolded**

The proportions of documents using “brain fog” and “fog” has significantly increased between the historical and recent period, while those using “constant”, “memory”, “memory loss”, “memory problems”, and “mental fog” have significantly decreased (all  $P<0.02$ ).

**Table 3: Clinical findings whose mentions are most associated with mentions of “brain fog”. Raw paragraph cooccurrence counts and NPMI are shown**

Clinical Finding	Cooccurrence with “brain fog”	NPMI
Memory impairment	133	0.358
Impaired concentration	26	0.357
Memory dysfunction	92	0.353
Sleep drunkenness	100	0.339
Poor concentration	14	0.317
Fatigue	683	0.308
Forgetful	42	0.307
Poor focus	12	0.304
Adrenal insufficiency	12	0.296
Confusion	44	0.281

Clinical findings associated with mentions of “brain fog”, as measured by Normalized Pointwise Mutual Information (NPMI) of their occurrences at the paragraph level, included *Memory impairment*, *Impaired concentration*, and *Memory dysfunction*.

## Limitations

The sample is restricted to online-active individuals and is therefore not representative of the broader population of people living with narcolepsy or idiopathic hypersomnia. Additionally, participation in the online groups studied is not limited to individuals with a confirmed diagnosis; findings may differ across platforms and communities that were not included in this analysis. Finally, data were not analyzed separately by diagnosis, so potential differences between the narcolepsy and IH populations remain an area for future research.

## Conclusions

This social listening analysis demonstrates that these online CDH communities primarily associate “brain fog” with memory impairment, as well as with concentration impairment. The community’s linguistic evolution captured across 14 years suggests the community organically develop shared language that evolved from memory-related phrases to “brain fog.” The methodology delivers real-world evidence at community scale, offering unique insights into authentic patient experiences that are difficult to capture through traditional research approaches.

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**Authors and institutions:** Zachary Cline<sup>1</sup>, Anne Marie Morse<sup>2,3</sup>, Frederick Ascencion<sup>4</sup>, Matthew Horsnell<sup>5</sup>, Jennifer Gudeman<sup>6</sup>, Judy Fallon<sup>6</sup>, Christopher DeFelice<sup>1</sup>, Maria Picone<sup>1</sup>

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Total Word Count: 324/350 (excluding title, authors and institutions)

### **Introduction:**

The term "brain fog" lacks clear definition and is likely interpreted differently across conditions, between individuals, and between patients and clinicians. Using social listening, we analyzed 14 years of central disorders of hypersomnolence (CDH) community discussions to reveal authentic patient experiences and evolving lexicon of brain fog for the sleep community.

### **Methods:**

We analyzed 554,312 documents (posts/comments) from 2 subreddits (r/narcolepsy and r/idiopathichypersomnia) and a private Facebook group (PWN4PWN) using vector semantics to determine words often used in the context of “brain fog” as well as phrases used in a similar way to “brain fog”. Usage of these phrases was compared over two timespans: historical (2011-2015) and recent (2017-2025). Documents were also run through a proprietary analytics engine that recognizes mentions of clinical findings as well as their relation to the author (eg, actually experienced, hypothetical) in social media text.

### **Results:**

Analysis revealed context words most associated with “brain fog” were “clears”, “forgetfulness”, “lifted”, “memory”, “fatigue”, “drunkenness”, “dissociation”, “concentration”, “cognitive”, and “constant”. The top 40 similar phrases included synonyms (eg, “fog”, “mental fog”, “fogginess”) and symptom descriptions like “difficulty concentrating”, “inability to focus”, “poor memory”, “forgetfulness”, and “lethargy”. The yearly proportion of documents using “brain fog” and related “fog” words grew steadily until 2017 and has been consistently >1% of documents thereafter. The proportions of documents using “brain fog” and “fog” has significantly increased between the historical

and recent period, while those using “memory loss”, “memory problems”, and “mental fog” have significantly decreased (all  $P < 0.02$ ). Associated clinical findings included *Memory impairment*, *Memory dysfunction*, and *Impaired concentration*.

**Conclusion:**

This social listening analysis demonstrates that these online CDH communities primarily associate “brain fog” with memory impairment. The community’s linguistic evolution captured across 14 years suggests the community organically develop shared language that evolved from memory-related phrases to “brain fog.” The methodology delivers real-world evidence at community scale, offering unique insights into authentic patient experiences that are difficult to capture through traditional research purposes.

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**Disclosures:**

**ZC** is an employee of and owns stock options in TREND Community. Clients of TREND Community are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel Pharmaceuticals.

**AMM** has served as an investigator, consultant, speaker, and/or on advisory boards for Alkermes, Inc., Apnimed, Avadel Pharmaceuticals, Axsome Therapeutics, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, Lilly, Noble Pharmaceuticals, Novartis, and Takeda Pharmaceutical Co.; has received grant funding from Coverys Community Healthcare Foundation, Geisinger Health Plan, Harmony Biosciences, Jazz Pharmaceuticals, the National Institutes of Health, ResMed Foundation, and UCB Pharmaceuticals; is the Chief Executive Officer of DAMM Good Sleep, LLC; and serves as an advisor for FloraWorks, Neura Health, and OpenEvidence.

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**MH** is a consultant to Avadel; has received compensation or honoraria from Alkermes, Axsome Therapeutics, Centessa Pharmaceuticals, and Harmony Biosciences.

**JF** is an employee of Alkermes, Inc.

**JG** was an employee of Avadel Pharmaceuticals and is a consultant to Alkermes, Inc.

**CD** is an owner of and owns stock options in TREND Community. Clients of TREND Community are pharmaceutical and biotechnology companies including, but not limited

to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel Pharmaceuticals.

**MP** is an owner of and owns stock options in TREND Community. Clients of TREND Community are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel Pharmaceuticals.