

Examples of HD in Everyday Life

Huntington's disease (HD) can manifest in different ways depending on the individual, however the following are examples of some common difficulties that someone with HD might experience.

Recalling people, faces and names

"I have seen my social worker five or six times over the last year or so. I don't remember what she looks like."

"I don't remember what people look like after I meet them. When I fell at the supermarket awhile ago, a lady sat with me until I could stand up (at least 10 minutes). We talked and then I walked over to the washroom to see if I could walk. When I came back, I looked for her, but had no idea what she looked like".

Communication & following conversations

When I start a sentence, I don't always know what the right thoughts and expressions are to finish it even when I am knowledgeable on the topic. I have trouble enunciating sometimes and I really have to concentrate to pronounce the right word at the right time.

I don't always have a problem understanding - I am just not able to follow a conversation, particularly a long one. I don't retain a lot of what I hear or read.

Processing information & decision making

I was always a good navigator because I like maps and have a good sense of where things are. I could picture where to go when given directions. Now, I don't picture anything. I just get confused.

Options throw me. I used to be able to take in a lot of information, sift through it and quickly make decisions that were logical and sensible. Now, if I'm given a choice between two simple options, I'm slow to decide and not certain with my choice.

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Physical Changes

"By chance, I stumbled and fell and thought nothing of it until it became a regular occurrence. Now, I avoid leaving the house when I don't have to because I'm afraid of falling and embarrassing myself."

"I have noticed that my hands and arms twitch unexpectedly, particularly when I'm tired. I'm worried that people will think I'm anxious or under the influence of drugs or alcohol."

Recognising Social Cues

"In social situations I'm slow to see when I should offer help. When friends visit with a problem, I don't always realise I could help until after they've gone. I never think to pick up the phone to talk to friends or family."

"Recently I was at a close friend's funeral and everyone around me was crying and for some unknown reason I started to laugh. Everyone was looking at me but I wasn't sure why."

Behavioural Changes

"I find I get more frustrated than normal when things don't go the way I expect them to and I can't control my frustration. I had an appointment which was delayed by 15 minutes and I got very upset with the receptionist."

"I got really angry at my son because he took the remote control from me and changed the channel but I didn't realise until later how irrational I was with him until my wife told me later."