

The Huntington Society of Canada (HSC) recognizes that some individuals at-risk for HD may choose not to participate in clinical trials. Choosing to participate in clinical trials is a personal decision; the Society encourages those who are interested to consult with their neurologist, HD clinic team, HSC Resource Centre Director or Family Service Worker to understand all aspects of this decision.

The following are some potential questions to frame your discussion with a clinician and determine expectations before, during and after a clinical trial. This is not a complete list, it is meant to give you some ideas on what you might ask when consulting a clinician. We suggest you choose the questions that are most important to you and consider additional questions that you feel are relevant.

About the Trial

- What exactly is a clinical trial?
- Why do you think participating is a good idea for me?
- What clinical trials are available for me to participate in?
- Do I have to go through predictive testing to participate?
- How often will I have appointments?
- How long will the appointments be?
- Is there someone I can talk to who has been in the trial?
- What do the researchers hope to achieve from this trial?
- Can you provide information about this trial that I can review with my family doctor?

Technical Questions

- What does informed consent mean?
- What kinds of tests and treatments are involved?
- How long, if I choose to participate, will I be involved in this clinical trial?
- What are the exclusions that would prevent me from participating in this trial?
- Can I or should I bring a support person/family member to my clinical trial appointments?
- How long do I have to make up my mind about joining this trial?
- Who will know if I am on a placebo or the actual treatment?
- If I experience improvement during the treatment, will I have access to the drug after the trial?
- Will I be told about the trial's results?
- How will my health information be kept private?
- What are my rights as a participant?

Risks and Benefits

- What are the possible side effects or risks of the new treatment?
- What are the possible benefits?
- How do the possible risks and benefits of this trial compare to those of the standard treatment?
- What happens if I decide to leave the trial?

Point of Contact Questions

- Who can I speak with about questions I have during and after the trial?
- Who will be in charge of my care?

Costs

- Where is the clinical trial located?
- Will I have to pay for any of the treatments or tests?
- Will my travel expenses be covered?
- What is the process for reimbursement?
- Who pays if I'm injured in the trial?
- Who can help answer any questions from my insurance company?
- What happens if I lose income based on trial participation?

How Will This Affect Me?

- How could the trial affect my daily life?
- How often will I have to come to the hospital or clinic?
- Will I have to stay in the hospital during the clinical trial? If so, how often and for how long?
- Are there any dietary restrictions or instructions for this trial?
- Will the treatment prevent me from working or participating in regular activities?
- What if I have side effects? Who do I call? Which ones are serious and need immediate attention?
- How would participating in this clinical trial affect my ability to participate in other trials at the same time or at a later date?
- Will I have check-ups after the trial?
- Will information be shared with my family doctor or specialist?

Treatment Choices

- What are my other treatment choices, including standard treatments?
- How does the treatment I would receive in this trial compare with the other treatment choices?
- What will happen without treatment?

RESOURCES

Find Clinical Trial Locations in Canada Online at www.huntingtonsociety.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: <https://contactme.cloud/form/huntingtonsociety>

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

Informational fact sheets for family and friends impacted by HD are available to view, print and download at www.hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/