

Checklist for participating in research studies: what should I ask?

Alzheimer *Society*

How do I find out about research studies happening in my community?

Please visit www.tdn.alz.to for information about research studies taking place in Toronto.

We suggest that you use this check sheet to take note of the details of each research study that interests you. *Make a copy for each study you are considering and leave one blank to use as a master copy.*

Name of research study: _____

Contact information/website: _____

Date: _____

1. Details of the research study

What is the purpose of the study?

Why is this study important?

Has this study been approved by a Research Ethics Board? Yes No

What type of study is it?

Clinical trial (I might receive a new drug device, diet or exercise program)

Observational study (I might undergo extra interviews and/or tests, but I will not be given a new drug, device, diet or exercise program)

Who can participate?

Who cannot participate? (*for example: can I still take my medications?*)*

Who will be responsible for my care during the study? _____

Can I leave after it is started? Yes No

Are there any negative consequences for leaving early?

What kind of tests and experimental treatments are involved?

**Note: If you are told that you need to stop taking your medications, you should first discuss this with your family caregivers and health-care providers.*

How long will the study last? _____

What is the time commitment? _____

What else is required of participants? _____

Is hospitalization required at any time? Yes No

What happens if my memory or overall health gets worse while I am in the study?

Do I need to have an available friend or family member to accompany me to the study? Yes No

If "yes," what are their responsibilities and time commitment?

What type of long term follow up, if any, is part of this study?

Will results of the study be shared with me? Yes No

If I have abnormal results, will they be shared with me? Yes No

Who funds the study? _____

Where are the study sites in

- my country my province
 my community neighbouring States, provinces, communities?

2. Risks and benefits:

What are the possible side effects and adverse reactions?

How will my safety be protected?

How will my privacy be protected?

How will the study impact my current treatment and care?

3. Costs:

Are there any costs associated with the study that I need to pay for? Yes No

If "yes," what are the details?

Will I be reimbursed for other expenses? Yes No

Notes



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