

## Brain bank hopes to beat dementia

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It's one of the scariest prospects facing HIV-positive people. The possibility of developing AIDS-related dementia or other brain and central nervous system diseases fills many of us with justifiable fear. Like mental illness, brain disease strikes at the very core of who we are.

The Australian National NeuroAIDS Brain and Tissue Bank is a pioneering new project that researchers hope will help unlock the mysteries of this challenging and often distressing group of conditions.

Unlike opportunistic infections, which occur as the result of reduced immune system function in people with lowered CD4 counts, AIDS-related dementia is believed to be directly caused by the action of HIV on brain cells. And despite improved treatments and reduced rates of most AIDS-related illnesses, the prevalence of dementia among people with AIDS is actually rising, as people are surviving longer with the disease.

Around 30 percent of people with advanced HIV disease will experience some form of neurological problem at some point.

At the Alfred Hospital in Melbourne, infectious diseases physician Edwina Wright has been working for several years to establish Australia's first HIV brain bank.

"Neurological diseases, whether you're HIV positive or not, whether you're just in the community and you've got a parent with Alzheimer's, they just unravel your life," Wright says.

"Once you start losing your sense of who you are and your memory, I think that really frightens people."

These conditions can have a devastating impact not just on the patients, but their loved ones as well. "I saw a lot of that when I was a young registrar at Fairfield in 1990-91: these gay men, having a relationship, they're out, they're living and working and one of them gets dementia and the whole gestalt, everything changes and you go from being lover to carer. And it's awful."

Operating through the Alfred and Sydney's St Vincent's Hospital, the brain bank, modelled on a successful US project, was launched in 2003 and is due to commence enrolments shortly. The brain bank will collect tissue samples from HIV-positive people after their death, but the strength of the project comes from the information participants provide during life.

As well as consenting to the removal of their brain and some other tissues in the event of their death, participants in the project will be given annual neuropsychological examinations, medical exams and blood tests. The annual 3-4 hour checkups will help the researchers monitor the neurological and psychological health of the participants and build up a detailed picture of the individual's medical history, which will eventually be linked to the stored tissues.

"So during life you're, in a sense, gathering fantastic information about neurocognitive health and neurological health of your patients," Wright explains. "Then at the time of their death, they have given permission for their brains to go into a brain bank, so what that gives you is this really powerful resource where you've got a really well characterised group of people, you know exactly how they were performing with their thinking, et cetera, up to the time that they pass away."

Wright admits that the subject of donating your brain for scientific research creates a degree of uneasiness, both for potential participants and researchers. "It's always awkward in a way talking about this because it's in anticipation of their mortality, in a way you're anticipating their mortality right up front," she says.

But she is hopeful that, as in the US, positive people will see the potential scientific benefit and sign up. As well as reflecting the "well-recognised altruism or philanthropic nature of the HIV-positive community," she says that this probably reflects the degree of anxiety that many positive people still feel about their psychological and neurological health.

“The neurological aspects of HIV I think are some of the toughest — they’re hard to diagnose, they can be hard to treat, you can still have long-term weakness and deficit. But on the upside, HIV is one of the very few dementias that is treatable and you can reverse the damage,” says Wright.

“It’s so wonderful to treat somebody and the fog lifts and they concentrate better and they perform better,” she explains. “So you’ve got a treatable dementia and that’s such a blessing to know that and to be able to work with that.” But we need to know more.

The tissue bank is likely to be a valuable resource for researchers investigating other AIDS-related illnesses. Progressive multifocal leukoencephalopathy (PML — a rare, poorly understood, and often fatal viral infection of the brain); opportunistic infections such as toxoplasmosis, cryptococcal meningitis and CMV; and long-term drug toxicities in the brain are all likely candidates for research.

The nature of the project means that the brain bank is a long-term undertaking. Some of the questions the brain bank could help answer are still emerging, including the risk of developing Alzheimer’s-like dementia in HIV-positive people, and the relationship of [hep](#) [1]Any inflammation of the liver. It is usually caused by viral infection, toxic agents or drugs but may be an autoimmune response. It is characterised by jaundice, abdominal pain, liver enlargement and sometimes fever. The different types of viral hepatitis include hepatitis A (formerly called infectious hepatitis), hep B (serum hepatitis), hep C (formerly called non-A, non-B hepatitis), and hepatitis D, E, F and G. C coinfection, smoking, ageing and testosterone levels on the development of brain disease.

Wright is quick to stress that the brain bank itself will not be performing this research, but will provide tissue samples for researchers who are looking at these conditions. Careful ethical controls have been developed governing access to material donated to the project.

The ethical issues associated with joining the project have also been very carefully considered. To prevent any suggestion of coercion, doctors will not be able to recommend the project to their patients, and people with pre-existing psychological or neurological conditions will not be able to participate.

With a target of 30–70 enrolments a year, Wright says she is hopeful that word of mouth and community awareness of the program will encourage people to consider participating.

Why should positive people consider joining this project?

There are some direct benefits for participants. “Once a year you’ll have the opportunity to have a good assessment of your mood and stress levels, how you’re thinking and performing, and those results will go back to your care provider,” Wright says, “and if we do pick up anything that worries us that will be conveyed to your care provider.”

But more importantly, the project is an opportunity to participate in potentially a huge number of research projects over the long term. “So your goodwill is taken into the future, and I think a lot of people are likely to benefit.”

“ If you’re involved in this project you will make a huge difference. ”

## Fact file

Participants will attend either the Alfred or St Vincent’s for one visit (2–3 hours) per year. Where possible these visits will be coordinated with regular clinic appointments to save time.

- Neuropsychological tests (memory, concentration, etc.) and psychological assessment (for depression, anxiety, mood disturbance).
- General physical exam, blood tests (CD4, [viral load](#) [2]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma., drug levels) and medical history will be recorded in a stringently-controlled database.
- Participants will be asked to provide a blood sample for storage and possible future genetic testing.
- Consent for participating in the project is reviewed every year and participants can withdraw at any time.
- After death, a limited post-mortem examination is performed, and the brain and some small samples of other tissues are removed.

For more comprehensive information or to enquire about participating, contact Edwina Wright on (03) 9276 6078 or Fairlie Hinton on (03) 8344 1900.

- [dementia](#)

**Links:**

[1] <http://www.napwa.org.au/glossary/term/97>

[2] <http://www.napwa.org.au/glossary/term/416>