

Museum of Human Disease Donor Information Statement (post-mortem donations)

You are invited to donate a pathology specimen from your body to the Museum of Human Disease at UNSW Sydney for the purpose of pathology education and medical research. Your donation will make possible the training of health care professionals as well as the health education of school students and the wider community. The University accepts pathology specimens in accordance with the provisions of the *Human Tissue Act 1983*. Please take time to read the following points relating to the donor program before completing the Consent Form.

Discussing your wishes with your doctor and next-of-kin or executor

You should discuss with your healthcare provider whether they think donating part of your body will be feasible and advisable. We will require a case history from your healthcare provider and/or a pathologist.

Please note that we can only take post-mortem donations from an autopsy, but autopsies are not often conducted in New South Wales and will require approval from a number of hospital and health authorities. Therefore it's important to note that even with an intention to donate and signed consent forms from your next-of-kin that it may not be possible to arrange for the donation after your death. Your doctor may be able to give you more of an idea on the likelihood of being able to arrange for an autopsy upon your death, so it's important to discuss this with them.

If you are planning to donate a specimen from an autopsy after your death, you will need to sign the MoHD Donor Consent Form for Post-mortem Donations, as well as any other paperwork required by your healthcare providers for the release of your case history. The University also requires that your next-of-kin co-signs the MoHD Donor Consent Form for Post-mortem Donations after your death. The order of seniority of next-of-kin for an adult is as follows: spouse or domestic partner, son or daughter, mother or father, brother or sister. If you do not have an available next-of-kin or executor, you may contact the NSW Trustee & Guardian, as they can be assigned as your executor.

NSW Trustee & Guardian: Telephone: 1300 364 103 Website: www.tag.nsw.gov.au

It is also desirable that you discuss your intentions with the executor(s) of your will. Inserting a provision in your will to the following effect will assist in drawing the attention of your executor(s) to this matter:

"I have expressed the wish for and consented to the removal of a human tissue specimen from my body during an autopsy after my death and for this specimen to be preserved and donated to the UNSW Museum of Human Disease for use in medical and health education programs and that consent has not been withdrawn or revoked by me.

Letting your health care professional or next-of-kin know of your wishes

Any doctor, nurse or care worker attending to you should also know of your intentions so that in the event of your death, they can inform the University as soon as possible, as well as letting appropriate medical staff know that a tissue sample is intended to be preserved.

The Museum of Human Disease should be contacted on **(02) 9065 0330** or emailed at diseasemuseum@unsw.edu.au during business hours.

Note that if your death was unexpected and/or at a private residential address, unless the treating physician is willing to issue a death certificate immediately, the police must be the first point of contact.

Once the University is advised of your death

Provided that an autopsy has been authorised and the indicated specimen has been removed, and provided that all consent paperwork has been appropriately filled out and received, the Museum of Human Disease will arrange for the transport of the specimen to the UNSW Sydney campus in Randwick and proceed to preserve your donated specimen and mount it in a display pot. Upon receipt of the specimen, museum staff will enter the details of the specimen into a physical ledger and electronic database; case history and consent paperwork will also be uploaded into the electronic database.

Once the specimen has been properly preserved, it will be mounted in a display pot for placement in the Museum of Human Disease and for use in the Museum of Human Disease's medical and public educational programs.

Risk Assessment: The University acknowledges that the specimen has inherent risk and takes responsibility for this risk from the point and time of collection.

Circumstances which may prevent the University accepting your donation

The University welcomes your valued offer of a donation, **but some circumstances may prevent the acceptance of your specimen donation.** These circumstances may include, but aren't limited to:

- Extensive damage to the specimen
- Certain communicable diseases (for example, prion diseases) where the risk of transmission to staff is deemed too high
- If too much time has elapsed between death and notification of the university
- Where medical authorities have declined to perform an autopsy



- Planned University shutdowns (e.g. Christmas/New Year break)

Please note that due to these factors and possibly others, a signed Consent Form intending donation **does NOT guarantee acceptance of your specimen donation**. Therefore, the UNSW Museum of Human Disease cannot be held liable for any costs incurred through the rejection of a donation for any reason.

Privacy of your medical information

The case history, medical imaging and other medical information provided with your donation will be used anonymously, without your name or any other identifiers being used. The University will make every endeavour to ensure your anonymity, however, complete anonymity cannot be assured as it may be possible, for example, for a relative, close family friend or health care worker who looked after you in hospital to identify you from the information provided.

Transfer of your specimen to another campus or Medical School

The University may sometimes transfer specimens from its main campus in Kensington to one of its rural clinical schools for teaching. The University may on occasion loan specimens to another medical school or other institution for teaching and education. In these circumstances, the museum will keep appropriate records of all transfers and loans to other institutions and campuses.

Complaints can be made to an independent ethical committee

Should you have any complaints concerning the arrangements for donation consent, or your next-of-kin have any complaints about the procedures involved in donation, these should first be resolved with the Museum Team Leader of the Museum of Human Disease on (02) 9065 0330. Failing that, complaints may be directed to the HREC Coordinator at UNSW Sydney on (02) 9385 6222 or email humanethics@unsw.edu.au.

Lodging your Consent Form and your right to revoke your consent

The Consent Form with the donor section completed and signed must be lodged with and accepted by the UNSW Museum of Human Disease prior to your death. Please be aware you are free to withdraw your consent to donate your body in writing at any time prior to your death without prejudice. A Revocation of Consent Form can be [downloaded from our website](#). Alternatively, you can request one by contacting the Museum of Human Disease (see Contacts).

Any further questions

If you have any further questions, please feel free to ask us.



Contacts

Museum of Human Disease

Phone: (02) 9065 0330

Email: diseasemuseum@unsw.edu.au

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Australia

