



South Glasgow University Hospitals Division

THE USE OF RESIDUAL TISSUES

Patient Information Booklet



What is tissue?

The human body is made up of cells that come together to form a large number of tissues. Sometimes the tissue forms organs such as lungs, liver appendix etc. Other tissues do not form organs. Blood, bone and skin are good examples. At times doctors need to remove tissue as part of your treatment (often during a surgical operation) or to find out what is wrong with you.

Doctors and scientists need human tissue to do medical research and teaching.

You are being treated in a teaching hospital that in addition to caring for patients has responsibilities for training medical students, nurses and other health care professionals. The hospital also has a commitment to improve health care by supporting medical research.

Your doctor may take tissue from you during the course of your treatment and any that is surplus to that required for your treatment can be used for teaching and research.

You can take part in this work. You can donate your tissues. This leaflet will help you to decide. It is important that you think about this and read the information carefully.

What do you do with my tissue after diagnosis?

When you get an operation the doctor may take some tissue from your body. They will send this tissue to a pathologist who will explain or confirm what is wrong with you.

The pathologist, who is a doctor that specializes in the examination of tissue, would normally get rid of any tissue he does not need. South Glasgow University Hospitals Division would like to keep some of this residual or 'left over' tissue for medical research and teaching.

During your treatment the doctor may take body fluids (for example blood and urine) for analysis. Some of these fluids may also be 'left over' and could also be used for medical research and teaching.

Your doctor will not take more tissue than is needed for your care.

Do I have to take part?

It is up to you to decide if you want to take part. Your decision will not affect your treatment, care or diagnosis.

If you decide to take part, you can change your mind at any time. You do not need to give a reason. Just tell your doctor at this hospital. They will dispose of any tissue stored, within the Division.

What will you use my tissue for?

We've listed below the reasons why it's important for us to collect and store your tissues.

- . ■ Research into diseases and medical conditions.
- . ■ Produce better and safer drugs.
- . ■ Teach doctors and laboratory staff.
- . ■ Audit - make sure that we keep a check on the quality of our care to patients.

Why do you need human tissue for research?

Doctors and scientists need human tissue for medical research. From it they can see and understand how a particular disease or problem starts and progresses. They can also try out different drugs and tests on the tissue. They might find new medicines and treatments. They might also find ways of diagnosing a disease earlier.

Where will doctors or scientists use my stored tissue?

- . ■ Greater Glasgow Health Board
- . ■ Wider NHS
- . ■ Universities
- . ■ The commercial sector

All researchers must prove that they are following current legal and ethical guidelines for their research.

Will you use my medical notes?

Researchers need to know the medical history of the person who donated the tissue. We need your permission to take this information from your medical notes. A trained health care worker will do this in confidence.

We will remove your name, address and hospital number before giving your information to researchers. They will not be able to identify you.

What if researchers find new information about my health?

Usually the information discovered during research is not relevant to your care or treatment. Researchers will not tell you or your doctor the results of their work.

Will the researchers test my tissue for inherited (genetic) disorders?

Researchers may test for inherited disorders. An inherited disorder can pass from parent to child. But the researchers will only have a code number for your tissue. The results of these tests will not be traced back to you. Researchers will only use the results of their tests for medical research and teaching purposes.

Will anybody make a profit from my tissues?

Under UK law it is illegal to sell tissue for profit. The South Glasgow University Hospitals Division may charge researchers a fee to cover the costs of collection, preservation and storage of tissue. The hospital also uses considerable amount of staff knowledge and skills ("know-how") to explain what is wrong with you. This "know-how", and your tissue is valuable information for researchers. The hospital will use money it gets from sharing this information with researchers to improve its services.

Tissue analysis is one of many stages in the development of new treatments. Researchers will analyze tissues from lots of people. They may develop a new drug, treatment or test. A pharmaceutical company or other researchers may then make a profit. It will not be possible for you to make a claim for money because you donated tissue. Any drug, treatment or test developed may help all of us in the future.

I want to help ... what do I do next?

If you are happy to let your residual or 'left over' tissue to be used for medical research, you must sign the consent form (Version: 1 Date: 22/07/04) for the donation of residual tissue for research and teaching. The research nurse will show you where.

I would like to find out more?

You can phone the research nurse 0141 201 1183

Thank you for reading this information.

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