

## Cancer – Collection of Tissue Post Mortem.

Report from Brighton Workshop August 2012.

The problem with cancer is not only the deranged growth, but also the mutability of cells and the consequent heterogeneity of tumours. How to treat a cancer which has one set of characteristics in the primary tumour, and another in metastatic tumours? And what if some metastatic tumours - which may be anywhere in the body - have unique and individual characteristics? How can treatment be decided upon in these circumstances?

We might question further: Are biopsies taken to ascertain treatment representative of the cancer as a whole? Might prescription of appropriate treatment be hindered because tumours may be inaccessible and biopsies cannot be obtained with which to find the driver of the cancer? For the patient, this makes for a desperate situation.

Dr Rosalie Fisher, Radiation Oncologist, took kidney cancer as an example of disease which shows these challenging features. Her objective is to obtain tissue from patients post mortem, and discover how tumours change as they progress. There are also bio-markers to discover (currently there are none) to enable treatment effectiveness to be monitored.

In sum, to understand the vast puzzle that is cancer and create effective treatment, science needs to understand how tumour tissue varies and changes throughout its structure and period of growth and spread. Part of the answer lies in collection and analysis of tissue: of the normal tissue in which the cancer originates, and the tumour in both primary form and metastatic growth. Comprehensive tissue samples can be taken after death, when tumour tissue in difficult-to-access sites can be obtained with relative ease, but patients may find this concept startling and somewhat offputting. So how to educate the public so they know the value of such samples?

Rosalie Fisher asked members of the audience for consultation and advice on how to take forward the concept of post mortem tissue collection.

She showed us that kidney cancer is notoriously difficult to treat. Some tumours have little improvement after treatment with new biological agents. For the patient, this means a poor prognosis and high symptom burden. For this form of cancer, there is no reasonable bio-marker indicating potential outcomes for any of the 7 therapies currently available. Why no marker? This is because there is no tissue collection available for rigorous analysis to discover and understand the molecular relationship between primary and secondary tumours.

Tissue collected from living patients allows analysis of tumour sites, but biopsies have their own challenges and risks, whereas fresh tissue from recently deceased patients allows research to continue at no risk.

Such collection seems simple, but Rosalie wanted to know how patients might be approached before death, to discuss consent and research protocol. While society is grateful to patients who make this gift, the process is onerous and challenging for patients, who may need to put aside personal wishes for a home death surrounded by family and friends. There will need to be access to mortuary and post mortem facilities, which implies that a hospital death is likely, and relatives may countermand

the patient's wishes at the last minute - something we were surprised to find is possible.

The idea of collecting tissue after death is not new. The Alzheimer's Society and Multiple Sclerosis Society recognise the importance of obtaining tissue for research, and have devised policies and guidelines for those individuals who wish to consider doing so. The Human Tissue Authority also have information about this, and other forms of tissue donation.

At a meeting in Newcastle organised by the Collaboration of Cancer Biobanks, on 10 October, Rosalie expanded her argument to an audience of researchers. A pathologist told the audience that post mortem services were being wound down nationally, and services were contracting – it is felt that the need has diminished. Consequently, the availability of an expert to dissect out the required tissue may be in question.

After thinking about the logistics of time and place of death, availability of pathology staff and services, would you want to donate tissue after death? As far as the donor is concerned, recommendations are to involve the family at a very early stage so they are not faced with a difficult situation at a very difficult time. Involve also the GP, the clinician, and the nurse. Only sign up when the full process has been explained, and after full consideration of all the facts available. Coroners are usually very understanding it seems, and pathologists have great respect for those people who do donate. Donors are assured that their remains will be treated with the utmost respect, and that desired burial customs will not be compromised. This most generous of selfless acts will help research find cures for the scourge of modern diseases.

Cambridge Human Anatomy Centre has an annual service for all those who have given their bodies for use in anatomy studies, as do many teaching hospitals. This article published in the Guardian on 16 June 2012 explains more and includes a very moving tribute to their donors from a group of medical students.

<http://www.guardian.co.uk/lifeandstyle/2012/jun/16/donate-body-to-medical-science>

The HTA website offers information about tissue donation after death:

<http://www.hta.gov.uk/bodyorganandtissuedonation/howtodonateyourtissueforresearch.h.cfm>

<http://www.hta.gov.uk/bodyorganandtissuedonation/howtodonateyourbody/donatingyourbrain.cfm>

And the Alzheimers Society has blazed a trail:

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=116](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=116)

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