Referral Guidelines for Individuals With a Family History of Cancer
Cancer Genetics Service for Wales

Contacts

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We will accept referral where the following criteria are met

Breast Cancer

- 1 first degree relative diagnosed at 40 years or less
- 2 first degree relatives or 1 first degree and 1 second degree relative on the same side of the family, diagnosed at 60 years or less
- 3 first or second degree relatives on the same side of the family diagnosed at any age
- 1 first degree male breast cancer
- A first degree relative with bilateral breast cancer
N.B. breast cancer can also be inherited through the paternal side of the family

Breast / Ovarian Cancer

- Minimum: 1 of each cancer in first and second degree relatives
  (If only one of each cancer, the breast cancer diagnosed under 50 years)
- A first degree relative who has both breast and ovarian cancer

Ovarian Cancer

- 2 or more ovarian cancers on the same side of the family, at least one of whom is a first degree relative

Colorectal Cancer

- 1 first degree relative diagnosed at age 45 or less
- 2 first degree relatives (incl. both parents) or 1 first degree and 1 second degree relative on same side of the family, diagnosed at any age
- 3 relatives, all on the same side of the family (at least 1 should be a first degree relative)
- Familial Adenomatous Polyposis (FAP) or other polyposis syndromes
- Hereditary non polyposis colorectal cancer
N.B. Families with cases of colorectal and endometrial cancer may also be referred

Other Cancers

- A family history of a known single gene cancer syndrome (e.g. von Hippel-Lindau disease, multiple endocrine neoplasia, retinoblastoma)
- "Related Cancers": There are some rare cancer syndromes (e.g. Li Fraumeni syndrome and Cowden syndromes) where a variety of different cancers occur within a family.
- A family history of 2 or more cases of the same cancer in first or second degree relatives (e.g. gastric cancer, prostate cancer, renal cancer, pancreatic cancer, melanoma)
- In any family where there is suspicion of a hereditary aetiology, the possibility of referral should be discussed on an individual basis

These guidelines are the result of an All-Wales multidisciplinary consensus group meeting and feedback from GP focus groups. They are subject to ongoing validation.
The Cancer Genetics Service

5-10% of cancers of the breast, ovary and colon are due to an inherited predisposition. The Cancer Genetic Service for Wales (CGSW), part of the All-Wales Genetics Service, has been established to provide a service for individuals who meet the criteria for referral. Our remit is to assess the risk of cancer based on the reported family history, to work with relevant specialist clinicians and recommend screening strategies where appropriate. The referral criteria suggest who may be at significantly increased risk of an inherited form of cancer.

Process: On receipt of a referral

- Questionnaire sent to patient, to identify family history and baseline information. (We only take the referral further if the questionnaire is returned.)
- Where necessary, family history clarified and confirmed.
- Risk assessment process to categorise patient as ‘High’, ‘Moderate’ or ‘Average’ risk.
- Patient, referring doctor and GP informed of risk category.
- All high-risk and some moderate-risk patients offered an appointment in Cancer Genetics clinic.
- All patients given contact details for Cancer Genetics Service and invited to recontact us in the event of a change in family history.

Average risk

We aim to reassure this group that, on the information given, their risk is not significantly raised above that of the general population, so extra surveillance is not suggested. They should continue standard health awareness and screening as for the general population.

Moderate risk

We aim to facilitate or coordinate ongoing management between primary care and appropriate specialist clinicians (e.g. local breast or colorectal surgeons) or screening organisations (e.g. Breast Test Wales). Patients may be referred directly by the Cancer Genetics Service or we will suggest an appropriate referral route for the GP. In some cases laboratory investigations may be recommended to help clarify a patient’s risk status.

High risk

In addition to suggesting the involvement of other specialist clinicians and recommending appropriate surveillance, this group will be seen in the Cancer Genetics clinic and genetic testing may be offered in some families.

An appointment in the Cancer Genetics clinic offers

- The time to discuss concerns about a family history of cancer and implications for both the patient and other family members.
- Where appropriate:
  - Referral or recommendation for appropriate screening/surveillance.
  - Storage of DNA and organisation of genetic testing, where appropriate.
  - Opportunity to participate in research studies.

All Wales Queries:

Cancer Genetics Service for Wales,
Institute of Medical Genetics,
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Heath Park, Cardiff CF14 4XN
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Copies of these guidelines in Welsh are also available from this address.