



GUIDELINES FOR THE USE OF GENOGRAMS IN PALLIATIVE CARE



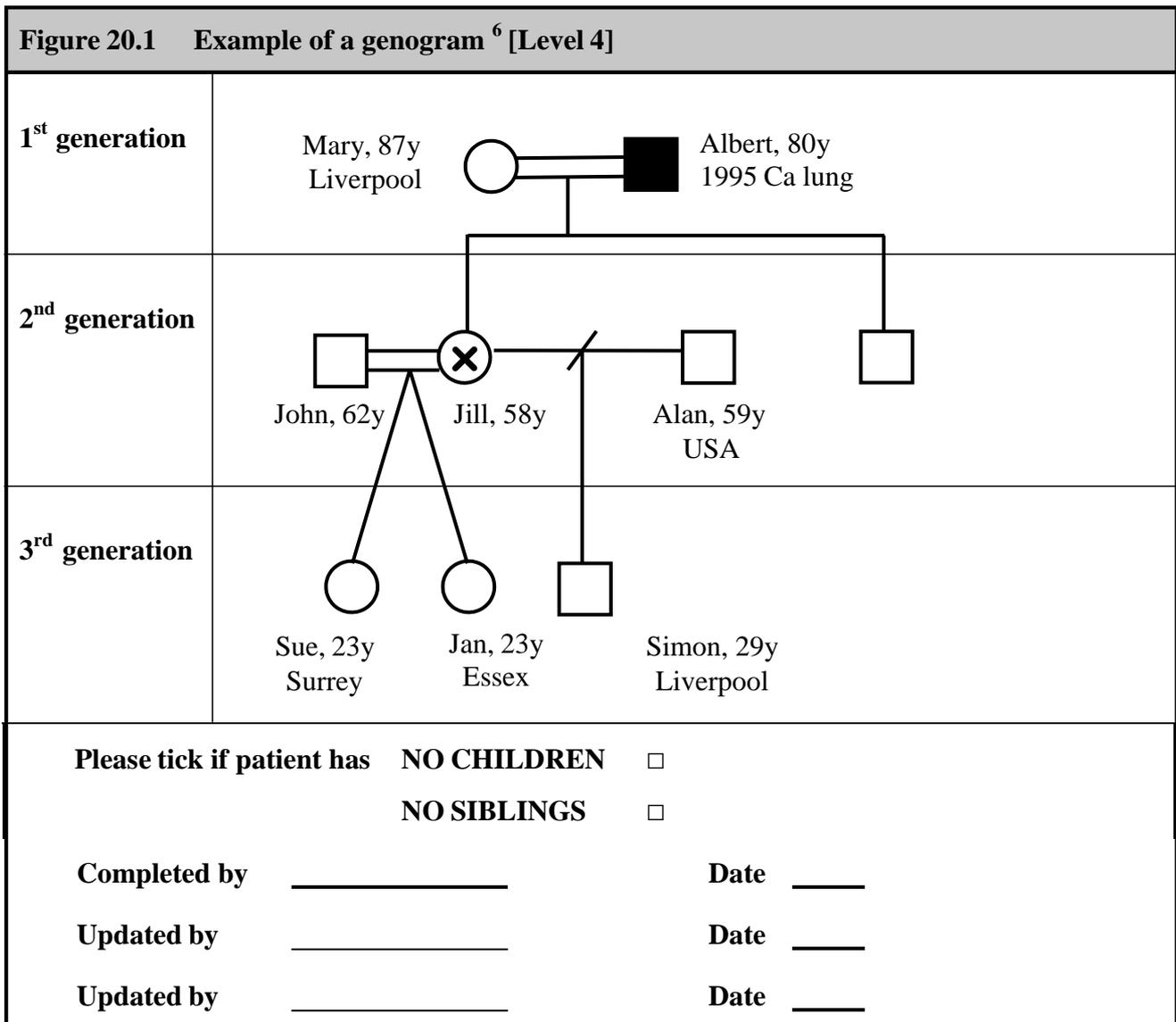
20.1 GENERAL PRINCIPLES

- Specialist palliative care encompasses the social, emotional and spiritual care of the patient and their family, and the physical needs of the patient. Recognition and understanding of the patient's social circumstances may be as influential in the relief of distress suffered by patients and their families/carers as the identification and palliation of physical symptoms.¹
- The genogram has been widely promoted as a useful tool for gathering, recording and displaying family information in order to practice family centered care.^{2, 3, 4}
- Genograms have the scope to record three broad categories of information:⁵
 - Basic family structure (biological and legal relationships across generations).
 - Information about individual family members (demographic data, personality characteristics, emotional, behavioural and medical problems).
 - Family relationships (patterns of closeness, conflict and estrangements amongst family members).
- The benefits of compiling genograms with patients include:
 - Encouraging a holistic comprehensive assessment which encompasses physical and psychosocial aspects.^{2, 6}
 - Facilitation of communication with patients, families and other health care professionals.⁷
 - Providing reminiscence opportunities for the patient.²
 - Providing a record that consideration has been given to the family unit and its influence on the patient and their needs. This can then be audited in the future.⁷
 - The identification of possible hereditary disease.^{5, 8}

20.2 GUIDELINES

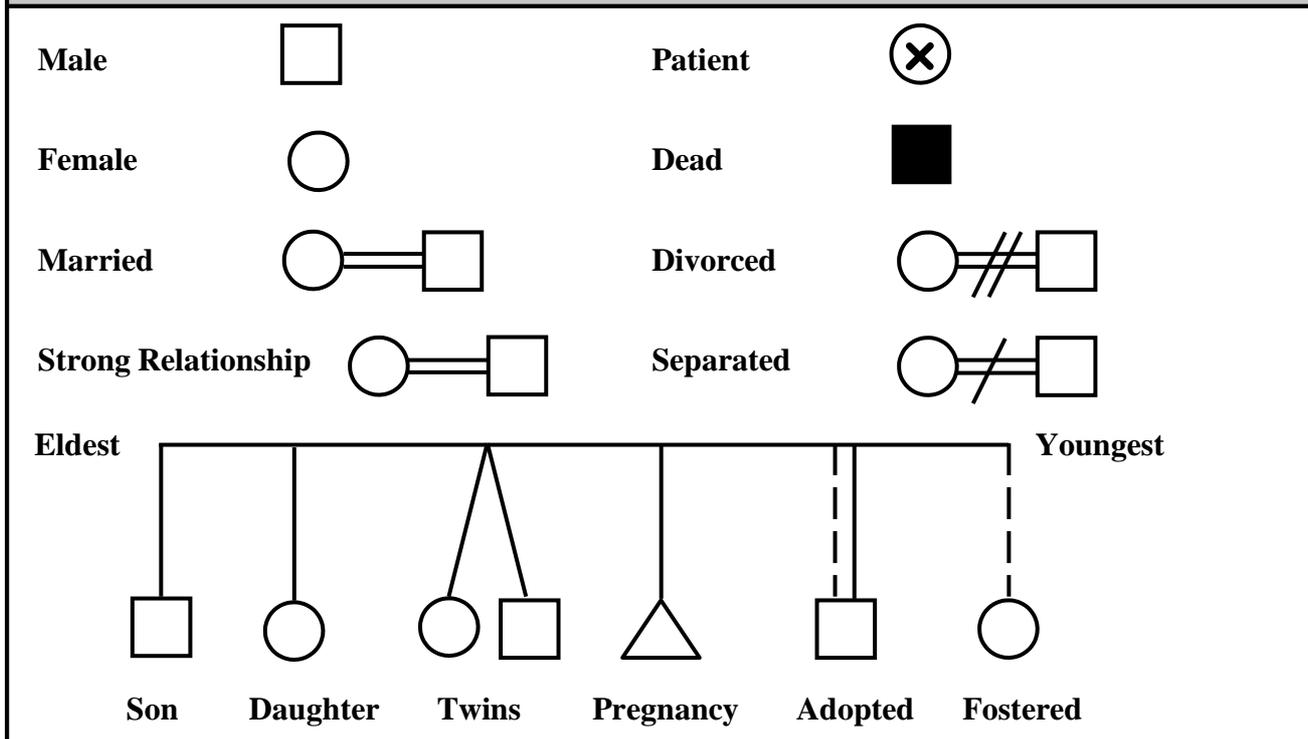
- All patients should have the opportunity to compile a genogram with a specialist palliative care worker during their initial assessment. [Level 4]
- The genogram should be recorded in documentation available to all disciplines i.e. the multidisciplinary notes.⁶ [Level 4]
- The genogram is a living document that may be updated by any member of the multidisciplinary team on discovery of new information. Any changes or additional information to the genogram should be signed and dated.⁶ [Level 4]
- All genograms should include at least three generations and should adhere to the notation / key provided (see Figures 20.1 and 20.2). [Level 4] Notation outside the palliative care setting may differ.⁶ [Level 4]

- Negative assessments (such as the absence of children /siblings) should be recorded (see Figure 20.1).^{5,7} [Level 4]



- The patient should be aware that relevant information given during completion of genograms may be shared with other specialist palliative care workers.⁶ [Level 4]
- It would be best practice to include a basic genogram in referrals between specialist palliative care settings if the patient gives permission for this.⁶ [Level 4]
- Completion of genograms may identify the possibility of a hereditary disease. If this occurs it should be raised with the physician in charge who may need to discuss referral to the Merseyside and Cheshire Clinical Genetics Service with the patient and family.⁹ [Level 4]
- Figures 20.3 and 20.4 give further information on the local Clinical Genetics Service and the referral criteria. [Level 4]

Figure 20.2 Annotations commonly used in genograms ¹⁰ [Level 4]



Referral Guidelines for Patients Concerned due to Family History

- Patients should initially be referred to the Family History Surveillance Clinic for either breast or bowel cancer if this is available locally.

Referral process

- Following referral the patient has telephone contact or a face to face appointment with a genetic counsellor to collect further information. Further clarification and confirmation of the relevant diagnosis will then occur. This may take several weeks.
- The patient's GP, the referring doctor and the patient all receive information on risk grouping and are advised about screening where appropriate (see Table 20.2).
- Contact details for further information are given in Table 20.3.

The functions of the cancer genetics service are:

- To provide risk assessment, information, and psychological, emotional, physical support to individuals with an increased risk of developing cancer due to their family history.
- To use a multidisciplinary team approach to assess the needs of individuals and the appropriate level of intervention and care required.
- To provide support and counselling to the high risk families already identified.
- To provide information, training and support for healthcare professionals who provide genetic information to families through either primary care or cancer clinics.

The genetics clinics provide the following services:

- Time to discuss issues at length.
- Making or confirming a diagnosis.
- Providing understandable information about the condition.
- Discussion of the risks of becoming affected with the condition in the future.
- Discussion of risks to future children.

And where appropriate:

- Follow up of other family members at high risk.
- Storage of DNA from affected individuals and organisation of molecular genetic testing.
- Discussion of the advantages and disadvantages of gene testing options.

Clinical genetics staff include:

- Genetic Counsellors: Nurses with experience in genetic counselling or scientists with a qualification in genetic counselling.
- Physicians: Geneticists are medical consultants who specialise in Clinical Genetics.

Referral categories:

- Only 5-10% of cancers of the breast, ovary and colon are due to an inherited predisposition. **The Family History Breast Surveillance Clinics** supported by the **Merseyside and Cheshire Cancer Genetics Service** assess the risk of cancer based on the reported family history and work with the relevant specialists to recommend further screening strategies where appropriate. The referral criteria suggest who may be at a significantly increased risk of inherited cancer and who may benefit from a referral to the Clinical Genetics Service. This service offers genetic risk assessment and recommendations for clinical surveillance if appropriate. Referrals can be discussed with a member of the genetics team (see Figure 20.4). Types of referral to the cancer genetics services are detailed in Table 20.1

Figure 20.4 Referral criteria for patients with a family history of cancer: Merseyside and Cheshire Clinical Genetics Service ¹¹

| Breast cancer | Breast/ ovarian cancer | Colon cancer | Other cancer syndromes |
|---|---|---|--|
| <ul style="list-style-type: none"> • One first degree ^a relative diagnosed at ≤40 years old. • Two first degree relatives diagnosed at ≤50 years old. • Three first degree relatives at ≤60 years old (on the same side of the family). • A first degree relative with bilateral breast cancer. <p>NB Breast cancer may also be inherited through the paternal side of the family.</p> | <ul style="list-style-type: none"> • Minimum: one of each cancer in first degree relatives (if only one of each cancer). • A first degree relative who has both breast and ovarian cancer (breast cancer ≤50 years old). • One relative with ovarian cancer and two relatives with breast cancer at ≤60 years old, who are first degree relatives. • Two or more ovarian cancers; at least one first degree relative affected (on the same side of the family). | <ul style="list-style-type: none"> • One first degree relative diagnosed at ≤45 years old. • Two first degree relatives (on the same side of the family). • Both parents. • Three relatives, all on the same side of the family (at least one should be a first degree relative). • Familial Adenomatous Polyposis; Familial Juvenile Polyposis; Peutz-Jeghers Syndrome. • Hereditary Non Polyposis Colorectal Cancer (revised Amsterdam criteria ^b) | <ul style="list-style-type: none"> • Patient from a family with a known single gene cancer syndrome: Von Hippel-Lindau disease; Multiple Endocrine Neoplasia (MEN), retinoblastoma. • Related cancers i.e. rare cancer syndromes where a variety of different cancers occur within a family e.g. Li Fraumeni syndrome and Cowden syndrome. If there is a high index of clinical suspicion, the possibility of referral should be discussed on an individual basis. |

a) First degree relative = parent or sibling. A second degree relative = uncle, aunt, nephew or grandparent.

b) Revised Amsterdam criteria = 2 relatives with colon cancer (one ≤50 years old) plus one relative with either cancer of the uterus, colon, ureter, stomach or ovary ≤50 years old.

Table 20.1 Types of referral to the cancer genetics service ¹¹

| | |
|---|--|
| <p>Breast cancer Ovarian cancer Familial bowel cancer Hereditary non-polyposis colon cancer (HNPCC) Familial adenomatous polyposis (FAP)</p> | <p>Rarer more specific cancer predisposition syndromes i.e.</p> <ul style="list-style-type: none"> – Von Hippel Lindau disease – Gorlins syndrome – Neurofibromatosis Type 1 and Type II – Li Fraumeni syndrome – Ataxia Telangiectasia and chromosome breakage disorders |
|---|--|

Table 20.2 Management of different risk categories ¹¹

| Low risk | Moderate risk | High risk |
|---|---|--|
| This group of patients are reassured that on the information given their risk is not raised to a significant degree above that of the general population. Extra surveillance is not suggested. It is clearly stated that individuals in this group still have the same risk (or perhaps slightly higher) of cancer as any other individual of the same age in the general population. They should continue the standard health awareness and screening as the general population. | Ongoing management between primary care and appropriate specialist (for example the local Family History Screening Clinic) is recommended. An appropriate referral route is suggested /or discuss options for the GP and patient to consider. | In addition to suggesting the involvement of specialist surveillance, this group will be offered a genetic clinic appointment, and if requested genetic testing may be pursued in some families. |

Table 20.3 Contact information ¹¹

| | |
|--|---|
| Family History Breast Screening Clinics | Various locations including: Countess of Chester Hospital NHS Foundation Trust North Cheshire Hospitals NHS Trust Royal Liverpool and Broadgreen University Hospitals NHS Trust Southport and Ormskirk Hospital NHS Trust St Helens and Knowsley Hospitals NHS Trust Aintree University Hospitals NHS Foundation Trust |
| Merseyside and Cheshire Clinical Genetics Service Dr L Greenhalgh Dr I Ellis Dr A Fryer Ms C Benjamin - Genetic Associate | Alder Hey Children's NHS Foundation Trust Eaton Road Liverpool L12 2AP |
| All Clinical Genetics Enquiries | 0151 802 5000 |
| Appointment enquiries | 0151 802 5001/5002 |
| Department Fax | Fax: 0151 252 5951 or 8025095/5096 |
| Services Manager Mr Matt Wardle | 0151 802 5010 |
| Chester Clinical Genetics Service Mrs S Rowe - Genetic Associate | Mosten Lodge Countess of Chester Hospital NHS Foundation Trust Liverpool Road Chester Tel: 01244 364754 or 01244 364770 Fax: 01244 364770 |

20.3 STANDARDS

1. All patients referred to a specialist palliative care team (hospital, community or hospice) should have a completed genogram recorded in the multidisciplinary notes as part of the initial assessment.^{6,7} [Grade D]
2. All genograms should be signed and dated at the initial assessment.⁶ [Grade D]
3. Genograms should be reviewed and updated as necessary, at a minimum of 3 months following the previous assessment, and signed and dated each time.⁶ [Grade D]
4. Genograms should be compiled according to the annotation given in Figure 20.2.⁶ [Grade D]
5. The minimum content of the genogram should include 3 generations (children, parents, siblings, grandchildren or grandparents) and should highlight significant relationships (spouse, partner). For these relationships the following should be recorded:⁷ [Grade D]
 - Name, age, location, deaths.
 - Age at death, years since death, cause of death (if appropriate).

20.4 REFERENCES

1. Ferrell B. The Family. In: Doyle D, Hanks GWC, Macdonald N (eds). *Oxford Textbook of Palliative Medicine*. 3rd edition. Oxford: Oxford University Press; 1998. p.909-918.
2. Herth KA. The root of it all: Genograms as a nursing assessment tool. *J Gerontol Nurs* 1989; **15(12)**: 32-37
3. Puskar K, Nerone M. Genograms: A useful tool for nurse practitioners. *J Psychiat Ment Health Nurs* 1996; **3(1)**: 55-60.
4. Rogers J, Durkin M, Kelly K. The family genogram: an underutilized clinical tool. *N J Med* 1985; **82(11)**: 887-892.
5. Like RC, Rogers J, McGoldrick M. Reading and interpreting genograms: a systematic approach. *J Fam Pract* 1998; **26(4)**: 407-412.
6. Merseyside and Cheshire Palliative Care Network Audit Group. *Use of Genograms in Specialist Palliative Care*. Expert Consensus. March 2005.
7. Lioffi C, Hatira P, Mystakidou K. The use of genograms in palliative care. *Palliat Med* 1997; **11(6)**: 455-461.
8. Lallou F, Evans G, Hopwood P. Investigating genetic predisposition to cancer. *Eur J Palliat Care* 2000; **7(5)**: 183-184.
9. Lallou F, Kerr B, Friedman JM, Evans D (eds). *Risk Assessment and Management in Clinical Genetics*. Oxford: Oxford University Press; 2005.
10. McGoldrick M, Gerson R. *Genograms in Family Assessment*. New York: Norton; 1985.
11. Merseyside and Cheshire Clinical Genetics Service. [Internet] Available from: http://www.lwh.me.uk/html/gen_clinical.php. [Last accessed 15th November 2009]

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