Gynaecology CRG (Lancs & South Cumbria)

Follow Up Guidelines V6.0

** VALID ON DATE OF PRINTING ONLY – all guidelines available on the Strategic Clinical Network website : GMLSCSCN Gynae NSSG webpage

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Background

There have been numerous reasons as to why patients following treatment for a gynaecological cancer are followed-up at the hospital by clinicians at regular intervals for many years. These have included:

Detection of disease recurrence
Regular clinic follow-up may enable early detection of disease recurrence. Depending on the disease site, stage and previous treatment this may improve the chance of salvage. It is generally acknowledged that recurrence beyond 3 years post treatment is uncommon in any gynaecological oncology disease sites.

Symptom management
Gynaecological cancer follow-up clinics enable expert management of symptoms associated with treatment side effects as well as symptoms of active diseases. It must not be forgotten that this is also performed in the community utilising specialist personnel such as palliative care and lymphoedema specialists.

Patient reassurance
Many patients feel they benefit from regular follow-up and are reassured when no evidence of recurrent disease is found. Some patients however become anxious prior to their follow-up appointment.

Outcome Data
Reviewing patients regularly in follow-up clinics enables accurate outcome data to be measured.

Benefit of clinician
Oncology clinicians benefit from reviewing successfully treated patients in clinic. Trainees also benefit from seeing living proof of effective treatments.

British publications addressing the value of regular follow-up for gynaecology oncology patients with endometrial, cervical and vulval carcinoma have suggested there may be little or no benefit from regular follow-up. It has also been suggested that regular routine clinic follow-up may evenbe harmful for patients in terms of delaying their presentation for review at the onset of symptoms suggesting possible recurrence. Unfortunately, there is no high quality evidence as to the value of follow-up in gynaecological oncology. A recent piece of research undertaken at a unit revealed that patients and staff felt that follow-up should be individual, holistic and based on patient choice.

There are several Government documents and initiatives suggesting that routine follow-up should be changed in order to improve services. Below is a list of a selection of documents and what they recommended / suggested with regard to follow-up.

- Improving Outcomes in Gynaecological Cancer (1999) – There is no evidence to support routine follow-up for women whose cancer is in remission.
- Improving Communication in Cancer Care (2003) – Improvements regarding communication are required.
- NHS Cancer Plan (2004) – Services should be patient centred.
- Ten High Impact Changes for Service Improvement and Delivery (2004) – Avoiding unnecessary follow-up and for it to be in the most appropriate setting.
- Applying High Impact Changes to Cancer Care (2005) – It should be clinically appropriate & patients' experiences should be improved.
- National Cancer Survivorship Initiative – Vision (2010) – Tailored support for patients in remission.

An alternative model of follow up has been commenced at Pan-Birmingham and Kent & Medway Cancer Network in the form of patient initiated follow-up. Detailed patient information is provided at an "exit" interview at the end of treatment (surgery, chemotherapy or radiotherapy). The patient is educated regarding symptoms suggestive of a possible disease recurrence. Contact details of the nurse specialist are given and the patient is encouraged to telephone her at any time to discuss any concerns they may have regarding recurrence of disease or side effects related to treatments. The nurse specialist can then triage the patient appropriately, for urgent review by a clinician, to the General Practitioner, to a special service such as lymphoedema clinic or for discussion at the next multidisciplinary team meeting. The model of care is attractive in that it empowers patients and enables them to access care at short notice when required. It also helps patients to progress beyond the "sick role" as soon as they have recovered from treatment. Most patients develop a relationship with the clinical nurse specialist that begins at the time of diagnosis and usually continues throughout the patient's treatment. The CNS usually becomes an essential link with the clinical team. This resource should be incorporated when planning changes to follow- up guidelinesand their link and knowledge regarding the patients should be used harnessed.

There is a proposal for a research study of nurse led telephone follow up of endometrial cancer (L&SCCN and UCLAN).

In the absence of quality evidence, we should continue with routine regular follow-up in the clinical setting for the majority of gynaecological patients but with a maximum follow-up of 3 years. All patients will be followed up at the referring cancer unit in conjunction with the cancer centre personnel on completion of treatment. At the same time, it is possible to rationalise the scheduleof routine clinic reviews, and supplement this with an integrated model of patient initiated follow-up.The follow-up schedule should be discussed with each patient and their wishes taken into consideration. Each plan of follow-up should be recorded in the notes, the GP informed, and patients given a copy of the plan.

In order to help patients, understand the rationale for changing follow-up and encourage them to progress beyond the sick role completion of treatment and follow up interviews are being suggested. These could be run by the nurse specialists and allow time for issues regarding recovery such as physical emotional, sexual, body image or social aspects to be discussed. Detailed information should be given regarding symptoms that may suggest a recurrence of disease and contact details given regarding who and how to contact personal in order to be seen quickly at the next available follow-up clinic. Leaflets should also be produced explaining the follow-up procedures within the network.

Range of routine clinic review which can be considered as reasonable

- Initial post treatment clinic review
- 3 – 6 monthly review post completion of treatment (1st year)
- 3 - 6 monthly review 1 year after completion of treatment (2nd year)
- 3 – 12 monthly review 2 years after completion of treatment (3rd year)

The above are suggestions only and clinicians should negotiate with patient times and frequency of follow-up acceptable to patient and clinician. Where patients have undergone treatment by more than one speciality (e.g. surgery and radiotherapy) it is suggested that the initial post treatment follow-up is performed by the surgeon after treatment and then by the clinical oncologist after completion of radiotherapy. The consultant providing the last treatment should then follow-up the patient but have the option of sharing or transferring the follow-up if more appropriate.

Clinical nurse specialists would be able to arrange for the patient to be reviewed at any time on an urgent basis, in addition to the standard regime as described. Patients would be given contact details of other members of the team at the completion of treatment interview enabling them to instigate their own follow-up if required in between the scheduled appointments.

Patients requiring chemotherapy

- Initial post treatment clinic review
- As the minimum standard routine clinic review
- To increase follow-up dependent on how patient is clinically
- To negotiate with patient times and frequency of follow-up acceptable to patient and Clinician.

These patients are likely to have more advanced disease and have a higher risk of local, regional and distant relapse, their follow-up may need to be adjusted to assess the treatments morbidity and relapse status. These patients should be seen by the clinical oncology team. Patients should also be given the opportunity to attend a completion of treatment interview following their initial treatment in order to be given details of symptoms that would indicate a recurrence, contact details of whom and how to contact the team urgently if required and to discuss any physical emotional, sexual, body image or social aspects following their initial treatment. Patients could instigate their own follow-up in between scheduled appointments if required.

Patients requiring radiotherapy or chemo-radiotherapy

- Initial post treatment clinic review
- As the minimum standard routine clinic review
- To see patient as frequently as required dependent on treatment related morbidity
- To increase follow-up dependent on response to treatment
- To negotiate with patient times and frequency of follow-up acceptable to patient and clinician.

These patients are likely to have more advanced disease and have a higher risk of local, regional and distant relapse, their follow-up may need to be adjusted to assess the treatments morbidity and relapse status. These patients should be seen by the clinical oncology team. Patients should also be given the opportunity to attend a completion of treatment interview following their initial treatment in order to be given details of symptoms that would indicate a recurrence, contact details of whom and how to contact the team urgently if required and to discuss any physical emotional, sexual, body image or social aspects following their initial treatment. Patients could instigate their own follow-up in between scheduled appointments if required.

Disease and treatment related morbidity

Review in follow-up clinic will remain available on a basis of need. In addition to patient initiated review more frequent review can be initiated by any members of the multidisciplinary team on the basis of need. For example, patients with treatment related morbidity may require more frequent regular review in a follow-up clinic. Patients could instigate their own follow-up in between scheduled appointments if required.

Clinical Trials

Patients involved in clinical research and trials should undergo follow-up as prescribed by the trial protocol. They should be encouraged to participate in a completion of treatment interview in order to progress beyond the sick role. It would also give them the opportunity to discuss any physical emotional, sexual, body image or social problems. They would be given information regarding symptoms that would indicate a recurrence and contact details, so they could access the follow-up clinic at any time in between scheduled follow-up if required.

Very Low Risk Patients

- Adequately staged FIGO stage 1 ovarian tumours of borderline malignant potential.
  - These groups should be managed with patient initiated follow-up alone.

- Carcinoma of the cervix FIGO stage 1A
  - These patients should be managed as per high grade CIN under the NHSCSP cytology guidelines (not suitable for HPV 'test of cure').

Disease recurrence in these particular patient groups above is so rare that they do not require any structured routine clinic reviews beyond the initial post treatment appointment. It is likely that these patients would also benefit from a completion of treatment interview with the CNS to allow time for discussion regarding any physical, emotional, sexual and body image issues following treatment. At the same interview details of how to contact any member of the team urgently could be given along with symptoms that could suggest a recurrence. Any patients who feel there is a need for concern could instigate follow-up by liaising with a relevant member of the team in order for them to be seen in a timely manner.

Nordin, et al., Mode of detection of recurrent gynecological malignancy: does routine follow-up delay diagnosis and treatment? International Journal of Gynecological Cancer. 16(5):1746-1748, September/October 2006

Fung-Kee-Fung, et al., Follow-up after primary therapy for endometrial cancer: a systematic review. Gynecol Oncol. 2006 Jun;101(3):520-9.

Kew, et al., The role of routine follow-up after gynecological malignancy. Int J Gynecol Cancer. 2005 May-Jun;15(3):413-9.

Olaitan, et al., A critical evaluation of current protocols for the follow-up of women treated for gynaecological malignancies: a pilot study. Int J Gynecol Cancer. 2001 Sep-Oct;11(5):349-53.

End of Life Pathway

The WHO describes palliative care as 'the active, holistic care of patients with advanced, progressive illness'.[1]

The hub of any patient's medical health is the GP, they are in an ideal position to provide and coordinate this care for a number of reasons:

- they have long-established relationships with their patients which are so important at this critical time in a patient's life
- they are used to dealing with co-morbidity and uncertainty
- they are trained to treat patients holistically which is central to the palliative care approach.

GPs have to be able to provide high quality, equitable care, and to work together effectively with specialist teams if they are to provide the best primary palliative care for all who require it.

There is an increasing imperative to be able to recognise the needs of all patients nearing the end of their lives, not just those with cancer, and to be able to extend some of the developments in care provided for cancer patients to those with other illnesses, which constitute 75% of all deaths. A large proportion of patients receive news of palliative disease which will lead to end of life from the secondary care and steps need to be put in place to ensure provisions are met, this becomes more relevant when the time frame for commencing end of life provision is approximately one year before death ie at the time of advancing disease.

Proactive end of life care

In order to provide optimal care for any patient nearing the end of their life, i.e. not just in the terminal or dying phase, but in their last year, we need to be able to do three things:

- identify where a patient is on their illness trajectory – do they have years, months, weeks or days to live? This then allows proactive management, calmer planning and less 'fire-fighting' crisis management
- assess their needs, and those of their family/carers, in the light of their advance care plan
- plan (using a management plan) and then provide their care according to the patient's preferences and varying needs, at different times.

A key point is for all hospital and hospice clinicians who recognise that a patient may be in their last year of life to notify the patient's GP and recommend that the patient is added to the palliative care register. The basis for this lies in the End of Life Care Strategy.

End of Life Care Strategy

The strategy was developed over a period of a year by an advisory board led by Professor Mike Richards and six working groups, consulting over 300 stakeholders. It became apparent that a whole systems approach was required. Accordingly, the Strategy strongly recommends that a care pathway approach should be followed both for care and the commissioning of end of life care.

Key Steps

Identification of people approaching the end of life, and initiating discussions about preferences for end of life care;

Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly;

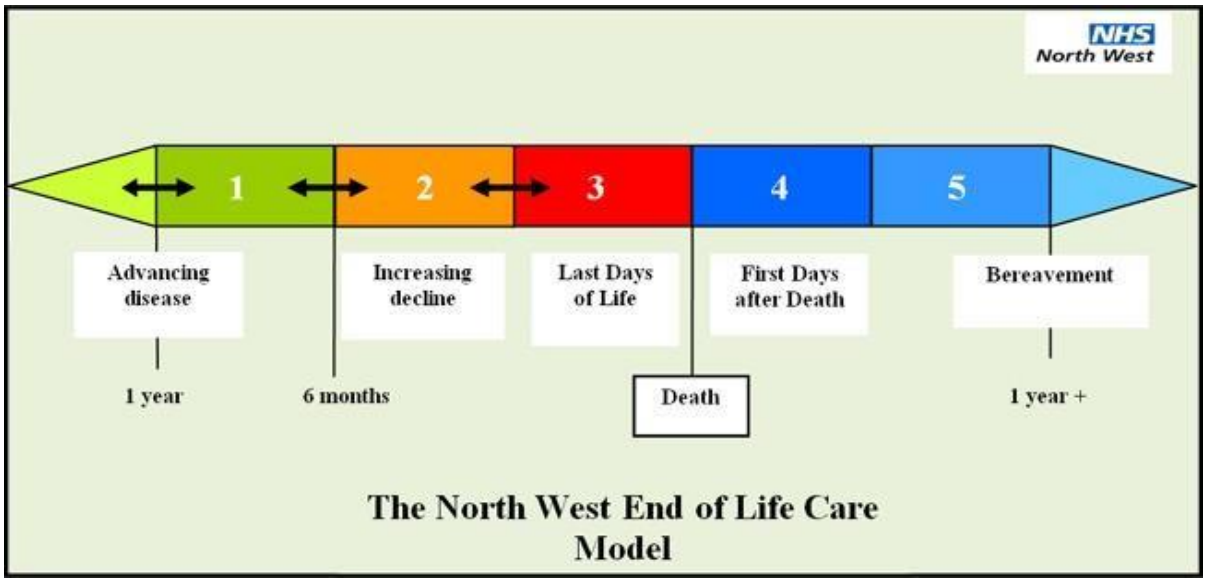
Coordination of care;

Delivery of high-quality services in all locations;

Management of the last days of life;

Care after death; and

Support for carers, both during a person's illness and after their death.



The story of a patient's health from diagnosis of a life-limiting illness can be seen with this model. The model comprises five phases as described below with some examples of practice highlighted.

1. **Advancing disease** – timeframe: 1 year or more.

Example of practice required -the person is placed on a supportive care register in General Practitioner (GP) practice/care home. The person is discussed at monthly multidisciplinary practice/care home meetings.

2. **Increasing decline** – timeframe: 6 months [approximate].

Example of practice required -DS1500 eligibility review of benefits, Preferred Priorities for Care (PPC) noted, Advance Care Plan (ACP) in place and trigger for continuing healthcare funding assessment

3. **Last days of life** – timeframe: last few days.

Examples of practice required - primary care team/care home inform community and out of hours services about the person who should be seen by a doctor. End of life drugs prescribed and obtained, and Liverpool Care Pathway (LCP) implemented.

4. **First days after death** – timeframe: first few days.

Examples of practice required include prompt verification and certification of death, relatives being given information on what to do after a death (including D49 leaflet), how to register the death and how to contact funeral directors

5. **Bereavement** – timeframe: 1 year or more.

Examples of practice required include access to appropriate support and bereavement services if required.

As health professionals working within gynae oncology, we treat patients who fit all parameters of the end of life scale, what is required of us is to be aware of whereabouts on this scale our patients fit and advise the GP, District Nurses, Macmillan Nurses accordingly so they can be transferred as appropriate to the primary care end of life register so all their needs can be anticipated and met at the primary level.

References

1. Cancer pain relief and palliative care. Report of a WHO Expert Committee. *World Health Organ Tech Rep Ser* 1990; **804:** 1-75.
2. http://www.stch.org.uk/healthcareProfessionals/EndofLifeCareIssues/EndofLifeCareStrategy.asp
3. http://www.endoflifecumbriaandlancashire.org.uk/info_health_socialcare_professionals/model.php
4. www.goldstandardsframework.nhs.uk
5. NICE http://www.nice.org.uk/guidance/QS13