

Personalised follow-up after treatment for endometrial cancer

Information for patients/relatives/carers

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Introduction

This personalised follow-up information has been specially designed by cancer specialists to support you when you have completed your primary treatment for endometrial cancer.

The information is based on evidence demonstrating that for well people after treatment, there is no advantage to scheduling appointments at fixed intervals where you have to attend a hospital appointment, and instead a supported self-management approach is usually more suitable.

Furthermore, research has shown that regular routine appointments do not help prevent cancer returning and specifically in identifying new problems.

Personalised follow-up involves you, as the patient, being in control of your follow-up care. It means that should you choose to follow the supported self-management pathway; your day-to-day life will not be disrupted by regular hospital appointments; instead, you can quickly gain access to the gynaecology team and hospital when you need to within your follow-up period.

The following sections provide a summary of what you can expect when on the supported self-management pathway.

Treatment summary

At the end of your surgical treatment, you will have received a treatment summary.

Your treatment summary provides information about your diagnosis and treatment(s), as well as how your follow-up care will be organised.

This includes:

- Your planned anti-cancer treatments following surgery
- The timescales in which you started and should complete your anti-cancer medication
- Some of the common side-effects of treatment
- Signs and symptoms to report to us or your GP
- Holistic needs assessment information
- Further help and support and how to contact the gynaecology team.

Your treatment summary will be copied to your GP, so they have access to information about your personalised pathway

Three-month follow-up

Approximately three months after your treatment, you will have received a follow-up appointment. This will more than likely be with a consultant and cancer nurse specialist. At this appointment, your suitability to join the supported self-management pathway will have been discussed and you will have chosen whether to accept moving on to this pathway. If you did not wish to move onto the supported self-management pathway or were unsuitable, you will remain on the professional-led pathway which means that you will continue to have appointments at fixed intervals.

Patients who are on the professional-led pathway will have three-monthly follow-ups for two years after surgery, then six-monthly for years three to five. If you originally chose to remain on the professional-led pathway and later feel you would prefer to move to the supported self-management pathway, you should contact your cancer nurse specialist so this can be arranged.

Surveillance

There are currently no routine surveillance tests for recurrence of endometrial cancer. Over 90% of recurrences in all endometrial cancers present with symptoms. It is therefore important you are aware of what to look out for and what to do if you become concerned about anything.

You should contact the gynaecology team or your GP if you experience any of the following:

- Vaginal bleeding
- Persistent vaginal discharge
- New unilateral or bilateral leg swelling
- New persistent low abdominal pain or discomfort which persists for two weeks or more
- Change in bowel or bladder habit which persists for two weeks or more
- Persistent loss of appetite, nausea, or weight loss
- New persistent breathlessness
- New back pain which persists or progresses over two weeks or more.

You are also encouraged to participate in both the breast and bowel national screening programmes, as there are some shared lifestyle risk factors with endometrial cancer.

Your cancer medications/ treatments

Following surgery, you may be prescribed brachytherapy, chemotherapy, radiotherapy, or immunotherapy. Your oncologist and treatment nurses will provide you with further information regarding this.

These treatments can cause side-effects. **Please inform us of any side-effects using one of the contact numbers below:**

- The oncology team: 01623 622515 plus one of the following extensions:
 - Secretaries: 6217
 - Chemotherapy nurse: 3061 or 3872
- Rapid Response at Nottingham City Hospital: 0115 9628066.

Possible side-effects of treatment

All treatments (surgery, chemotherapy, radiotherapy, brachytherapy, and immunotherapy) have the possibility of some side-effects and some of these can last longer than others. Not everyone will experience side-effects and some patients may experience more difficulty with them than others.

Below are some of the common side-effects you may experience:

- Bladder and bowel symptoms:
 - ♦ Changes in bowel habits such as diarrhoea or constipation
 - ♦ Cramps or spasms in the bowel
 - ♦ Bleeding from the back passage
 - ♦ Needing to pass urine more frequently
 - ♦ Unable to wait to empty the bladder
 - ♦ Blood in urine
- Shortening and/or narrowing of the vagina
- Lymphoedema of the legs (fluid swelling)
- Menopausal symptoms
- Sexual or psychosexual problems.

Through the Macmillan Hub at King's Mill Hospital, the gynaecology specialist nurses or the Maggie's Centre (based at Nottingham City Hospital), a referral can be made for rehabilitation services such as dietitians, physiotherapists, counsellors, psychologists, and occupational therapists that have experience of helping people manage side-effects of treatment.

Late effects of treatment

Most patients will leave cancer treatment behind and continue life with few or no health problems, but for others there may be ongoing physical and/or emotional challenges that they will experience daily for the rest of their lives. These are known as the late effects of treatment and include any side-effects resulting from radiotherapy or chemotherapy treatment that take several months to settle. Some people may also develop side-effects many months or sometimes years after treatment has finished.

Late effects vary from person to person; everyone experiences side-effects differently and an assessment of your needs as an individual may be required. It is not always possible to predict if or when late effects from radiotherapy treatment will occur. If you feel you may be experiencing late effects from your treatment, it is important to seek help from the Nottingham Late Effects Service or your medical team.

Some late effects might improve or go away with time, whereas others could be permanent. If late effects of treatment do occur, it does not mean that your medical team did anything wrong. In most cases, the effects could not have been avoided.

Radiotherapy is excellent at treating cancer cells, however, over time the cells in the treatment area that have been exposed to the radiotherapy can become damaged due to what is known as radiation induced fibrosis. This is a build-up of fibrotic tissue (just like scar tissue) that makes tissues less stretchy. Fibrosis is often irreversible and as it builds it can cause hardening, restriction and tightening along with shrinkage of tissues and muscles. It can therefore cause pain and affect the normal functioning of that part of the body.

It is important to remember that radiotherapy only affects the area of the body being treated. Changes to a part of the body outside the treatment area will not have been caused by the radiotherapy treatment.

If you feel that you are experiencing a late side effect from your radiotherapy or chemotherapy treatment, then the Nottingham Late Effects Service can help. This is a clinic dedicated to helping patients (who are six months after treatment) manage and live well with the late effects from treatment.

This is a self-referral service, and you can contact them via the Radiotherapy Information and Support number on 01159 627976 or email: LateEffects@nuh.nhs.uk

Late effects from radiotherapy/ chemotherapy treatment to the pelvis

This involves issues with the functioning of your bowel and bladder.

Patients can experience:

- An increase in urinary output, pain and discomfort, bleeding and altered flow.
- Looser bowel motions, increased frequency, wind, pain on opening your bowels, bleeding, and difficulty passing motions.
- Problems with the skin around the pelvic area, and in and round the back passage.

Other commonly reported effects include:

- The altered ability to have and maintain a physical sexual relationship; this can be a lack of desire or the inability to have penetrative intercourse due to tightening, pain and dryness of the vagina and surrounding area, along with feeling different about how your body looks.
- Fatigue. Some patients report that this is still a problem for them up to 10 years after treatment has ended, along with associated psychological and emotional issues.

For patients that have had chemotherapy, you can experience whole body effects such as:

- Menopausal symptoms including hot flushes, low mood, and joint pain.
- Gastrointestinal problems such as problems with constipation and diarrhoea.
- Peripheral neuropathy, which is tingling in your hands and feet.
- Headaches and memory/cognitive problems.

Feelings and emotions

Everyone will have different feelings when they no longer need to see their medical team regularly.

Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment. Many worry about the cancer coming back. This is very normal and usually these anxieties lessen with time.

Realising that there is a problem and getting help is the most important thing you can do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life. If you are finding it difficult to cope, your gynaecology cancer nurse or GP may be able to arrange an appointment for counselling. It may also help to contact a local or national support organisation such as Macmillan Cancer Support. Their contact details can be found at the back of this booklet.

The personalised follow-up telephone service

Once you have started on the supported self-management pathway, you should call the personalised follow-up contact number about any new symptoms that you are concerned about or other issues you may have. The aim of the telephone service is to provide helpful advice and allow you to have rapid access back to the Gynaecology Cancer Team as required.

Our contact number is 01623 622515, extension 3073.

If you are on the professional-led pathway and require some support in between your scheduled appointments, this service is also open to you.

Our team

The Gynaecology Cancer Team is made up of:

- Miss Nivedita Das, Lead Cancer Consultant*
- Mr Srini Vindla, Deputy Lead Cancer Consultant*
- Mr Will Dudill, Cancer Consultant*
- Suzanne Goralik, Cancer Nurse Specialist
- Sarah Halsall, Cancer Nurse Specialist
- Alison Wright, Cancer Coordinator
- Kathryn Nuttall, Gynaecology Matron.

**Please note that for appointments with the medical team, you may be seen by another consultant or specialist doctor working in the team.*

Our commitment to you

If the gynaecology cancer nurse feels the symptoms you are experiencing may represent a new cancer diagnosis or be related to your previous cancer diagnosis, an appointment will be arranged at one of our clinics within two weeks of you telephoning us. If necessary, further investigations will be organised and an outpatient appointment may be arranged to receive the results. For patients continuing to experience side-effects of treatment, there are several other clinics and support services which you can be referred, or sign-posted to.

Sometimes verbal advice (via the telephone service) may replace the need for an outpatient appointment. In these cases, a written letter will be sent to you and your GP. We hope that this enhances and promotes your ability to care for yourself once treatment has been completed and enables you to benefit from the team's expertise as required.

The telephone service is open Monday to Friday, 8.30am to 4.30pm and may be answered by the cancer coordinator, a clinical nurse specialist, or may go to the answering machine which is checked routinely throughout the day. If your call is not answered immediately, please leave your name, telephone number, hospital number (if you have it) and a short message, and your call will be returned by the end of the next working day.

Life after treatment

Once treatment is over, people often want to know what they can do to stay healthy. You may have questions about your diet, exercise, and general well-being which we would be happy to address.

Some of the specialist services we can offer are:

- Mindfulness courses
- Counselling and support
- Lymphoedema services
- Look good, feel better workshops
- Support with managing:
 - Menopausal side-effects
 - Fertility/sexual issues
 - Body image issues.

Spring into Action

Spring into Action is a clinic organised by physiotherapists which offers individual advice about making positive changes to levels of physical activity and/or diet after cancer treatment. If you wish to attend, you can self-refer by contacting 01623 622515 extension 3221 or 6030 or speak to the gynaecology team.

HOPE course

The Macmillan six-weekly Help to Overcome Problems Effectively (HOPE) course concentrates on focusing and rediscovering inner strengths and resilience to help individuals cope emotionally, psychologically, and practically.

Referrals can be made via the Gynaecology Cancer Team or the Macmillan Information Support Hub.

Maggie's Nottingham

Located at Nottingham City Hospital, Maggie's Nottingham offers a range of cancer support from courses, casual classes, self-help, support groups and help with money worries, or just a calming space with friendly faces. Information is located at the end of this booklet.

Welfare and benefits advice

If you are experiencing issues with housing, employment, immigration, financial or welfare benefits, you can get help by contacting the Gynaecology Cancer Team or the Macmillan Information Support Hub, who can complete a referral to the Macmillan Money and Work Advisors. Their contact details are at the end of this booklet.

Medicines information

If you have any questions or concerns about medication started by your cancer doctors, please contact the Gynaecology Cancer Team for advice. If you have any questions or concerns regarding medications started by your GP or holistic/complementary medications, please contact your GP or a local pharmacist.

Finally

If you are worried about something to do with your endometrial cancer, or the treatment that you have had for it, please contact the gynaecology clinical nurse specialists. They would rather see you with something that turns out to be nothing, than for you to be at home worrying. They are there to help you, so please call if you have any questions or concerns.

Useful contacts and support

Cancer Care Map Directory	Website: https://www.cancercaremap.org/
Gynaecology personalised follow-up telephone service	Telephone: 01623 622515, extension 3073
Go Girls support group	Telephone: 01305 255719 / 07780 467061 Website: http://www.gogirlssupport.org
Late Effects Clinic (Nottingham City Hospital)	Telephone: 01159 627976 Website: lateeffects@nuh.nhs.uk
Macmillan Cancer Support	Website: http://www.macmillan.org.uk/
Macmillan Information Support Hub	Telephone: 01623 622515, extension 6499
Macmillan money and work/benefits advice	Telephone: 01274 987 600 Website: financialguidance@macmillan.org.uk
Maggie's Centre Nottingham	Telephone: 0115 924 6210 Website: nottingham@maggies.org
Oncology secretaries	Telephone: 01623 622515, extension 6217
Pelvic Radiation Disease Association	Website: http://www.prda.org.uk/
Physiotherapy	Telephone: 01623 622515, extension 3221 or 6030
The Eve Appeal	Telephone: 0808 802 0019 Website: http://eveappeal.org.uk

Further sources of information

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them. If you require a full list of references (if relevant) for this leaflet, please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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