



Oxfordshire Oesophageal
and Stomach Organisation

REGISTERED CHARITY No: 1152733

Checklist for Patients, Family and Carers

Introduction

A confirmed diagnosis is *the most difficult time* for any individual and their family, facing many uncertainties and unknowns, it feels like hitting a brick wall. This is a checklist of helpful questions to consider and use at various stages throughout diagnosis and treatment. The checklist has been developed by patients who have had cancer, been successfully treated and are now recovered. This is not an exhaustive list but covers much of the common ground we all experience. You don't need to ask all of these questions, just consider which ones meet your own individual needs.

The cancer pathway

The 'pathway' describes a series of key steps from first **diagnosis**, further tests and investigations (**staging**), followed by **treatment plans** depending on individual circumstances, then **surgery** if it is possible, and finally **recovery**.

1. Diagnosis and Further Tests

GPs are not able to make a formal diagnosis but will refer the patient to a hospital for investigative tests. Soon after initial test(s) an 'outpatients appointment' is arranged with a **specialist consultant** to discuss the results. Having a family member or supportive friend present at this meeting can be very helpful. It is often difficult to take in and remember everything that is said. Take a note pad and pen to jot down the key points raised at the meeting. You may wish to ask a few questions - here are a selection to choose from:

- Where is the cancer?
- Why is it making it hard to swallow?
- Can it be removed?
- What further investigations need to take place?
- How long will this process take?
- Is there a risk of it spreading during this time?
- What are the treatment options available?
- Is an operation a possibility?
- Will I need to stay in hospital?
- Will I be able to eat normally again?
- Who can I talk with at the hospital if I need medical help or advice?
- Are there others that have been through this I can seek support from?
- Can I carry on working?
- Can I travel with this diagnosis?
- What happens next?

It is likely that further tests will be needed to fully establish the location and extent of the cancer so that the most effective treatment plan can be put in place. These will be carried out in a timely fashion.

2. Treatment plans

The next step is to meet with an **Oncologist** who specialises in recommending the most effective treatment plan. Modern chemotherapy and radiotherapy treatments are increasingly more effective at reducing the size of cancers and stopping them from spreading. Again, having a companion at this meeting can provide valuable support. The following questions can be helpful:

- Is the cancer treatable?
 - What treatment plan do you recommend?
 - How effective is this kind of treatment?
 - What does it entail?
 - When will it start and for how long will it last?
 - Can you explain the typical side effects of this kind of treatment?
 - Are there any clinical trials that I might be considered for?
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- Will there be follow-up tests to see how well the treatment has worked?
 - Will I be offered elective surgery to remove the cancer?
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- What happens next?

3. Surgery and Recovery

When the treatment plan is concluded, further tests are needed to establish the next course of action, in particular whether or not it is possible to remove the cancer by surgery. Another outpatient's appointment will be arranged for the **specialist consultant** to review the results and discuss the options. The following questions can be helpful:

- Has my treatment to date worked well or not?
 - What is the best option for me?
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- If it is operable, can it be a cure?
 - What does the operation entail?
 - What are my chances if I chose not to opt for surgery?
 - How soon can surgery be carried out?
 - Who will conduct the surgery?
 - Typically, how long will I stay in hospital?
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- Will there be any long-lasting side effects of the surgery?
 - Will I need any further chemotherapy or radiotherapy treatment?
 - Will there be any follow-up monitoring and support after surgery?
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- How long will it take me to recover?
 - Will I be able to work again?
 - What happens next?

We hope these notes are of good use to you, and that you do well throughout your treatment. You are not alone! Please do not hesitate to contact us at OOSO for support and advice, 7 days a week 10am-4pm on: 0775 9996969 (Matt Carter)