



Oxfordshire Oesophageal  
and Stomach Organisation

REGISTERED CHARITY NO: 1152733

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## OOSO Annual Forum Summary

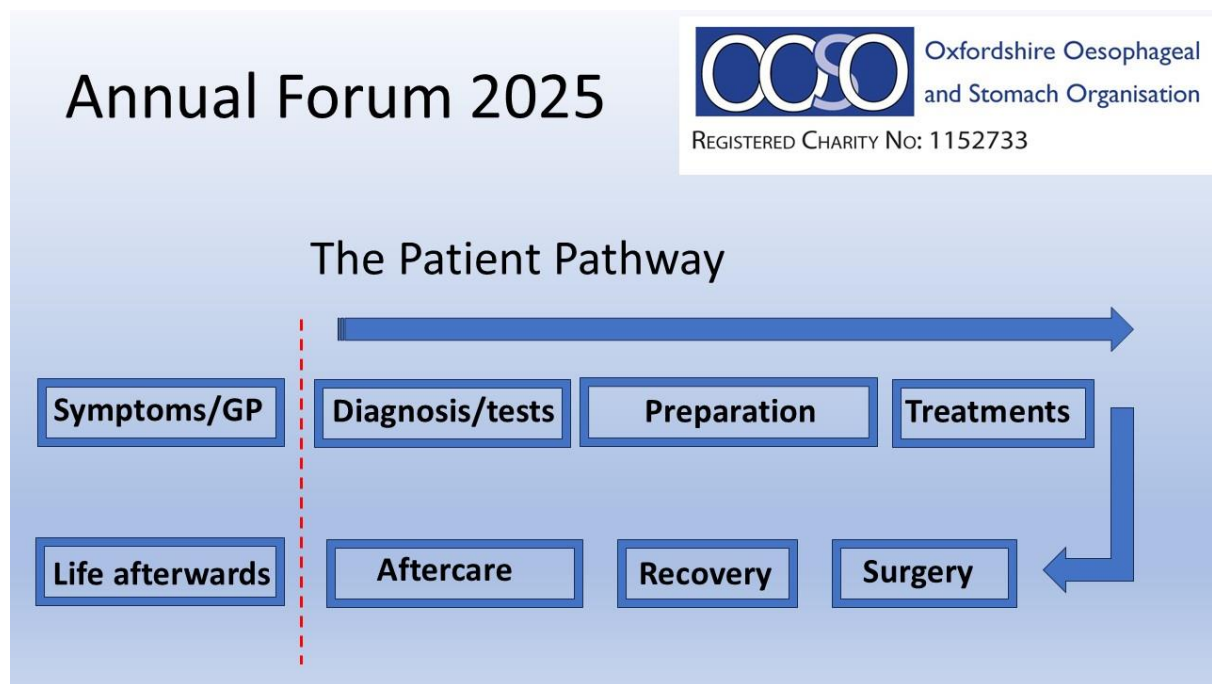
**Date:** 18<sup>th</sup> March 2025

**Venue:** Great Milton village hall

**Attendees:** 70 guests (14 senior clinicians, 56 patients, family, friends)

**Theme:** The patient pathway, what's important, what's difficult, what could be better

**Workshop:** Eight tables with 8-9 guests per table. One of the eight patient pathway topics noted in the diagram discussed at each table and fed back to the group.



## Summary

### **Table 1: Symptoms, GPs**

#### The most important things

- Knowing what the key symptoms are
- Having easy face to face access to a GP who knows about these terrible cancers, takes them seriously and acts quickly
- All age groups taken seriously

#### What was most disappointing / difficult

- Not recognising the symptoms or not having any symptoms
- Waiting for a GP appointment – can be weeks, months
- Inconsistency between GPs
- A late referral from a GP could be fatal
- Waiting for a referral, sometimes it takes far too long

#### What could be better

- Greater awareness amongst the wider public
- Greater awareness amongst GPs and tighter accountable guidelines around referrals, difficulty swallowing, acid reflux and weight loss being key indicators
- Mobile test centres and community diagnostic centres able to take referrals and walk ins (i.e. missing out the GP), testing using the cytosponge capsule and endoscopy on site, i.e. not having to go into hospital
- Better online information in a trusted NHS space, i.e. to stop people trying Mr Google and getting very poor information causing unnecessary anxiety

### **Table 2: Diagnosis, tests**

#### The most important things

- The GP is crucial in getting a quick diagnosis
- Support from family and friends
- Knowing what tests are needed, when and how
- The testing pathway to happen quickly and sensitively
- Being confident the endoscopist is experienced

#### What was most disappointing / difficult

- Awareness of symptoms – sadly symptoms often happen when too late
- Some GPs have little or no experience of these cancers, causing potentially very serious delays
- Tests are very stressful, especially with long waits for results, it is possibly the hardest part of it all waiting for results, and how they are communicated
- Endoscopy wait times are very inconsistent, 2-week wait could become 4 weeks for an urgent referral
- Endoscopy without sedation is very uncomfortable and distressing, sedation should be standard despite slowing down the patient queue. Apparently better results are observed in patients with sedation, cancer less likely to be missed
- The testing pathway for some feels too long when you have a life threatening disease

#### What could be better

- GPs act quickly and consistently
- Having a quick and sensitively delivered diagnosis
- Understanding very quickly what tests and treatments are likely
- Ensuring no delays
- More patient focussed testing, reducing anxiety and discomfort
- Clear emotional support and for mental health if needed

### **Table 3: Preparation, communication**

#### The most important things

- Being near a hospital and easy parking, when ill this is very important
- Sensitive communication always with empathy
- Emotional and mental health support if needed throughout
- OOSO and Maggie Centre are a great support for patients and carers
- A comprehensive information pack – informed consent
- Having a defined timeline, knowing what's coming up and when
- Having the CNS and dieticians at the end of the phone

#### What was most disappointing / difficult

- Uncertainty, delays and waiting
- Not having all the information to hand

#### What could be better

- A simple written pathway and next steps document
- Short videos describing the various stages of the pathway
- More emphasis around emotional support throughout
- Introduced to OOSO earlier at the diagnosis stage
- More information about the long-term effects, living afterwards
- An aftercare plan

### **Table 4: Treatments, therapies**

#### The most important things

- Being confident (knowing) the best treatment is being given
- Having the treatments explained very clearly, what, when, why
- Knowing who to contact if there's an issue
- Not having to travel too far, especially for radiotherapy
- Feeling cared for and kept up to date with what's going on
- Being able to contact the hospital / CNS if not feeling well through treatment
- Support of a carer or friend

#### What was most disappointing / difficult

- Receiving multiple letters for the same appointment, confusing, frustrating and unnecessary cost to the NHS
- Having treatments cancelled, or delays due to errors preparing the therapy drugs or them not being available
- Parking when feeling very ill, this must be easier

#### What could be better

- Benchmark best practice, show what a good consistent service looks like
- More information about side effects during and after
- Short videos, podcasts, visual delivery of information

### **Table 5: Surgery**

#### The most important things

- Having confidence in the surgeon and team
- Outpatient appointments - face to face explanations with diagrams
- Information written and available
- A second person, family/friend to be present to listen and feedback
- CNS present for consent
- Being able to speak with former patients and share the experience

#### What was most disappointing / difficult

- Having an appointment cancelled at short notice
- Having no bed in intensive care available, delaying the surgery date
- After discharge, having a GP that might not understand the after effects of surgery

#### What could be better

- Make it routine to record appointments – use phones if necessary
- Short information videos explaining the surgery
- GPs provided with more information and have a better understanding of issues
- GPs and the hospital to be better joined up, be on talking terms

### **Table 6: Recovery**

#### The most important things

- Being able to speak with other former patients and share the experience
- Knowing what to expect in recovery, having clear information about recovery up front
- Maintaining points of contact with the hospital – most importantly the CNS, surgeon and dietitian. And oncologist if scans aren't positive

#### What was most disappointing / difficult

- Anxiety afterwards, facing more appointments and scans, the possibility of cancer returning
- Hitting low points after discharge, not knowing what side effects to expect and how to deal with them
- Very challenging on mental health

#### What could be better

- More help with mental health recovery
- Scheduled chats with a CNS and dietitian afterwards

## **Table 7: Aftercare**

### The most important things

- Having a structured aftercare plan
- Maintaining points of contact with the hospital – most importantly the CNS, dietitians
- Being able to meet with other former patients and clinicians to share the experiences

### What was most disappointing / difficult

- Feeling abandoned after discharge, very scary
- Whist some side effects are common, everyone recovers differently
- Some side effects are harder to manage e.g. dumping syndrome, maintaining weight, food absorption, aches and pains
- It's an emotionally difficult time for the patient, carer, family and friends
- GPs not being aware of these cancers, side effects and issues afterwards

### What could be better

- Having a more structured aftercare plan
- GPs being more aware
- More support for carers and family

## **Table 8: Life afterwards**

### The most important things

- Eating and diet
- Having as near normal daily routine as possible
- Being able to socialise normally
- Maintaining good mental health, trying to stay positive
- Learnt more at OOSO café catch ups and zoom meetings than anywhere else

### What was most disappointing / difficult

- Small meals, and dietary complications, trying to eat enough and enjoy it!
- Maintaining weight, food keeps us alive!
- Impacts in social life, meals out, holidays, exercise, can't trust what the body's going to do!
- Family stresses on our behalf
- Own mental health, slow recovery, don't feel hungry, are my side effects age or treatment related
- Some have more day-to-day problems after surgery than before

### What could be better

- More support/information with long-term living after cancer
- Keeping in contact with own CNS long term if required
- Help with mental health if needed