

# Managing my illness

Let me help you with colorectal cancer

You are not alone; I have been there too....

and me...



and me...



and me...



and me...



and me...



and me...



EuropaColon

... because life matters

## Forward

I was 52 when I was diagnosed with Stage IV colorectal cancer. The primary was in the ascending colon and it had spread to a 15cm tumour in the left liver. I was told that treatment could only be palliative and my prognosis was for three to five months at best.

I am still here today, seven years after that day and five years in remission. I have undergone two courses of chemotherapy and fought for a new advanced treatment, finally paying for it myself. The tremendous success allowed me to have an operation in which both tumours were removed.

Unfortunately, after another course of adjuvant treatment, my cancer returned in my lymph glands. More chemotherapy just took it away!

It seems impossible, but I have had no treatment since that day. I know that I am alive because I managed my illness, researched information on medicines, and asked many questions. I queried anything I was unsure about and made sure that I was able to get help when I needed it.

This booklet will help you to do the same. You can use it throughout your cancer journey and it will help you to manage your illness. You will have all the information you need at hand for an emergency. It is often difficult to remember details such as medication and the doctor's number when you are rushed into hospital!

It will also guide you, the patient, in preparing before an appointment and in asking questions; generally being an active participant in your own healthcare team, enabling you to take an active role in your journey.

Along with a group of six more patients across Europe, I send an important message to you...

Never lose hope. It is the most important and most effective of all medicines.



**Barbara Moss**  
United Kingdom



**Aysen Cevik**  
Turkey

Sometimes you have to rest for a time. Enjoy it.

Talk about your feelings with people you like and do everything that can make you happy.



**Marta Satler**  
Slovenia



**Celeste Correia Ramos**  
Portugal

Don't be afraid! Take hold of your life and believe that you can make the difference. Don't give up.

Hope is the early bird on the darkest day of your life!



**Wolfram Nolte**  
Germany



**Jolien Pon**  
Netherlands,

You are not alone!  
We stand by you.

You should NOT be intimidated by it. Knowing and facing cancer releases an inner strength that will set you free.



**Dora Constantinides**  
Cyprus

**Practical information:**

Name:

Date Of Birth:

Hospital No:

National Insurance Number (If relevant):

Home phone:

Mobile:

Religion:

**Medical Contact Phone Numbers:**

GP:

Out of Hours Number

Hospital Name

Tel

Oncologist:

Oncologist's secretary name

Tel

Oncology Unit contact name

Tel

Accident and Emergency for cancer treatment

Palliative nurse name

Tel

Hospice:

**My next of kin:**

Name

Name

Address

Address

Tel

Tel

Mobile

Mobile

## List of current medication

It is a good idea to include a copy of your last prescription and any other medical information when you file these pages. You may travel, even abroad, while on treatment. It is useful to have a description of your current medication, including chemotherapy and frequency of treatment ready.

Medicine name

Strength

Times per day

## Allergies

## Be Prepared for an Emergency

Keep an overnight hospital bag ready with the following items, but keep it out of sight:

Comfortable sleeping garment

Sensible slippers

Underwear

Toiletries: toothbrush, toothpaste, razor, towel, comb, make-up, perfume,

Book or magazine

Paper and pen

A thin dressing gown

Tissues

## Last minute things to remember:

Mobile phone & charger

Keys

Money

Chocolate

Fruit

**Contact list for family and friends:**

<b>Name</b>	<b>Phone</b>	<b>Email</b>	<b>Twitter Address</b>
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**Contact list of other patients you meet:**

You may find it helpful to talk to other patients going through a similar experience.

<b>Name</b>	<b>Phone</b>	<b>Email</b>	<b>Twitter Address</b>
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### Contact details of charities:

Name	Helpline	Email
Bowel Cancer UK	+44 (0)207 940 1760	

### Contact details for patient advocates.

Get support from someone who has had the experience. Later, you can help others have better outcomes too.

Name	Phone	Email	Twitter Address
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## Preparing the meeting with your doctor:

This is about you: your life and your health. Nobody knows about this better than you. So it is important to establish a clear and interactive communication with your doctor and others who are taking care of you.

Being diagnosed with bowel cancer will be a shock, and it will probably be difficult to take in all the information you are given.

Most people find it helpful to take a family member or a close friend to the appointment, and it's a good idea to take a notebook and pen. We also found this useful as we could discuss matters before and after each appointment.

It is up to you to decide whether you prefer to receive detailed information about your illness and treatments or just the basic necessary. If you do want to know, then ask your doctor or nurse as many questions as you like about your diagnosis and treatment options. Don't rush in to a decision about your treatment. Read all the information you are given, and do your own research on line – and ask for a second meeting with your doctor or nurse if you are unsure about anything.

You want to be sure you get the best possible treatment and the best possible chance of a cure. You might want to watch this video for more ideas.

[www.nhs.uk/conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Introduction.aspx)

## Here are some ideas to consider that might help you prepare your notes for your first meeting with your oncologist.

- How do I feel (afraid, anxious, confident)?
- What are the symptoms, in general, with this type of cancer?
- How are they treated?
- What are the side-effects?
- Are the side effects long-term?
- Will this affect my sex life? If so, is there anything that can help?
- Does this affect fertility?
- What types of treatment are available for me? (surgery, chemotherapy, radiotherapy and biologics)
- What do you recommend for me?
- Are there any other effective treatments that are not available locally?
- I've heard about biomarker testing and in particular the importance of a RAS test. Is it possible for me to have a RAS test to help determine the best medicine for me?
- Can I have a copy of my blood test readings?
- I understand that a CEA is a tumour marker indicator. Have you taken a CEA test for me? Can you explain my reading to me?

## My Treatment Plan

Ask for a written treatment plan so that you can share this with other clinicians and nurses when you need to.

Also ask whether you can make another appointment before treatment to ask further questions, if you feel you need to.

### Preparing the meeting with your surgeon:

In some cases, you may meet your surgeon before your doctor. Here are some questions that might help you to prepare for this meeting. Also refer to the questions for your doctor (above).

- What are my treatment options?
- Please describe the extent of my cancer.
- Do you expect any complications?
- Is it likely that I will have a stoma?
- If so, can this be reversed?
- Will I have chemotherapy and a biological, or radiotherapy to follow?
- What are my options?
- Are there any other effective treatments that are not available locally?

## Treatment and side-effects

During treatment, you are likely to feel different and it can be worrying.

If you are in pain, note down and ask whether it can be controlled.

You will be ready to ask your consultant. Sometimes, it is comforting to be reassured that pain can be 'normal'!

**Date**

**Side-effect**

**Time**

### Questions to ask at my next appointment:

Having made notes of your progress and concerns, you will be prepared for your following appointments. Make sure to write down anything you wish to say or to ask when you think of it. You should have a 24 hour contact number for hospital care. Do use this if you need to.

You should not hesitate, however, to phone your nurses or doctor's secretary for advice during working hours.

**Question**

**Response**

## **Additional sources of information: (needs to be local sites)**

Disclaimer: These are suggested reference points and not endorsed by Europacoln.[www.europacoln.com](http://www.europacoln.com)

- [www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)
- [www.patient.co.uk](http://www.patient.co.uk)
- [www.macmillan.org.uk](http://www.macmillan.org.uk)
- [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)
- [www.nhs.uk/conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Introduction.aspx)

## **Things to find out about:**

Diet and exercise help you to feel better and to take a more positive approach. They also help to reduce the risk of recurrence of colorectal cancer. Do ask for advice on these issues.

- Diet
- Exercise
- Smoking
- Alcohol
- Personal Issues: Support for me and my family
- Counselling
- Children
- Carers
- Work
- Financial circumstances
- Benefits
- Wills.
- Rehabilitation and balance

Information on Clinical Trials can be found here:

<http://www.europacoln.com/clinicaltrials.php?Action=Clinicaltrials>

## Notes

## Notes



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## **Expert Patients Advisory Group**

Chair: Barbara Moss (United Kingdom)

Aysen Cevik (Turkey)

Celeste Ramos (Portugal)

Dora Constantinides (Cyprus)

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Marta Satler (Slovenia)

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