



Decision Aid for Patients with Metastatic Colorectal Cancer Facing a Treatment Decision

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Introduction

Your doctor has explained that your cancer, which started in your colon or rectum, has spread or has returned in another part of your body. Once cancer has spread, it is called metastatic. There is treatment for your cancer, even though that treatment will not cure your cancer.

Everyone has different needs when it comes to learning about his/her illness, and when it comes to making decisions about treatment. Some people want all the information available about their cancer, while others want to know very little. When making decisions about treatment, some people want their doctor to decide, while some want to decide for themselves. Others want to share the decision with their doctor. All of these options are reasonable. The best option is the one which best suits you and your needs.

This booklet is designed to help you and your doctor reach a treatment decision in whichever way you prefer.

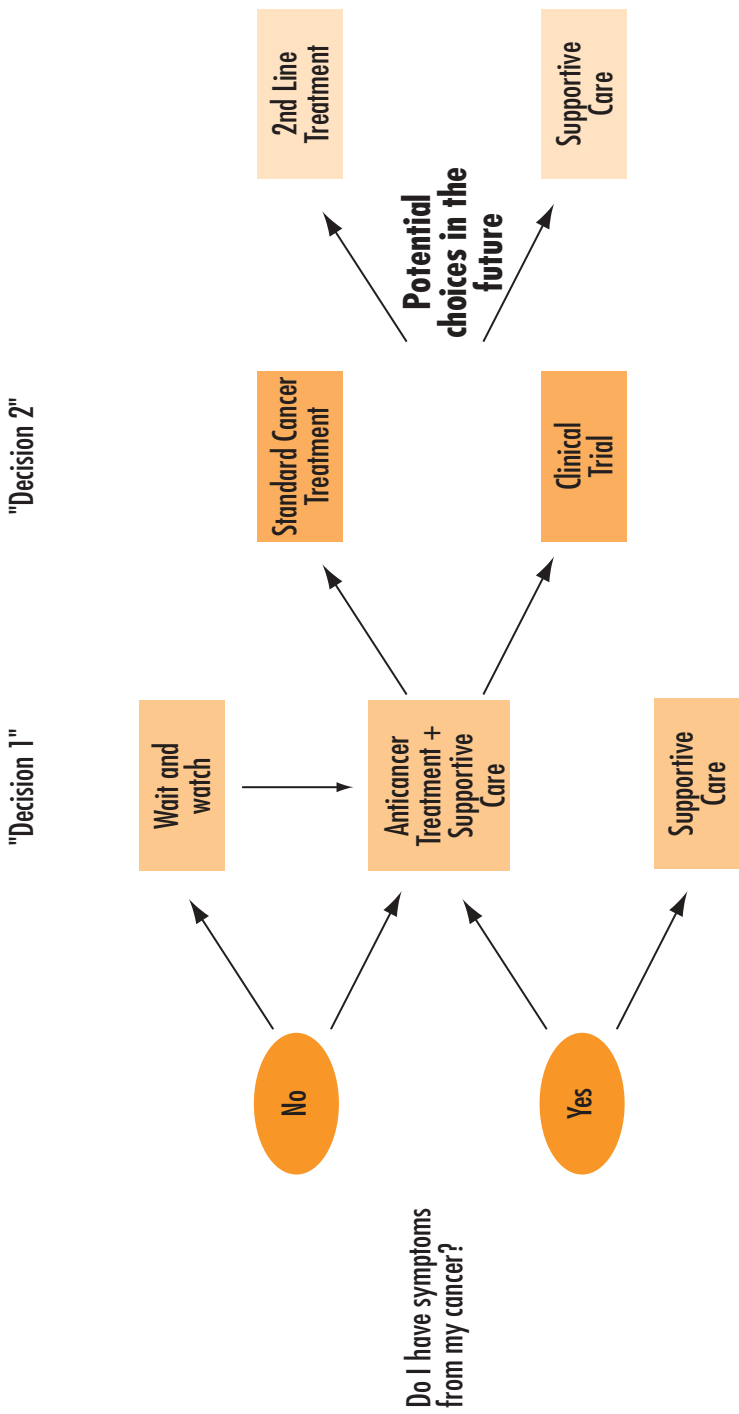
After talking about your diagnosis with your doctor, there are questions you may wish to address. These include:

Do you have symptoms from your cancer?	Yes	No	You and your doctor may want to watch how you feel for the next few months. Or you may want to consider treatment now, but there is no definite benefit in starting chemotherapy early if you have no symptoms. ¹
What treatment approach would you like to take?	Supportive Care	+/- Anticancer Treatment	These approaches are explained on page 3.
If you decide to have anticancer treatment, should it be	Standard Treatment	or Clinical Trial	This is explained on pages 11-14 and page 23.

Finally, additional chemotherapy may be an option in the future, if you and your doctor feel it is appropriate.

2nd Line Treatment	Supportive Care
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Overview of Management Options



Decision 1:

What are the main approaches in the treatment of my cancer now?

There are 2 main approaches to care after you've been diagnosed with advanced disease:

1. Supportive care²

The aim is to keep you comfortable, maximize your quality of life and cause as few side effects as possible. Treatment may include pain medications such as morphine and blood transfusions if they will help you feel better and if you wish to have them. Supportive care does **not** include chemotherapy, but may include **local anticancer treatment** such as **radiation** to a painful area, or even **surgery**, to help relieve a bowel blockage for example.

2. Adding Anticancer treatment to Supportive Care

The aim of this treatment pathway is to attack the cancer, using **chemotherapy**. It may prolong your life, and may help improve your symptoms by shrinking the cancer or stopping its growth, but it may also cause side effects. Not everyone benefits from chemotherapy, and side effects can be severe, even life-threatening. This treatment approach includes the **supportive** measures described above.

Additional options that your doctor may discuss

Watch and Wait

For **people with no symptoms from their cancer**, a **third pathway** is possible – to follow how you feel over the next few months, and consider delaying anticancer treatment until you develop symptoms. Starting treatment now or later doesn't appear to affect overall survival.¹ If you and your doctor decide on this option, the rest of the information in this decision aid will not be relevant until you develop symptoms.

Changing your treatment strategy

It is important to remember you can always stop one form of treatment, such as chemotherapy, if the side effects are too great. There is **no** such thing as a **wrong treatment choice**. The choice which suits you best is the right one, and this depends on what is important to you.

Personal Support

Many people living with the diagnosis of advanced colorectal cancer benefit from support in coping with their illness. This may be from family or friends, through books, counselling, religious or other spiritual support. Some people need support for their family, nursing care at home, and/or to meet people going through a similar experience. Your health care team are able to provide support and advice for you and your family in dealing with this disease and treatment. Please do not hesitate to ask your doctor what resources are available – some contacts are included on page 24.

What are your doctor's goals in looking after you?

Doctors have several goals when caring for patients with metastatic cancer³. These include:

1. **Helping you live as long as possible;**
2. **Preventing symptoms from cancer for as long as possible;**
3. **Relieving any symptoms you may be having because of your cancer;**
4. **Improving your overall well-being; and**
5. **Promoting hope.**

While your doctor will do his or her best to meet some or all of these goals, you should make sure your doctor is aware which goals are most important to you (e.g. your quality of life, or to live as long as possible, or both). This way, you and your doctor can determine which treatment is best for you.

How does your doctor decide which treatment to recommend?

Your doctor takes into account 3 sets of factors when making a treatment recommendation.

The first set of factors is about **your health**:

- Are you fit enough for chemotherapy and its side effects?
- Do you have health problems other than your cancer?

The second set of factors relates to **your cancer**:

- Has it been changing or growing very quickly?
- Where is it in your body, for example is it in your liver or lungs?

The third set of factors relates to **your values**:

- What is important to you? For example, is quality more important to you than length of life?

Reasons for Choosing

Supportive Care Alone

I am having difficulty managing now. Will the side effects of chemo make me worse?

The cancer isn't causing me any symptoms

I don't want any more tests or needles

I don't want chemotherapy



Anticancer Treatment plus Supportive Care


I feel ready to start treatment now.

I feel well and strong. I can cope with chemo and its side effects

The treatment may help me live longer

I want aggressive treatment





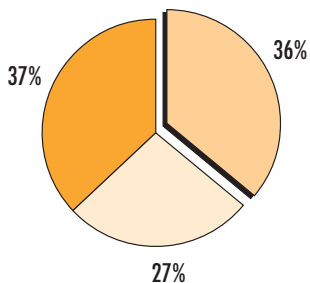
The next two pages talk about the potential gains from chemotherapy. Some of this information deals with how long people may live on average, with and without chemotherapy. It is important to remember that these are statistics which apply to a group of people, and not to an individual like you.

Some people find information about life expectancy useful; others find it useful at some stages of their illness, but not at others. If you do not think this information would be helpful to you at the moment, please turn to page 10, and skip pages 8 and 9.

What effect will the 2 different treatment pathways have on my cancer?

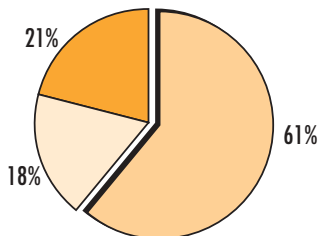
The figures below are different ways of showing information about the effects of treatment (gathered from randomised trials, the highest quality medical evidence)^{4,5}.

Supportive Care



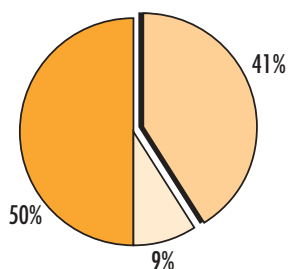
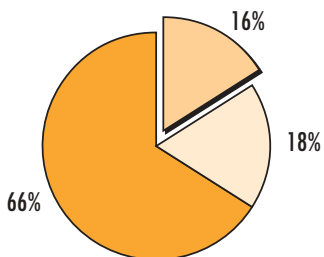
Anticancer Treatment plus Supportive Care

6 months time



- Cancer worse
- Died from Cancer
- Cancer better or not worse

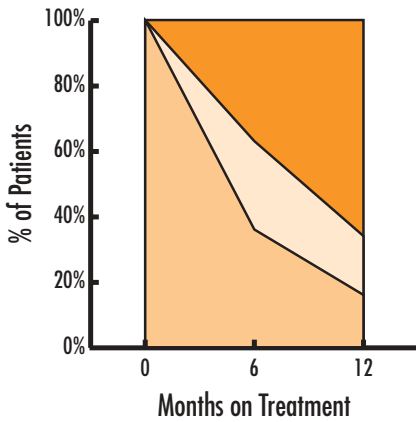
1 year's time



What effect will the 2 different treatment pathways have on my cancer?

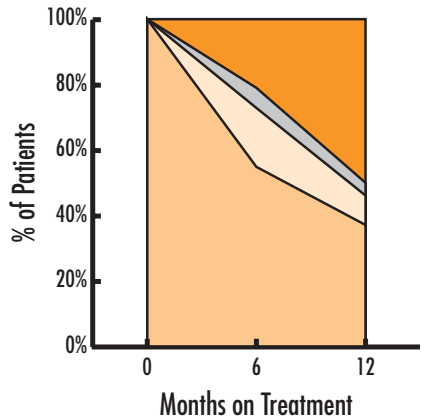
Supportive Care

Median survival Half of the people live longer than 8 months and half of people live that long or less.



Anticancer Treatment plus Supportive Care

Half of the people live longer than 12 months and half of people live that long or less.



■ Died from Cancer
■ Cancer worse

■ Treatment side effects
■ Cancer better or not worse

What differences are there between the 2 treatment pathways?

	Supportive Care	Anticancer Treatment + Supportive Care
• Will my pain and cancer symptoms be treated ?	Yes	Yes
• Will I be offered interpersonal and spiritual support?	Yes	Yes
• Will I receive chemotherapy ?	No	Yes
• Will I be offered radiation treatment or surgery if it could relieve my cancer symptoms?	Yes	Yes
• How often will I need to come in to the hospital clinic ?	About once every 1 to 3 months and when you have problems plus possible extra visits for tests	Can vary from once every three weeks to once a week or more often
• How often will I need blood tests ?	This varies , but whenever you have symptoms suggesting a blood abnormality, and for some doctors, at each visit (every 1 to 3 months)	Varies from once a week to every 3 weeks (before chemotherapy is given) or if you have symptoms suggesting abnormal blood tests
• How often will I need x-rays or CT scans ?	Varies depending on your symptoms, but likely every 2 to 3 months or less often	Usually after every 2 or 3 chemotherapy cycles (every 2 or 3 months)

Decision 2:

If you have decided to try anticancer treatment plus supportive care

There are options that you and your doctor can discuss. These are:

1. Standard treatment

At present there are different standard anticancer treatments for metastatic colorectal cancer. These options include:

- a. tablets
- b. a combination of drugs given intravenously and/or with tablets.

The treatment plan recommended will be influenced by your overall health and discussion with your doctor. Treatment will continue if it is of benefit in treating your cancer, provided the side effects are acceptable.

Or

2. A Clinical Trial

You may be interested in hearing about clinical trials, or experimental cancer treatments. If you are interested in participating in a research study or discussing any particular trial be sure to ask your doctor about what might be available for your type of cancer. If you wish to acquire additional information on trials you can access the National Cancer Institute (USA) www.cancernet.nci.nih.gov website (see page 23).

The Standard Treatments and their possible impact on my life

2 weekly cycles of Capecitabine tablets daily

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Cycle 1 ¹ Chemo Day 1	² Chemo Day 2	³ Chemo Day 3	⁴ Chemo Day 4	⁵ Chemo Day 5	⁶ Chemo Day 6	⁷ Chemo Day 7
⁸ Chemo Day 8	⁹ Chemo Day 9	¹⁰ Chemo Day 10	¹¹ Chemo Day 11	¹² Chemo Day 12	¹³ Chemo Day 13	¹⁴ Chemo Day 14
¹⁵	¹⁶	¹⁷	¹⁸	¹⁹	²⁰	²¹
Cycle 2 ²² Chemo Day 1	²³ Chemo Day 2	²⁴ Chemo Day 3	²⁵ Chemo Day 4	²⁶ Chemo Day 5	²⁷ Chemo Day 6	²⁸ Chemo Day 7
²⁹ Chemo Day 8	³⁰ Chemo Day 9	³¹ Chemo Day 10	¹ Chemo Day 11	² Chemo Day 12	³ Chemo Day 13	⁴ Chemo Day 14
⁵	⁶	⁷	⁸	⁹	¹⁰	¹¹

 Chemotherapy given on these days

 Side effects most likely to be felt on these days

Convenience

- a treatment taken in tablet form (3-6 tablets)
- taken at home twice a day
- every day for 2 weeks then 1 week off (1 cycle)

Side effects

Diarrhoea, mild nausea and tenderness of palms & soles of feet.

Tumour Response rates^{6,7,8}

25%

Patients usually remain on treatment for about 4½ months.

48hr Infusion every 2 weeks Oxaliplatin or Irinotecan, 5FU and Folinic acid

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1 Cycle 1 Chemo Dose 1 Pump on Day 1	2 Chemo Pump Day 2	3 Chemo Pump off Day 3	4	5	6	7
8	9	10	11	12	13	14
15 Cycle 2 Chemo Dose 2 Pump on Day 1	16 Chemo Pump Day 2	17 Chemo Pump off Day 3	18	19	20	21
22	23	24	25	26	27	28

 Chemotherapy given on these days

 Side effects most likely to be felt on these days

Convenience

- three drug combination, Oxaliplatin or Irinotecan, 5FU and Folinic acid
- given at home
- as a continuous infusion through an intravenous pump which you wear at home over 48 hours.
- every 2 weeks (1 cycle)

Side effects

Tingling and numbness (oxaliplatin), nausea, diarrhoea (irinotecan), and lowering of blood counts.

Tumour Response rates¹³

50%

Patients usually remain on treatment about 6 months.

Capecitabine chemo tablets daily for 14 days plus IV (intravenous) chemo irinotecan or oxaliplatin on day 1 every 3 weeks

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Cycle 1 ¹ Chemo Pills + IV	² Chemo Pills	³ Chemo Pills	⁴ Chemo Pills	⁵ Chemo Pills	⁶ Chemo Pills	⁷ Chemo Pills
Cycle 1 ⁸ Chemo Pills + IV	⁹ Chemo Pills	¹⁰ Chemo Pills	¹¹ Chemo Pills	¹² Chemo Pills	¹³ Chemo Pills	¹⁴ Chemo Pills
¹⁵	¹⁶	¹⁷	¹⁸	¹⁹	²⁰	²¹
Cycle 2 ²² Chemo Pills + IV	²³ Chemo Pills	²⁴ Chemo Pills	²⁵ Chemo Pills	²⁶ Chemo Pills	²⁷ Chemo Pills	²⁸ Chemo Pills
²⁹ Chemo Day 8	³⁰ Chemo Pills	³¹ Chemo Pills	¹ Chemo Pills	² Chemo Pills	³ Chemo Pills	⁴ Chemo Pills
⁵	⁶	⁷	⁸	⁹	¹⁰	¹¹

 Chemotherapy given on these days

 Side effects most likely to be felt on these days

Convenience

- Chemo pills taken at home twice a day for two weeks and then one week off (1 cycle)
- IV chemotherapy on one day every three weeks

Side effects

- Diarrhoea, nausea (irinotecan), tenderness of palms and soles of feet (capecitabine) tingling and numbness (oxaliplatin) and lowering of blood counts.

Tumour reponse rates ⁽¹⁴⁻¹⁷⁾

- 40 – 60% in initial studies

What will the side effects be?

Supportive Care

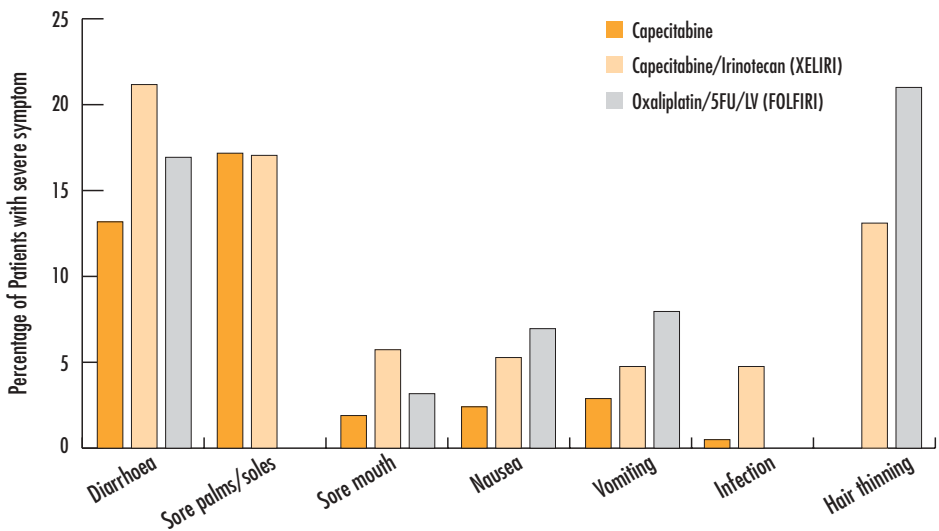
The only side effects might be from pain medicine (constipation, dry mouth, mild nausea) or local anticancer treatments (such as radiation).

Supportive Care + Anticancer Treatment

Depending on the type of chemotherapy you and your doctor choose, the side effects may vary. Some people have few side effects, while others can have more severe side effects. Almost all people notice some effects from chemotherapy. If you do get severe side effects, your doctor may **delay your next treatment** by a week, **reduce your dose** of chemotherapy, or **change** or **stop treatment**.

Most common severe treatment-related side-effects^{7, 9, 14}

The graph below shows the percentage of patients who have severe side-effects from the different standard anticancer treatments. Severe side-effects means that patients experience some considerable distress as a result of their treatment, and might need treatment or hospital admission for these side effects. It is important to remember that more patients than those shown below will have milder side effects.



What are the pros and cons of supportive care?

Pros

- My symptoms will be controlled
- I will not have side effects from cancer treatment
- I will have less interruption in my daily life without frequent trips to hospital for treatment
- Other reasons:
-

Cons

- I worry that I'm not doing anything to try and control the cancer
- Other reasons:
-

What are the pros and cons of adding anticancer therapy to supportive care?

Pros

- May help me live longer
- May improve my cancer symptoms
- If my symptoms improve, I may be able to use less of other medicines such as morphine (which may have side effects)
- I feel I'm doing something to fight the cancer
- Other reasons:
-

Cons

- I will have side effects from anticancer treatment
- There is no guarantee treatment will work
- I'll need more tests and needles if I have chemotherapy
- Inconvenience of frequent visits to hospital for me and my family
- I may have less free time
- I may need additional medicines to manage side effects of the anticancer treatment
- Other reasons:
-

Arriving at a treatment decision

Arriving at a decision can be thought of as a series of 7 steps. You have already carried out 3 of these steps:

1. Understanding your situation
2. Learning about your treatment options
3. Reviewing the pros and cons of those options

The next 4 include determining:

4. How important these pros and cons are to you
5. If you want more information or more discussion with your doctor
6. Who should make the decision—you, your doctor, or shared between you
7. Where you are leaning —towards supportive care alone or adding anticancer treatment?

The next page shows examples of how other people view the pros and cons of different treatment options. This will be followed by your own worksheet¹⁸, where you list the pros and cons of your options in boxes, and shade in the boxes according to how important these are to you. Shade in the whole box if the statement is very important, half of the box if it is somewhat important to you, and do not shade at all if the statement is not important to you.



Tom's Worksheet

Weighing up the pros and cons of supportive care versus active treatment

Cons of adding Anticancer Treatment	Pros of adding Anticancer Treatment
<p>Chemotherapy side effects Cousin with breast cancer had terrible side effects.</p>	<p>I may live longer I have lived to a good age.</p>
<p>Frequent tests, trips to hospital I have to take the bus or a taxi to get there.</p>	<p>My symptoms from cancer may improve I don't really have any symptoms right now.</p>
<p>Less free time for myself I try to play golf every day if I can.</p>	<p>I feel like I'm fighting the cancer I'm not a quitter.</p>
<p>No guarantee treatment will work It didn't work for my cousin.</p>	<p>I may be able to stop my other medications I'm not on any other medicines right now.</p>
<p>Other I can always start later if I change my mind.</p>	<p>Other</p>

Where am I leaning?

Supportive Care Adding Anticancer Treatment

Are there any more questions you would like to ask?

Can I start active treatment later if I want to?

Who should make the decision about treatment?

<input type="checkbox"/>	I would prefer to make the decision	<input type="checkbox"/>	I prefer that my doctor make the final decision, but strongly	<input type="checkbox"/>	I prefer to leave all decisions about treatment to my doctor	<input checked="" type="checkbox"/>	I'm not sure who should make the decision
<input type="checkbox"/>	I prefer to make the final decision after considering my doctor's opinion	<input type="checkbox"/>	I prefer that my doctor and I share responsibility for the decision	<input type="checkbox"/>	I prefer to leave all decisions about treatment to my doctor	<input type="checkbox"/>	I'm not sure who should make the decision

Anna's Worksheet

Weighing up the pros and cons of supportive care versus active treatment

Cons of adding Anticancer Treatment	Pros of adding Anticancer Treatment
Chemotherapy side effects I am strong – I can handle it.	I may live longer I have my family to live for.
Frequent tests, trips to hospital My husband or I can drive to hospital.	My symptoms from cancer may improve I am having a lot of lower back/stomach pain.
Less free time for myself I can have free time after treatment is over.	I feel like I'm fighting the cancer I can't give up fighting, because of my family.
No guarantee treatment will work True.	I may be able to stop my other medications The morphine is very constipating.
Other	Other My brother had chemotherapy and he wasn't too sick with it.

Where am I leaning?

Supportive Care Adding Anticancer Treatment

Are there any more questions you would like to ask?

Do I need any more tests? When can I start?

Who should make the decision about treatment?



I would prefer to make the decision I prefer that my doctor and I share responsibility for the decision I prefer that my doctor make the final decision, but strongly to my doctor consider my opinion I'm not sure who should make the decision

Your Worksheet

Weighing up the pros and cons of supportive care versus active treatment

Cons of adding Anticancer Treatment	Pros of adding Anticancer Treatment
Chemotherapy side effects	I may live longer
Frequent tests, trips to hospital	My symptoms from cancer may improve
Less free time for myself	I feel like I'm fighting the cancer
No guarantee treatment will work	I may be able to stop my other medications
Other	Other

Where am I leaning?

Supportive Care Adding Anticancer Treatment

Are there any more questions you would like to ask?

Who should make the decision about treatment?

I would prefer to make the decision
 I prefer to make the final decision after considering my doctor's opinion
 I prefer that my doctor and I share responsibility for the decision
 I prefer that my doctor make the final decision, but strongly consider my opinion
 I prefer to leave all decisions about treatment to my doctor
 I'm not sure who should make the decision

Shade in the whole box if the statement is very important, half of the box if it is somewhat important to you, and do not shade at all if the statement is not important to you.

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Clinical Trials for Patients with Metastatic Colorectal Cancer

Clinical trials are research studies, and often test how useful new treatments are, or compare them to what is used currently. There may be trials available that your doctor may discuss with you. If you are interested in participating in a trial, or wish to learn more about trials for your cancer, please ask your doctor.

Who can join the trial?

People who have **bowel cancer that has spread** outside the bowel, are **over 18 years** of age, have been carefully assessed and have been found suitable and **want to participate** in a trial.

Why join a trial?

We are continuously looking at ways to improve on the overall care for cancer patients. People often want to participate in trials as the new drug/s may not be available any other way. The new treatments may lead to control or even cure of cancer. Through these trials, which it may not benefit you directly, you will be a part of researching existing treatments and identifying new treatment strategies which will hopefully improve health outcomes for cancer patients.

How do we know which treatment is better?

The reason for doing a trial is to find out whether one treatment is better than another treatment. There are controlled trials or randomised trials. Controlled trials compare two or more treatments to determine which is more effective. Randomised trials are controlled trials where treatment is selected for each person at random. When on a study you will be carefully monitored by your doctor looking closely at when (or if) your cancer starts to grow, the side effects of the treatment and your quality of life while on treatment. Comparisons of those outcomes will be measured against patients who have received the other treatment/s.

Who is providing money to carry out this study?

Clinical trials can have different sponsors, who are funded by pharmaceutical companies, National or Regional research funding organisations. There is no additional cost to you if you participate in a trial.

Support Services

Different people have different needs for support. There are a variety of support services available. These are a list of a few support services, and you can find out about more services through them. Also feel free to ask your doctor or nurse for more information.

Canadian Cancer Society

Metropolitan Toronto Region, 20 Holly St., Suite 200 Toronto ON M4S 3B1
Tel. 416-440-3330 Toll free 1-888-939-3333 (outside Metropolitan Toronto)
fax 416-440-3331

Different programs available at the Canadian Cancer Society include:
Cancer Information Service, Cancer Society Volunteer Drivers, Cansurmount:
Cansurmount volunteers make one-to-one visits with cancer patients, and are matched based on a similar diagnosis, age, etc. Living with Cancer: self-help groups for patients, families and friends to provide emotional, social and practical support and guidance. Cancer Connection Peer Support Program: telephone support program which links people with cancer with trained support volunteers who themselves have had cancer, or who have looked after someone with cancer. Call 1-800-263-6750.

Wellspring

The Coach House. 81 Wellesley Street East, Toronto ON M4Y 1H6
Tel. 416-921-1928

London and Region. 231 Human St., London ON N6A 1N6, Tel. 519-438-7379

Wellspring offers a variety of programs, many of them for no fee:
Support Groups. Specific groups for patients, caregivers, parents and children.
Coping Skills: teaches exercises and relaxation programs to promote well-being, improve stress management and relaxation.

Princess Margaret Hospital

610 University Avenue, Toronto ON M5G 2M9, Tel. 416-946-2000

Patient and Family Library (main floor): open Monday to Friday, 9AM to 4PM, with a variety of books, videos, pamphlets and the PMH Computer-based Patient Education Program.

Coping with Cancer: This educational program includes
Step 1: the Healing Journey Program (www.healingjourney.ca);
Step 2: Skills for Healing

Princess Margaret Hospital Lodge.

University Health Network, 545 Jarvis Street, Toronto ON M4Y 2H8

Accommodation: for those who live out-of-town or have difficulty travelling to hospital for daily appointments, accommodation can be arranged at the lodge. Fee includes accommodation with 24-hour Registered Nurse available, shuttle bus to hospital, programs including education and counselling.

Home Support

Toronto CCAC Tel. 416-506-9888
York Region CCAC Tel. 905-895-1240, Toll Free: 1-888-470-2222
Durham Region CCAC Tel: 1-800-668-5835
Peel Region CCAC Tel. 905-796-0040
Or consult your phone book for the CCAC office nearest you.

Community Care Access Program: provides health and personal support services to assist clients to live at home. Services are provided at no cost to those who are eligible. Ask your doctor if you wish to be assessed for this program.

Interlink Community Cancer Nurses:
620 University Avenue, Suite 701 Toronto ON M5G 2C1
Tel. 416-599-5465 or Fax 416-599-5972

These nurses specialise in care and support of people with cancer and their families, including counselling and education about pain relief. Patients and family can self-refer.

Hospice Association of Ontario

Tel 1-800-349-3111

Hospices give people with a life-threatening illness the opportunity to be cared for at home, with a focus on caring and quality of life.

Internet resources

Colorectal Cancer Association of Canada (CCAC/ACCC)	www.ccac-acc.ca
Colon Cancer Alliance	www.ccalliance.org
Colorectal Cancer Network	www.colorectal-cancer.net
Patient Advocacy Foundation	www.patientadvocate.org
Patient Advocates in Research	www.painetwork.org
National Cancer Institute (USA)	www.cancernet.nci.nih.gov

Questions and Notes

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