I HAVE METASTATIC
COLORECTAL OR
BOWEL CANCER:
WHAT DOES IT MEAN?

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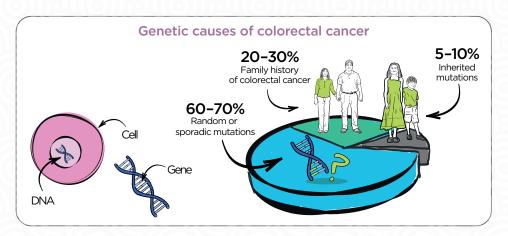
### INTRODUCTION

- You have been diagnosed with metastatic colorectal (or bowel) cancer

   a type of cancer that develops in the bowel, which can then spread to
   other parts of the body¹
- This leaflet explains how this cancer can develop and the influence of changes to genes, called mutations, on your treatment

# WHAT CAN CAUSE METASTATIC COLORECTAL CANCER?

- In the cells of your body, short sections of DNA called genes control how cells behave and grow<sup>2,3</sup>
- Changes (or mutations) in some genes can cause cells to grow and multiply too quickly; this uncontrolled growth can lead to colorectal cancer<sup>3</sup>



#### Inherited mutations:

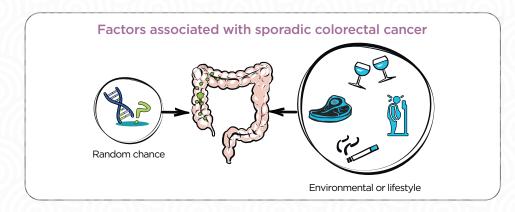
 Only 5-10% of colorectal cancer cases are inherited – these are caused by specific identified mutations passed on in families<sup>4</sup>

## Family history:

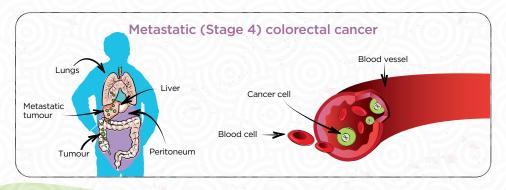
 If several close relatives in a family have had colorectal cancer, other relatives may be at risk of developing it; these family members may benefit from early cancer screening<sup>5,6</sup>

### Random (or sporadic) mutations:

- 60-70% of colorectal cancers are not inherited and happen by chance these mutations are not passed on in families<sup>7</sup>
- Older age, environmental or lifestyle factors like smoking, a diet rich in processed and red meat, and high alcohol intake, can make it more likely for someone to get colorectal cancer<sup>4,5</sup>
- Random mutations can also develop without a known cause<sup>2</sup>

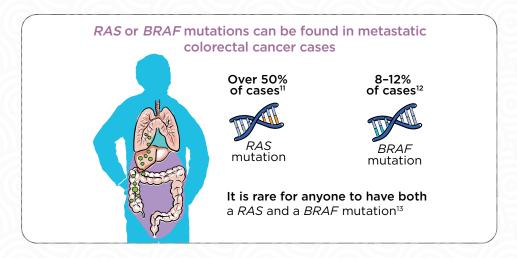


- If colorectal cancer is left untreated it usually grows slowly before starting to spread to other parts of the body, to nearby or distant organs via the bloodstream such as the lining of the abdomen (peritoneum), liver and lungs<sup>8,9</sup>
- When colorectal cancer spreads outside of the bowel it is called Stage 4 or metastatic colorectal cancer<sup>8,10</sup>



# WHAT DOES IT MEAN IF I HAVE A RAS OR A BRAF MUTATION?

- There are different types of metastatic colorectal cancer, which require different treatments<sup>10</sup>
- Treatment decisions are affected by the specific **gene mutations** that are present<sup>10</sup>
- We know that mutations in **genes called** *RAS* and *BRAF* are important in the development of metastatic colorectal cancer<sup>11</sup>
- The RAS and BRAF genes control how cells function, grow and multiply<sup>10</sup>
- Mutations in the RAS or BRAF genes disrupt these normal processes, leading to uncontrolled cell growth and cancer<sup>11</sup>

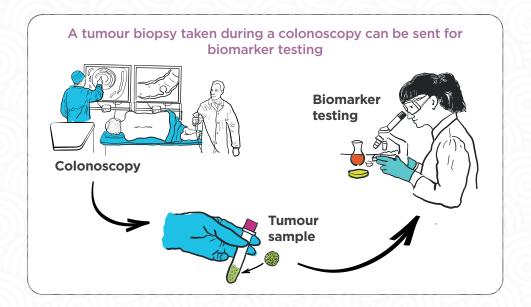


### If you have mutations in either the RAS or BRAF genes:

- The cancer may grow more quickly, so your treatment may need to be adapted<sup>11,14</sup>
- You, your doctor and healthcare team will discuss the best treatment plan, looking at which treatments will be the most suitable and in what  ${\rm order^{10}}$

# HOW WILL I KNOW IF I HAVE A MUTATION AND WHY DOES IT MATTER?

- When diagnosed with metastatic colorectal cancer, your doctor may take a sample of the tumour (biopsy) during a colonoscopy<sup>12</sup>
- The tumour biopsy will be sent to a laboratory to find out whether you have any mutations; this is sometimes called biomarker testing (or molecular testing)<sup>12</sup>
- This is important to understand your cancer and choose the best treatment<sup>12</sup>
- Ask your healthcare team about biomarker testing and whether you have any gene mutations<sup>10</sup>





Follow the QR code for an animation providing further information on metastatic colorectal cancer and what it means to have a RAS or BRAF mutation

# HOW WILL I KNOW THE RIGHT TREATMENT FOR ME?

### Choosing the right treatment for you may depend on:10

- Your overall health
- The type and location of the cancer
- If you have mutations in particular genes like RAS or BRAF
- Which treatments you have already received
- Side effects you have had with other treatments

### Treatments for metastatic colorectal cancer can include:



## Radiotherapy<sup>15</sup>

 Radiation is a local treatment applied to one area of the body to kill mainly cancer cells



## Surgery<sup>10</sup>

- An operation to remove cancerous tissue
- The type of surgery depends on where the cancer has spread



## Chemotherapy<sup>16</sup>

- A standard treatment for cancer
- Often used to make the tumour smaller
- Mainly kills cancer cells as they usually grow and multiply faster than other cells



## Targeted therapy<sup>16</sup>

Targets the specific changes or mutations found in cancer cells to stop them from growing



## Immunotherapy<sup>16</sup>

 Helps your body's own defence system (the immune system) to kill cancer cells



#### Combinations<sup>16</sup>

 A combination of therapies, such as chemotherapy plus a targeted therapy or an immunotherapy

### Side effects

- Side effects of different treatments can include:
  - Tiredness, diarrhoea, nausea and vomiting, skin rashes, difficulty breathing, weight loss, joint and muscle pain, weakened immune system, tingling or numbness in your hands and feet<sup>16</sup>
- Occasionally, people experience changes to their sex life<sup>16,17</sup>,
   difficulty concentrating or remembering things (sometimes called chemobrain or brain fog)<sup>18</sup>, or their fertility may be affected<sup>16</sup>
- If you have concerns or if you experience any side effects, speak to your healthcare team straight away

## Biomarker testing

 Knowing your molecular profile to see if you have a RAS or BRAF mutation is important so that you and your healthcare team can choose the most suitable treatment for you<sup>10,12</sup>

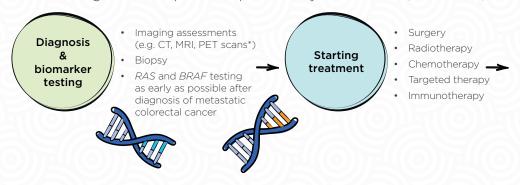
## Ask your healthcare team for more information about your treatment options

- They will advise on the best course of treatment, follow-up and supportive care for your cancer type, and will change your treatment plan according to your needs
- Your healthcare team can also advise you if there are any suitable clinical trials you could take part in 10,19

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## WHAT COULD MY TREATMENT

You might find it helpful to keep a note of your test results, treatments, side



#### **DIAGNOSIS & BIOMARKER TESTING**

My test results

#### STARTING TREATMENT

My treatments

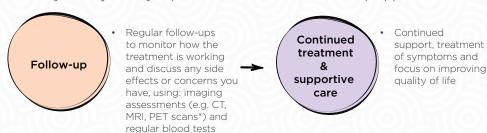
## IS THERE ANYTHING ELSE I CAN DO?10

- Feeling anxious, stressed, or low in mood at times is perfectly normal.
   Speak to your healthcare team to get more practical, medical and emotional support, and to be directed to a counselling service if needed
- Talk to your friends and family about how you are feeling
- Contact your local patient organisation for support and advice during your treatment journey
- Don't be alone talk to other patients who have also been affected by cancer to share tips and advice

\*CT, computed tomography; MRI, magnetic resonance imaging; PET, positron emission tomography

## JOURNEY LOOK LIKE? 5,10,12,14,17

effects and your day-to-day experiences to discuss at follow-up appointments



#### **FOLLOW-UP**

#### CONTINUED TREATMENT

My follow-up

Other notes

 Colores and All about cancer represents patients with colorectal and other cancers. Read here for more information on tips for daily life, how to take care of your well-being, potential treatment options and to find your local patient organisation

The cancer organisations also organise courses for patients with metastatic cancer:

http://www.kaikkisyövasta.fi/hoito-ja-kuntoutus/kuntoutus/kuntoutuskurssit/

Peer support helps to support both the sick person and their loved one www.colores.fi/tuki/ and www.colores.fi/laheiselle/

## WHO ARE MY HEALTHCARE TEAM?

**Note:** the healthcare team can vary depending on each hospital as well as on the individual patient case. Additionally, most members of the healthcare team may be connected, but not all.

### Different healthcare specialists involved in your care might include:

- Oncologists (doctors treating cancer)
- Surgeons
- Oncology nurses
- Psychologists
- Dieticians
- Pharmacists
- Occupational therapists
- ... among others<sup>17</sup>



· Below, you can add the contact details of your healthcare team

Speciality	Name	Contact number	Location
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## WHAT DO I NEED TO DISCUSS WITH MY HEALTHCARE TEAM?

 It can be helpful to write down any questions you have and take them with you to your medical appointments so that you can discuss them with your healthcare team

- Here are some example questions that you may want to ask and discuss<sup>10</sup>
  - What kind of colorectal cancer do I have and what does it mean for me?
  - What are the results of any diagnostic/biomarker tests I have had?
  - Do I have any gene mutations?
  - What are my treatment options?
  - What will this treatment do?
  - What side effects may I have? When? How long will they last?
  - What should I do if I experience side effects?
  - Who should I call in an emergency?
  - Who can I reach out to for emotional support or counselling?
  - Where can I get support on lifestyle changes, such as diet or exercise?
  - What does my diagnosis mean for my family?

# INFORMATION TO MANAGE MY COLORECTAL CANCER DAY TO DAY

- Your healthcare team is best placed to discuss your colorectal cancer with you and highlight any concerns you have
- Additional sources of information include:
  - Websites of colorectal cancer patient organisations in your area:
     www.colores.fi
     https://digestivecancers.eu/
  - Website with Finnish treatment guidelines and ESMO, a European medical society for cancer:
     www.terveysportti.fi/apps/dtk/ltk/article/hsu00007
     https://www.esmo.org/for-patients/patient-guides/colorectal-cancer
  - Official websites of the university hospitals:
    www.terveyskyla.fi/syopatalo/syopataudit/suolistosyövät
    www.terveyskyla.fi/vertaistalo
    www.terveyskyla.fi/kuntoutumistalo
    www.terveyskyla.fi/kuntoutumistalo/kuntoutujalle/syöpäsairaudet/
    liikunta-ja-syöpä

## WHERE CAN I FIND MORE INFORMATION?



Follow the QR code for an animation providing further information on metastatic colorectal cancer and what it means to have a RAS or BRAF mutation

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This booklet does not replace the advice of your healthcare professional. BE SURE TO ASK YOUR HEALTHCARE PROFESSIONAL ABOUT ANY QUESTIONS OR CONCERNS YOU MAY HAVE ABOUT YOUR SPECIFIC MEDICAL CONDITION TREATMENT PLAN

Thank you to our partner in patient perspectives and insight, Digestive Cancers Europe (DiCE), and its members for their collaboration





