Colorectal (bowel) cancer
INDIVIDUAL SURGICAL FOLLOW-UP INFORMATION

This booklet contains information for you and your family/whānau about your bowel cancer diagnosis and individual treatment programme.
Having a colon or rectal cancer diagnosis is a different journey for every person. Once treatment is complete some people find it hard to remember what happened, and what their doctors have told them about their diagnosis. There is a lot of information to take in, and many people have questions about what happens next for them. Many people with colorectal cancer are very likely to be cured, and can resume a healthy life. A few have more worrying disease, or disease that can no longer be cured. Whatever your individual situation is, we want you to have good information about your diagnosis, treatment and follow-up.

We believe it is important for people to be involved in discussing what follow-up would be best for them, and being informed about how best to look after their own health once their treatment is complete. The hospital is here to help should a concern develop, but for many people they will no longer need to be a hospital patient and can follow-up with their general practitioner (GP).

This booklet is designed to help record details of your cancer, the treatment you have had and what your individual follow-up plan will be.

You can take your booklet with you to keep for your records. You may wish to share it with your family/whānau and GP. If you have any questions about anything in your booklet, please ask your surgeon, the cancer nurse or your GP.

**SUPPORT IS AVAILABLE**

For most people, the first port of call if they have health concerns, is their GP or Iwi health provider. Your GP can contact your surgeon or oncologist if you need to be seen by Surgical Services again.

Some people have difficulty adjusting psychologically to having a cancer diagnosis and experience distress which affects their wellbeing. There is a cancer psychology support and counselling service available. Please let your GP, surgeon, oncologist or oncology nurse know if you would like to be referred.

The oncology nurses at the hospital also provide support. Their direct dial number is 06 348 1289. If you need to speak with the oncology social worker, please phone 06 348 3007.

For general support and advice, the Cancer Society can help. The Cancer Society can be contacted on 0800 226 237 (Wanganui Centre Office: 06 348 7402) or visit their website: www.cancernz.org.nz.

Beat Bowel Cancer Aotearoa also has information on their website: www.beatbowelcancer.org.nz or you can get in touch with them by emailing: info@beatbowelcancer.org.nz.

To you and your family/whānau who are walking this journey, kia kaha – stay strong.
INDIVIDUAL TREATMENT SUMMARY

This section records the treatment you have had for your bowel cancer.

Pre-operative treatment (for rectal cancer)

☐ No pre-op treatment needed  ☐ Chemotherapy  ☐ Radiotherapy (radiation)

Operation/s

Operation 1: Date: Days in hospital:
☐ Laparoscopic  ☐ Open  ☐ Elective  ☐ Acute
☐ Right hemicolecctomy
☐ Extended right hemicolecctomy
☐ Subtotal colectomy

Stoma placed:
☐ Not required  ☐ Temporary  ☐ Permanent  ☐ Colostomy  ☐ Ileostomy

Complications:

Operation 2: Date: Days in hospital:

Post-operative treatment

☐ No post-operative treatment needed

Chemotherapy  ☐ Yes  ☐ No  Radiotherapy  ☐ Yes  ☐ No

Specialists

Surgeon: ☐ Aiono  ☐ Bonnet  ☐ Lill  ☐ Skavysh  ☐ Other:  ☐ N/A

Medical oncologist:  ☐ N/A

Radiation oncologist:  ☐ N/A

Follow-up in surgical clinic is usually within six weeks of surgery, then at one year. After that, most people can be followed up by their GP and referred back to surgical clinic as needed.

Your one year follow-up clinic due (approx date):
INDIVIDUAL COLORECTAL CANCER HISTOLOGY

Histology is the laboratory report on the cells seen in your bowel cancer. This gives information about how your cancer might behave. Most bowel cancers are cured with surgery, and with or without chemotherapy and/or radiation.

Cancer type

☐ Adenocarcinoma  Other:

Cancer location

Differentiation

☐ Well  ☐ Moderately  ☐ Poorly*

T - Tumour

☐ T1 (into bowel lining)  ☐ T2 (into bowel wall)  ☐ T3 (through bowel wall)  ☐ T4 (beyond bowel wall)

N - Nodes

☐ N0 (no nodes)  ☐ N1 (1-3 nodes)  ☐ N2 (4 or more nodes)  with cancer / total nodes found

M - Metastatic

☐ M0 (none)  ☐ M1 (metastasis)  ☐ Mx (not yet known)

Lymphovascular invasion

☐ No  ☐ Yes*

Perineural invasion

☐ No  ☐ Yes*

Stage

☐ 1  ☐ 2 (low risk)  ☐ 2 (high risk*)  ☐ 3  ☐ 4

Other information (eg. incomplete excision*)

Final diagnosis  Stage:  T  N  M

Note: Stage 2 cancers are divided into Low Risk Stage 2 and High Risk Stage 2 depending on if it has any of the risk features marked with *.
IS MY COLORECTAL CANCER LOW OR HIGH RISK?

The chance of long-term survival (at least five years) depends on how advanced your cancer is at diagnosis (the tumour stage), as well as how good your general health is. Most recurrences happen in the first three years. Patients who survive five years are generally considered cured, although occasionally late recurrences can happen.

<table>
<thead>
<tr>
<th>Cancer stage</th>
<th>5 year survival rate</th>
<th>Tumour size/spread</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1 (T1 or 2, N0, M0)</td>
<td>93%</td>
<td>Small, no nodes</td>
</tr>
<tr>
<td>Stage 2 (T3 or 4, N0, M0)</td>
<td>72-85%</td>
<td>Large, no nodes</td>
</tr>
<tr>
<td>Stage 3 (any T, N1-3, M0)</td>
<td>44-83%</td>
<td>Cancer spread to nodes</td>
</tr>
<tr>
<td>Stage 4 (any T, any N, M1)</td>
<td>8%</td>
<td>Metastatic disease</td>
</tr>
</tbody>
</table>

Some people with metastatic disease still have a chance of cure. For people with resectable (can be removed with an operation) liver metastasis, the chance of five year survival is still 30-50 percent as long as all the metastatic disease can be removed surgically. Palliative chemotherapy is also possible and can help extend life expectancy.

Some people who were in poor health prior to their operation are at higher risk of other health problems during and after their surgery e.g. stroke, heart attack, pneumonias. Sometimes the physical and mental stress of the operation can reduce their ability to cope and function in their own home, and increased supports are needed.

Should incurable metastatic disease develop, then early referral to hospice for symptom treatment and support is recommended. Research shows early contact with hospice actually lengthens survival as well as improving quality of life for people with metastatic disease. For more information contact Wanganui Hospice on 06 349 0080 or visit www.hospicewanganui.org.nz.

A list of Iwi health providers can be found on the WDHB website at wdhb.org.nz under the ‘Our Community’ tab or ask your oncology nurse (phone 06 348 1289) to send you a list.
SYMPTOMS TO REPORT

Many people’s colorectal cancer will be cured with surgery, with or without chemotherapy and/or radiation. Should a recurrence, metastatic disease or a new cancer occur, sometimes more treatment can be offered. For some people, long-term survival is still possible.

After your operation, your bowel habits may be erratic, or different to before your operation. It can take some time to settle down and get used to a ‘new normal’. If you are finding your bowel movements too frequent or difficult to control, your doctor can prescribe fibre supplements and anti-diarrhoea medication to help.

Symptoms to report to your GP include:

- rectal bleeding
- difficulty passing a bowel movement
- black tarry stools
- unexplained weight loss
- mucus in the stool
- change in bowel habit (looser or more frequent)
- lumps or masses in your tummy
- extreme fatigue.

Often symptoms are not due to cancer, but should still be checked with your GP. If your GP is concerned about a new symptom or finding on examination, they will refer you to Surgical Services.

GENETICS (FAMILY HISTORY)

Sometimes cancer can run in the family due to a cancer gene shared between relatives. If other family members develop bowel cancer or related cancers (endometrial/uterine cancer, or cancers of the stomach, ovary, small intestine, pancreas, kidney or brain) please discuss this with your GP, as a referral for genetic testing may be needed. Most bowel cancers are not caused by a cancer gene.

For relatives of people who develop bowel cancer at a young age (under 55 years old), or where two or more close relatives have bowel cancer (or a related cancer), surveillance colonoscopy is offered to check their bowel. This can be arranged through their GP.

Other family members affected by cancer – see GP to discuss if more cancers develop:

<table>
<thead>
<tr>
<th>Relative</th>
<th>Cancer type</th>
<th>Diagnosis age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
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<tr>
<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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FOLLOW-UP FOR COLORECTAL (BOWEL) CANCER

There is some evidence that follow-up for bowel cancer can improve the chance of finding potentially treatable metastatic disease and new cancers.

Follow-up for bowel cancer usually includes:

1. Follow-up with your doctor to report bowel symptoms, for examination of abdomen, rectum every six to 12 months, or as required (if new symptoms occur).

2. Carcinoembryonic antigen (CEA) level blood test at least six-monthly for five years (may do yearly for lower risk cancers e.g. Stage 1, Low Risk Stage 2), or as symptoms occur.
   a. Younger and highly motivated patients may prefer three monthly CEA testing.
   b. Some patients may decide against CEA testing e.g. needle phobia, or when the anxiety of testing outweighs the benefit.

3. For patients with Stage 2 and 3 cancer, at least one CT scan of abdomen, between one and three years after surgery to detect liver metastasis.

4. Full colonoscopy before surgery or within one year post-op, then at three years after operation, then five-yearly until age 75 (unless high risk polyps are found or health deteriorates).

5. Lifestyle changes (if needed) e.g. stop smoking, maintain healthy weight, diet and exercise.

If your GP is concerned about your CEA level, your CT scan result, or a new symptom or finding on examination, they will refer you to Surgical Services. Normal CEA levels may be reassuring, but this test is not 100 percent accurate at detecting cancer recurrence. For people who do not wish to consider further major surgery if the cancer returns or a new cancer develops, it is perfectly reasonable to decide not to have these checks. The need for follow-up can be reviewed with your GP if there is a change in your health making investigations or treatments risky.

Please book your own GP appointments for bowel cancer follow-up, or ask your GP if they can set up a recall.

INDIVIDUAL CHECKLIST

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Histology discussed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up plan created</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurring CEA blood test form given</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CT scan after one year requested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surveillance colonoscopy requested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetics referral done</td>
<td></td>
<td>Not needed currently</td>
</tr>
<tr>
<td>Cancer psychology referral done</td>
<td></td>
<td>Not needed currently</td>
</tr>
<tr>
<td>Cancer Society referral done</td>
<td></td>
<td>Not needed currently</td>
</tr>
<tr>
<td>Iwi health provider resource given</td>
<td></td>
<td>No</td>
</tr>
</tbody>
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INDIVIDUAL FOLLOW-UP PLAN

No active follow-up planned (report symptoms as needed)

Stomal reversal needed:

Yes  No  Approximate date: ________________

Active follow-up with GP (abdominal and rectal examination; report symptoms; review results):

Yes  No

*Six-monthly for three years, then annually for two years
Anually for five years

CEA level before surgery: ____________________________ Note: smoking and other illnesses sometimes cause an elevated CEA

Check CEA level blood test:

Yes  No (decision not to monitor CEA)

* Three-monthly for three years, then six-monthly for two years

* Six-monthly for three years, then annually for two years
Anually for five years

Full colonoscopy:

Done before surgery  Not done prior - do now  Decision not to do full colonoscopy

After that:
Next due (three years): ____________________________  No further colonoscopy

Flexible sigmoidoscopy at 1 year (rectal cancer - Stage 2 & 3) Due:

CT scan of abdomen (Stage 2 & 3, between years 1-3) Due:

Alternative follow-up arranged as per clinic letter dated:

Whanganui District Health Board

100 Heads Road, Private Bag 3003
Whanganui 4540, New Zealand

find us on
Whanganui DHB