

Name: _____

Should I have my bowels “hooked up” (anastomosis) when removing my rectal cancer?

A decision aid for patients with rectal cancer

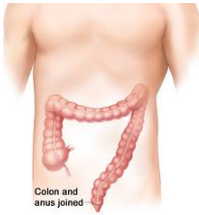
This decision aid is for you if:

- You have rectal cancer treatable by surgery
- Your surgeon has suggested having your bowels hooked back up at surgery

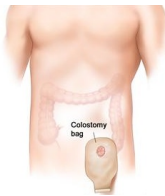
What is rectal cancer?

- Rectal cancer is a tumour located in the last 15 cm of the intestine.
- It is a difficult cancer to treat as it grows close to the muscles involved in the control of bowel movements and gas.
- The first goal of treatment is to remove all of the tumour for the best chance of survival.
- The second goal of treatment is to achieve acceptable bowel function.
- Although having your bowels hooked up is commonly recommended there is another option of having a permanent stoma (bag). These options are described next.

What are your options to remove the tumor?



Bowel hook up (Anterior Resection): The rectum is removed and the two healthy ends of bowel are reconnected. Your surgeon may need to create a temporary stoma (bag) to allow the hook up to heal. This temporary stoma produces more liquid stool with little odour. After 4-6 months the temporary stoma is reversed. After recovery, bowel movements are likely to be less predictable, more frequent, including at night, and urgent. Most people are able to manage this change. Some patients have poor control and have another operation for a permanent stoma. Patients who have radiation are more likely to experience changes in their bowel habits.



Permanent stoma (Abdominoperineal Resection): The rectum and anus are removed. The area of the anus is permanently closed and the bowel is not hooked up. The bowel is brought out to the skin and a stoma bag is attached. Following recovery, bowel movements will become more regular and predictable (e.g. morning and night). The bag controls smells and release of gas. Daily stoma care is necessary such as cleaning the area, changing the bag and applying creams. The costs of these materials may be covered. Most people resume their normal activities.

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What other health factors may affect your choice? Check any that apply.



Do you currently have bowel problems?

| | Never | Once a week | More than once a week | Daily |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| 1.1 Accidental leaks of gas? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.2 Accidental leaks of liquid stool? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.3 Accidental leaks of solid stool? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.4 Wear a pad because of accidental leaks of liquid or solid stool? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> None of these apply to me | | | | |



Do you have problems getting to the bathroom?



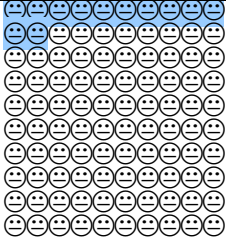
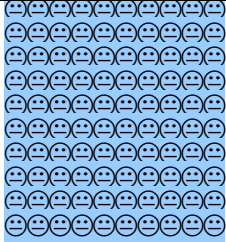
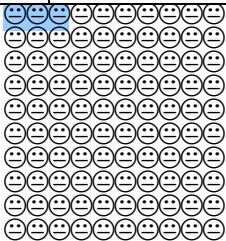
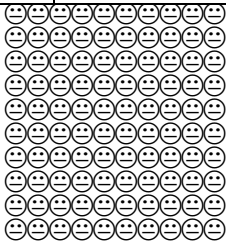
| | Yes | No |
|---|--------------------------|--------------------------|
| 1.5 Difficulty walking? | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.6 Use a wheelchair? | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.7 Job/lifestyle limits easy access to bathrooms? (eg. Outdoors) | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> None of these apply to me | | |

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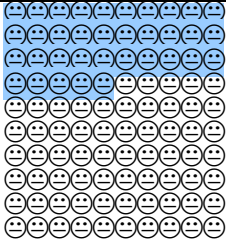
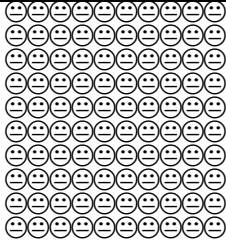
Step 1: What are the benefits and harms of each option?

What does the research show?

Blocks of 100 faces show a 'best estimate' of what happens to **100 people** after surgery and up to 4 years after who have their bowels reconnected or a permanent colostomy. Each face(😊) stands for one person. The shaded areas show the number of people affected. There is no way of knowing in advance if you will be one of those affected. You should discuss with your surgeon if you have any risk factors for these outcomes.

| |  |  |
|--|--|---|
| Benefits | Bowel hook up | Permanent stoma |
| 85 fewer people have a permanent stoma if they have their bowels reconnected. | 12 get a permanent stoma | 100 get a permanent stoma |
| By avoiding a permanent stoma you also avoid the complications of a permanent stoma such as: | 85 avoid a permanent stoma | 0 avoids a permanent stoma |
| <ul style="list-style-type: none"> • hernia of the stoma • bowel sliding out through the stoma • skin irritation around the stoma • problems with healing or infection where the anus was closed |  |  |
| Risks | | |
| 3 more people who have their bowels reconnected with a temporary stoma return to the operating room (OR) because of a life-threatening leak at the connection site. This may mean extra treatments, longer hospital stay and a longer recovery. You may need to be treated in the intensive care unit. | 3 return to the OR | 0 return to the OR |
| This number is higher for people who do not have a temporary stoma when their bowels are reconnected. In this case, 11 more people will return to the OR. | 97 avoid this | 100 avoid this |
| |  |  |

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| |  |  |
|--|--|---|
| Risks continued | Bowel hook up | Permanent stoma |
| <p>35 more people will complain of some form of incontinence following bowel hook up. The majority has minor incontinence (accidents) to gas and liquid stool. 14 people (out of 100) experience major incontinence to solid stool.</p> <p>All of these people choose to wear a protective pad in their underwear.</p> | <p>35 wear a pad</p> | <p>0 wear a pad</p> |
| | <p>65 avoid a pad</p> | <p>100 avoid a pad</p> |
| |  |  |
| <p>Problems from either surgery:</p> <p>Some people who have either surgery report worsening of their urinary or sexual function. The number of people who report this problem is the same for both surgeries.</p> <p>Urinary problems include difficulty emptying the bladder. There may also be problems of leaking urine, which is more common in women.</p> <p>For men, sexual problems may include impotence or ejaculation problems. For women, sexual problems may include vaginal dryness, pain during intercourse, problems with arousal or achieving orgasm.</p> | | |

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Step 2. Which reasons to choose each option matter most to you?

Common reasons to choose each option are listed below.

Mark ✓ how much each reason matter to you on a scale from 0 to 5.

'0' means it is not important to you. '5' means it is very important to you.



Reasons to...

Choose to have your bowels hooked up

| | Not Important | | Somewhat Important | | Very Important | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | [0] | [1] | [2] | [3] | [4] | [5] |
| 2.1 How important is it for you to have bowel movements the usual way? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2.2 How important is it to you to avoid the inconvenience of caring for a stoma? (e.g. emptying the bag, cleaning the area, applying creams and buying bags) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2.3 How important is it for you to avoid the complications of a permanent stoma? (including wound healing problems, stoma hernias, and skin irritations) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



Reasons to ...

Choose a permanent stoma

| | Not Important | | Somewhat Important | | Very Important | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | [0] | [1] | [2] | [3] | [4] | [5] |
| 2.4 How important is it that your bowel movements are more predictable, less frequent and less urgent? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2.5 How important is it for you to avoid incontinence (leaking) of stool or gas? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2.6 How important is it to for you to avoid having multiple surgeries? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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List other reasons that are important

List other reasons that are important

Now, thinking about the reasons that are most important to you...

If you definitely prefer a permanent stoma, check the box far to the right.

If you definitely prefer a bowel hook up, check the box far to the left.

3.1 If you are uncertain, check the centre box

| | | | | | | | | | | | | | | |
|---------------|--|--|--|-----------|--|--|--|-----------------|--|--|--|--|--|--|
| | | | | | | | | | | | | | | |
| Bowel hook up | | | | Uncertain | | | | Permanent stoma | | | | | | |

Choice predisposition © AM O'Connor 1996

Step 3: What else do you need to prepare for decision-making?

KNOWLEDGE



Find out how well this decision aid helped you learn the key facts.

Check the best answer.

| | Bowel hook up | Permanent stoma | Don't know |
|--|--------------------------|--|---------------------------------------|
| 4.1. Which option has the <u>highest</u> chance of needing a second surgery? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4.2. Which option cannot be reversed? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4.3. Which option has the <u>highest</u> chance of hernia and wound healing problems? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4.4. Which option has the <u>highest</u> chance of incontinence (accidents) of stool or gas? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4.5. Do you know enough about the benefits and side effects of each option? | | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

Check your answers at the bottom of the page

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DECISIONAL CONFLICT



Find out if you have uncertainties.

| | | Strongly agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |
|------|--|---------------------------|--------------------------|---|--------------------------|------------------------------|
| | | [0] | [1] | [2] | [3] | [4] |
| 5.1 | I know which options are available to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.2 | I know the benefits of each option. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.3 | I know the risks and side effects of each option. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.4 | I am clear about which benefits matter most to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.5 | I am clear about which risks and side effects matter most to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.6 | I am clear about which is more important to me (the benefits or the risks and side effects). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.7 | I have enough support from others to make a choice. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.8 | I am choosing without pressure from others. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.9 | I have enough advice to make a choice. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.10 | I am clear about the best choice for me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.11 | I feel sure about what to choose. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.12 | This decision is easy for me to make. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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| | | Strongly agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |
|------|--|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| | | [0] | [1] | [2] | [3] | [4] |
| 5.13 | I feel I have made an informed choice. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.14 | My decision shows what is important to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.15 | I expect to stick with my decision. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.16 | I am satisfied with my decision. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Decisional conflict scale © AM O'Connor 2005

The information is not intended to replace the advice of a healthcare provider.

A final decision can only be achieved through discussion with a healthcare provider.

Step 4. What are the next steps?

PREPARATION FOR DECISION MAKING



Find out if you are ready to communicate with the doctor.

| Did this educational material ... | Not at all | A little | Some-what | Quite a bit | A great deal |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 6.1 Help you recognize that a decision needs to be made | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.2 Help you think about the pros and cons of each option? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.3 Help you think about which pros and cons are most important? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.4 Help you organize your own thoughts about the choices? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.5 Help you think about how involved you want to be in this decision? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.6 Help you identify questions you want to ask your doctor? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.7 Prepare you to talk to your doctor about what matters most to you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.8 Prepare you for a follow-up visit with your doctor? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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Preparation for Decision Making Scale © Graham & O'Connor 1995
This information is not intended to replace the advice of a health care provider.

Answers for the key facts: 1. Bowel hook up 2. Permanent stoma 3. Permanent stoma 4. Bowel reconnection

Content editors: AS Scheer, RC Wu, RP Boushey, PL Roberts

Funded in part by: PSI, ASCRS. All Authors have declared no conflict of interest.

Format based on the Ottawa Personal Decision Guide © 2000, A O'Connor, D Stacey, University of Ottawa, Canada.

Publication date: [date published]. For more information contact the corresponding author: AS Scheer, ascheer@toh.on.ca. Technical information available at url (tbd).

Readability: FK Grade level 8.

References:

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6. Lange MM, Mass CP, Marijnen CAM, Wiggers T, Rutten HJ, Klein Kranenberg E, van de Velde CJH, cooperative clinical investigators of the Dutch Total Mesorectal Excision Trial. Urinary dysfunction after rectal cancer treatment is mainly caused by surgery. *British J Surg* 2008; 95: 1020 – 1028.
7. Lange MM et al. Risk factors for sexual dysfunction after rectal cancer treatment. *Eur J Cancer* 2009; 45(9): 1578 – 88.

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Your feedback on the decision aid

We would like to know what you think about the education package you have just received.

1. Please rate each section, by circling 'poor', 'fair', 'good', or 'excellent' to show what you think about the way the information was presented on:

| | | | | |
|-----------------------|------|------|------|-----------|
| General information | poor | fair | good | Excellent |
| Surgical options | poor | fair | good | Excellent |
| Risks and benefits | poor | fair | good | Excellent |
| Questions and answers | poor | fair | good | Excellent |

2. The length of presentation was (*check one*)

too long

too short

just right

3. The amount of information was (*check one*)

too much information

too little information

just right

4. I found the presentation (*check one*)

slanted towards taking permanent stoma

slanted towards taking bowel hookup

balanced

5. How clear is the information in the decision aid? Check the best answer

Everything was clear

Most things were clear

Completely balanced

Some things were unclear

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Many things were unclear

6. Would you recommend this decision aid to patients? Check the best answer

I would definitely recommend it

I would probably recommend it

I would probably not recommend it

I would definitely not recommend it

Comments:

7. What did you like about the decision aid?

8. What suggestions do you have to improve the decision aid?

9. Which version of decision aid did you prefer? (Choose paper version or web version)

What is the highest level of education you have achieved?

High school or less

Trade certificate/diploma

College diploma/degree

University degree