

Shared Decision Making – rectal cancer

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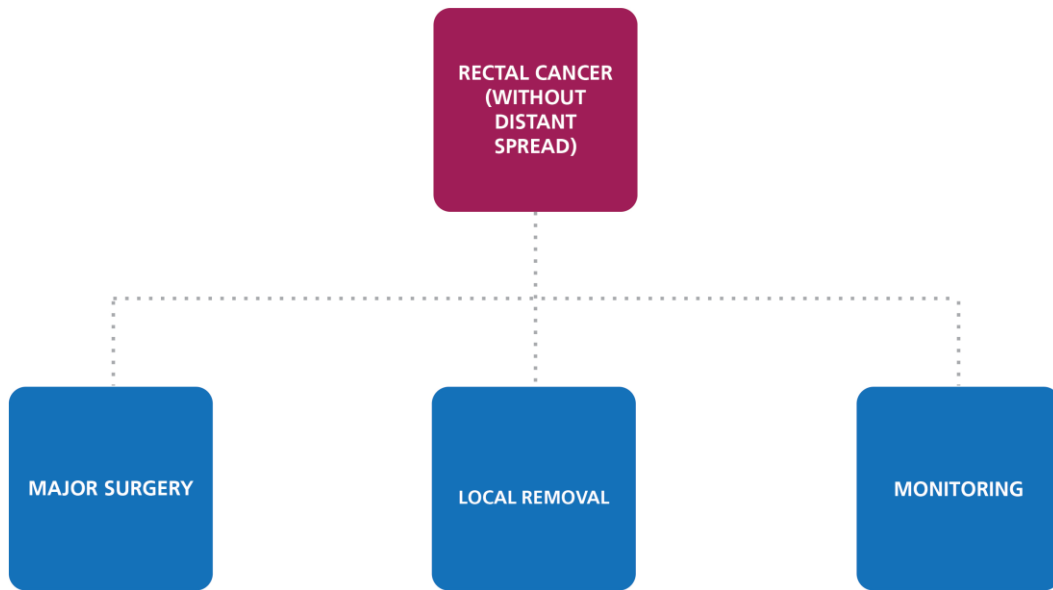
Deciding what to do about rectal cancer (without distant spread)

This short decision aid is to help you decide what to do about your rectal cancer. You can use it on your own, or with your doctor, to help you make a decision about what's right for you at this time.

This decision aid is for people who have rectal cancer that has not spread (metastasised) beyond the rectum or nearby lymph nodes, and has not spread to any other distant parts of the body.

There are three main options for treating rectal cancer (without distant spread). The choices are:

- Major surgery. This means having an operation to remove a large section of the rectum. People who have this operation may also have radiotherapy or chemotherapy (these are called adjuvant treatments).
- Local removal. This means having an operation to remove a small section of the rectum around the cancer. People who have this operation may also have radiotherapy or chemotherapy (adjuvant treatments).
- Monitoring. This means monitoring the cancer and, if needed, treatment to help the symptoms and pain. This option doesn't remove or shrink the cancer, and doesn't treat or cure the cancer
- Which treatment people can choose, and the effect a treatment has on their cancer, depends on a number of factors, including the type of cancer they have, how fast it is likely to grow, the size of the cancer, and their general health.



What are my options?

	Major Surgery	Local Removal	Monitoring
What is the treatment?	An operation to cut out the cancer from a large section of the rectum by removing the tumour through cuts in the abdomen.	An operation to cut out the cancer from the rectum, along with some healthy tissue around the tumour where there may be some cancer cells, using instruments inserted through the anus (back passage).	This means monitoring the cancer to see if it is growing and, if needed, treatment to help the symptoms and pain. This option doesn't remove or shrink the cancer, and doesn't treat or cure the cancer.

	Major Surgery	Local Removal	Monitoring
What is the effect on length of life?	<p>People with rectal cancer can die from things other than cancer.</p> <p>The numbers below do not take account of the fact that some deaths are from causes other than rectal cancer.</p> <p>In one group of people who had major surgery to treat early stage rectal cancer, 81 in 100 were still alive five years after having treatment.[12]</p>	<p>People with rectal cancer can die from things other than cancer.</p> <p>The numbers below do not take account of the fact that some deaths are from causes other than rectal cancer.</p> <p>In one group of people who had local removal to treat stage 1 rectal cancer, between 69 and 83 in 100 people were still alive five years after having treatment.[13]</p>	<p>People with rectal cancer can die from things other than cancer.</p> <p>The numbers below do not take account of the fact that some deaths are from causes other than rectal cancer.</p> <p>Monitoring will not help people live longer.</p> <p>Overall, around 50 in 100 people diagnosed with rectal cancer live for at least five years after diagnosis.[14]</p> <p>We don't know how many of these people chose not to</p>

			have treatment.
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	Major Surgery	Local Removal	Monitoring
What is the effect on stopping cancer from returning?	<p>Cancer can come back after major surgery.</p> <p>Rectal cancer can come back in the same place or, more commonly, in another part of the body.</p> <p>Having major surgery to remove rectal cancer can affect how likely it is that rectal cancer comes back.</p> <p>In one group of people with early rectal cancer who had major surgery, between 2 and 9 in 100 had their tumour come back in the same place within five years of having surgery.[13]</p> <p>For most people with rectal cancer, major surgery is the only treatment that has a chance of permanently stopping rectal cancer from returning.</p> <p>How likely rectal</p>	<p>Cancer can come back after local removal.</p> <p>Rectal cancer can come back in the same place or, more commonly, in another part of the body.</p> <p>Having local removal to remove rectal cancer can affect how likely it is that rectal cancer comes back.</p> <p>In one group of people with early rectal cancer who had local removal, between 9 and 20 in 100 people had their cancer come back in the same place within five years of having surgery.[13]</p> <p>How likely rectal cancer is to come back depends on the type of tumour, as well as the type of treatment chosen.</p>	<p>Monitoring does not remove rectal cancer, so the cancer will not have gone away. It will still be present in the body.</p> <p>Deciding to wait before having treatment will mean rectal cancer will not go away. This may mean it is less likely to be cured.</p>

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	Major Surgery	Local Removal	Monitoring
What is the effect on stopping cancer from spreading?	<p>Having major surgery to remove rectal cancer can affect how likely it is that rectal cancer spreads.</p> <p>In one group of people with early rectal cancer who had major surgery, between 2 and 9 in 100 had their tumour come back elsewhere in the body within five years of having major surgery.[13]</p> <p>How likely rectal cancer is to spread depends on the type of tumour, as well as the type of treatment chosen.</p>	<p>Having surgery to remove rectal cancer can affect how likely it is that rectal cancer spreads.</p> <p>In one group of people with early rectal cancer, between 6 and 21 in 100 people who had local removal saw their cancer come back elsewhere in the body.[13]</p> <p>How likely rectal cancer is to spread depends on the type of tumour, as well as the type of treatment chosen.</p>	<p>Monitoring does not stop rectal cancer from spreading to other parts of the body.</p> <p>Without treatment, rectal cancer will progress to a more advanced stage and may no longer be curable.</p> <p>Monitoring may help detect whether cancer has spread to another part of the body.</p> <p>People who are having monitoring whose cancer spreads to other parts of the body can decide to have treatment.</p> <p>Deciding to wait before having treatment may mean rectal cancer is more likely to spread.</p>

	Major Surgery	Local Removal	Monitoring
What is the effect on quality of life?	<p>Having major surgery to treat rectal cancer can affect quality of life.</p> <p>In one group of people who had major surgery for rectal cancer, they felt better both physically and emotionally, had more energy, and were less bothered by things like sexual problems after their treatment compared to before they had treatment.[14]</p> <p>Major surgery can cause a permanent or temporary stoma. This can affect people's quality of life.[15]</p> <p>Both anterior resection and abdominoperineal resection seem to affect quality of life by about the same amount as each other.[14]</p>	<p>We don't know if having local removal for rectal cancer has an effect on quality of life. There haven't been many studies that have looked at this.</p> <p>Quality of life after having treatment for rectal cancer depends on lots of things, not just the type of treatment chosen.</p> <p>Local removal can cause side effects, including faecal incontinence (loose stools). [16] This may affect people's quality of life.</p>	<p>We don't know if choosing not to have treatment has an effect on quality of life.</p> <p>There haven't been many studies that have looked at this.</p>

	Major Surgery	Local Removal	Monitoring
What are the side effects or complications of treatment?	<p>Having major surgery for rectal cancer can cause complications. How likely complications</p>	<p>Having local removal for rectal cancer can cause complications. How likely complications</p>	<p>Monitoring does not cause side effects or complications.</p> <p>Deciding to wait</p>

	<p>are depends in part on things like people's age and general health.</p> <p>In one group of people who had major surgery for early rectal cancer, around 47 in 100 had complications after treatment.[12]</p> <p>Some of the most common problems that affect people who have major surgery happen early, in the days and weeks after treatment. These can include pain in the first few days after the operation. Painkilling medication can help with this. Some people have some difficulty eating. This usually goes away on its own within 24 hours for most people.</p>	<p>are depends in part on things like people's age and general health.</p> <p>In one group of people who had transanal endoscopic microsurgery for early rectal cancer, around 8 in 100 had complications after their treatment.[12]</p> <p>Some of the most common complications that affect people who have local removal happen early, in the days and weeks after treatment. These can include bleeding in the rectum, a tear in the bowel (perforated bowel), or problems with the wound like leaking or stitches coming loose. These are not permanent and can be treated.</p>	<p>before having treatment may mean rectal cancer is more likely to spread and less likely to be cured.</p> <p>Rectal cancer that continues to grow may cause problems such as blocked bowels (bowel obstruction).</p>
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	Major Surgery	Local Removal	Monitoring
How much time is spent in hospital or having treatment?	<p>People who have major surgery usually need to stay in hospital afterwards for around 10 days, depending on their overall health and</p>	<p>People who have local removal may be able to leave hospital either the same or the next day, depending on things like their health.</p>	<p>People who have monitoring don't have to spend time having treatment to treat or cure cancer.</p> <p>People who choose to may have regular</p>

	<p>whether they have problems after the operation. This may be shorter for people who take part in an enhanced recovery programme.</p> <p>After this it may take up to six months to recover.</p> <p>Some people may need less time than this. It's difficult to predict how long it will take before you feel fully recovered from your operation.</p>	<p>Some people may need further treatment for rectal cancer after having local removal.</p>	<p>appointments or treatments to help them manage their pain or help the symptoms of rectal cancer, such as blood transfusions or laser therapy to help bleeding inside the bowel.</p>
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	Major Surgery	Local Removal	Monitoring
<p>What are the other consequences of treatment?</p>	<p>Major surgery for rectal cancer leaves a visible scar.</p> <p>Some people who have anterior resection need to have a permanent stoma.[17] In a national survey of people who had anterior resection for rectal cancer, 24 in 100 people had no stoma at all, 38 in 100 people had a stoma that was reversed within 12 months, and 38 in 100 people still had a stoma 12 months after treatment.[18]</p>	<p>Transanal excision or transanal endoscopic microsurgery doesn't leave a visible scar.</p> <p>We don't know if having transanal excision or transanal endoscopic microsurgery affects how people feel about their body and appearance. There haven't been many studies looking at this.</p>	<p>We don't know if having monitoring has other consequences.</p> <p>There haven't been many studies looking at this.</p>

	<p>It is not possible to tell whether someone will definitely need a permanent stoma before the operation.</p> <p>A surgeon will try to avoid a permanent stoma wherever possible, unless the operation is likely to damage the anal sphincter muscles. Damage to these muscles can cause faecal incontinence.</p> <p>Having a stoma may affect how people feel about their body and appearance. This may affect their confidence. We don't know if having a colostomy affects quality of life.[19]</p>		
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What are the pros and cons of each option?

People with rectal cancer have different experiences about the health problem and views on treatment. Choosing the treatment option that is best for the patient means considering how the consequences of each treatment option will affect their life.

Here are some questions people may want to consider about treatment for rectal cancer:

- How important is it for them to have a treatment that gives them the best chance of a longer life?
- How important is it for them to have a treatment that gives them the best chance of curing their cancer?
- How important is it for them to have a treatment that doesn't affect their daily life too much?
- Are they willing to live with untreated rectal cancer?
- Are they willing to take the risk of side effects or complications from treatment?

- Are they willing to spend time in hospital or having treatment?
- Are they willing to have a stoma or a visible scar after treatment?
- How important is it for them that their sex life is not affected by treatment?
- How important is it for them that their fertility is not affected by treatment?

How do I get support to help me make a decision that is right for me?

People using this type of information say they understand the health problem and treatment choices more clearly, and why one treatment is better for them than another. They also say they can talk more confidently about their reasons for liking or not liking an option with health professionals, friends and family.

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