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

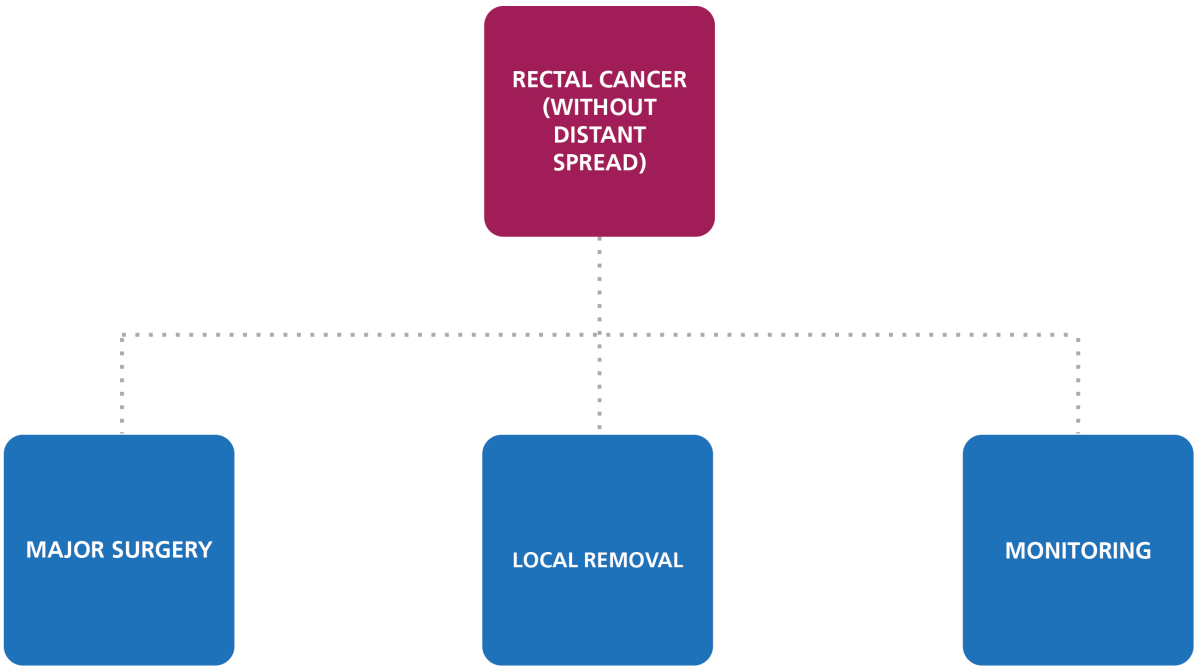
This short decision aid is to help you decide what to do about your rectal cancer. You can use it on your own, or with your doctor, to help you make a decision about what's right for you at this time.

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?

Treatment	What is the treatment?
Major surgery	This means having an operation to cut out the cancer from your rectum by removing it through a cut in your abdomen. People who have this operation may also have radiotherapy or chemotherapy (these are called adjuvant treatments). In **anterior resection**, a surgeon makes cuts in your abdomen and then removes the part of your rectum containing the tumour, along with nearby lymph nodes and tissue. He or she will then join your colon to the remaining part of the rectum so that, after the operation, you will pass stools in the usual way. Sometimes, to give the area time to heal, you may need an opening in the skin of your abdomen, called a stoma. Usually this can be reversed and the intestines reconnected around eight weeks later. In the meantime, you wear a stoma bag over the stoma to collect your stools. In **abdominoperineal resection**, the surgeon makes cuts in the abdomen, and another in the area around the anus. This allows the surgeon to remove the part of the rectum around the anus (back passage) and the tissues surrounding it, including the sphincter muscle (a ring of muscle around the end of your rectum). After you have your rectum removed in this way, you will need a way to pass your stools out of the body. This is called a colostomy. A surgeon stitches the end of your colon to an opening in the skin of your abdomen called a stoma. Your stools then pass through the stoma into an ileostomy bag.
Local removal	This is an operation to remove a small section of the rectum around the cancer using instruments inserted through the anus (back passage). Local removal is also known as local resection. People who have this operation may also have radiotherapy or chemotherapy (these are called adjuvant treatments). **Transanal resection** (also known as transanal excision) is done with instruments inserted through the anus. The surgeon cuts through all layers of the rectum to remove cancer as well as some surrounding tissue, and then closes the opening in the rectal wall. It is usually done with general anaesthetic. In **transanal endoscopic microsurgery** (TEM or TEMS), a surgeon inserts a specially designed magnifying scope through the anus and into your rectum, and uses it to remove the tumour from the wall of your rectum. This can also be done with a general or local anaesthetic.
Monitoring	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. A part of monitoring may mean having regular checks to see what is happening to your cancer. Monitoring also involves treating your symptoms, like laser therapy to stop any bleeding inside your bowel, or blood transfusions if you have lost a lot of blood. Monitoring also involves treatments to help you manage your pain (palliative treatments). You can discuss with your doctor exactly what kinds of treatments might be available to help you. You can also see a specialist nurse who can advise you on what types of foods to eat and ways to stay as healthy as you can for as long as possible.

Treatment	What is the effect on length of life?
Major surgery	People with rectal cancer can die from things other than cancer. The numbers below do not take account of the fact that some deaths are from causes other than rectal cancer. 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.[1]
Local removal	People with rectal cancer can die from things other than cancer. The numbers below do not take account of the fact that some deaths are from causes other than rectal cancer. 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.[2]
Monitoring	People with rectal cancer can die from things other than cancer. The numbers below do not take account of the fact that some deaths are from causes other than rectal cancer. Monitoring will not help people live longer. Overall, around 50 in 100 people diagnosed with rectal cancer live for at least five years after diagnosis.[3] We don't know how many of these people chose not to have treatment.

Treatment	What is the effect on stopping cancer from returning?
Major surgery	Cancer can come back after major surgery. Rectal cancer can come back in the same place or, more commonly, in another part of the body. Having major surgery to remove rectal cancer can affect how likely it is that rectal cancer comes back. 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.[4] For most people major surgery is the only treatment that has a chance of permanently stopping rectal cancer from returning. How likely rectal cancer is to come back depends on the type of tumour, as well as the type of treatment.
Local removal	Cancer can come back after local removal. Rectal cancer can come back in the same place or, more commonly, in another part of the body. Having local removal to remove rectal cancer can affect how likely it is that rectal cancer comes back. 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.[5] How likely rectal cancer is to come back depends on the type of tumour, as well as the type of treatment.
Monitoring	Monitoring does not remove rectal cancer, so the cancer will not have gone away. It will still be present in the body. Deciding to wait before having treatment will mean rectal cancer will not go away. This may mean it is less likely to be cured.

Treatment	What is the effect on stopping cancer from spreading?
Major surgery	Having major surgery to remove rectal cancer can affect how likely it is that rectal cancer spreads. 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.[6] How likely rectal cancer is to spread depends on the type of tumour, as well as the type of treatment.
Local removal	Having surgery to remove rectal cancer can affect how likely it is that rectal cancer spreads. 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.[7] How likely rectal cancer is to spread depends on the type of tumour, as well as the type of treatment.
Monitoring	Monitoring does not stop rectal cancer from spreading to other parts of the body. Without treatment, rectal cancer will progress to a more advanced stage and may no longer be curable. Monitoring may help detect whether cancer has spread to another part of the body. People who are having monitoring whose cancer spreads to other parts of the body can decide to have treatment. Deciding to wait before having treatment may mean rectal cancer is more likely to spread.

Treatment	What is the effect on quality of life?
Major surgery	Having major surgery to treat rectal cancer can affect quality of life. 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.[8] Major surgery can cause a permanent or temporary stoma. This can affect people's quality of life.[9] Both anterior resection and abdominoperineal resection seem to affect quality of life by about the same amount as each other.[10]
Local removal	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. Quality of life after having treatment for rectal cancer depends on lots of things, not just the type of treatment chosen. Local removal can cause side effects, including faecal incontinence (loose stools).[11] This may affect people's quality of life.
Monitoring	We don't know if choosing not to have treatment has an effect on quality of life. There haven't been many studies that have looked at this.

Treatment	What side effect or complications does the treatment have?
Major surgery	Having major surgery for rectal cancer can cause complications. How likely complications are depends in part on things like people's age and general health. In one group of people who had major surgery for early rectal cancer, around 47 in 100 had complications after treatment.[12] 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.
Local removal	Having local removal for rectal cancer can cause complications. How likely complications are depends in part on things like people's age and general health. In one group of people who had transanal endoscopic microsurgery for early rectal cancer, around 8 in 100 had complications after their treatment.[13] 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.
Monitoring	Monitoring does not cause side effects or complications. Deciding to wait before having treatment may mean rectal cancer is more likely to spread and less likely to be cured. Rectal cancer that continues to grow may cause problems such as blocked bowels (bowel obstruction).

Treatment	What other consequences does treatment have?
Major surgery	People who have major surgery usually need to stay in hospital afterwards for around 10 days, depending on their overall health and whether they have problems after the operation. This may be shorter for people who take part in an enhanced recovery programme. After this it may take up to six months to recover. 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. Major surgery for rectal cancer leaves a visible scar. Some people who have anterior resection need to have a permanent stoma.[14] 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.[15] Before the operation it is not possible to tell whether someone will definitely need a permanent stoma. 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.[16]
Local removal	People who have local removal may be able to leave hospital either the same or the next day, depending on things like their health. Some people may need further treatment for rectal cancer after having local removal. Transanal excision or transanal endoscopic microsurgery doesn't leave a visible scar. 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.
Monitoring	People who have monitoring don't have to spend time having treatment to treat or cure cancer. People who choose to may have regular 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. We don't know if having monitoring has other consequences. There haven't been many studies looking at this.

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?