

**LYNCH CHOICES**

Welcome to Lynch Choices™

- Lynch syndrome (Lynch) is an inherited condition that increases the chance of developing certain cancers. The type of cancer depends on the genes involved.
- This website helps people with Lynch to make choices that are right for them. It is designed to be used with support from the genetics service, GPs, healthcare teams in the community, charities and patient groups.
- If you are concerned about Lynch but have not been diagnosed, please speak to your GP or genetics service.
- Each session below helps you think about your choices at home, so you are ready to talk through your choices with a GP, genetics or other specialist.

Thinking about my choices

Taking aspirin to lower the chance of cancer

Having an operation to remove womb and ovaries, to lower the chance of cancer

Support and information

Chances and symptoms of cancer

Cancer screening

Living with genetic risk of cancer

Talking to family

Lifestyle

More support

Lynch Choices™ was funded by Cancer Research UK and developed with researchers at the University of Southampton, together with patients including people with Lynch syndrome. Many other experts also helped redesign the website. [Meet the team](#)

This is a beta/draft version in development and should not be shared or used for medical decision making.

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a)

What are my choices?

- Aspirin lowers the chance of getting bowel cancer. We don't yet know if aspirin also lowers the chance of getting other cancers for people with Lynch syndrome.
- You can choose to:
  - Take aspirin every day
  - Not take aspirin every day
  - Or wait to decide later.
- You should not start taking aspirin daily before speaking to your GP or genetics service.
- We don't yet know the best dose of aspirin. Most people are prescribed 150-300mg a day, depending on their weight. If you are taking 75mg of aspirin, you might want to speak to your GP or genetics service to check this is still the best dose for you.
- This session will help you decide what is right for you at the moment.

This picture shows where your small and large bowel are:

large bowel

small bowel

[Click here](#) to see how your bowel works

How will this session help me?

Decisions about your health can be difficult, and there is no right or wrong choice. This session helps you think about your choices and what they mean for you.

It gives you:

- Brief information about your choices, followed by more details if you want them.
- Support to help you think about what's important to you.
- A summary to take back to your GP or genetics service or talk about with your family.

b)

Thinking about my decision

Here is a summary:

Print or download

|   |  |
|---|--|
| Why might I choose an operation?                    | People with Lynch syndrome have a higher chance of getting womb cancer, and sometimes ovarian cancer depending on which gene the variant is in.  |
| What are my options?                                | You can choose to have an operation to remove your womb to lower the chance of getting cancer. Or you can choose not to have the operation, or wait to decide.<br><br>Most people with Lynch syndrome also have their ovaries and fallopian tubes removed at the same time as the womb. If you have a PMS2 variant, you would not need to have your ovaries and fallopian tubes removed because the chance of these cancers is similar to people who do not have Lynch syndrome.<br><br>The operation is not recommended before age 35-40 years. Before having the operation, people need to be certain they do not want to try to become pregnant.<br><br>Gene-specific guidelines for Lynch can be found on the <a href="#">UK Cancer Genetics Group website</a> . It might be helpful for your doctor to look at these. |
| What are the benefits of having the operation?      | The operation would lower your chance of getting womb and cervical cancer as much as possible.<br><br>If the cervix is removed, you would no longer need screening.  |
| What are the disadvantages of having the operation? | You could no longer become pregnant, if you want.<br><br>Removing the ovaries would cause menopause, if already. You may have some side effects of the menopause. Hormone Replacement Therapy, called HRT, can reduce the symptoms if you have your ovaries removed before menopause.<br><br>You will probably need 1 to 5 days in hospital. It usually takes a few weeks to recover from the operation.   |

At your appointment

You might like to look at [this website](#) with your GP or gynaecologist, which shows how your chance of cancer changes over time.  
And they may want to review the latest guidelines [here](#) or [here](#).  
[Click here](#) to see some general questions that can be useful to ask your doctor when making a decision about your health.

A copy of your answers as a reminder:

It is important to me to lower my chance of getting womb or ovarian cancer as soon as possible

Doesn't really matter to me

Matters to me a little

Matters to me a lot

It is important to me to not have to worry about getting womb or ovarian cancer

Doesn't really matter to me

Matters to me a little

Matters to me a lot

It is important to me to keep my options open for becoming pregnant in future

Doesn't really matter to me

Matters to me a little

Matters to me a lot

It is important to me to avoid possible side effects and time to recover from the operation

Doesn't really matter to me

Matters to me a little

Matters to me a lot

It is important to me to avoid possible health problems or side effects of the menopause, such as hot flushes, low mood or low sex drive

Doesn't really matter to me

Matters to me a little

Matters to me a lot

Any additional reasons you added that are important to you:

I have questions about my HRT prescription

Click to print or download this page

c)

Lynch Home > Chances and symptoms of cancer > What are the chances of getting bowel cancer?

What are the chances of getting bowel cancer?

- Some people like to know how likely they are to get cancer, to help them decide about taking aspirin.
- These images show the average number of people who get bowel cancer in the UK by the age of 75, with and without Lynch syndrome.
- These numbers are for people who do not take aspirin every day.

Click here to see information for a different Lynch variant

|   | Number who develop bowel cancer in their lifetime |
|---|---|
| Women with a MSH2 gene variant, Lynch syndrome without taking daily aspirin | <br>Just under 5 out of 10                        |
| People in the general population without taking daily aspirin               | <br>Fewer than 1 out of 10                        |

- However it is not possible to know precisely what will happen to any one person, or when.
- Some people with Lynch syndrome will never develop cancer.

More information

What affects my chances of getting bowel cancer?

What are the symptoms of bowel cancer?

Return to more details page

Continue to 'Chances and Symptoms of Womb Cancer'

d)

Jade, age 65, found that taking aspirin wasn't right for her

Finding out about aspirin from a support group

I saw about taking aspirin when I joined the Lynch Syndrome UK group online, and was surprised as no-one had mentioned it to me when I was diagnosed with Lynch.

My GP said it wasn't right for me

I made an appointment to see my GP about it, but they looked at my age and my overall health and said it wasn't right for me. I was a bit disappointed as I think it would have reassured me to take aspirin.

I still wasn't sure so checked with my GP and pharmacist later on

About six months later I saw another discussion about aspirin and cancer online and this made me worry about whether I should be taking it. I made an appointment to see my GP again and also spoke with a pharmacist, just to check. This was really helpful because we agreed that taking aspirin wasn't right for me. She explained why the chance of side effects goes up with age, and how aspirin may not be great for people with asthma.

My GP told me about other things I can do

She also suggested I speak to my GP about how I might change my diet a bit to lower my chance of bowel cancer, which has been helpful. I guess no medicine is right for everyone, and it was good to know I had checked it out.

Go back to 'More details about taking aspirin'

Continue to thinking about my decision

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Illustrations by Lily Barnett, @gcnotes

**Figure 1.** Screenshots from the draft version of Lynch choices, showing a) landing page, b) part of the aspirin decision aid, c) printable summary and checklist from values-based decision support exercise from hysterectomy decision aid, d) visual presentation of cancer risks using icon arrays, e) example patient story