PATIENT EDUCATION

DECISION AID

FOR LUNG CANCER SCREENING WITH COMPUTERIZED TOMOGRAPHY (CT)
yes?

no?
Deciding whether or not to go through lung cancer screening is not easy. Here is up-to-date information provided by doctors from the American Thoracic Society to help you make an informed choice.
**Basic Lung Cancer Information**

Lung cancer is:
- By far the leading cause of cancer death.
- The 3rd most common cancer in the United States.
  - Usually doesn’t cause noticeable problems until it is relatively big, or it has spread to other parts of the body (this is called “late-stage”).
  - Most people are diagnosed with late-stage lung cancer.
- Often cured with surgery when found early (“early-stage”).

Go to [www.thoracic.org/patients](http://www.thoracic.org/patients) for additional information about lung cancer.

**What is cancer screening in general?**

- Screening is looking for a disease before a person has symptoms.
- Screening gives a very large benefit (saving a life) to a few people.
- But screening also causes small harms to everyone and can cause a large harm to a few people.
- The goal is to only screen people with the best balance of benefits to harms.
What is lung cancer screening?

• Screening is used to find early-stage lung cancer.
  • Early-stage lung cancers can often be cured by surgery.
• Lung cancer screening looks for early lung cancers using low-dose computed tomography (LDCT). LDCT is a CT (“CAT”) scan that uses a low dose of radiation.
• An LDCT uses a computer and a series of chest x-rays.
• Lung cancer screening is recommended every year until you no longer have the risk factors described on page 6.
  – The most important thing to do to prevent lung cancer is to quit smoking, as reviewed below and on page 6.

• Screening is NOT: A reason to keep smoking.
• Regardless of your decision for screening or what we see on your CT, you should work with your health care provider to reduce your chance of getting lung cancer.
  – It is strongly recommended that you stop smoking if you currently smoke.
  – Don’t start smoking again if you have already quit.
  – Stopping smoking is important even if you don’t have any signs that smoking has hurt your lungs.
  – Stopping smoking also reduces your chance of getting heart problems and other diseases, and will improve your quality of life.
Should I get screened?

Screening is NOT: The right choice for everyone.

• In patients at low risk of getting lung cancer, screening is likely to cause more harm than benefit.

You should consider being screened if you have all three of these risk factors:

• You are 55–80 years old.
• You are a current smoker or a former smoker who quit less than 15 years ago.
• You smoked at least 30 pack-years (this means 1 pack per day for 30 years or 2 packs a day for 15 years, etc.).

If you have all three of these risk factors, most experts, including the United States Preventive Services Task Force and the American Thoracic Society, recommend talking to your health care provider about screening.

Most insurance plans now pay for lung cancer screening, but you should check that your CT will be covered.
You are unlikely to benefit from screening if:

- You are younger than 55 or older than 80 years of age.
- You are unwilling to have treatment (usually surgery) for lung cancer if it is detected on screening.
- You smoked less than 30 pack-years (equal to 1 pack/day for 30 years or 2 packs/day for 15 years) or quit smoking more than 15 years ago.
- You have other medical problems that make it unsafe for you to get lung surgery.
  - People who cannot safely have surgery have not been studied to see if the benefits of screening outweigh the risks.
  - People who cannot safely have surgery are more likely to die of something other than lung cancer.
  - People who are too sick to have surgery are likely to suffer more harm than benefit.
- You are unwilling to be screened every year until you no longer have the risk factors.
- You already have symptoms of lung cancer.

For additional information about surgery for lung cancer, go to www.thoracic.org/patients.

Symptoms of lung cancer

- New cough that won't go away.
- Change in chronic cough.
- Coughing up blood.
- Weight loss without trying.

TALK TO YOUR HEALTH CARE PROVIDER IF YOU HAVE ANY OF THESE PROBLEMS.

For additional information about signs and symptoms of lung cancer, go to www.thoracic.org/patients.
Why should only people with these risk factors consider screening?

- The recommendation (or advice) to get screened is based on research studies done to look at the risks and benefits. Researchers have only shown a benefit in these groups.
- People without these 3 risk factors will likely suffer more harm than benefit from screening.

Should I consider getting screened if I don’t have these risk factors?

- Probably not.
  - Most people, even with other risk factors, will still have a very low chance of getting lung cancer.
  - Most health professional groups do not recommend it.
  - Currently, we don’t know if people with other risk factors will benefit.
  - Talk to your primary care doctor or a pulmonologist (lung doctor) about your personal risks and benefits of screening.

Other risk factors for lung cancer include:

- Family history of lung cancer
- Exposure to asbestos or radon
- Exposure to someone else’s smoke (“secondhand smoke“)
- Certain lung diseases like emphysema or fibrosis

Talk to your doctor about ways that might help you reduce your risk of getting lung cancer. Go to www.thoracic.org/patients for additional information about lung cancer prevention.
What does research say about the benefits of lung cancer screening?

- In the biggest study of lung cancer screening, the National Lung Screening Trial (NLST), showed that:
  - Screening reduced the lung cancer death rate by 20%.
    - For every 1,000 people who didn’t get screened, 21 died of lung cancer.
    - For every 1,000 people who did get screened, 18 still died of lung cancer.
  - Other ways to think about these numbers:
    - For every 1,000 people who get screening for lung cancer, 3 fewer died of lung cancer because of screening.
    - About 300 people need to be screened to save one life from lung cancer.
SCREENED (1,000 PEOPLE)

**BENEFITS ADDED by Screening**

There were 3 fewer deaths from lung cancer in people SCREENED compared to the NOT SCREENED group. However, **18 PEOPLE still died** from lung cancer in a group of 1,000 people who were SCREENED.

**HARMS ADDED by Screening**

**365 IN 1,000 PEOPLE SCREENED** experienced a **FALSE POSITIVE** result such as a spot on the lung that required further testing.

**25** of those false positive results led to an **INVASIVE PROCEDURE** like a biopsy or surgery.

**3 PEOPLE** developed a **MAJOR COMPLICATION** from the invasive procedure.
21 PEOPLE DIED from lung cancer in a group of 1,000 people who were NOT SCREENED. This was 3 ADDITIONAL DEATHS from lung cancer compared to the group that was SCREENED.
Could my benefits be different?

- Even among people with the risk factors for lung cancer screening, different people may have different chances of benefiting from it.
- The number of people who benefit changes with different risk factors.
- **It is important to consider what the following numbers mean to you.**
- People who are at high risk for getting lung cancer may benefit more from screening.
  - For those in the **highest risk** group in the largest study of lung cancer screening:
    - 6 out of 1,000 didn’t die because of screening.
    - About 160 people need to be screened to save one life from lung cancer.
    - People at higher risk than average are often older and/or heavier smokers or have a family history of lung cancer or emphysema.
- Some people have a **lower risk** of getting lung cancer and have a lower chance to benefit compared to the “average” person in the study.
  - For those in the **lowest risk** group in the largest study of lung cancer screening:
    - Over 5,000 people need to be screened to save one life from lung cancer.
    - People at lower risk than average are often younger and have fewer pack-years of cigarette smoking.
- If you’d like to get an estimate of your personal risk of getting lung cancer, you can visit http://lungcancerrisk.s3-website-us-east-1.amazonaws.com.
- People at high risk who don’t get screened **every year** will have much less benefit than people who do.
What are the harms of lung cancer screening?

• Can miss the most dangerous types of lung cancers. Even after screening, many people still die of lung cancer.
  • In the largest study of lung cancer screening, 18 out of 1,000 people were screened and still died of lung cancer.

• Radiation exposure.
  • Radiation can cause cancer.
  • The amount of radiation from screening CTs is low, so the risk of dying from lung cancer caused by the radiation is very low (much lower than the number of people who benefit).

• Many false alarms
  • It is common to find a nodule in the lung.
    – Nodules are “spots” in the lung that are sometimes very early lung cancer. However, most of the time they do not turn out to be cancer (sometimes referred to as benign nodules).
    – In the largest study of lung cancer screening, 365 people out of 1,000 had a false positive result (usually because of a pulmonary nodule).
Harms (cont.)

• People with false positive results often get:
  – More CT scans.
    – *Most often, we recommend people with nodules get another CT scan in 3 to 12 months to make sure the nodule is not growing.*
    – *Extra radiation—though still a low-dose.*
  – Invasive Procedures (biopsies and surgery).
    – 25 out of 1,000 had an invasive procedure.
    – 3 out of 1,000 had a major complication.
    – Very rarely someone died because of the procedure.
  – Stressed and anxious.
    – *It is normal to have increased stress after these findings.*
    – *It can be very stressful waiting for several months to see if your nodule has grown.*

• **False** belief that it is OK to keep smoking.
  • Regardless of your screening results, smoking will increase your risk of getting lung cancer and many other diseases.

• Treatment for a slow-growing lung cancer that would not have caused problems even if you never got treatment (sometimes called “overdiagnosis” or “overtreatment”).
  • 1 out of 5 lung cancers detected by screening grow very slowly and won’t cause problems during a person’s lifetime.
  • But it is often hard to wait and see if this is the kind of cancer you have and most people get treated.
What can my doctor do to reduce these harms?

- Give you as much information about screening and your results as you want.
- Work with a team of lung cancer experts to address any suspicious findings.
- Use expert guidelines to help avoid unnecessary procedures.
- Help you to quit smoking regardless of what your screening results might be.
- Talk with you about ways to reduce stress about the lung cancer screening process.
- Have a system to remind you to come back for follow-up screening.
What will happen if I decide to get screened?

- You will get an appointment for the CT scan.
- You will lie still on a CT table for about 10 minutes.
- You will get a “low-dose” radiation CT.
- You will be contacted with the results and the follow-up plan.
  - Make sure all your questions are answered.
  - If you have a nodule, follow-up will be arranged.
  - Talk to your doctor about how you are doing with the results, especially if you are stressed or anxious.
- You should expect to have CT scans at least once a year until you do not meet the criteria for lung cancer screening.
The Bottom Line

- Screening people at high risk of getting lung cancer can save lives.
- But the number of people who benefit is small.
- All people who get screened can suffer harms.
- Screening people at low risk of getting lung cancer will cause more harm than benefit.
- No matter what you decide about screening, work with your health care provider to quit smoking.

Your decision:
- □ Yes, get screened
- □ No, don’t get screened
- □ Still thinking

I’m still undecided, how can I make this decision?

- It is normal to be undecided after getting this information.
- Remember, there is no hurry to make this decision.
- The following exercise can help:
Share Your Values and Preferences With Your Health Care Provider

List the reasons to be screened or not screened and then rate how important they are to you:

**YES—get screened**
1. __________________________________________ __________
2. __________________________________________ __________
3. __________________________________________ __________

Some people decided to get screened because they felt:
- Screening was a part of doing everything they could to be healthy.
- The benefit of possibly saving their life was worth the harm.
- Their doctors would try to manage the possible harm.

**NO—don’t get screened**
1. __________________________________________ __________
2. __________________________________________ __________
3. __________________________________________ __________

Some people decided not to get screened because they felt:
- The benefit was small and the harms were too great.
- Waiting to hear about the possibility of lung cancer would be too stressful.
- They wouldn’t want surgery if lung cancer was found.
- The testing is too expensive compared to the possible benefits.

Write down other questions you have:
____________________________________________________
____________________________________________________
____________________________________________________

Talk to your doctor about your values and preferences with regards to screening.
Contact Information

Primary Care Doctor:
__________________________________________
__________________________________________
__________________________________________

Pulmonary Doctor:
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Radiology Diagnostic Imaging Center:
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Appointments:
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For additional information about lung disease, visit the ATS Website at www.thoracic.org/patients