

Shared Decision Making in Primary Care

Charles Brackett

Kate Clay

10/7/05

Your next patient:

65 y.o. man with htn and OA
coming in for a yearly
physical. HCM is up to date
other than the last PSA being
checked 16 months ago.

Patient's Expanding Role in Decision Making

- Annals 8/16/05

- Relationship: paternalism → partnership
- Increasing patient autonomy
- Broader access to information
- Expanding clinical options
- Rising costs
- Ascendancy of chronic illness
- Complex tradeoffs
- Greater accommodation of personal values

TREATMENT-RELATED DECISIONAL CONFLICT:

Is the treatment ...

- An Option ?
- A Guideline ?
- A Standard
of Care ?



Incr. uncertainty
&
Incr. likelihood
of
decisional
conflict

D.M. EDDY, 1992 : ASSESSING HEALTH PRACTICES & DESIGNING
PRACTICE POLICIES

Challenges to SDM

- Different patient preferences for role
- Literacy/numeracy
- Time/money
- Clinician knowledge: statistical details
- Clinician bias
- Health care system is slow to evolve



Decision Aids

- adjunct to counseling
- inform re options, benefits, risks
- specify probabilities of outcomes
- clarify personal values & norms
- guide in deliberating & communicating
- empower patient



Decision Aids

Print/video/decision boards/audiotape/web formats

- Improve balance, accuracy, consistency of information
- Expand counseling beyond time constraints of busy office visits
- Increase patient involvement in decision making
Reduce decisional conflict
- Improve realistic expectations
- Lower decisional conflict
- Decrease number who are undecided
- Improve knowledge, concordance between values and choices



PSA video



Shared Decision Making Service

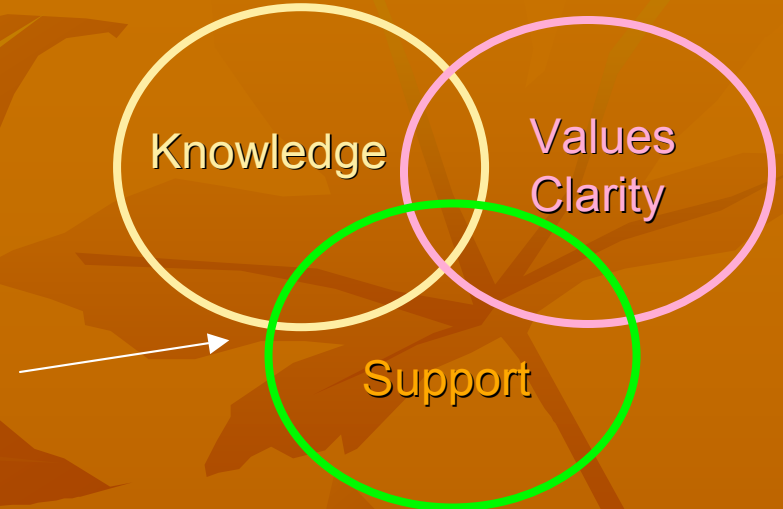
Help With Making Your
Health Care Decisions

Decision Counseling

- Clinicians without Informed-Choice Training
- Clinicians with Informed-Choice Training
- Trained third party: Decision Counselors

Decision Quality

- Decision support is a process of:
 - assessing decisional needs
 - intervening to address individual needs
 - evaluating the quality of decision making
- A Quality Decision is Informed and Values-based
- Decision quality improves with:
 - Patient decision aids
 - Personal health coaching by nurses using a structured decision guide



(IPDAS 2005; Kennedy, JAMA, 2002; O'Connor, Cochrane Lib, 2003; O'Connor, 2002)

Conclusions

- A good decision is informed and values - based
- Knowledge, values and support needs should be assessed and addressed
- Decision aids and decision support protocols can improve decision quality
(Kennedy, JAMA, 2002; O'Connor, Cochrane Lib, 2003; O'Connor, 2002)
- but only if they are imbedded in care pathways



Logistical Challenges

- Timing
- Space/resources
- Coordinating mailings or in-office viewing
- Support staff time/overhead



Patient acceptance

DHMC Center for Shared Decision Making
FIMDM Decision Aid Loans
Time period: 1 January 2003 - 30 June 2005

1

Patient Decision Aid Loans

Circulation, demographic characteristics, and questionnaire response summary

Category	FIMDM Video	Count	(%)	Year to date 2005	YTD (dvd)	2004	Avg Age	Female %	Ques N	Ques Comp	Switch Pref	Trt Pref Pre Vid	Trt Pref Post Vid	Res DCS	Sat PREP	Avg Rating
BACK	Herniated Disc: Treatment Choices	362	(19%)	177		50	45.7	46 %	191	(67%)	27 %	(58%)	(71%)	78	84	Good
	Spinal Stenosis: Treatment Choices	292	(15%)	119		62	68.6	55 %	190	(77%)	22 %	(70%)	(80%)	77	87	Very Good
	Chronic Low Back Pain: Managing Pain	251	(13%)	209	(91)	5	46.3	54 %	91	(59%)	23 %	(70%)	(81%)	76	79	Good
	Acute Low Back Pain: Treatment Choices	3	(0%)	3		0	74.0	67 %	1	(50%)	100 %	(100%)	(0%)	88	78	Good
BREAST	Early Breast Cancer: Choosing Surgery	28	(15%)	50	(2)	58	59.1	100 %	112	(90%)	8 %	(59%)	(70%)	78	91	Very Good
	Breast Reconstruction: Right for you?	217	(12%)	64	(5)	48	53.3	99 %	114	(83%)	11 %	(71%)	(78%)	78	93	Very Good
	DCIS: Treatment Choices	66	(4%)	21	(2)	17	56.0	97 %	20	(95%)	30 %	(70%)	(68%)	78	93	Very Good
	Early Breast Cancer: Adjuvant Therapy	27	(1%)	10	(1)	1	60.5	96 %	18	(85%)	33 %	(56%)	(72%)	75	80	Very Good
KNEE/HIP	Knee Osteoarthritis: Treatment Choices	76	(4%)	34	(5)	10	63.2	57 %	52	(77%)	25 %	(71%)	(86%)	83	83	Very Good
	Hip Osteoarthritis: Treatment Choices	49	(3%)	38	(10)	0	58.3	49 %	31	(78%)	23 %	(86%)	(80%)	76	84	Very Good
CARDIAC	Coronary Artery Disease: Living With	90	(5%)	57	(43)	0	65.0	16 %	83	(94%)	10 %	(95%)	(99%)	80	85	Very Good
	Coronary Artery Disease: Treatment Choices	4	(0%)	1		1	69.3	50 %	3	(75%)		(100%)	(100%)	71	86	Excellent
PROSTATE	Prostate Cancer: Treatment Choices	78	(4%)	33		7	66.1	5 %	52	(81%)	21 %	(63%)	(73%)	75	86	Very Good
	BPH: Treatment Choices	7	(0%)	3		2	67.1	0 %	4	(57%)	50 %	(25%)	(75%)	81	88	Very Good
OB/GYN	BUC Fibroids: Treatment Choices	37	(2%)	6	(1)	12	45.6	100 %	26	(74%)	15 %	(85%)	(92%)	79	86	Very Good
	BUC Abnormal Bleeding: Treatment Choices	14	(1%)	5	(3)	3	46.1	100 %	8	(62%)	25 %	(75%)	(100%)	85	85	Good
	Ovarian Cancer: Reducing Risks	4	(0%)	1		2	56.3	75 %	1	(50%)		(0%)	(0%)	42		Good
GIM	PSA test: Right for you?	17	(1%)	3	(2)	3	60.9	0 %	9	(60%)	33 %	(78%)	(100%)	85	94	Very Good
	Colon Cancer Screening	4	(0%)	4		0	60.3	75 %	1	(100%)	100 %	(100%)	(100%)	79	39	Good
Other	Peace of Mind: Advanced Directives	5	(0%)	1		1	45.0	60 %	0	(0%)						
	Total	1884	(100%)	839	(165)	282	55.9	64 %	1013	(78%)	20 %	(69%)	(79%)	78	86	Very Good

COLUMNS

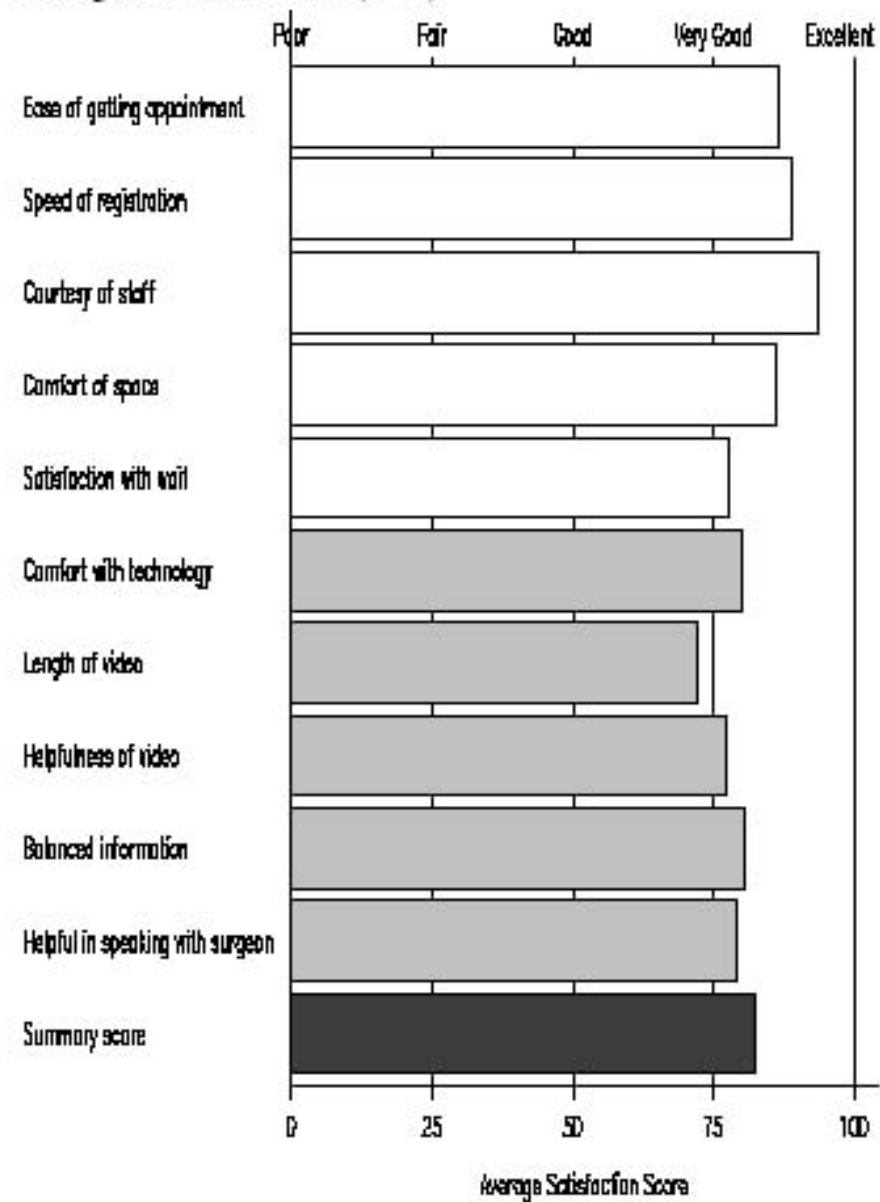
- Count (%): DA frequency (column %), Year to date 2005 (dvd): 1/1 - 6/30/2005 total(dvd) count, YTD 2004: 1/1 - 6/30/2004 total, Avg age: average patient age, Female %: percent female
- Ques N: returned questionnaires, Ques Comp: % eligible loans with a questionnaire, Switch Pref: % changing treatment preference (before vs. after video), Trt Pref: % indicating a treatment preference
- Res DCS: Resolution of Decisional Conflict score (Annette O'Connor, 1993): Scores >= 75 are associated with those who make decisions; scores <= 62.5 are associated with those who delay decisions.
- Sat PREP: Satisfaction with Preparation for Decision Making (Ian Graham, Annette O'Connor, 1996), Average DA Rating scale: (Poor, Fair, Good, Very Good, Excellent)

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Res DCS	Sat PREP	Avg Rating
78	84	Good
77	87	Very Good
76	79	Good
88	78	Good
78	91	Very Good
78	93	Very Good
78	93	Very Good
75	80	Very Good
83	83	Very Good
76	84	Very Good
80	85	Very Good
71	86	Excellent
75	86	Very Good
81	88	Very Good
79	86	Very Good
85	85	Good
42		Good
85	94	Very Good
79	39	Good
78	86	Very Good

Satisfaction with Intake Appointment

Average satisfaction scores (n=74)



Next patient:

61 y.o. woman in for follow-up of COPD and DM. You note that she had a sigmoidoscopy 6 years ago and last FOBT 2 years ago

The background of the slide is a solid orange-brown color with a faint, stylized pattern of autumn leaves. The leaves are in various shades of brown and orange, creating a subtle texture.

Colon cancer screening video

Resources to Support Decision Making

- Ottawa Health Research Institute
 - <http://decisionaid.ohri.ca/index.html>
- WebMD
 - <http://www.webmd.com/>
- Collaborative Care
 - <http://www.collaborativecare.net>
- Mayo Clinic
 - <http://www.mayoclinic.com>
- DHMC Center for Shared Decision Making
 - <http://www.hitchcock.org/dept/csdm>



Ottawa Decision Aids

▸ *Ottawa Personal Decision Guide*

A-Z Inventory of Decision Aids

Cochrane Systematic Review

▸ *Cochrane Inventory*

▸ *CREDIBLE Criteria*

Training in Decision Support

Evaluation Measures

Resources

OHRI

- Ottawa Decision Aids
- Ottawa Personal Decision Guide
- A to Z Global Inventory of Patient Decision Aids
- Cochrane Systematic Review: Efficacy of Patient Decision Aids
- Training in Decision Support
- Evaluation Measures
- Resources

www.ohri.ca/decisionaid



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- [Are You Living Right for a Long and Strong Life?](#)
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decision PSA

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▶ **PSA Testing - Prostate** Learn About PSA Testing & What Your PSA Level Means - Get the Facts.
[Avodart.com](#)

◦ [Should I have a prostate-specific antigen \(PSA\) test to screen for prostate cancer? -- Wise Health Decision](#) 

Use this worksheet to help you make your **decision**. After completing it, you should have a better idea ...Should I have a prostate-specific antigen (**PSA**) test to screen for prostate cancer? Yes No Unsure If the **PSA**

[WebMD Medical Reference from Healthwise](#)

◦ [Should I have a prostate-specific antigen \(PSA\) test to screen for prostate cancer? -- Medical Information](#) 

What is prostate cancer? - Prostate cancer, the abnormal growth of cells in the tissues of the - prostate ...Should I have a prostate-specific antigen (**PSA**) test to screen for prostate cancer? Most cases of prostate cancer...

[WebMD Medical Reference from Healthwise](#)

◦ [Men Happy With Cancer Treatment Decision](#) 

Most men are pleased with their choice of prostate cancer treatment, a new survey shows...Men Happy With Cancer Treatment **Decision** Study Suggests Most Satisfied With Prostate Cancer Treatment April 29,

[WebMD Medical News Archive](#) | [See all News](#)

◦ [The Screening Tests You Need](#) 


When it comes to preventing disease, knowing when to get tested is key...Breast Cancer As the most common cancer among women -- and the second deadliest cancer among women, behind lung cancer, breast cancer...

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◦ [New Tool May Help Prostate Cancer Patients Peer Into the Future](#) 

For some cancers -- prostate cancer being one of them -- choosing the best course of treatment can be an agonizing **decision** being one of them -- choosing the best course of treatment can be an agonizing **decision** Now a newly developed

Interested in learning more about prostate cancer?

Click here for more information about prostate cancer education and advocacy Web sites.  **CANCERINFO.NET**

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Health Guide A-Z

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Should I have a prostate-specific antigen (PSA) test to screen for prostate cancer?

healthwise

topic contents

- [Introduction](#)
- [Medical Information](#)
- [Your Information](#)
- [Wise Health Decision](#)
- [References](#)
- [Credits](#)

Introduction

This information will help you understand your choices, whether you share in the decision-making process or rely on your doctor's recommendation.

Key points in making your decision

The [prostate-specific antigen \(PSA\) test](#) is the most common test used to screen for [prostate cancer](#). About 75% of U.S. men age 50 or older have undergone PSA testing.¹ [Digital rectal examinations](#) (DREs) are commonly done with PSA tests as part of screening for prostate cancer. If you are thinking about having a PSA test, consider the following risks and benefits of screening.

- If you are in your 50s or 60s and in good health, you may choose to have the test because prostate cancer is common and cancer treatment could result in a number of cancer-free years

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for
prostate
cancer
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Should I have a prostate-specific antigen (PSA) test to screen for prostate cancer?

healthwise

topic contents

- [Introduction](#)
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Wise Health Decision

Use this worksheet to help you make your decision. After completing it, you should have a better idea of how you feel about having a PSA test. Discuss the worksheet with your doctor.

Circle the answer that best applies to you.

I'm only 51 and want to find out now, while I'm in robust health, if I have cancer in my prostate.	Yes	No	NA*
My health is not so good, and I'm not sure I am up to pursuing cancer testing and treatment.	Yes	No	NA
It is important for me to know if I have cancer, even if it is early and not causing symptoms yet.	Yes	No	Unsure
If the PSA test and any necessary cancer treatment will not add years to my life, I am not sure it's smart to get tested.	Yes	No	Unsure
I don't want to have to get tests and then more tests just to find out if I have a cancer that is small and not growing fast.	Yes	No	Unsure
A PSA test may not be a good screening test for me because I have an enlarged prostate and am aware that my PSA levels will always be higher than normal.	Yes	No	NA
I am concerned that I might end up with urinary and erection problems if I have treatment after positive results from a PSA test.	Yes	No	Unsure
There's a history of prostate cancer in my family, and I will do anything I can to avoid	Yes	No	NA

prostate
cancer
information

?



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comprehensive
collection
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caregiver resources.



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Catharine F. Clay

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CollaborativeCare.net


welcome

CollaborativeCare.net is an online service of the [Foundation for Informed Medical Decision Making](#) and [Health Dialog](#). CollaborativeCare.net provides decision support to individuals making choices about their healthcare. Collaborative Care® is based on the Foundation's concept of [Shared Decision-Making](#)®. It helps patients become informed about their medical options, communicate effectively with their doctors, and achieve better overall health outcomes. CollaborativeCare.net currently features decision aids for breast cancer patients and information for men deciding whether to have a Prostate Specific Antigen (PSA) test.

Health Dialog and the Foundation are committed to helping breast cancer patients get the decision support they need to make the treatment choices that are right for them. At the CollaborativeCare.net [Breast Cancer Center](#), you will find audio-visual presentations on thirteen crossroads in a breast cancer patient's path, text overviews of evidence-based information relevant to each decision, research abstracts, related links, and photos of the results of mastectomy, lumpectomy, and reconstruction.

On the [PSA Decision](#) pages, you will find information on ordering a Shared Decision-Making® video program entitled "Is a PSA Test Right for You?" This program provides unbiased information about getting tested for prostate cancer. A Consumer Reports review of this program found it to be "balanced, objective, and useful to men making a decision about whether to undergo prostate-cancer screening."

What is Shared Decision-Making®?
Click here



news

- [Order a Shared Decision-Making® Video](#)
- [CollaborativeCare.net a Great Link at SusanLoveMD.org](#)
- [CollaborativeCare.net wins WWW Health Award](#)
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- [NewsHour on Prostate Screening](#)

Support for decisions that matter most.

Home | [PSA Decision](#) | [Breast Cancer Center](#) | [Helpful Links](#) | [Contact](#) | [About Us](#)

Done Internet

CollaborativeCare.net

"I'm part of the process. Everyone can feel good about themselves."
"Take the time. You won't feel as afraid. You won't feel overwhelmed."

Breast Cancer Center

Studies have shown that patients who play an active role in the decisions affecting their healthcare are more satisfied with the care they receive. Bringing the patient into the decision-making process through Shared Decision-Making® is what Collaborative CareSM is all about.

To help you think about what's important to you, doctors from the Foundation for Informed Medical Decision Making, have developed the decision tools on this site that are produced and distributed by Health Dialog, Inc. The audio-visual presentations on each topic spotlight the opinions and stories of real women and the decisions they made. This site provides you with the latest medical information, research and professional opinions about breast cancer to help you learn about your options and, with your doctor, choose what's right for you.

The topics below address crossroads in breast cancer decision-making you may want to learn about. Click on a topic for details and the option to view a fast-loading, multimedia presentation on thirteen different issues relating to breast cancer:



- [Prevention and Screening](#)
- [Diagnostic Testing After Abnormal Test Results](#)
- [Treatment After a Recent Diagnosis of Breast Cancer](#)
- [Monitoring and Care After Treatment](#)
- [Further Treatment if Cancer Returns](#)

Learn About

[Prevention and screening](#)

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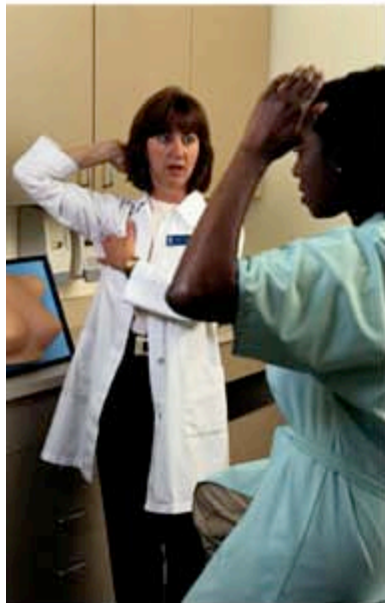
[Further treatment if cancer returns](#)



- Nancy

It helped to acknowledge that as bad as this horrible thing is, you can come back from it and you can live your life. It might be a new 'normal' but you can come back and you can live with it.

Support for decisions that matter most.



Most Breast Lumps are Not Breast Cancer

- As few as 5 in 100 lumps prove to be cancer

Play Pause Rewind Close The Breast Cancer Center at CollaborativeCare.net

Read Summary Supporting Research Related Links

Foundation Contributing Editors:

Debasish Tripathy, MD
Laura Esserman, MD, MBA

Learn About

Prevention and screening

Diagnostic testing after abnormal test results

Treatment after a recent diagnosis of breast cancer

Monitoring and care after treatment

Further treatment if cancer returns



- Margie

When the doctors feel that you have some solid information and they feel that they have also imparted some good information to you, then whatever decision you make, everybody feels good about it.

Support for decisions that matter most.

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Internet

Treatment Decisions

Oct. 5, 2005

Health Decision Guides

Do you face a major decision for treating or preventing a condition, or managing your reproductive health? These tools enable you to weigh the pros and cons of different options, to help you choose the approach that's best for you.

- [ACL Injury](#)
- [Adjuvant Therapy for Breast Cancer](#)
- [Carpal Tunnel Syndrome](#)
- [Children's Middle Ear Infections](#)
- [Colon Cancer Screening](#)
- [Early-Stage Breast Cancer](#)
- [Early-Stage Prostate Cancer](#)
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Colon Cancer Screening

Health Decision Guide

Oct. 5, 2005

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THIS DECISION GUIDE

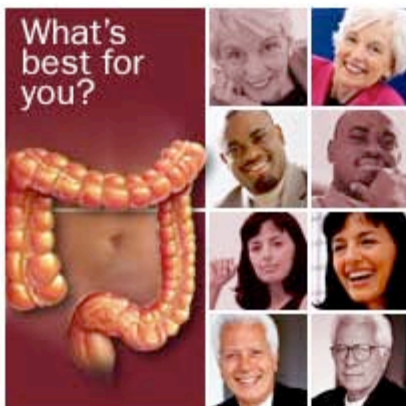
Welcome

[About colon cancer](#)
[Screening options](#)
[Meet the Mayo Clinic doctor](#)
[Things to consider](#)
[Related links](#)

Welcome

By [Mayo Clinic staff](#)

What's
best for
you?



Colon cancer — which includes cancers of both the colon and the rectum — is the second leading type of cancer death in the United States. Just as not smoking goes a long way in preventing lung cancer, regular testing for and removal of colon polyps — small, protruding clumps of cells on the inside wall of the colon — can prevent colon cancer. Whether or not you've decided to get screened, you may feel overwhelmed by all the testing options available to you.

Factors to consider

This guide is designed to help you make an informed decision about your screening options. As with most things, one size doesn't fit all. Think of yourself and your doctor as partners in the decision-making process. Your decision about what screening test(s) is best for you will most likely be based on a number of factors, including your:

- Age
- Medical history
- Comfort level

As you make your way through this guide, you'll learn about how colon cancer develops and whether you're at increased risk of this disease. You'll also get a detailed look at what's involved with each of the most commonly used screening tests, and you'll see and hear directly from a Mayo Clinic gastroenterologist. Whichever screening test(s) you choose, know that if you're at average or higher-than-average risk of colon cancer, some screening is better than no screening. Proper screening and early



Colon Cancer Screening

Health Decision Guide

Oct. 5, 2005

FORMAT TO PRINT: [This section](#) | [All sections](#)

THIS DECISION GUIDE

Welcome

About colon cancer

Screening options

[Barium enema](#)

- [Pros and cons](#)

[Colonoscopy](#)

- [Pros and cons](#)

[Fecal occult blood test](#)

- [Pros and cons](#)

[Flexible sigmoidoscopy](#)

- [Pros and cons](#)

[Emerging tests](#)

- [DNA stool test](#)

- [Virtual colonoscopy](#)

Meet the Mayo Clinic doctor

Things to consider

Related links

Pros and cons

If you're 50 or older and at average risk of colon cancer, one screening option is a colonoscopy every 10 years and an annual FOBT. However, the decision is a personal one and is influenced by your priorities and concerns. When it's time to decide which test(s) to have, consider these points concerning colonoscopy:

Pros	Cons
It's designed to screen the entire colon.	Sedation is needed.
It's the most sensitive test for detecting precancerous polyps and cancer.	Preparing for the test — emptying the colon with laxatives — and the test itself can be unpleasant.
Biopsy and removal of polyps or abnormal tissue often can be done during the procedure itself.	There's a slight risk — about one to three in 1,000 — of perforating the wall of the colon or rectum or causing significant bleeding and infection. This risk is somewhat higher — about 23 in 1,000 — if polyp removal is involved.
If you're 50 or older and have Medicare benefits, coverage includes a screening colonoscopy every 10 years, but not within 48 months of a screening sigmoidoscopy.	It's more costly than the other tests — \$400 or more. Additional fees may apply.
If you're at higher risk, also called high risk, Medicare covers a colonoscopy every two years.	It isn't always covered by insurance.

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Colon Cancer Screening

Health Decision Guide

Oct. 5, 2005

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Things to consider

When choosing a colon cancer screening method, know that — whatever you decide — if you're at average or higher risk of colon cancer, some screening is better than no screening. Choosing a screening test isn't always an easy decision, but it's a potentially lifesaving one. When weighing your screening alternatives, discuss the issues with your doctor. That dialogue often makes for the best decision. Questions to consider discussing with your doctor include:

What preparation is involved?

Each test requires some preparation on your part. Some test requirements are more stringent than others. A large factor in the success of your test is your willingness and ability to properly prepare your colon. At times, this may be uncomfortable or inconvenient, but it's necessary for the test to be effective. As part of your decision, you may want to consider your willingness or ability to follow the various preparation instructions. This may — to varying extents — include significantly altering your diet and medicine intake, using laxatives or enemas, or both.

How convenient is it?

Consider:

- What you have to do to prepare for the test
- The length of time the test runs
- The frequency of testing
- The need for sedation, which — depending on your doctor's recommendation — may mean that you can't drive for up to a day
- The possible need for follow-up testing to investigate a false-positive finding or to remove or biopsy tissue.

What about cost and insurance issues?

How does cost or insurance coverage factor into your decision? What tests does your insurance provider cover? Would you pay out-of-pocket if need

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