

Deciding on treatment: a step on your journey.

One step at a time.

After being told that you have prostate cancer, the next step on your journey may be to participate in the decision on which type of treatment might be best for you and your family. It is up to you how much you want to be involved in coming to a decision about treatment or if you prefer to have the decision made for you. Whilst this may sound daunting to you at first, it has been shown that the more you and your family are involved in helping to make the decision about treatment, the more satisfied and confident you will feel with your treatment. It doesn't mean that you need to make this decision on your own; doctors, nurse specialists and other men who have been in this same position will give you information, help and support along the way.

It is an important decision and one which you don't need to rush into. In fact, it may take a few weeks before you are able to talk over the options with everyone you would like to or need to. So, take your time; think about what is important to you, the advantages and drawbacks of each treatment option and how these might affect you and your lifestyle. It is far better to choose your treatment carefully now, rather than rushing ahead with a treatment which may not be best for you in the long run.

It is beneficial to talk over treatment options with both the urologist and oncologist involved in your care. It may be helpful if you, your partner, family member or friend jot down notes during your appointment. On the other hand, you can ask if the doctor would mind you audio-recording what is said so you have the chance to listen as many times as you want at home. This can help you understand what is said at this appointment. Another benefit, is that it can help you make the most of your next appointment, as you can make a list of questions to ask the doctor or specialist nurse or ask them to explain something to you again.

In the Early Prostate Cancer booklet, there is a list of possible questions at the end of each treatment option you might like to ask the urologist or oncologist, and space for any questions of your own. Filling in the chart below may help you speak to the doctors too. It will show them what matters most to you and how you feel about each treatment, then, if necessary, they can explain more about the advantages or drawbacks if you are still unsure.

If you have a spouse, partner or family, you will most likely want to include them in helping you come to a decision as they, too, will be affected by the treatment choice that you make. If you (and possibly your family), fill in the chart below then you can start to talk about what matters most. It may help you to start talking about your treatment decision.

You may want to speak to men (and their families) who have had the particular treatments you are considering. On the other hand, if you don't want to talk to others, you may prefer to read personal stories about how other men came to their decisions and what mattered most to them.

After considering what everyone has said, you should be in a better position to make your own decision.

I need to know my results.

If you don't know these, then you can ask for them from your specialist nurse, consultant or GP. If you don't understand what they mean, ask the doctor or specialist nurse to explain them to you. My results are:

PSA level:

Gleason score:

Stage:

Prognostic grade group:

My cancer is termed:

Low-risk

Intermediate-risk

High-risk

I need to make a decision on treatment for my prostate cancer.

The treatment(s) which have been recommended for me are:

- Active surveillance Robotic assisted radical prostatectomy
Laparoscopic radical prostatectomy Open radical prostatectomy
EBRT EBRT with hormone therapy Brachytherapy
Brachytherapy with hormone therapy Hormone therapy
Clinical trial Watchful waiting

If you don't understand why you have been offered some treatments and not others, then you can ask the doctor or specialist nurse to explain this to you.

Ask yourself:

Do I have all the information on the treatments that I need or want?

Yes No

Do I know the advantages and drawbacks of each choice?

Yes No

If not, who am I most comfortable talking to, asking for more information and getting support from?

The urologist or oncologist involved in my care My GP

The specialist nurse involved in my care

Men (and their families) who have faced the same decision making process as me

Men who have had the treatments I am considering

How involved would I like to be in reaching a decision?

- i. Fully involved/in control of the final decision
- ii. Partially involved/participate in shared decision making with the consultant
- iii. Not involved/prefer the consultant to make a recommendation and/or decision for me

So, how far along am I in making my decision?

Made my choice Almost made my choice

Still thinking about it Haven't thought about it yet

Weighing it all up.

If you are still struggling to make your decision, maybe filling in the chart overleaf will help.

Step 1

Fill in the choices you have been given and the reasons you would choose or avoid this option. To do this, you may want to look at the information on advantages and drawbacks in the booklet. Another way of doing this is by looking at the headings in the 'Side effects at a glance' table on page 10, then listing these and how you feel about each one. However, you and your family may have thought of your own advantages or drawbacks.

Step 2

How you feel about each treatment matters too. You may like to put a number beside each advantage or drawback to show how much this **means to you**. The higher the number the more this means or matters to you.

- | | |
|------------------------------------|--------------------------------|
| 4 this matters a lot | 3 matters more than not |
| 2 doesn't matter either way | 1 doesn't matter a lot |
| 0 doesn't matter at all | |

My choices are	Advantages Reasons for me to choose this option are	How much this matters to me	Drawbacks Reasons for me to avoid this option are	How much this matters to me
1.				
2.				
3.				

Now that you've started to think about your choices, is there one which you think may be most suitable for you? _____

Are you clear in your own mind that this is the right choice for you?

- | | |
|---|---|
| <input type="checkbox"/> I know what to choose | <input type="checkbox"/> Fairly sure of my choice |
| <input type="checkbox"/> Leaning towards this treatment | <input type="checkbox"/> Not sure at all |

Have you been told when you need to make this decision by?

Yes No Date _____

Is there anything eg. event, holiday, work which has a bearing on your treatment decision? _____

Now that you have spoken with others and read the information, before finally deciding you may have some questions of your own to ask the doctor or specialist nurse or perhaps just asking them to go over something with you again. You can use the boxes opposite to write any questions you have, and take them to your consultation, to ensure that your questions have been addressed. It may be helpful to refer back to the suggested questions in the booklet.

Page number in *Early prostate cancer explained* booklet:

Active surveillance	pages 41-44	Questions	page 44
Radical prostatectomy	pages 45-59	Questions	page 58 & 59
External beam radiotherapy	pages 59-67	Questions	page 67
Brachytherapy	pages 68-76	Questions	page 75 & 76
Hormone therapy	pages 76-80	Questions	page 79 & 80

Date/ Question	
Date/ Answer	
Date/ Question	
Date/ Answer	
Date/ Question	
Date/ Answer	
Date/ Question	
Date/ Answer	

Treatment options at a glance

Although this chart provides a quick guide to treatments available, it is best to read the Early Prostate Cancer Booklet for more information and talk options over with

Treatment and what it is	Invasive treatment Pre-planning needed	Age	Treatments suitable for those with Low, Inter or High Risk cancer	General health
Active surveillance (page 41) No immediate treatment but regular monitoring	No No	50-75	Low Very occasionally Intermediate	Older men with other health conditions. Younger men fit for other treatments at later date
Radical Prostatectomy (page 45) Prostate removed during surgery	Yes. Minimal Access Surgery being less so Possibly pelvic floor exercises	Less than 75	Low Inter Sometimes High-risk	Otherwise fit and healthy and fit for anaesthetic
External Beam Radiotherapy (page 59) High energy x-ray beams accurately aimed at prostate	No Yes, to find exact position of prostate. Sometimes markers of gold fiducial seeds are placed in prostate to ensure accurate targeting. A treatment plan is then devised	Any age	Low Inter High	Fit, otherwise healthy men but also suitable for men with other health conditions
LDR Brachytherapy (page 68) Tiny seeds that emit radiation placed in prostate. The prostate must measure less than 50cc	Minimally invasive Yes. To measure the size and shape of your prostate to ensure the number and position of seeds are correct. Hormone therapy may possibly be needed	Possibly younger men	Low Inter	Must have a strong flow of urine. Men who have not had EBRT. Less suitable if had a TURP previously
Hormone Therapy (page 76) Reduces the amount of testosterone. Aim is to shrink or slow tumour growth. Can be given in combination with EBRT or LDR brachytherapy	Very minimally invasive May start with tablet for a week or two before and possibly after injections	Any age	Inter High	If prescribed then it is usually suitable for all men

your consultant or specialist nurse. Please remember, this is a general guide. Please ask your consultant who will give more specific advice for your particular circumstances.

Potential cure	Anaesthetic	Hospital stay	Catheter	Time off work	Treatment given as
No	No	None	No	None	Deferred/postponed treatment. Monitoring and tests until PSA rises and other tests indicate treatment is necessary
Yes	Yes - general	Between 1-5 days, depending on procedure and recovery	Yes	Between 3-8 weeks depending on type of surgery and work	Surgery
Yes	No	No. However every out-patient appointment must be attended	No	Not necessarily needed	Doses of radiation called fractions. Mon – Fri for between 4-8 weeks
Yes	Yes - general. Occasionally a spinal may be used.	A few hours or possibly overnight	Not usually	A few days to a week	Surgical implant of seeds
No	No	No	No	No	Monthly, 3 monthly or 6 monthly injection just under the skin in the tummy area or into the buttock

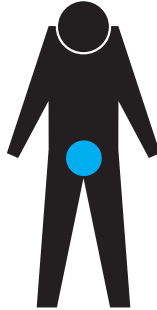
Follow ups and possible side effects at a glance

Although this chart provides a quick guide to follow up after treatment, and possible side effects of treatment, it is best to read the Early Prostate Cancer Booklet for more information and talk options over with

Treatment and what it is	Follow up appointments	How do I know treatment has worked	Further options	Difficulties with erections when might this happen
Active Surveillance	May be slight variations but usually PSA every 3-6 months. DRE every 6-12. Possibly biopsy every 1-3 years. Consideration of MRI scan		Prostatectomy EBRT LDR brachy Hormone therapy	No effect
Radical prostatectomy	6-8 weeks after surgery then usually every 3-6 months for 2 years	PSA drops quickly and level will be practically undetectable, usually less than 0.1ng/ml	EBRT Hormone therapy	May occur immediately after surgery. This may improve for up to 2 years after surgery
EBRT	Regular appointments every 3 months	PSA levels will drop slowly and will reach its lowest level about 1-2 years after EBRT	Hormone therapy Cryotherapy In selected cases, surgery	Can occur soon after treatment but may develop up to 2 years after treatment
LDR Brachytherapy	PSA blood test in about 3 months and then 3-6 monthly afterwards	PSA level often falls slowly over a few years	Hormone therapy Cryotherapy In selected cases, surgery	May develop possibly up to 3 years after treatment
Hormone therapy	PSA levels checked every 3-6 months	PSA level will fall to very low levels but may rise slowly in time	Radiotherapy Clinical trials Chemotherapy	Because of reduction of testosterone, this is a common side-effect

your consultant or specialist nurse. Please remember, this is a general guide. Please ask your consultant who will give more specific advice for your particular circumstances.

Incontinence	Bowel difficulties	Tiredness	Bleeding	Hair loss due to treatment	Possibility of secondary tumour due to treatment	Infertility
No effect	No effect	No effect	No effect	No		No effect
For most men it takes between 3-6 months to gain full control but it may take up to a year	Most likely some constipation after surgery	Possibly just after surgery	Not common but can happen	No	No	Yes Dry orgasm
May need to pass urine more often, urgently and during the night	May need to open bowels more often, urgently and motions may be looser	Probably. This can build up over the course of treatments	No	Yes. At site of treatment but not on your head	Very small increased risk of radiation induced cancer in pelvic area 5-10 years after treatment	Discuss with your doctor
May have a slow stream and need to pass urine more often	Lower risk of bowel difficulties than with EBRT	Not usually	Possibly some blood stained urine and/or ejaculate just after surgery	No	Very low risk and indeed it is very uncommon	Usually but discuss with your doctor. Use a condom for first 6 ejaculations
No	No	Yes. As well as - mood swings, hot flushes, breast swelling, bone thinning	No	No		Loss of sexual desire



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