Spotlight on guides

Additional Prostate Scotland guides available which may be helpful:

Spotlight on Caring for you indwelling catheter

Spotlight on External Beam Radiotherapy for prostate cancer

Spotlight on prostate conditions and erectile dysfunction

Spotlight on prostate biopsy

Spotlight on pelvic floor exercises for men

Spotlight on prostate brachytherapy

Spotlight on incontinence as a symptom of prostate problems

Spotlight on removing the prostate by minimal access surgery

Spotlight on Active surveillance

Spotlight on Hormone therapy

Spotlight on Watchful waiting to manage prostate cancer

Spotlight on Treatment for an enlarged prostate

DECISION MAKING

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

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

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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; urologists, oncologists, Clinical Nurse Specialists (CNS) 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 consultants 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 urologist, oncologist or CNS or ask them to explain something to you again. You may also find the additional 'Spotlight on' guides from Prostate Scotland helpful.

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 urologist, oncologist or CNS 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 or you can watch films on our website by clinicians and men talking about treatments for prostate cancer.

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 your results, then you can ask for them from your CNS, consultant or GP. If you don't understand what they mean, ask the urologist or CNS 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.

Active surveillance	48 - 51	☐
Robotic assisted radical prostatectomy	51 - 66	☐
Laparoscopic radical prostatectomy	53 - 66	☐
Open radical prostatectomy	53	☐
EBRT	68 - 76	☐
EBRT with brachytherapy	77	☐
EBRT with hormone therapy	68 - 69	☐
Brachytherapy	78 - 86	☐
Brachytherapy with hormone therapy	80	☐
Stereotactic body radiation therapy	86 - 95	☐
Hormone therapy	96 - 100	☐
Cryotherapy	100 - 104	☐
Watchful waiting	105	☐
Clinical trial		

(For more information on clinical trials see Advanced prostate cancer explained booklet 4)

If you don't understand why you have been offered some treatments and not others, then you can ask the urologist, oncologist or CNS 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 CNS 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 ☐
Prostate buddy from a prostate cancer support group ☐

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 'at glance tables' on pages 10-14, 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.				

Another resource that might help to make your decision are the films on the Prostate Scotland website.

Early prostate cancer explained.
By Mr Seamus Teahan, Consultant Urologist, Forth Valley Royal Hospital, Larbert. This film discusses symptoms, stages of prostate cancer, Gleason score, an overview of treatments and side-effects as well as an introduction to deciding on treatment.
prostatescotland.org.uk/disease-tests-and-treatments/early-prostate-cancer

Active surveillance and the natural approach to prostate cancer
Chris Garner describes his approach when diagnosed with prostate cancer researching for himself the causes of prostate cancer then looking at and trying natural/complimentary therapies. He discusses what active surveillance is and how the cancer might be monitored.
prostatescotland.org.uk/help-and-support-for-you/active-surveillance-monitoring

Surgery for prostate cancer
Professor Alan McNeill, Consultant Urologist at the Western General, Edinburgh and Trustee of Prostate Scotland discusses the types of surgery and in particular the benefits of robotic assisted surgery. He explains what happens during and after the operation, plus the potential side-effects of the surgery.
prostatescotland.org.uk/help-and-support-for-you/surgery-remove-prostate

A story about one man's prostate cancer journey
Larry Foster gives the background to his diagnosis, the treatment options he was given and how he finally settled on choosing a radical prostatectomy. He talks about his recovery, running a half marathon 12 weeks after his operation and getting back to walking and climbing.

Prostate cancer and robotic assisted prostate cancer surgery - one man's experience
Bruce Loughlin discusses his treatment and being one of the first patients to have robotic assisted prostate cancer surgery (prostatectomy) at the Western General Hospital, Edinburgh in 2016.

External beam radiotherapy (EBRT)
Dr Duncan McLaren, Consultant Oncologist, at the Western General, Edinburgh provides information on EBRT and the different ways that it might be used. He discusses what EBRT is, the machine used to deliver EBRT, the course of treatment, when hormone therapy might be used in conjunction and the potential side-effects of EBRT.
prostatescotland.org.uk/help-and-support-for-you/external-beam-radiotherapy-ebrt

Brachytherapy
Dr Duncan McLaren, Consultant Oncologist, at the Western General, Edinburgh discusses who might be suitable for brachytherapy and why hormone therapy might be necessary before brachytherapy. He explains what brachytherapy is, how the seeds are implanted and potential side-effects of the procedure.
prostatescotland.org.uk/help-and-support-for-you/bracytherapy-treatment-prostate-cancer

Brachytherapy
Charlie Porteous tells his story about diagnosis, biopsy and why he decided that brachytherapy was the right choice of treatment for him.

Hormone therapy
Dr Duncan McLaren, Consultant Oncologist, at the Western General, Edinburgh provides information on how hormone therapy works by removing testosterone. He discusses the different ways that hormone therapy might be useful and the side-effects of hormone therapy.
prostatescotland.org.uk/help-and-support-for-you/hormone-therapy

Hormone therapy
Peter Phillips tells his story of how at the age of 44 he was diagnosed with prostate cancer with a PSA level of 10,800. He talks about his treatments over the years and chats about the side-effects and the way he remains positive.

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?

☐ I know what to choose ☐ Fairly sure of my choice

☐ Leaning towards this treatment ☐ 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, you may have some questions of your own to ask the urologist, oncologist or CNS or perhaps just asking them to go over something with you again before finally deciding on which treatment you think will suit you best. You can use the boxes opposite to write any questions you have, and take them to your consultation, to ensure that all your questions or concerns have been addressed.

Date/ Question	
Date/ Question	
Date/ Question	
Date/ Question	
Date/ Question	
Date/ Question	
Date/ Question	
Date/ Question	

This chart is meant as general guidance. As procedures may vary from hospital to hospital, ask for more advice from staff at the hospital you are attending. If you have been given specific guidance by the hospital, then it is important that you follow their guidance. Some men will not fit all of these categories and would need additional conversations with their consultant urologist or oncologist to discuss their treatment options.

DECISION MAKING

prostate scotland

	Risk Group of prostate cancer	General health	Potential cure	General Anaesthetic	Hospital stay	Catheter	Time off work	Treatment as	Follow up appts	How do I know treatment has worked	Further treatment options	Difficulties with erections	Incontinence	Bowel difficulties	Tiredness	Bleeding	Hair loss due to treatment	Possibility of Secondary tumour due to treatment	Infertility	Invasive treatment	Pre-planning
Active surveillance No immediate treatment but regular monitoring Page 48	Low Very occasionally intermediate	Fit for other treatment at a later date	No	No	None However all out-patient appointments must be attended	No	None	Deferred/postponed treatment. Monitoring and tests until PSA rises and/ or other tests indicate treatment is necessary. If the man decides upon active treatment	May be slight variations but usually PSA every 3-4months, annual DRE, repeat MRI scan periodically. May or may not have biopsy periodically	This is not a treatment PSA will be monitored	Prostatectomy EBRT EBRT with seed boost SBRT Brachytherapy Hormone therapy	No effect	No effect	No effect	No effect	No effect	No	Discuss with your urologist/ oncologist or CNS	No effect	No	No
RARP Prostate removed during surgery Page 51	Low Intermediate Sometimes high risk	Otherwise fit and healthy for anaesthetic/surgery	Yes	Yes - general	Often only 24 hours after surgery. May be slightly longer depending on recovery	Yes around 1- 2 weeks. May be slightly longer	3- 8 weeks	Surgery	6-8 weeks after surgery then usually every 3-6 months for 2 years	PSA drops very quickly and will be almost undetectable, usually less than 0.1ng/ml	EBRT Hormone	Usually immediately after surgery and can take up to 2-3 years to recover and will often need medication	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 (not due to the prostatectomy)	Dry orgasm	Yes. Minimal access being less so	Pelvic floor exercises
EBRT High energy x-ray beams focused on the prostate Page 68	Low Intermediate High	Fit, otherwise healthy men but also suitable for men with some other health conditions	Yes	No	No. However all out-patient appointments must be attended	No	Not necessarily needed but sometimes required	Doses of radiation called fractions. Nowadays higher doses delivered in a shorter time period often only 20 days	Regular appointments every 3 -6 months for the first 2 years	PSA levels will drop slowly and will reach its lowest level about 1-2 years after EBRT	Hormone therapy Cryotherapy In selected cases surgery Focal salvage brachytherapy may be considered	Can occur soon after treatment but may develop up to 2 years after treatment	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. Ask your oncologist for more information	Discuss with your doctor	Partially to implant gold fiducial seeds	To find exact position of prostate to ensure accurate targeting. Treatment plan devised.
SBRT Similar to EBRT but using a tracking system Page 86	Low Intermediate	Medically fit for treatment	Yes	No	No. However all out-patient appointments must be attended	No	Not necessarily needed but sometimes required	High doses of radiation called fractions are very accurately targeted to prostate using a special tracking system. 5-7 fractions over 1-2 weeks	Every 3 -6 months for the first 2 years	PSA often falls most in the 1st year Continues to reduce for about 2 years. PSA may spike sometimes	Cryotherapy HIFU Focal salvage brachytherapy Surgery	One recent study has suggested that 25% of men experienced a decrease in erectile function after SBRT.	May need to pass urine more urgently and during the night	May need to open bowels more often & urgently. May need to pass more wind and have some cramps	Probably. This may build up over the course of treatment	No	Possibly at the site but not on your head	Very small increased risk 5-10 years after treatment Ask your oncologist for more information	Discuss with your doctor	Partially	To put tracker and gold fiducial seeds into the prostate
EBRT followed by implanting seeds Page 77	Intermediate High	Medically fit for treatment	Yes	Yes	All EBRT out-patient appointments must be attended. Short hospital stay for seed implants	Not usually	A few days because of seed implants	(23 fractions) of external beam radiotherapy given for 5 days a week; Followed 2 weeks later by the boost of seed implants	Every 3 -6 months for the first 2 years	PSA will fall in the months after your implant. May 'bounce or spike' around 2 years	Focal re-implant of seeds Hormone therapy	Can occur soon after treatment but may develop up to 2 years after treatment	May need to pass urine more often	May need to open bowels more often	Probably. This may build up over the course of treatment	Possibly some blood stained urine after the seed boost	Possibly at the site but not on your head	Very small increased risk of radiation induced cancer in pelvic area 5-10 years after treatment. Ask your oncologist for more information	Discuss with your doctor	Partially to implant seeds	As EBRT. Measuring prostate and ensuring number and position of seeds are correct
Brachytherapy Tiny seeds that emit radiation implanted into the prostate Page 78	Low Intermediate	Must have a strong flow of urine. Less suitable if had a TURP previously	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 that emit radiation.	PSA blood test in about 3 months then 3-6 monthly afterwards	PSA will fall in the months after your implant. May 'bounce or spike' around 2 years	Cryotherapy In selected cases surgery Hormone therapy Focal re-implant of seeds	May possibly develop up to 3 years after treatment	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	Minimally invasive to implant seeds	Yes. Measure the size and shape to ensure the number and position of seeds implanted are correct. Hormone therapy may possibly be needed
Hormone Reduces amount of testosterone with aim to shrink or slow tumour growth. Page 96	Intermediate High	If prescribed then it is usually suitable for all men	No	No	No	No	None	Monthly, 3 monthly or 6 monthly injections just under the skin in the tummy area or buttock. Often injections are done at the GP Practice	Regular check-ups with PSA monitoring	The PSA level will fall to very low levels but may rise slowly in time	Novel hormone therapy Chemotherapy Non curative or palliative Radiotherapy Clinical trials	A common side-effect is loss of libido and not being able to get and keep an erection	No effect	No effect	May get tired easily and lack energy as well as hot flushes, mood swings, weight gain. Tiredness can be a longer term difficulty	Perhaps a tiny amount from the needle puncturing the skin when giving the injection	Longer term hormone therapy may lead to loss of hair on underarms, legs and genital area	Over time the prostate cancer may start to grow again, called castrate-resistant prostate cancer	Loss of libido/ sexual desire	Very minimally invasive (injection)	May start with a tablet for a week or two before and after injections
Cryotherapy Special probes are used to freeze prostate tissue to kill the cancer cells Page 100	Recurrent prostate cancer	Generally fit and well. No bothersome lower urinary tract symptoms	In Scotland it is used if there is a recurrence of prostate cancer for salvage treatment	Yes	Night before and night of the operation	Yes and for up to 2 weeks afterwards	A month	Uses for low temperature (-40) from a special probe to kill the cancer cells	Week 1, week 6 Then 3, 6,9 and 12months Possibly by phone consultations	PSA level should fall	This will depend on fitness and PSA level	Most likely. High risk of damage to nerves around prostate	Often this is the case and may need to use pads	Possibly constipation. A mild laxative is prescribed	Not usually	Small amounts blood in urine for a few days and bleeding from area where probes inserted	No	Not known	Discuss with your doctor	Yes. To insert probes through the perineum	Pelvic floor exercises
Watchful waiting. No active treatment but check-ups by your GP. Page 105	Any risk category but when the cancer has not spread	Additional health conditions	No. A way to manage the cancer	No	No	No	No	No active treatment but waiting to see if the cancer grows or changes	Usually every 6 -12 months with your GP but you may also be seen by the hospital team on occasion	This is a way to manage and monitor your cancer	Potentially hormone therapy	Usually no change in the quality of erections	No effect	No effect	No effect	No effect	No effect	You will have check-ups with your GP/hospital team and should let them know of any changes in your symptoms or new symptoms	Possibly because of other health conditions	No	No