

A Layman's Guide to Prostate Cancer and Prostate Diseases in Ireland

Men Against Cancer

Support Group for Men with Prostate or Testicular Cancer

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Contents

Men Against Cancer	3
Facts about Prostate Cancer in Ireland	4
Worried about your prostate?	5
The Prostate Gland	6
Is there anything about the location of the prostate?	7
Digital Rectal Examination	8
Prostate Diseases that are not Cancer	8
Enlarged Prostate - BPH	9
Diagnosing Prostate Cancer	9
PSA - Prostate Specific Antigen	10
Prostate Cancer Treatments in Ireland	13
New Treatments for Advanced Prostate Cancer	14
Prostate Cancer, Diet, & Exercise	19
Rapid Access Prostate Cancer Clinics	21
Radical prostate treatments in Private Hospitals	21
Irish Cancer Society	22

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	MAC
	MAC is a volunteer patient support group for men with prostate or testicular cancer and for men who have other prostatic conditions. MAC was founded in 1993 and for some years operated as one of the Irish Cancer Society's peer-to- peer patient support groups. With the dissolution of the Society's own groups MAC now operates on an independent basis but with continued cooperation with the Society. Many MAC members participate in the Society's Survivors Supporting Survivors programme and other patient support programmes such as Daffodil Centres and The Volunteer Driving Service .
	MAC services are free of charge and members carry out its work in the following ways:
	* Peer-to-peer support - trained volunteers talk to newly diagnosed men about heir initial diagnosis or recurrence.
	* Many of the referrals to MAC volunteers come from the ICS Helpline, from the hospital-based Daffodil Centres and from community-based cancer groups and centres as well as personal contacts.
С	Publications-MAC produces information leaflets, occasional newsletters and other information material and members contribute articles to various print nedia and the MAC website.
	* Members meet patients in Rapid Access Clinics and Daffodil Centres and other hospitals.
	* Public and private meetings where MAC members talk about their own experiences and about the developments in prostate cancer diagnosis and treatment in Ireland.
	* MAC is a member of the European Prostate Cancer Coalition – Europa Uomo and through this organisation MAC has access to the leading European prostate cancer researchers and clinicians.

Facts About Prostate Cancer in Ireland

Over 3,000 men are diagnosed with prostate cancer in the Republic of Ireland each year and that number is rising steadily but only about 500 men die of the disease each year. These figures show that most men who get a prostate cancer diagnosis will not die of the disease. There are several reasons suggested for this:

A greater use by family doctors in Ireland of the PSA test as a screening procedure. This opportunistic PSA screening means that rare, potentially lethal, prostate cancers are caught earlier and can be treated more effectively.

· Most prostate cancers are slow growing and may never cause death.

• The reorganisation of cancer services in the voluntary and public hospitals into eight designated centres, combined with the introduction of Rapid Access Prostate Cancer Clinics with their Multi-Disciplinary Teams, provide an opportunity for swift referral, biopsy and advice on treatment options.

• Increased public awareness through the work of the Irish Cancer Society, the Movember movement, the 40+ community-based cancer support organisations affiliated to the ICS who are being trained by the Society, and other organisation such as the Marie Keating Foundation which has developed a prostate cancer support service in recent years.

• Better treatments in surgery and radiation and oncology. Also, for men who develop advanced prostate cancer there are now new treatments, if their earlier treatments fail.

* And peer-to-peer support from the trained volunteers in MAC – Men Against Cancer.

Worried about your prostate?

Early stage prostate cancer is usually without symptoms. Before the current screening tests men tended to present with symptoms which are generally associated with troublesome conditions caused by the enlargement of the prostate. In some cases it was discovered that the man had both an enlarged prostate and prostate cancer. With modern day tests these early stage cancer tumours are found using blood tests followed by biopsy. Late stage or advanced prostate cancer is more likely to show symptoms. If you have any concerns about your prostate or any of the issues referred to in this booklet please talk to your family doctor about your concerns.

She/he may ask you questions about symptoms such as:

* Why are you concerned?

* Are you having any difficulties passing urine?

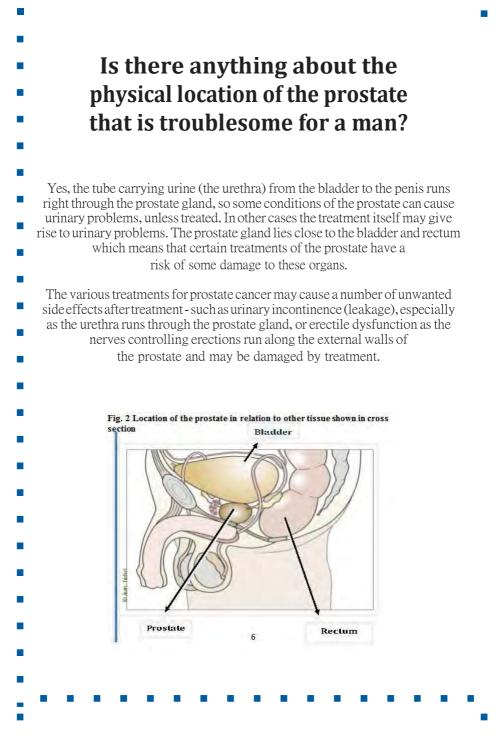
- * Have you seen any blood in your urine?
- * Are you having difficulty emptying your bladder?
 - * Are you having to get up at night to urinate?
 - * Have you any pain and, if so, where?
 - * Have you been running a temperature?
 - * Is your sexual function affected?
- * Did anyone in your family have prostate cancer?

The answers you give to these questions will help the doctor decide on the next step, if any, to recommend to you. Your doctor will also want to check your family history and other relevant factors before advising you on your next steps. The doctor may suggest that you should have a simple blood test called a PSA test. If your doctor thinks your PSA result is higher than it should be, for your age, then you may be referred to a specialist for a biopsy or your symptoms may indicate that you have a bacterial infection of your prostate and that you need a course of antibiotics. If you are of African or Afro-Caribbean origin your risk of contracting prostate cancer is higher than for those of European ancestry.

Most men who have biopsies do not have prostate cancer. A higher than normal PSA result may be due to a non-malignant enlarged prostate or due to an infection of the prostate. Most biopsies are negative for prostate cancer. But where a cancer is confirmed

many men will have the low risk form of the disease.

Wha	at is the prostate and what does it do? It is a small gland, usually about
It se	the size of a walnut, deep inside the pelvic region of the body. ecretes a prostatic fluid which is a major component of a man's semen it plays a role in the muscle contraction called orgasm that signals the end of a normal sex act, or at least the end of the erection.
ferti of tl by th wh Th	hy is the prostatic fluid so important? In order for a single sperm to lise an egg produced by a woman's ovaries the sperm must first get out he ejaculate – the clump of tens of thousands of sperm cells produced he testicles (testes). The prostate produces certain chemical substances hich helps the separation of individual sperm from the seminal fluid. his separation is essential to allow sperm to swim a huge distance in ve terms, and at very considerable speed relative to their size, to mee up with an egg before any other sperm can do so.
	Fig. 1 Groin area shown in cross-section
	bladder sphincter [internal] prostate sphincter [external]



Digital Rectal Examination (DRE)

Because the prostate lies up against the bowel or is only millimetres away from the rectum, a doctor can easily feel the prostate by using a gloved finger in the rectum (digital rectal examination or DRE). This examination can tell the doctor if the surface of the prostate is regular or if there are any hard zones which might indicate the presence of a tumour. While the prostate itself has no function in achieving an erection of the penis, as previously mentioned, the nerves needed for an erection adhere to its sidewalls and can be affected by surgical or radiation treatment.

Not all GPs will perform a DRE, some prefer to have this done by a specialist.

Prostate Diseases That Are NOT Cancer

Urinary Symptoms

Relative to its size and weight the prostate is the cause of more disease than any other organ in our body. Luckily, most of this disease is not cancer. Problems of the prostate are very often seen as problems with emptying the bladder. Urinary symptoms, however, may result from several diseases like a bacterial infection (prostatitis) or an enlarged prostate (BPH) and these causes should always be ruled out first before an investigation is even started to confirm the presence of prostate cancer.

Prostatitis

Prostatitis (pronounced prosta-tight-iss) is an acute infection of the prostate caused by bacteria and characterised by fever, chills and urinary urgency. It is a rare but serious disease. Hospitalisation may be required if there is no clear improvement in 24 hours because of the dangers from the invasion of bacteria into the blood system.

There are also a common condition in practically all men after age 50, called chronic prostatitis or inflammation in some prostate zones caused by the stagnation of the secretions or reflux of urine. Very few cases of chronic prostatitis are caused by bacteria. This condition requires patience, maybe even psycho-social support, such as counselling, for the patient.

Enlarged Prostate (Benign Prostatic Hyperplasia - BPH)

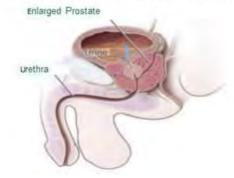
An enlarged prostate is usually due to BPH (benign prostatic hyperplasia) and is one of the most common conditions in middle-aged and elderly men.

Some of the symptoms are:

a decrease of the urinary stream,
waking up in order to empty the bladder,
sometimes urgency, and
most frequently - dribbling after urination.

If treatments fail to improve a patient's complaints, surgery can solve the problem by removing the excess prostate tissue and leaving the outer prostate in place. This procedure is called a transurethral resection prostatectomy (TURP). This is **not** the same as a standard prostatectomy (surgical removal of the prostate gland) sometimes used in cases of prostate cancer.

Fig.3 Cross section Enlarged prostate (Benign Prostatic Hyperplasia - BPH)



Diagnosing Prostate Cancer

The process of diagnosing prostate cancer often starts with a PSA test and a Digital Rectal Examination. The PSA Test is discussed below, but it must be emphasized that the PSA test, while a marker test, is not a prostate cancer test.

What is Prostate Specific Antigen?

PSA does its work in the semen. When semen is ejaculated it is a clot of thick liquid. Imagine how difficult it is for an individual sperm to escape this thick ejaculate in order to swim to the egg to fertilise it.

The Prostate Specific Antigen is one of the compounds produced by the prostate. It is a special kind of protein which interacts with other chemicals. This enables PSA to break other proteins into smaller pieces. This process transforms the seminal fluid into a lighter, more free-flowing liquid that allows individual sperm to swim free to perform their function.

PSA is produced in large amounts in the prostate and some of the excess PSA leaks into the bloodstream where it actually has no function. It is this PSA that can be measured in the laboratory with tests that are extremely sensitive so that they can measure very small amounts of PSA in the blood.

The level of PSA measured in the blood may be a useful indicator for a man and his doctor to discuss whether any action is required. If a biopsy of the prostate is thought necessary this may confirm the presence or otherwise of prostate cancer tumours.

Elevated PSA is not a diagnosis of prostate cancer

It is important to repeat that an elevated PSA alone is not a diagnosis of prostate cancer. Even where men - say 60-70 years of age - have a PSA reading in excess of twice the normal PSA level for their years almost half do not have a positive cancer finding on biopsy.

If there is PSA in a blood sample then somewhere in the body there is prostate tissue producing PSA. If the prostate itself has been removed by a surgical procedure or has been destroyed by radiation then the continuing presence of PSA means that there is prostate cancer tissue left behind or is growing in other parts of the body - this condition is known as a metastasis (pronounced meh-tast-a-sis).

Biopsy

There are also special new laboratory tests and prostate cancer risk calculators all designed to reduce the risk of over – treatment of the patient. Some of these techniques will show more precisely where in the prostate gland a tumour might be found, so that, if a biopsy is necessary, it can be targeted to that site.

If the PSA test result looks suspicious, the man's doctor will send him to an urologist for an ultrasound guided biopsy. This ultrasound technology is the same used to visualise an unborn baby, but in the case of a prostate biopsy it uses specific probes. The probe, which enables the urologist to visualise the prostate, is inserted into the rectum. The urologist sees an image of the prostate on a screen and this allows the doctor to measure the size of the prostate and to see if there are any unusual or irregular spots.

These spots indicate parts of the prostate with a different density which may eventually prove to be cancerous.

The doctor will use in the biopsy a spring-loaded instrument to cut out small cores of prostate tissue which are sent to the laboratory. A biopsy is an invasive procedure which can be uncomfortable and there is a slight risk of infection. Other tests are under development and review which may reduce the number of biopsies by eliminating non-suspicious prostates, but before any active or radical treatment is recommended a confirmatory biopsy will be necessary.

MRI Scanning for Prostate Tumours

TRUS (Trans-Rectal Ultra-Sound) biopsies can sometimes cause infections and for other more technical reason doctors have been trying to reduce the number of invasive biopsies, without compromising the patient's health, by using other techniques. One of these methods is a type of Magnetic Resonance Imaging called multiparametric MRI. This technique is being used more frequently to look at suspect tumours more closely with a view to reducing the number of biopsies, but when thought necessary this type of MRI can also indicate the most opportune areas of the prostate to be sampled by the biopsy needle. This type of MRI also allows for a more extensive examination of the prostate than is possible using the conventional TRUS. There are also new laboratory tests and prostate cancer risk calculators all designed to reduce the risk of over – treatment of the patient and assist the treating physician in deciding whether to recommend proceeding to a biopsy.

Grading the Biopsy - Gleason Score

Prostate cancer is a disease with many aspects. Its aggressiveness can be estimated by a specialist following the microscopic examination of biopsy specimens. The standard classification for measuring the possible aggressiveness of a tumour is the Gleason Scoring system; it runs from totals of 6 to 10. A highly trained pathologist examines the tissue samples under a microscope. The tissue sample is examined to determine how frequent is the occurrence of cancer cells compared to healthy prostate cells and how differentiated (disordered) are the prostate cancer cells compared to normal healthy cells. The overall Gleason scores are in the range of 6, 7, 8, 9 or 10. Scores of 6 and some 7s being considered Low Risk and 8-10 High Risk. The grading gives the treating team an understanding of how quickly the cancer might grow and, therefore, the treatment options. Other factors in assessing the best treatment

are extra-capsular spread, spread into the seminal vesicles, and how the prostate gland feels to the touch and the patient's PSA level. For prostate cancer, as for

 most solid tumours, the final diagnosis is made by the pathologist examining the prostate tissue under a microscope.

When In Doubt – Repeat the Test!

It is possible that, despite a suspicious PSA result, a series of biopsies may not show any sign of cancer then the urologist can propose to wait and repeat the tests some months later. This is a normal procedure; remember prostate cancer is not normally a fast growing tumour.

Decision Making

Prostate cancer has some 'advantages' over others cancers. It is mostly slow growing so that a man and his family have plenty of time (say 3 months) to take into all personal facts including any other ailments, the predictive factors of the cancer and to discuss in-depth all available methods of cure or control - with their various side-effects - before making a decision.. The specialist doctor should provide the man and his family with correct, reliable information on his individual choices starting with the indications for biopsy and on to treatment/non- treatment options where indicated.

Prostate Cancer treatments in Ireland

As with many cancers, there is no such thing as "the prostate cancer". Every man is different, so is every prostate cancer. This combination of unique factors means that every man needs individualised treatment which recognises that every mans prostate cancer is different. For most patients it is difficult to compare their treatments.

Below is a brief overview of the main treatments available in Ireland at the time of writing. These are subject to change and the current position should be checked by the patient or their doctor.

Watchful Waiting

Some men are diagnosed with prostate cancer but they also suffering from some other life-threatening diseases (known as co- morbidities) which
indicates that they have a limited lifespan. To subject such men to an active treatment programme for prostate cancer may not extend life and may
adversely affect their quality of life for their remaining time for such men. This does not mean that their symptoms, such as bone pain, should not be treated as part of the patient's overall care.

Active Surveillance - AS

Active Surveillance should be distinguished from Watchful Waiting. AS is for men who can still expect curative treatment, but who choose to defer treatment until their situation changes – either clinically, socially or psychologically. Most prostate cancers develop slowly and almost never cause serious (life threatening) disease. For men with these kind of tumours active surveillance can be a reasonable option. These men are carefully monitored with regular PSA tests and, if needed, biopsies. The objective is to keep open the option on curative treatment, if needed. In the meantime, the man is spared the likely side-effects of radical treatment.

Radical Prostatectomy

Depending on the age of the man and on his specific type of cancer, a total removal of the prostate can be a good treatment option. Given the explanation above, about the location of the prostate, it is easy to understand that problems can arise. The possible and undesired side-effects of this form of treatment may result in incontinence due to surgical damage to the sphincter muscle which controls the release of urine from the bladder. In addition, there may be impotence due to nerve damage because the nerves controlling erections are located on the exterior wall of the prostate gland.

A radical prostatectomy can be performed using one of several techniques such as conventional open surgery, laparoscopic surgery where a number of small incisions are made by the surgeon, still hands-on the patient, and

robot- assisted surgery where the surgeon is physically away from the patient operating controlling the operation remotely on a screen and via his binocular microscope. Each technique may have different advantages and drawbacks and costs and not all these techniques are universally available in Ireland.

Radiation Treatment

Radiation can kill tissue, both good and bad. Radiation treatment today will be administered in a very precise way so that most healthy tissue will be protected from damage. Radiation treatment can be given also with implanted radioactive seeds (low-dose brachytherapy) or with external beam radiation (EBR). The latter option has modern technical variants that limit the exposure of healthy tissue to a minimum. For radiation treatment, unwanted side effects are incontinence and impotence, but also radiation damage to bladder and rectum which may not become apparent for some years. Recent advances in the modes of radiation delivery have allowed for effective treatment with greatly reduced side-effects.

Androgen Blockade (AB) Androgen Deprivation Therapy (ADT)

ADT is often called hormone therapy. The male sex hormone testosterone stimulates the growth of prostate tissue and of prostate cancers. Lowering testosterone in the blood slows growth of a prostate cancer.

Several drugs can be prescribed by a man's doctor to lower his testosterone level. To monitor the effectiveness of this treatment the man's PSA and testosterone level will be tested. ADT may affect sexual life (libido), bone density, body weight, mood, may cause fatigue and even depression.

Chemotherapy

When the ADT treatments fail and nothing else seems to be working your doctor can propose to use chemotherapy. These drugs interfere with normal reproduction of cells and impact on cancer cells that reproduce faster than most normal cells. Chemotherapy slows down the evolution of a cancer, but it cannot cure prostate cancer.

Advanced Prostate Cancers

For reasons not yet fully understood, hormone treatment (ADT) or androgen blockade (AB) often ceases to work after a period of years when the prostate cancer cells become resistant to the treatment. Clinicians describe such patients as 'refractory'. When the man has been on hormone therapy his testosterone production is suppressed, and it is as if the man had been castrated – this was once the treatment for advanced prostate cancer. The refractory patient is referred to by the clinicians as having Castrate Resistance Prostate Cancer – CRPC. In most men the cancer metastasises or spreads to other locations in the body, usually bone and men with this condition are known as metatastic Castrate Resistant Prostate Cancer – mCRPC. Some CRPC men don't appear to metastasise immediately and these are referred to as non-metatastic CRPC.

New Treatments

In the past the only treatments available for CRPC patients were not particularly effective and the survival of men after becoming refractory was often measured in months. In recent years, however, a number of new therapies have been introduced for both metatastic and non-metatastic CRPC patients. These preparations have different pathways at a chemical level and are now used usually after chemotherapy. They prolong survival, but they do not appear to provide a cure.

A frequent feature of mCRPC is spread of tumours to the bones. There is now a medical preparation called Radium 223 dichloride, an alpha emitter, which selectively targets bone metastases without damage to healthy tissue.

Treatments Overseas

There are a number of other diagnostic and treatment procedures which are not currently available in Ireland for reasons of our population size or the cost of licensing or because many of the treatments are still seen as controversial or unproven in terms of conferring a benefit in terms of overall survival.

Some Irishmen have used Cryotherapy as a second line treatment when their initial treatment failed. Cryotherapy freezes the prostate and kills the prostate cancer cells. This is available in the UK and one of MAC's peer-to-peer volunteers has undergone this treatment in Sunderland, England.

Other examples of treatments available abroad are HIFU (High Intensity Focused Ultrasound).

Men and their families often go to great expense and dislocation when they decide to avail of non-standard treatment abroad. The conventional wisdom is to seek evidence that the proposed treatment is proven to confer an advantage in terms of overall survival and/or quality of life and that the treatment has undergone follow-up for 5, 7 or better still, 10 years. If such information is not available then the treatment should be regarded as experimental.

Side Effects of Treatment

One of the main reasons why urologists, radiologists and medical oncologists are now giving more emphasis to Active Surveillance to men with non-lifethreatening prostate cancer is because of the concern that there may have been overtreatment of men in the past. Radical prostate cancer treatments, whether surgery or radiation, cause side effects. For some men, their treatment greatly affects their Quality of Life (QoL).

For most men the side-effects wane within a year of surgery or radiation, for others the side-effects can be more long term. The most common side effect is urinary incontinence, especially after surgery because of the re-sectioning of the urethera. In many instances this can be treated effectively by systematic use of pelvic floor exercises, but for some men this just doesn't work. One of their urinary sphincters fails to recover and do its job properly. A simple procedure involving the insertion of an artificial urinary sphincter has proven a boon to men who were plagued with post-operative incontinence.

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A common condition in those who had radiation treatment is an urgency incontinence – where you have the severe need to empty the bladder even if it is nowhere near full. Pelvic floor exercises help with this also.

As the more widespread use of PSA screening by GPs is leading to the discovery of prostate cancers at a younger age, the big side-effect for sexually active

men is erectile dysfunction after treatment. With early stage cancers which have not spread outside the prostate gland it is also easier for the surgeon to undertake nerve-sparing surgery which can greatly increases the chances of

- resumption of sexual function after radical treatment. Radiation damage to the nerves can difficult to overcome but again for many men the degree of
- dysfunction lessens in the first year after treatment and sexual function can be assisted by the use of Viagra or Cialis and other preparations.

"Use IT Or Lose It"

One of the maxims in combatting erectile dysfunction is "use it or lose it". After surgery or radiation treatments the sooner sexual activity is resumed (within reason) the better.

For years the side effects of cancer, including prostate cancer, were not given the degree of attention that is now developing. The Irish Cancer Society has recently taken a very important initiative in opening pilot side-effects clinics in two of the eight designated cancer hospitals to focus on patient side-effects for all cancers (Galway UH and Dublin). It is likely that, when operational, these clinics will have a fair degree of business from men who have undergone radical surgery or radiotherapy for their condition.



Prostate Cancer, Diet & Exercise

It is widely believed among prostate cancer survivors and some clinicians that diet and exercise may be factors in the incidence of prostate cancer in the western world. In the Orient the incidence of prostate cancer has been very much lower than in the West.

African-American Men at Risk

It is an established fact that men of African-American and Afro-Caribbean heritage are much more likely to get prostate cancer than their Caucasian fellowcountrymen. We also know that if Asian men come at a young age to live in the West that their prostate cancer rate becomes more like that of their Western

contemporaries.

We also know that in Asian countries, which have traditionally had negligible prostate cancer rates, deceased elderly men tend to be found to have indolent cancer tumours in their prostate. This would indicate that the formation of cancer tumours in the prostate is a normal occurrence in men. The majority of men are completely unaware of them and untroubled by them.

Changing Diet

When men get a diagnosis of prostate cancer they often change their dietary regime but in truth, all men in their 50s and 60s should be changing their diet. They should be eating less red meat, more fish, more vegetables and more fruit. Weight gain, particularly around the midriff is known as a factor in certain cancers and Type II diabetes.

Lack of exercise is also a negative factor for health generally but for many prostate cancer patients it is particularly high risk. Men who are on long-term androgen blockage (hormone therapy) experience osteoporosis and may be

prescribed bone strengthening medication such as bisphosphonates

like women often take after the menopause.

Moderate exercise such a brisk walking and resistance training with light weights can promote bone growth and reduce the incidence of skeletal-related events (SREs) or bone fractures.

Green Tea, Red Wine, Tumeric, Broccoli, Pomegranate, Dark Chocolate, Blueberries et al.

Many foods are high in anti-oxidants and this food property is thought to protect against cancer development. The problem for prostate cancer survivors is that they have already developed the disease so increasing the intake of these anti-oxidants in the diet might be seen as a case of shutting the door after the horse has well and truly bolted. However, as a significant proportion of prostate cancer patients experience a recurrence of their cancer it is an issue which perhaps should be addressed. Whether the taking any of these foods or products high in anti-oxidants has any affect in preventing recurrence of prostate cancer is an open question.

Few of these foods and products have been subject to scientific testing such as randomised Phase III trials and long term follow-up.

A balanced diet, which is high in vegetables, some fruits and oily fish but low in saturated fats, salt and sugar and a big one for men - meat in moderation – maybe only a 100g (4 oz) per day would be good for us and the planet.

Diet is not enough - you must exercise even half an hour of brisk walking for 3 or 4 days a week is very beneficial. You don't have to beat yourself up with heavy work-outs in the gym.

Drink!

It has to be said that alcohol is an issue for anybody with cancer. Alcohol is converted to sugars and this is easily absorbed by the body leading to weight gain and may be a factor in the onset of Type II diabetes. If you can't give it up entirely try and confine yourself to 2 days of moderate drinking per week.

Rapid Access Prostate Cancer Clinics

* Beaumont Hospital, Beaumont, Dublin 9

* Mater Misericordia University Hospital, Eccles St. Dublin 7

* St James's Hospital, Thomas Street, Dublin 8

* St Vincent's University Hospital, Elm Park, Dublin 4

* Galway University Hospital, Galway

* University Hospital, Cork

* Regional Hospital, Limerick*} *Diagnostic Rapid Access Clinic

* Waterford Regional Hospital*}-not for radical prostate treatments

Prostate Cancer Treatments in Private Hospitals

* Bon Secours Hospital Group - Dublin, Cork

* Galway Clinic

* Hermitage Clinic, Lucan, Dublin

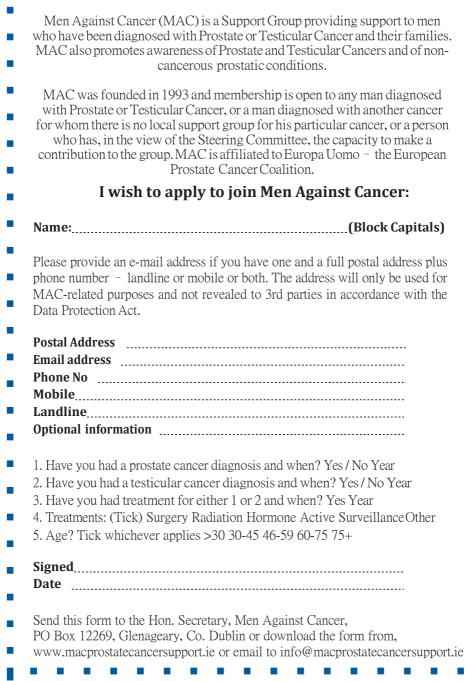
* Mater Private Hospital, Eccles Street Dublin 7.

* St Vincent's Private Hospital, Elm Park, Dublin 4.

* Beacon Hospital, Sandyford, Dublin 24

* Blackrock Clinic, Blackrock, County Dublin

Membership Application Form



NOTICE

This booklet is published by MAC- Men Against Cancer. It does not purport to offer medical advice. For medical advice consult your doctor, or a nurse in an ICS Daffodil Centre, or a nurse in a Rapid Access Prostate Cancer Clinic.

Multi-Disciplinary Team Essential To Optimal Personal Treatment

As every patient is entitled to his personal optimal treatment and holistic care, only a multi-professional medical team (also known as a multi-disciplinary team – MDT)can guide the patient to that goal. Men Against Cancer