

# MAN TO MAN

IRISH STORIES *of* HOPE  
IN PROSTATE CANCER



This book has been produced by Janssen  
in association with the Irish Cancer Society



The views and opinions reflected in this book are those of individual patients and do not represent the views or opinions of Janssen. Please consult your doctor if you wish to discuss any of the issues in this book in more detail.

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# FOREWORD



JOHN McCORMACK

*CEO*

IRISH CANCER SOCIETY

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

is a resource comprised of individual real-life stories of men with prostate cancer, which is designed to offer hope and support to other men living with the disease in Ireland.

Over 3,000 men are newly diagnosed with prostate cancer in Ireland each year and after skin cancer, prostate cancer is the leading cause of cancer in men. In Ireland, approximately 17,000 men are living with the disease and approximately 500 men die from the disease each year.

Developed by Janssen, in association with the Irish Cancer Society, the storybook is the result of research with people who have been affected by prostate cancer to find out what type of information would help them on their journey to recovery. The research found that not only do other patients with prostate cancer find comfort in hearing a real story, doctors and nurses can also draw on those patient experiences in order to further improve the patient journey for others.

Our genuine hope is that men and their families find this storybook a useful support, and seek further information or support from the Irish Cancer Society's network of services, which are detailed at the back of this book, or visit our website [www.cancer.ie/how-we-can-help/support](http://www.cancer.ie/how-we-can-help/support).

We sincerely thank all the men across Ireland who had the courage and generosity of spirit to share their personal experience to support other men living with the illness, and we thank the dedicated doctors who helped to identify these truly inspiring men.

Yours sincerely,  
John McCormack,  
**CEO**,  
Irish Cancer Society

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# INTRODUCTION

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*of* HOPE IN PROSTATE CANCER

•  
LEISHA DALY, PHD  
*Country Director*  
JANSSEN IRELAND



At Janssen, we aim to deliver the best supports, not only to doctors and nurses, but also to the patients and their families who need our treatments.

In order to achieve this, we work with, and listen to, healthcare professionals, academics, patients and their families, representative groups, policy-makers and health services in order to continually innovate and develop first class solutions to medical problems. Regarding prostate cancer, Janssen has been at the forefront of developing breakthrough medicines which have prolonged life and improved quality of life of patients. We also want to aid patients in their recovery and improve their day-to-day lives by offering therapeutic, educational and motivational support.

This collection of real life inspiring stories of hope from men with cancer is designed to offer hope and support to other men with their diagnosis and promote greater psychological supports for those living with the illness. We thank all the contributors for their bravery in sharing their inspiring stories so honestly, and are pleased to be in a position to encourage and facilitate this particular conversation between men and their families.

We at Janssen hope that our commitment to oncology will ensure that we continue to develop solutions and supports for patients across cancer care in Ireland. We thank the oncologists, doctors and nurses who encouraged patients to participate in this book and we thank the Irish Cancer Society for their participation and support. However the most gratitude must go to the men who contributed to this book; their stories of hope will give support to so many more men and their families in the years to come.

Yours sincerely,  
Leisha Daly, PhD  
*Country Director*  
Janssen Ireland

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# THE STORIES

Ciaran Smyth  
Luke White\*  
Jess Clooney\*  
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CIARAN SMYTH

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My name is Ciaran Smyth. I live in Limerick and am 68 years of age. I was diagnosed with prostate cancer on the 16th January 2008. I had been presenting with the symptoms for approximately four months and eventually it took a cystoscopy procedure to affirm my situation.

Prostate cancer is difficult to diagnose at the best of times. It proved classical as far as I was concerned with symptoms present and tests (both digital and analytical) proving negative. The affirmation was made by the cystoscopy. My next worry was if the cancer had travelled to my bones. In medical terms, if it had metastasised.

A bone scan confirmed it had. I will never forget the day I was told. I was stunned. The outlook was bad. My Gleason scale count was 8.9, and the cancer was in my right hip and my spine. I was told chemotherapy or radiation would be of little benefit. I was given the advice to get my affairs in order. That was hard.

The medication that I was given was hormonal and morphine based pain treatment, all in tablet form. After two years of this treatment, I developed hip pains. This was treated locally with radiation. Then, I was sent for 18 sessions of chemotherapy, and I elected to have this administered in The Mater Private in Dublin under the guidance of my consultant. I was also receiving some bone infusion during this time and I still receive this treatment. I have also volunteered for some clinical trials.

Right, this brings my story up to the present. A question I ask myself, with such a bleak diagnosis nearly six years ago, why the hell am I still around? I do not have the magic bullet answer. I do not think it is one thing but a combination of attitude, positive thought, visualisation, good food and a bit of exercise.

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**"I NEED ALL  
MY ATTITUDES  
CORRECT FOR  
MY BODY TO FIGHT  
THIS DISEASE."**

—  
**CIARAN SMYTH**

By attitude I mean have full confidence in your consultant. I do not read or think cancer. I know I will not get any benefit from this. I need all my attitudes correct for my body to fight this disease. Your consultant is the one who has gone through the learning to deal with your situation. Trust him.

Positive thought. It goes along with your attitude. Do not be thinking or reading cancer – it only prolonged my misery about my state. When first diagnosed it is understandable you go into a state of 'Why Me?', 'Poor Me', (Sentimentality), 'Shock'. Word gets out and you have to deal with people, whether it is close friends or the public, it has to be dealt with. I found this difficult, and I would advise other men to come to terms with this through prepared positive thought in answer to people's sympathy for your situation.

Visualisation is probably not for everyone but I found it of great benefit to me. I would not like to define it other than to term it as a loose type of meditation. The slight difference is you visualise yourself ridding your body of the cancer tumours.

Get yourself into a peaceful quiet place, relax, be aware of your surroundings, visualise your body being cleansed of the tumours by maybe sun rays or a waterfall, it could be microbes, whatever comes to your mind. This process can take as long as you like for each element.

I have adapted a diet that suits my blood type. There are many books that will give you recipes for whatever your category. This will take a bit of effort and help from your partner. I have also bought a juicer and make lovely drinks, mostly from vegetables, beetroot, spinach, celery, carrot, ginger and broccoli, adding an apple to give it some sweetness. I steer clear of juicing fruit only because of the sugar.

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I exercise by walking daily. It is good to keep yourself exercised so that your body can gainfully absorb the medication. It doesn't matter what you do, just find your own level and stick with it.

I do not know if any of the above is keeping me alive and I still have not answered why I am still around after six years and feeling good. But then again, I don't need to know the answer. Take every day as it comes.



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**LUKE WHITE\***



**MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER**

I am a priest, from Ennis, County Clare, who was first diagnosed with prostate cancer in December 2003.

To be given the diagnosis that one has tested positive for some form of cancer is a shocking and devastating blow to a person together with a sense of concern and alarm; Is this really true? Can I get through this? What will I do? One is left stunned, angry and asking the question “Why me?” Gradually that question changes to “Why not me?” and an acceptance of the prospects slowly begins to dawn. Doctors, nurses and caring staff, together with family and friends rally around and the treatment is faced – with much questioning – what does the future hold for me? Will I be around for important family events, important parish events. My dreams, my hopes, my expectations seem to fade into a sense of hopelessness. Others seem to take control of my life and of my future. Cancer is a life-changing experience for the person diagnosed, for their family and friends.

But we have come a long way from the days the word cancer could not be mentioned. Instead we heard he has ‘the boy’ or he has ‘the big C’, that day is gone thank God; at least now there is a willingness to talk and accept the fact. It is another form of the many sufferings, problems and inconveniences that all people have to face in life. The pain of unemployment, recession, emigration, bereavement, devastation because of inclement weather, addictions of different kinds – the list is endless. Whatever the person’s problem is, it has to be faced.

Over ten years ago my GP ran a series of blood tests that showed my PSA levels were rising gradually. I was referred to have a biopsy, which came back benign. However, my PSA kept rising and I had another biopsy in December 2004. The bad news came – I had prostate cancer. In one way I knew it was coming, but it left

me stunned and devastated.

I was lost and after much effort told friends and a cousin of mine. They did not know what to say. I had no surviving siblings, so I had no one to talk to outside of friends. I did not know how to feel about it. But it was a relief just to tell somebody. My cousin was a great support to me. He is involved with LARCC (Cancer Support Centre), Multypharnham, Co. Westmeath. He has been through prostate cancer. He visits me every so often and we can talk about worries I may have. I think that it is really important that one does not bottle up something like this; eventually I told colleagues as I did not know at that time what the future had in store for me or what treatment I would be having.

Eventually I began radiotherapy in The Galway Clinic. I began my trek to Galway for 37 sessions of radiotherapy. I regarded this as a fierce inconvenience. I kept working most of the time and travelled between Roscrea and Galway each day. Once I started the treatment I knew I needed to have something to look forward to if I was going to get through it.

I bought a calendar and I ticked off each day after treatment. I promised myself a sun holiday once I successfully finished my treatment. As soon as I finished my treatment I took off with seven of my closest friends from my teaching days to the Costa Del Sol.

When I got back I was appointed to a new parish that had a reduced workload and had to replace the retiring parish priest who was stepping down because of ill health. The people in the new parish were very supportive and encouraging. I built a very close relationship with my predecessor in my parish. He had an advanced cancer. We shared at a very deep level and were a great support to each other. I knew that the hand of God was in

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LUKE WHITE\*

my transfer to this parish. I was meant to meet this courageous man. He died of a brain tumour in January 2007 and I felt a great strength to go through this with him. He was an inspiration and an encouragement to me.

I was back working full time in the parish. My PSA was being monitored monthly, and to my horror it spiked again. I was referred to an oncologist, but unfortunately I found I could not relate to him. I was uptight and wanted reassurance, and he couldn't give me the reassurance I was looking for. I had counselling in Cancer Care West in Galway and decided to switch my oncologist. I was given the name of my present oncologist and I asked my GP to refer me to him. My new consultant gave me time and he patiently answered my questions. The answering of the questions is most important. I was on my own, so I probably asked the same questions a number of times and always got the patient understanding and compassion that left me satisfied. My advice to others is to make sure that you have a consultant to whom you can relate easily - it is most important.

Because of rising PSA, I was put on chemotherapy treatment in 2009.

I had sixteen sessions, one every three weeks. With anti-sickness medication, I did not get sick and thank God was able to continue working. The energy at times was not great, so I took it easy but always kept in touch with work to be done and did it at a slower pace. I found myself needing more rest. I took some exercise and a little golf. But all of this was at a reduced rate.

While my PSA dropped to 0.01 after the chemotherapy, it did not remain there. 2011 saw me back on chemotherapy again - this time I had twelve sessions. Through all of this the two tumours in my back were being contained by monthly infusions to strengthen

my bones. At the moment my PSA is rising again and I feel that I may be back on chemotherapy again in the near future. It is not a pleasant thought; it has given me a very good quality of life and enabled me to continue my priestly work.

Over the last ten years my whole lifestyle has changed. My social life has lessened and I find I do not have the energy to go to many concerts or films or to play golf. I am in bed at 10:30pm most nights. I continue to go to my counsellor in Cancer Care West. She says that I am working too hard and would need to realise that I am dealing with a serious disease, there is nothing in me that would tell me that I am dealing with cancer - I have no pain or ache, thank God. I am a workaholic and I find work a therapy. I have to be doing something. I cannot be stuck inside doing nothing. If I was I would be dead at this stage.

My main worry now is what does the future hold in store for me; when the consultant says, "That is it, I have tried everything and you have responded up to now, but now there is nothing more". There is the question of hospice care and palliative care, the loss of independence and control of my life. My faith has been my main coping mechanism up till now. I have developed a much stronger prayer life since I was diagnosed. I have learned to leave my life in the hands of a loving and caring God.

The God who has seen me through life up to now will see me through the unknowns of tomorrow. Jesus tells us in the Sermon on the Mount - "Do not worry about tomorrow, for tomorrow will worry about itself, each day has enough worry of its own". (Matthew 7:31) Jesus is inviting us to act in the now - to consciously fill our present with faith and trust in God and live every moment to the full.

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**JESS CLOONEY\***



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The year was 2000. The millennium was in and I was in a good place. I had a good job, a great wife and children, and a great family life. Jokingly, I had told my wife that after 24 years of marriage, I was going to have an affair and probably grow a ponytail.

In February of 2000, I attended my local GP for my annual D.O.E. Test. When he was conducting the medical examination, he told me that, for men like me who were approaching 50 years of age, a prostate exam was now the norm.

An examination of the prostate (Walnut Farm) took place. My doctor informed me that he did not like what he felt. He then took a blood test to confirm PSA and referred me to a brilliant urologist for further tests. I attended the urologist and was admitted to hospital within two weeks and had a prostate biopsy carried out under general anaesthetic. It was confirmed within a few days I had the 'dreaded prostate cancer.'

The Black Hole was upon me. When the results came back, the urologist telephoned me and my wife to discuss the results. He recognised the terror.

It was a great relief to both my wife and I to chat to, and gain reassurance from my urologist early on.

Three separate appointments for a CT scan, MRI scan and a visit to an oncologist were made on the day and things were going so fast, I thought I was on skates. From the GP to the urologist, from x-rays to the oncologist, it all took less than six weeks.

My first meeting with the oncologist was on 16th March 2000. All methods of prostate cancer treatment were outlined to my wife and I, and a prostate nurse was also allocated to me, whom I could



call at any time to discuss my diagnosis. Because of the age I was diagnosed with prostate cancer, I was asked if I would be interested in a clinical trial. I consulted with my wife and GP and decided that if it would be of benefit to future patients diagnosed with prostate cancer, I would do it.

The study trial consisted of the use of hormone treatment prior to radiation and then an evaluation to see if hormonal treatment was of benefit. Hormone treatment had some benefits but what they really wanted to find out was the optimal duration before commencing radiotherapy, which was approximately a period of four to eight months.

On 23rd March 2000, I received my prescription for hormonal treatment: eight months of tablets and injections. All the medical staff, from the clinical nurse, to oncologist, to my GP who would administer the injections, were now on board.

I would have to attend St. Luke's on May 18th and be updated on my progress to date. This was done by monthly blood tests, which were submitted to the hospital and, when analysed, I would be told by the prostate nurse how the drugs were performing.

As the months went on, my PSA level dropped – good news, as I was receptive to treatment. However, some side effects presented themselves, mainly: breast swelling; loss of sex drive; mood swings and lethargy. At all stages during treatment, the prostate nurse was a phone call away, and always very competent and reassuring.

At some stage, in July or August, as a result of the blood testing, I was taken off my therapy as it was affecting my liver function and I was getting bouts of nausea. In September 2000, I was told when the process of radiation would begin.

I was sent a detailed letter from my oncologist outlining what I was about to undergo. Namely, another CT scan, to ensure everything was still ok.

I was measured, x-rayed and a series of small pin prick tattoos were applied to the skin to reference treatment positions and also as a permanent record of the part treated. A treatment planning CT scan was also carried out. After this, the design of the radiation therapy was set in motion and would be completed in about one month.

On 10th November 2000, I received a letter from the hospital outlining commencement of the radiation therapy. It was to start on 15th November and consisted of 35 sessions from Monday to Friday.

I was delighted, and felt relieved that I had got this far. The 35 daily sessions flew and on 2nd February 2001, I was discharged from the radiation unit. I was then prescribed my life-long hormonal therapy treatment, which had to be administered by my GP. The treatment effectively switches off testosterone being made.

Whether I am lucky or unfortunate, it is now 13 years since I was diagnosed with prostate cancer. For the first five years, I had blood tests and oncology appointments on a three monthly basis. I did not have any major reactions to the hormonal treatment. I had occasional 'hot flushes', but they eventually ceased at the end of radiation. I did suffer from extreme tiredness and fatigue, but after a lot of bed rest and re-evaluation of lifestyle, this soon passed.

I have now been on the hormone treatment for the last 13 years. Have I suffered or had any side effects? Yes. Hormone treatment has had a very big say in the last 13 years of my life. I have gained a lot of weight, but due to tiredness, I have not got the energy to shift it. I eat a healthy diet but another side effect is muscle

**"LIFE IS FOR LIVING,  
HELPING OTHERS AND  
MAKING FRIENDS."**

|  
**JESS CLOONEY\***

weakness due to loss of muscle mass. Hormone therapy can also increase the risk of diabetes and this is another area I worry about. Also, memory problems can occur. Some men feel that they are not as sharp and that they're suffering from some memory loss. I, thankfully, do not have those problems and I put this down to being up-to-date with current affairs, having a fishing and gardening hobby and an interest in life in general.

Testosterone controls the production of hair. I have lost chest, pubic and body hair. However, I am not bald and I have a healthy beard. Nevertheless, 'hot wax' and 'Brazilians' mean melting candles and good soccer players to me now!

Osteoporosis is another common side effect of hormone therapy. In September 2005, my oncologist raised the issue with me and had a DEXA scan carried out to ascertain bone density. I showed mild weakness or bone thinning and he recommended three monthly sessions of injections in St. Luke's for treatment of this. However, he subsequently changed his mind, and in 2006 it was decided I should get this treatment once every year. Side effects are flu-like symptoms and aches or pains in the body joints.

As of yet, I have had no side effects. Maybe it is because I always had a very big calcium intake, milk, cheese and 'Black Porters'! Sexual function and hormone therapy are completely linked. Hormone therapy 'kills' sexual function, sexual desire and generally affects your desire or interest in sex altogether. A lot of books and studies put it quite bluntly as chemical castration or chemical neutering. It is very hard to accept. It plays hell with your emotions, causes mood swings and irritability.

You will have feelings of sadness, depression and of being inadequate or a waste of space. Believe me, I have been there and

still go there but thank God not as often. When you are in a very long relationship, the loss of sex is devastating and mind-numbing. I know for a fact that I will never enjoy the pleasure and sheer joy of sex again. I reason with myself, I miss it and I get upset. I do kiss, hug and cuddle my wife but I feel I am only doing it out of duty and I also feel that I do not put the same effort into it as when I was sexually active. I love and respect my wife for her loyalty and honesty and the loss and memories I have deprived her of. We had many conversations about sex and intimacy. Her explanation of how glad she is that I am alive and still here is some comfort but I still cannot get my head around it. My wife is my best friend and will always be. I have no desire for sexual contact of any kind. We have never discussed it with any GP or therapist or anyone.

At the end of the day, no-one will restore 'the spark' seeing as I am confined to hormone replacement therapy for the rest of my living days. I often wonder if the situation is as stressful for my wife as it is for me. I do not ask her as I feel she may have come to accept it and there is nothing to be gained. The uses of treatments for the loss of function were discussed by my wife and I with the oncologist at the commencement of treatment, and he was quite forthright in informing us that all methods were at least more frustrating than successful.

About 3,000 cases of prostate cancer are detected every year. However, men are not known for talking about their health and going to doctors. Information about prostate cancer is now readily available, and support channels are improving all the time. The crucial factor is that, like a car, men should have an annual MOT and have a PSA examination.

I have had a life threatening disease for 14 years. It is important for men to understand that early detection is the key. In the long term,

the statistics show that three out of four men with prostate cancer won't die as a result of their cancer. Prostate cancer is common, and the risk increases with age. It appears to be on the increase. But, is that due to doctors getting better at detecting it and insisting on prostate examinations?

When you are diagnosed with prostate cancer, it is as important to understand the disease as it is the treatment. With regard to hormone therapy, there is some evidence that it can increase the risk of other conditions such as cardiovascular disease and diabetes, if it is being taken long-term.

In 14 years I have seen a lot of sudden deaths or tragedies and upheaval, something I would never see when first diagnosed. I have the love and devotion of my wife, family and friends, and I value that very much. I live for the moment. I do not entertain whingers or moaners. Life is for living, helping others and making friends. Laugh, enjoy your hobbies, play music, talk to your God, be happy.

There is nothing I could do to prevent getting prostate cancer. I cannot change the fact that I have it. The real cause of what triggers prostate cancer is currently unknown. If I had to deal again with a treatment option would I go a different route? I would go the very same route. Hormone therapy.

I am very lucky. I have had 14 great years without any major side effects. Sure, there were problems and issues along the way. But, with the help of my family, friends and all the medical personnel and latterly, the Prostate Cancer Support Group at East Galway Cancer Support Centre in Brackernagh, Ballinasloe, hopefully I will be around for another 14 years and be able to give back, in some way, the encouragement and help that was given to me, and help others along on their cancer journey.

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**MARK OWENS\***



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For me, it all started in November 2003 or nearly ten years ago. I had just retired from nearly 40 years working with the ESB, and I was looking forward to enjoying my retirement.

I went to my GP for a pain in my shoulder that just wouldn't subside. As I hadn't been to my GP in a long time, he decided to perform a few routine checks, which included blood pressure, urine samples, a blood PSA reading etc. In addition to this he asked me questions about my general lifestyle and wellbeing. He noted that frequent nightly visits to the toilet (three to four times per night) were becoming a regular occurrence for me.

The pain in my shoulder ended up being muscular and went away after a few deep tissue massages. But, I was called back to my GP a few days later to discuss some of the other results he got back. He was concerned at my PSA reading as it was high. This, coupled with frequent visits to the toilet at night, led to me having more investigations carried out on my prostate. He referred me to a prostate specialist in Portlaoise General Hospital.

At my first consultation the doctor explained that I had prostate cancer but that it wasn't unusual for someone of my age. It was very slow moving and that it was treatable.

From day one I always believed there was a tomorrow. I wasn't shocked. I took it on the chin. I firmly believed there were ways to treat it. I immediately told my family, and I did absolutely everything the doctors asked of me.

The plan of action was to initially use hormonal therapy to slow the disease down and eventually look to have some radiation therapy in St Luke's to wipe it out completely. Removal of the prostate at my age (70 at the time) was not an option.



At a follow-up appointment in August 2004, my doctor referred me to another doctor, an oncologist at St Luke's in preparation for radiotherapy. I completed a series of scans and tests. During one of my follow up appointments, I was far from prepared for what he was about to tell me. The scan had shown a tumour in my right kidney. The tumour was to be further investigated with a biopsy, and if I agreed to it, an ultrasound.

As it turned out, my right kidney was completely infected with cancer. He closed my file in front of me and said that he could do no more, it was too far gone. I asked how much time I had but he said he couldn't tell me. I was devastated.

I was referred to a consultant in Tullamore Hospital to discuss treatment of the prostate and any options that I might have with regard to the kidney cancer. Upon further investigation, my CT scan showed the cancer was only in the kidney, it hadn't gone outside it.

My doctor explained that at the Tumour Board (where consultants discussed patients' problems and sought any possible solution available for the patient), another consultant had agreed to review my case with a view to surgically removing my right kidney completely. He explained that the operation had risks, but if successful, and he was confident that it would be, it would be well worth it. I was very willing to take the risk because without it, I was fighting two battles - one for the kidney and the other for the prostate. A waiting game ensued. I had to wait a while to get an appointment for the operation. But finally, on Good Friday, I was offered a cancellation slot and I jumped at the chance.

My kidney was removed, and, as far as the doctor could see, all the disease tissue, but obviously tests would be done further down the line to confirm this. I spent about a week in St James's Hospital recovering from the operation. I was very sore and extremely weak.

**"I CARRIED ON  
LIVING EVERY DAY.  
I FOUND SOMETHING  
TO DO. I DIDN'T LOOK  
DOWN. I GOT UP.  
I KEPT GOING"**

MARK OWENS\*

After the week, I was sent home to rest and recuperate. I had never been as weak or sore in all my life, but day by day, I improved and got a little stronger. I started by walking up and down the hallway of my house and gradually, I lengthened the walks to the garden and eventually to numerous times around the house.

The rest of 2005 was CT scans, MRIs and PSA readings to see what was going on with the prostate cancer. All this time, I was still getting medication to keep the prostate under control. Towards the end of 2005, it was agreed that I should go for radiotherapy at St Luke's Hospital in the New Year to radiate the bed of the kidney to ensure that the cancer was completely wiped out. I had a total of 37 sessions of radiotherapy. I did manage to hold onto my hair, but I lost my sense of smell completely and it has never returned.

In May 2006, I had an appointment with my doctor to see how the radiotherapy had worked and (to my delight) he informed me that I was in complete remission from the kidney cancer but that it would be monitored by regular scans and MRIs. This was a huge relief for me and my family. The risk had paid off.

My family was a major support to me throughout this entire time, helping me before, during and after surgery to get back on my feet and feel well again.

For the next few years I had a series of blood tests, and was put on a series of medications (one to replace the other when I had reactions) until May 2010 when I was brought to casualty in Tullamore Hospital with chest pain. We were afraid that it may be something to do with the heart, but thankfully we were wrong. It turned out to be muscular pain from overdoing work on the bog. I was warned off the bog - no more turf work for me! I was grateful that this episode had nothing to

do with the cancer or treatment.

In October 2010, I started to get very sick and weak. My tolerance to the new medication was gone. I couldn't eat and I felt extremely sick all the time. My PSA reading started to rise again. I was put on new treatment and had no side effects. This success continued well into 2012, but I started to feel sick again. I ended up back with my GP in July 2013 because I was so sick. I went into hospital for a period of time, and after some treatment I was allowed home.

I was glad to be home again, and I was hoping all would get back to normal. My family decided to take turns staying over so that they could help me during the night to and from the bathroom just until I got comfortable and we had chairs around the house so if I felt weak, I could just sit down.

I am back eating well, feeling good and active on a daily basis. My recent PSA levels have started to rise again, and so I'm about to be put on another drug therapy. I am able to sleep with no difficulty, but I won't be running after any sixteen year olds!

I think it's terrific that I have been with my doctor for ten years and I am able to keep going without difficulty. I can walk and do anything I want to do. I don't really feel tired or anything. Men need to know there is a tomorrow. Go forward. Keep moving.

I carried on living every day. I found something to do. I didn't look down. I got up. I kept going. This has always been my attitude. I have a brilliant doctor who has always been able to come up with a solution and change course if needed, and I have a great family who has given me so much love and support.

I always thought there was hope. And, tomorrow always comes.

MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

**MICHAEL DALY**



**MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER**

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

I was diagnosed with prostate cancer in March 2009. I was 52 years of age. I thought I had no symptoms, but in fact I did. I was suffering from erectile dysfunction, but because of maybe embarrassment and a bit of ignorance, I did nothing about it. I didn't feel sick or ill at all. After my wife's brother passed away from bowel cancer, I decided to go for an annual health check-up. This particular year, I went for my check-up and my blood test showed my PSA was rising, and I was recommended to go see an urologist in March 2009. Soon after, I had a biopsy.

You're on tender hooks when you have a biopsy. You have to wait anywhere up to six weeks after the biopsy before you receive any treatment. But, the body is a wonderful thing.

When you have the biopsy the prostate is damaged or irritated and actually attaches itself to the bowel to recover, it's like how Big Brother looks after Little Brother, and the doctors have to wait for it to detach before they can do any treatment or surgery. Some people think the biopsy is uncomfortable, but this was by no means painful. Two weeks came and went and I heard nothing, so I thought I must be fine!

Three weeks later, I was playing golf one Sunday morning, and I felt ill. When I came home, I passed a lot of blood. I went straight to the hospital. It turned out I got septicemia (blood poisoning) from the biopsy. I never realised how sick I really was. I was prescribed antibiotics to treat the septicemia, and I felt much better after treatment.

I was then called in to meet the urologist and I was told that I had a tumour on my prostate. My wife was with me at the time. It was a huge shock for us both. You need someone with you when something like that happens. I only heard about an eighth of what

was said that day. I heard words like ‘curable’ and ‘treatable’ and I hung on to those words – tight!

All the options were explained to me, and I decided to opt for surgery in September. I wanted it out and gone. I had to wait a while for a bed in Galway University Hospital, but I had great faith in my doctor, and that he would get it all, and he did. My hospital experience was very good. I received outstanding care and treatment.

After surgery getting your life back on track is difficult. I was in a high dependency ward overnight, and I started to feel the pain once the epidural wore off. I was on pain medication to help it, and I had a catheter. The catheter takes a lot of getting used to. You can get reactions to the catheter, spasms and the top of your penis can get quite sore. After surgery you need help because you have limited mobility. You need a support network around you. I was so lucky.

My family, while shocked initially, were wonderfully supportive. They made it easy for me. The Ballinasloe district nurses were incredibly supportive; one nurse was waiting for me outside my house the night I returned home from hospital. Whatever money they’re paid, it’s not half enough. They are worth their weight in gold, and I can’t thank them enough for their ongoing support.

When you are diagnosed with prostate cancer, you realise quickly who your friends are. There can be a change in people. Your real friends will support you and may call you once a week, and this type of support is great and I was fortunate to have these types of people around me to keep me going.

My dad used to bring me to hurling or football matches growing up, and he used to always say the only way to win is to not give the

ball away, and this is how I looked at cancer. I couldn't 'give the ball away.'

We now know that before you have surgery, you need physiotherapy. Anyone who has gone through this radical surgery will know that you have to build up your pelvic floor muscles to help you with incontinence and erectile dysfunction. Your muscle has a memory. So, train first! Your muscles will remember, and they will help with recovery from surgery or treatment. I think this advice would have really helped me, and I'm happy to share it with other men who find themselves in a similar situation. You wouldn't run out on the pitch on the day of an All-Ireland to play a match without training, would you?

I consider myself the lucky one. I wake up every day thanking God that I'm over the ground. When I went through this, there was no support really for men. We didn't know you could get support, and there was little or no information available to us. There is a lot more openness now. Media and sports personalities are talking about it, and it makes it more acceptable. We now have a prostate support group called PSA Ireland.

Cancer affects people in different ways. Recovery varies among people. I would say that each man's cancer is his own. You will never have two men with the same diagnosis who were affected in the same way. However, men need to listen to and hear others' stories. Read this book, or find out from your surgeon what other people in your area have been through and talk to them about it. They will tell you their story and help you through it. They will tell you what it feels like, and how to cope.

I would advise men to watch the East Galway Cancer Support Centre DVD entitled *PSA Ireland: Aftercare for Prostate Surgery*.



**"MY DOCTORS ALWAYS  
SAID 'GO AND CHECK  
YOU HAVEN'T GOT  
PROSTATE CANCER,  
NOT THAT YOU  
HAVE IT?'"**

—  
**MICHAEL DALY**

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

Contact the centre for a copy on (090) 964 2088, or visit the website [www.psaireland.com](http://www.psaireland.com).

I don't think anyone goes through cancer treatment without suffering from depression. If I was advising other men, I would say know that it's coming and be prepared for it.

My blackest day was the day the catheter came out. It was one of the worst days of my life, which I got through with great difficulty, when I discovered I was incontinent, reality hit. I started to go downhill. After a few days, I went to the supermarket and I needed to go to the bathroom, but there was only urinals. I was in floods of tears and had to go home.

When you are first told you have cancer you are shocked. But the incontinence is – in my opinion – ten times as bad as the surgery itself. You learn to cope. I only go to the pub now if I know there is a clean toilet that is easily accessible to me, and my friends understand.

I'm great now. I was off work for a year, but I'm back working again. I play golf and music. I'm learning how to play the concertina. I did this because it was something I always wanted to do, and I got a second chance in life – so why not?

I think distractions are a great thing. Music and crossword books were a saving grace to me. I would go through a couple of them in a week to keep the mind active. My wife was also great at thinking of things. If I was having a bad day, people who lived miles away would just magically appear in the house to call in, and it was only afterwards I would realise what she was up to!

My family has been a huge support to me. My wife helped me

through it all. When we decided to tell our son, he coped by fundraising and raising awareness in men about prostate cancer, this is where the DVD came from. I think it's helpful to have told your children. I don't think my son would have forgiven me had I not told him. My son is more aware now and knows to test himself when he gets older, and to be more aware of his health.

One thing often left unsaid is the financial side of a cancer diagnosis. If you are well established then you are OK. But, many of us on a normal wage don't have a huge amount of savings. When you get sick, it creates a huge strain on the family finances, and the psychological effects of everything kick in. You are the main bread winner and you want to provide, but you no longer can. It has a bearing on you. A lot of unexpected costs can cause financial headaches. I was very lucky and got a medical card, but most are not so lucky and there should be more support available to those men and their families.

Prostate cancer is a silent killer. My doctor told me years later that I was lucky to have been diagnosed early.

A lot of people let it go, and don't get annual check-ups and by the time they discover it - it may be too late. There are different schools of thought on PSAs, but I'm sorry, I am Exhibit A. I wouldn't be here today if I didn't get the test and I'm totally for it.

My doctors always said "Go and check you haven't got prostate cancer, not that you have it!"

MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

**DESMOND CODY**



**MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER**

My name is Desmond Cody. I live in Kilkenny and I am 78 years of age. I was going to the bathroom very frequently in 2005, and I thought maybe something was wrong. I went to the GP, and I had a high PSA level. When they told me I had prostate cancer, I didn't think too much about it. I felt like I was fine, and I was working as an electrician at the time. After a few more tests, I was referred to get radiotherapy treatment at St Luke's in Dublin.

Luckily, I had no side effects caused by the radiotherapy treatment at all. I was self-employed, and lucky enough to be able to work throughout. Soon after the treatment ended, I got a scan and they discovered the cancer was in my bones. I was put on about 20 sessions of chemotherapy, but it had little or no effect. I wasn't fatigued or nauseous, so I continued to work.

Then, when my body didn't respond to the chemotherapy very well, they put me on a new drug. I have been on this treatment for about 12 months. I feel a bit groggy, but I don't know if it's the treatment or the cancer causing it. The last time I was with my doctor, she said the prostate cancer was shrinking a bit.

I go to the bathroom quite a lot at night time, but not so much during the day. The consultant says that's because I'm lying down and it's affecting the prostate, but other than that I feel normal.

I was always accepting and okay with my prostate cancer. I felt well, so I thought I had a good chance of pulling through. I was a little bit shaky when I swapped onto the new drug. For a moment, I thought this is serious, like there was no hope at all. But my prognosis is pretty good. I feel good. I don't feel like someone who is living with cancer. I feel old, but not sick with cancer.

My greatest support has been my wife. We have been married for

**"FOLLOW UP ON  
YOUR TREATMENT  
AND DON'T LET  
THINGS LINGER."**



**DESMOND CODY**

over 50 years. She is a great help. She ensures I take my tablets, and listens to me – sometimes! I have four children, two girls and two boys. I told them when I was initially diagnosed with prostate cancer. They took it bad. Worse than I did! I had to convince them I was okay. I was able to continue to go to work and go for a few pints with the kids, so that helped. I also have four grandchildren and they visit me often.

Now, I go to the clinic every six weeks for my treatment and then every six months I see the doctor. I usually have a CT scan before I see the doctor now.

I didn't know anything about prostate cancer before I was diagnosed. It was a friend who told me to get my prostate checked out when I was going to the bathroom a lot. I never went for an annual health check. A brother of mine had prostate cancer. He went in for an operation, and died of a sudden heart attack, which was a shock to all of us. So you just never know.

Now, I have been taking things easier. I slowed down about three years ago and left work. I miss work. If I had my health, I would be back to work in the morning. My son runs the family business now.

I tell my two boys to get annual health checks given my experience. But they won't listen to me. And they should.

Every man over the age of 40 years should get their prostate checked every year, and for any man who is diagnosed with the disease, follow up on your treatment and don't let things linger.

MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

**GERRY SCOULER**



**MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER**



Men generally ignore their symptoms, and I was no exception. I waited a long time before doing anything about my symptoms, and it was my partner, who is a carer by profession, who suggested I had prostate cancer.

I went to my GP and my PSA levels were checked. They were high. He referred me directly to a urologist in Galway. He ran a few tests, including a biopsy, and eventually told me in December 2013 I had prostate cancer.

When the urologist advised my partner to come with me for the appointment, I knew something was wrong. I asked him directly to tell me what the problem was. I had prostate cancer! My first question was “What? Do I have to give up my job?” He said, “No, not for the moment.” I wasn’t upset or bothered. I was more worried about giving up my work. I ran a Job Club for a community based group in Ballinasloe and I had been there for 15 years, and I liked it very much. I didn’t want to have to give up my job. The urologist referred me to an oncology consultant based in St Luke’s Rathgar. She recommended that I go to St Luke’s to undergo intensive radiotherapy.

In May 2004, I was getting ready for work and I had a call from the hospital to tell me they had a bed available for me straight away. I took it! I was there for eight to ten weeks receiving treatment.

I admit I was depressed during this therapy. I didn’t feel quite right. Before I went to Luke’s I had cancer, but I didn’t fully understand the implications of prostate cancer. The perception of Luke’s is that you walk in and leave in a box. I decided I would have to do something for my own psychological benefit, and I did.

I would get up every day at 8am, shave and shower, put on clean

clothes, go for a walk, get the papers and setup a routine for myself. I brought my laptop into the hospital and did work for the Centre. People would come to visit me, and speak in whispers asking, “Do you have the Big C?” That really disturbed me. I promised myself that if I got through treatment, I would openly talk about prostate cancer and the effects it can have on you. Men hide behind the disease, women are not afraid to talk about it.

I found people looked at me funny when they realised I had cancer. I felt they were always measuring me up for a coffin and this made me more determined than ever to get well, and back to work.

During the second phase of treatment, I got very weak and couldn't walk too much anymore. One day, after treatment, I remember going to see my boss. I told him I was sick, and he would need to find somebody else. He was very understanding and said, “Come in when you can, and when you feel like it.” Within two weeks, I was back to full health and back working full time. Support is hugely important, especially in the workplace. You just want to know in the back of your mind that it's there, and you're not worried about it.

Once you are in the health system in Ireland, they do follow up with you and take great care of you. But you really need to keep your appointments. Initially my appointments were every three months, and then they were pushed out to every six months. My PSA was down to zero at one stage, but not for long.

Last year, May 2013 my PSA began to rise again - jumping

in stages. I was introduced to another consultant who put me on chemotherapy because the prostate cancer had 'hopped onto my bones'; "hot spots" as they call it. Before I started on chemotherapy, I went into the local barber and shaved off all of my hair. I refused to watch my hair fall out slowly. It gave me a confidence boost, and allowed me to gain some level of control over what was about to happen to my body.

Chemotherapy floored me. I was on a zimmer frame. The worst part of it was that I couldn't taste my food. I was only eating to fill a void, but not enjoying it. Over a period of about four to five weeks, I lost about three stone. It fell off me. All my hair went, naturally.

I had not sooner recovered from the chemotherapy when I was back on it again. Each time I went back on the chemotherapy, it took its toll. I had it four times and then it ceased. I had a scan, and the prostate cancer hadn't really spread, which was great news.

I'm still feeling the effects of chemotherapy today. I lost my nails on my hands and my feet. I'm hoping they will grow back. I'm also terribly cold a lot of the time, and I have numbness in my feet. I have also had two hip replacements in the space of 18 months since I've gotten the cancer.

In October 2013, I was put on a new drug on a trial basis. This was by injection every four weeks and given by a specialist in UCG.

I completed this programme in March 2014 with a review in April 2014. With this new drug there have been very limited side effects – mainly tiredness.

I find having a plan in place is very helpful. This may not be for everyone, but it really helped me. When I get up now, I put on my

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|  
GERRY SCOULER

work clothes. For me, it's terribly important not to lie in bed and do nothing. I always try to have a plan in my mind to do something. I will go outside and spend a few hours in the garden, take a break in between and make a cup of cocoa. I will take exercise in short spurts, and sometimes I can get very frustrated or upset if I cannot do some of these things. However, it continues to be psychologically very important to me.

Again with men, I feel sorry for those living on their own and having no support at all. It's so easy to get depressed. I was depressed, and I kept a detailed diary during my chemotherapy treatment. I felt like I needed to document daily the detail of how I was feeling and my state of mind. It was like therapy.

I even did a flow chart. I still do this today. If I am on the mean line, it's a 'good day.' If I am below this line, I am having a bad day, and this helps me to acknowledge and accept it. It keeps the mind occupied and away from negative thoughts.

I have cancer. My philosophy about cancer is - a) there is no cure yet, b) you cannot contain it, and c) the treatment for cancer has improved dramatically - systems, drugs, care - it's all better. There are so many more options for people today.

I accept that if I die this afternoon from cancer, I will have no regrets. I certainly will not be complaining about the lack of treatment. It's a fact of life. You can have cancer. It can disappear. It can creep back up again. It will hide somewhere for a time, and it will re-appear again. I'm not losing a night's sleep about the whole thing.

Recently my friend died of cancer at the age of 57. That's life!!

MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

**WILLIE PENROSE TD**

MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER

My name is Willie Penrose. I am a TD with the Labour Party, and live in County Westmeath. I am 57 years of age. When I was first diagnosed with prostate cancer, I didn't have any major symptoms.

In 2010, my GP, who was very assiduous and had a holistic view of health, did a blood test and my PSA levels were high. I went for a biopsy at St James's Hospital, and afterwards the hospital called me, around the time of Cheltenham in March, to tell me that I was okay - it was clear. I was in great form.

A year later, I took another blood test, and my PSA levels looked a bit raised. My GP sent me for a second biopsy in May 2011. I remember it well. The secretary rang me. I was Minister for State at the time, and I just knew!

I knew my doctor would ring me himself if the news was good, and instead he asked to see me. I met him that evening at St James's Hospital and I said, "How severe is the cancer?" He sat me down, and we discussed all the various treatment options available. It had to be tackled.

He was a surgeon, and surgery was one way to deal with it, or radiation. That involved 37 sessions with concentrated radiotherapy and hormone treatment as well. They also discussed brachytherapy. The medical personnel gave me great advice, and didn't necessarily advocate for their own specialty. Then, I went home and discussed all the options with my wife.

One of the issues I had was that I was overweight, and it could cause a lot of issues. I was over 24 stone, and with the weight and notwithstanding the robotic surgery that can be used, it meant I might not heal as well and incontinence would be an issue - a lifelong issue. I decided to explore all avenues. I met with a number of people who had prostate cancer who discussed the

**"A PROBLEM SHARED,  
REALLY IS A  
PROBLEM HALVED."**

—  
**WILLIE PENROSE TD**



various pros and cons of their treatment with me. My friend who has prostate cancer said brachytherapy was a new and good method of treatment. So, I agreed to an assessment to see if I was a suitable candidate. The tests came back to say I was suitable, and on 6th September 2011, I got it done.

The brachytherapy, also known as internal radiotherapy, is suitable for localised prostate cancers and injects pellets directly into the affected area. I went into The Mater Hospital and within 24 hours, I was able for release. It was quick and targeted, and incontinence was less of an issue for me.

I didn't have any issues post treatment, and I started on the road to recovery. You are subject to a scan, reviews every six months and then again every year. I'm going for my review today. I have had a great recovery, and my PSA levels are down to 0.3, which is great.

Luckily, I had minimum disruption and inconvenience during my prostate cancer treatment. After treatment, I decided it was time to lose weight with diabetes as a threat. I set about losing the weight and I lost nine stone. I knew I would have been healthier if I was mobile, and able to move around easily. Once I spoke publicly about my prostate cancer, people from all over the country rang me up asking for advice. A lot of men called me, men who were reluctant to engage about their health. I told them about the simple blood test 'worth its weight in gold' and that early diagnosis is key.

Know that prostate cancer is highly curable once it's tackled in time. If you are diagnosed with prostate cancer, speak to other people who have been through the same experience. Rather than be dismissive, which, very often I was, listen to their advice. It is so important, and it's given for a reason. They will help you cope with the diagnosis and assist in terms of deciding on treatment.

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

There are so many success stories, and technology is improving all the time. I hear about new therapies for prostate cancer every week. Be sure to examine and explore all the various options with your own medical advisor. Family has been my greatest support, and everyone who has contributed to my story. A problem shared, really is a problem halved. My doctors have been fantastic, they are great people and very ordinary and able to explain things in lay man terms.

I was prepared for a positive diagnosis. It's not the end of the world. I remember thinking if I was to get cancer, this was the one to get! It was a bit of a consolation at the time. Other people are fighting other more aggressive forms of cancer every day, and they need to be tackled, and they are also winning.

Today I am in great health and form. I am looking forward to the future. I have an annual review, and I make sure to do what I'm told and stick to it. I count myself very lucky, and I appreciate everything.

I will continue to support other men living with this disease in any way that I can.

MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

**JOHN DOWLING**



MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

As I sat down to write this piece I could hardly believe that it was almost 12 years to the day that I heard my GP say, “Your blood tests were okay except for one which looks a little high and I think we should have a specialist look at it”. The consultant urologist later confirmed the prostate cancer after he did a biopsy; I had a PSA of 23 ng/ml and a Gleason Score of 6 and my PSA was too high for him to consider me a suitable case for surgery. I thought to myself that was just as well, because I had already eliminated surgery as an option and now I was saved the embarrassment of telling him. So I was handed over to a radiation oncologist which opened up another bewildering world of conformal external beams, brachytherapy, combinations of both, and even the option of doing nothing. I was told of the pitfalls or side effects of the proposed treatment and that I was at intermediate risk. I learned later that this meant I might develop a more advanced form of the disease.

There was a gradual dawning that my particular cancer had not been caught early, that the mainline treatments offered here or abroad had less than a 50:50 chance of being curative and that mine was not a case where I could wait and see how things progressed or indulge in unconventional treatments. The cancer cells had already progressed far enough thank you!

While I was notionally self-employed, for three months I suspended most of my work and became a full-time student of prostate cancer. The internet and the libraries were mined to feed this new studious hunger.

Meanwhile, I had to reassure my wife and daughters and my mother that I was not about to depart this mortal coil anytime soon (I hoped). They were not easy to reassure and in truth I wasn't too sure myself. My wife accompanied me to the meetings with the various consultants but, understandably, her anxiety was more

about me the husband rather than understanding the nature of my cancer and that was understandable if also a bit irksome. I had a couple of men friends of thirty years standing and they provided me with not only sounding boards, but in one case very practical assistance in the form of an introduction to my fourth consultant opinion. My second opinion was very unorthodox in that it was elicited from the US entirely by email following a very tangential introduction. This particular professor of urology said he would have no problem doing a prostatectomy on me even with a high PSA. He also gave me a lengthy exposition on the science behind the treatment proposed for me here in Dublin.

The third opinion was to a semi-retired urologist in New York who had Irish roots and he was very reassuring. As he described it, the aim of urologists is to ensure that their patients die of something else other than from prostate cancer. In the end, a distillation of the peer-reviewed scientific evidence and a careful consideration of the apparently conflicting advices gradually led me back to the original radiation oncologist so I cancelled my plans for treatment in the US and managed to get a significant refund on my ticket and I embarked on the long preparation for seven weeks of radiotherapy. I was scanned, measured, marked and medicated – having eight months of hormone treatment before and during the radiotherapy.

I managed to work while having treatment, but the thing I remember best about the treatment, apart from the imbibing of copious amounts of water, was the irregular meetings with same fellow-patients and our discussions, interrupted peremptorily by calls on one or other of us to go to ‘The Room’ to be zapped but resumed the following day as if there was no interruption. During the treatment period I cannot remember seeing my oncologist. It was only after treatment was over that we met up and reviewed what might lie ahead.

**"THERE HAVE  
BEEN ENORMOUS  
ADVANCES IN  
SURGICAL AND  
RADIATION  
TREATMENT."**



**JOHN DOWLING**

For nearly five years after treatment, everything appeared hunky dory and my PSA readings were as near zero as they could measure. During that time I had seen a Cancer Society leaflet looking for volunteers to do peer-to-peer support and I undertook the training course. It was only after that, that I joined Men Against Cancer (MAC) and have been involved on an active basis for some seven years. MAC has been on the go since 1993 and provides men with support after their diagnosis and tries to raise the level of awareness of this cancer among men in general. It was and is a small organisation. Until recently it was almost exclusively Dublin-based and I never heard of it until several years after my treatment.

No sooner had I got involved with MAC but my PSA started to rise slowly but surely so that by late 2008 I had discussed the matter with my oncologist and went onto hormone treatment again - but this time it was for life! In the meantime my wife was diagnosed with a long term illness and my daughters had well and truly flown the coop to Vancouver and Berlin so I had my hands full.

The next phase in my prostate cancer journey happened after I attended a conference in Stockholm in 2010, as part of a group of the European Prostate Cancer Coalition (Europa Uomo) of which MAC is a member, a number of papers were about a variant of my hormone treatment. I spoke to several consultants, including one who was himself a prostate cancer survivor and who sent me several papers on Intermittent Hormone Therapy (IHT) also known as Intermittent Androgen Treatment.

My treating consultant here in Ireland was not best pleased at my deciding to follow this treatment but he was accommodating to his

troublesome patient and I have been on and off hormone treatment now for the past four years. In the meantime I continue to work with MAC and talk to men who have been diagnosed with this cancer and give talks to community cancer groups.

Looking back over the years since I was first diagnosed I am struck by the extent to which the landscape has changed with regard to prostate cancer.

There have been enormous advances in surgical and radiation treatment. There is now a greater understanding that men with low-risk prostate cancer have a real option to postpone or avoid radical treatment by means of active surveillance and in Ireland we have seen the consolidation of treatment into a number of Rapid Access Prostate Cancer Clinics which provide high quality multi-disciplinary diagnosis and treatment within the public health system. Technically, the da Vinci machines, the image guided external beam radiation and the brachytherapy treatments have allowed for high quality treatment with hopefully fewer side effects. For the minority of prostate patients who are experiencing advanced metastatic cancer there are now effective treatments that were unknown only a few years ago.

Notwithstanding all these advances there is still a problem with many men not coming forward in time. Our gender is a couple of decades behind our womenfolk in the way they have raised awareness and campaigned for services for breast and cervical cancers. Hopefully, I will still be kicking and around for another few years to see men catch up in the years ahead.



MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

**BARRY MURPHY**

MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER

It all started in the year 2000. I was intending to go to the States on holidays with Maura, my wife. She wanted me to go to our GP before the trip to check up on blood pressure and the like. I went and had blood tests. The GP said, "You're as healthy as a hare but your PSA is high." He said to go on holidays and attend the consultant on my return, which I did. My PSA was reading 9. I didn't feel sick but I knew it was high and I had to accept that I had to do something about it.

I went to the urologist I was referred to and he recommended radium treatment. A few months later I was doing the radium treatment at 8.30am each day for 30 days in Cork. I'd drive to Cork, have the treatment, come back and go to work as usual; no complaints. I don't drink or smoke, I had a good appetite and I was working away and busy in the supermarket I owned. Some days I would go to Cork and it would not take long and other days you'd have to go back another day.

After this treatment my PSA was low and my oncologist was seeing me every three months but he always said, "That's not the end of this, always be prepared for your PSA level to go back up in time." He said that it would creep up on me. And boy, it did.

I got my bloods checked regularly and in 2013 it was up to 40.9, which was staggering. I had to be optimistic, there was no point in being a pessimist. The oncologist decided that I should have chemotherapy every three weeks and have treatment for strengthening of the bones. The chemotherapy was fine for the first three months, but it got tough. I was weak, I had no appetite, but I ensured I played golf once a week. I'd have my treatment on a Tuesday and play golf on a Wednesday. Sometimes, I would barely see the ball as I'd be so exhausted after the treatment, however, it was a great asset to me during my treatment. Getting time out to

**"I'D HAVE MY  
TREATMENT ON  
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A WEDNESDAY."**

|  
**BARRY MURPHY**

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

carry on with some level of normal activity meant that I still met up with people but more importantly I got to escape – there was never any talk of cancer, only the best score.

In December 2013 I completed my treatment and since then I have had a blood test and a scan every three months to see what my PSA levels are like. At that time my PSA had gone from 49.9 to 1.85! What a drop! It shows that the treatment was effective. My oncologist said to finish the course of treatment as even though it was a strong regime, it was working. My strength hasn't come back fully yet, but I know it takes a while. It's bound to take a while to get back to feeling normal after that dose of chemotherapy. I'm still taking medicine every month indefinitely which will keep my bones strong.

My experience of cancer, and the people I have met during my own cancer journey, has shown me that everybody's story and experience is different. Maura was the one who wanted me to have a check-up before holidays and it wasn't difficult to tell her that I had prostate cancer. My daughter is a medic so she talked a lot about the new treatments available. We never looked at it negatively. I was more annoyed about the fact I was retiring and dealing with the illness was putting me under pressure.

Our children are all grown up so speaking to them about my cancer was not too difficult. There are worse forms of it to have I think. The treatment affected me sometimes, and I had some urine problems, but other than that it all worked out fine, thank God. I'm 77, but my GP says I look 60! I feel fine today, thank God.

# JACK FROST\*



MAN TO MAN: IRISH STORIES  
*of* HOPE IN PROSTATE CANCER

## MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

One afternoon, I was listening to the radio during – what was – Prostate Cancer Awareness Week and a well-known broadcaster started talking about prostate cancer symptoms. One of the symptoms he mentioned was getting up to go to the bathroom frequently during the night, and, instantly – it registered. I had this symptom, amongst others.

In February 2005, I had a PSA test at my GP's – I had a PSA of 25. The GP arranged a meeting with a urologist in May 2005. A biopsy was carried out and the results came back to me in June confirming I had prostate cancer. I was 47 years of age.

Both my wife and I were present when the urologist confirmed the diagnosis. We were both taken aback by the news but the urologist assured us that treatment options had a high success rate. The treatment favoured by my urologist was a combination of hormone/radiotherapy.

My wife told our children of my diagnosis. My daughter was anxious to find out a bit more and had lots of questions – my son on the other hand never discussed it directly with me but knew what was going on through his mother. We tell him to get health check-ups, but he's not great for going to the doctor. We keep the pressure on!

At a follow up meeting with my GP the treatment options were discussed in more detail and surgery was also mentioned. However following discussion between the GP and urologist the advice was that hormone/radiotherapy was the best route of treatment.

As a build-up to the radiotherapy, I commenced hormone treatment in August 2005. I had my first meeting with the oncologist in November – scans were carried out and it was

explained in more detail to me what radiotherapy was and what to expect going through the process.

Prior to my radiotherapy commencing, the hospital in Cork organised an information evening whereby groups of patients and family members are brought through the whole process and the equipment and procedure is explained. My first radiotherapy session commenced in February 2006 and in all I had 35 sessions, run on consecutive days – five days a week for seven weeks. The treatment was extremely well organised, and my appointment time was always adhered to – my stay at the hospital was generally 45–60 minutes.

For the first week or two of radiotherapy I was fine but the impact of the treatment does build over time. The main impact for me was the urge to go to the bathroom to pass urine – this was almost hourly day or night and meant sleeping was constantly interrupted – passing urine at times was painful but relief was got through medication. Additionally I had bouts of diarrhoea but making changes to my diet corrected this – advice and support was always available at the hospital and the key thing was keeping the medics abreast of how I was feeling. Planning my car journeys was an important aspect so as to avoid being stuck in traffic when there may be a sudden need to use a bathroom. For the duration of my radiotherapy, I continued to work and my employer was very supportive at all times.

Once my radiotherapy finished, life went back to normal after three to four weeks. In the months following, my PSA reduced to 0.4 compared to 25 at the time of diagnosis.

During the period 2007–2010, I visited the urologist at approximately six month intervals. I was taking hormone suppressing tablets in

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three monthly blasts – three months on, three months off. My PSA levels during this period were initially okay and within tolerance, but each time they were checked they were approximately double the previous figure. My urologist was concerned and in January 2011 I underwent a number of scans.

The scans confirmed tumours in my bones around the area of my pelvis/prostate. The medical term used was metastatic, meaning the prostate cancer was now in areas that it was not initially diagnosed in. This was a low point for me and the family – I did question in my own mind should I have given more consideration to having surgery following my initial diagnosis. However my focus very quickly moved on to the next raft of treatment prescribed.

For the period January 2011 to August 2013, I was on a combination of hormone suppressing injections/tablets and an infusion of a substance to keep my bones strong. Both the injection and infusion were administered in a Cork hospital at 28 day intervals and the tablets I took daily. The various treatments resulted in my PSA initially reducing to acceptable levels, but by August 2013 had climbed again to 17. I felt fine during this batch of treatment.

In August 2013, I was again referred to an oncologist. Following more scans the oncologist recommended 10 sessions of chemotherapy, to be administered at three weekly intervals. For the duration of chemotherapy I am on steroid and anti-nausea tablets. The monthly injection for hormone suppressant has been replaced for now with an alternative six monthly one, and I continue to receive the monthly infusion to keep my bones strong.

The main side effects of chemotherapy for me occur in the five to seven days after receiving it. Food tastes rather bland, and sometimes extra sweet – I have partially overcome this by using

spicier foods, for example curries. The other side effect is tiredness so for the nights following chemotherapy I tend to go to bed early which helps a lot. By day seven following chemotherapy my system is more or less back to normal.

Prior to commencing chemotherapy the oncologist informed me that scalp cooling (can reduce/prevent hair loss in the scalp) was available at the hospital - this requires the wearing of a special cap which is connected to a machine, for the duration of each session of chemotherapy. The cap reduces the temperature of the scalp, which suppresses the flow of the chemotherapy drug to the scalp area. I decided to avail of the scalp cooling and to date have not had any hair loss in my scalp which is great - I have completed 90% of treatment.

The treatments for my cancer will continue. I remain positive for the future and do not allow useless, negative thoughts to linger in my mind. It is nearly nine years since my initial diagnosis and the support of family and an excellent medical and nursing team makes me confident for the future.



MAN TO MAN: IRISH STORIES *of* HOPE IN PROSTATE CANCER

# IRISH CANCER SOCIETY



SUPPORT & RESOURCES

**Irish Cancer Society:**

The Irish Cancer Society is the leading provider of advice, support and information in confidence on any aspect of cancer. Specialist cancer nurses are available through the National Cancer Helpline on:

Freefone 1800 200 700, email helpline@irishcancer.ie  
or at one of the Daffodil Centres Nationwide.

**The National Cancer Helpline:**

Freefone 1800 200 700 is open  
Monday - Thursday from 9am to 7pm  
and Friday from 9am - 5pm.

Further information and supports are available from cancer advocacy and support groups nationwide, details of which are available at the Irish Cancer Society website [www.cancer.ie](http://www.cancer.ie) and from the helpline. These include:

Men Against Cancer, a peer to peer support group for men experiencing prostate cancer [www.menagainstcancer.net](http://www.menagainstcancer.net)

Movember, which runs Prostate cancer Awareness Month each November. [www.movember.com](http://www.movember.com)

Survivors Supporting Survivors, a peer support group which provides men and women with the opportunity to speak with others who have been affected by prostate cancer.

Community based cancer support services affiliated to the Irish Cancer Society.





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