

Purple

PANCREATIC
CANCER
CONVERSATIONS

ISSUE #1

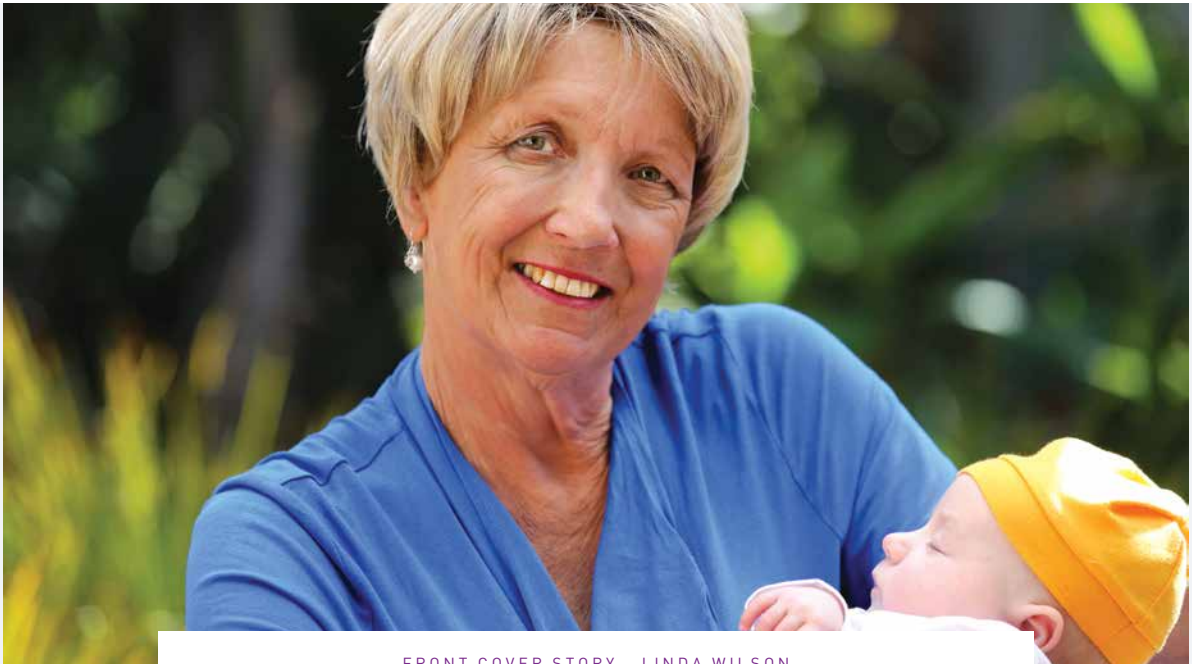


● Included in this issue:

PROF DAVID GOLDSTEIN
RON GIBSON
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GRAEME MAHER
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TAREANNA DUNN
PANCREATIC CANCER AND EXERCISE
THE FUTURE
QUALITY OF LIFE
WHY ME?
WHAT'S THE PROGNOSIS?
WHY CLINICAL TRIALS MATTER
CALL TO SCREEN TYPE 2 DIABETICS
ARE YOU ELIGIBLE FOR SURGERY?
PANCREATIC CANCER AND DIET
SUPPORT SERVICES



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FRONT COVER STORY - LINDA WILSON

“ Pancreatic cancer has changed my life; it will never be the same. At first I was devastated. I thought I had no future and I wondered, ‘Why me?’. Then I thought, ‘Why not me?’

I also felt relief, as I knew something was wrong with me, but until I was diagnosed, I had no answers. Now I had answers, but they were the worst I could imagine.

Somehow I was able to muster some positive thoughts and keep going.

It’s not always easy. You do have to work at pushing yourself to stay positive.

I am tempted to curl up on the couch at times, but I have learnt this is not a good thing.

My favourite phrase is ‘Never give up hope’. We would all love a cure, but hope is more than that.

To me, hope is reaching your next birthday, seeing your grandchildren play a game of basketball or football, or catching a great wave at the beach.

Last year, my youngest son became engaged, got married and had his first baby, Oliver. I never thought I’d see that! He was in medical school when I was diagnosed; I did wonder if I would even see him graduate.

My disease is metastatic, I am still having treatment, but every day I feel lucky and thankful I am still here.”

*** Linda penned these thoughts in April 2018. She is continuing on chemotherapy and her tumour markers are down. She is nearing 6 years post-diagnosis. More of her story can be found at page 10.**

“EVERY DAY I FEEL LUCKY AND
THANKFUL I AM STILL HERE”

PHOTOGRAPHY by RUSSELL BRIDGER

A look inside *Purple*



FEATURED

Ron Gibson considers himself "luckiest and unluckiest bloke"



FEATURED

Dr Mehrdad Nikfarjam explains which patients may be eligible for surgery



FEATURED

Graeme Maher's story:
Wendy Maher remembers her husband and his legacy

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Pancreatic cancer

statistics¹

Average age of diagnosis

72.8
years

Pancreatic cancer was the 10th most commonly diagnosed cancer in Australia in 2013 and was estimated to remain the 10th most commonly diagnosed cancer in 2017

5-year survival rate

7.7%

Projected deaths from pancreatic cancer in 2018

3006

1,563 males, 1443 females

Estimated number of new pancreatic cancer cases diagnosed in 2018

3,364

1,774 males, 1,590 females

In 2014, pancreatic cancer was the 5th leading cause of cancer death in Australia and was estimated to remain the 5th most common cause of death from cancer in 2017

References

1. Australian Institute of Health and Welfare 2017. Australian Cancer Incidence and Mortality (ACIM) books: Pancreatic cancer. Canberra: AIHW. AIHW 2017. Cancer in Australia 2017. Cancer series no. 101. Cat. No. CAN 100. Canberra: AIHW.

Introduction

By Professor David Goldstein

When I started my career in oncology, pancreatic cancer was regarded as an impossible challenge.

Even now, most patients given the diagnosis still believe that it is a fearsome, painful, incurable, and untreatable disease.

From a biological point of view, there is some kernel of truth in that. But today there are many things we can do. Treating this disease is no longer impossible.

In recent years, there have been some very positive steps forward, guided by careful clinical trials that build upon each other. While these steps are incremental, they are slowly changing the outlook.

These changes are gathering momentum. Recent information presented at international meetings suggests that a significantly greater number of people are benefitting from new research into this terrible disease – benefitting not only in terms of how long they live, but how well they live, with benefits in chemotherapy, surgery, radiation and supportive care.

If patients have a clearly operable case, the cure rate from surgery with adjuvant or neo-adjuvant chemotherapy is two or three times higher than it was five to ten years ago.

Even if a cancer has already progressed by the time of diagnosis, we now see some patients living for very extended periods of time. Importantly, their quality of life is substantially improved from the experience of patients even a decade ago.

Those patients that exceed expectations are giving valuable clues to extending that benefit to even more of our patients. Together with all the emerging insights into pancreas cancer biology, we are now being offered new pathways of care and a vision of treatment tailored to each individual that gives me confidence about the future.

I welcome the production of any information that helps patients with pancreatic cancer negotiate what is a very difficult journey.

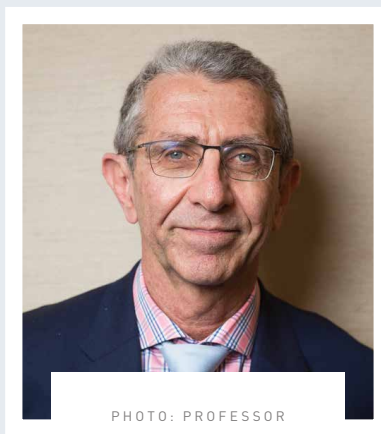


PHOTO: PROFESSOR
DAVID GOLDSTEIN

If you are one of those people who has been diagnosed, I hope that some of the stories included in this valuable booklet help you to realise that support is available, and that there are many solutions for the diverse problems a pancreatic cancer patient may experience.

I also want you to know that you have a right to expect appropriate support. This means comprehensive nursing and allied health support, alongside support from your medical oncologist. If you feel isolated or unsupported, don't hesitate to ask for more help.

Finally, I would like to reassure patients that researchers are doggedly pursuing and finding new information about pancreatic cancer.

There is no doubt that participating in research propels a field forward. Even those patients who have been part of trials that have not been successful are providing a valuable legacy. They are paving the way for the revelation of new answers and better treatments.

Patients are already living longer and I am certain this will continue to gather momentum over the next decade.

“I've been given a second chance”

Six and a half years ago, Alberto Marchetto realised his skin had taken on a yellowish hue. He was fit and healthy, so was not overly concerned. At his wife's urging, he visited a doctor and underwent testing for hepatitis. When results were negative, his doctor advised some further scans as a precautionary measure. This is his story.



“I was feeling okay and was about to play golf, and my wife insisted that I go and have the scans. So I went into hospital and that was it – I was diagnosed with pancreatic cancer.

My father died of pancreatic cancer, so it was like being hit with a sledgehammer. The surgeon told me he would only operate if the lesion had not spread. He warned me that if it had spread, I had between a year and 18 months to live

It was an incredible feeling to suddenly realise that I could die within months. This all happened over a weekend just after Christmas 2009. I underwent further tests, which, fortunately revealed no evidence that the tumour had metastasised. As a result the surgeon agreed to go ahead and perform a Whipples operation.

The Whipples was a ten-hour operation. The operation was successful, but my weight dropped from 80 kgs to 66-kgs. and began thinking that I'd have to buy clothes from the children's wear section for the next year or two.

During this time I was strongly advised to have chemotherapy, as there was no 100 % guarantee that there would not be a recurrence. Over 8 months I underwent 3 weekly chemotherapy sessions each month. While the waves of nausea were a challenge I was able to get on with my life and work.

However, in September 2010, scans revealed a secondary tumour in my liver and I was immediately put on an additional chemotherapy. The drug had a positive impact and reduced my liver tumour, allowing me to have a liver resection. Since that time there have been no recurring lesions.

My wife was a great support in helping me to adjust to a new regime of enzymes and smaller servings. I also remember feeling awkward in the way I responded or reacted when speaking to family and friends about cancer. At times, I felt awkward and exposed.

At the same time I think it's vital to keep family and friends 'on board'. Let them know what's happening and that you appreciate their concerns.

In hindsight, I should have been more open about what was happening to me.

Keeping fit was one of my biggest issues. I have always been fit and still remain as healthy as possible. I kept that up through months of chemotherapy. When I felt flat, detached, angry or put out, I would get out and walk for 6 to 10 kilometres. It was great therapy. I just wanted to get on with life as best as I could.

Acupuncture was a great adjunct to treatment, because it helped me to slow down and gave my body some rest. I tried to stay away from introspection and wondering, 'why me?'

I have been cancer-free now for six-and-a-half years. I was told at the five-year mark that I did not need to see my oncologist anymore, but I have an annual scan for peace of mind.

I am now 71 years old, with three grandchildren. I still work part-time as a university lecturer, and continue to travel.

It sounds a bit cheesy, but I am really enjoying life with family and friends. I continue to play golf and tennis, and walk five kilometres every day. Bushwalking is also a favourite pastime.

I do feel as if I was given a second chance."

*** Alberto shared his story in February 2018.**

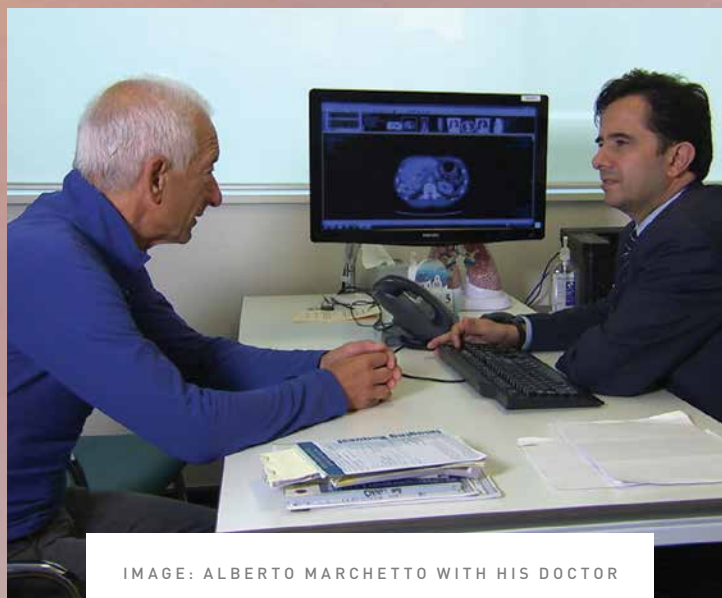


IMAGE: ALBERTO MARCHETTO WITH HIS DOCTOR
ASSOCIATE PROFESSOR NICK PAVLAKIS



When Wendy Maher hears the wind chimes on her back porch make their familiar tinkle, she likes to think it's her late husband Graeme paying a visit.

Graeme, a Victorian harness racing identity, died last year after a two year battle with pancreatic cancer. He was only 58 years old. Wendy was by his side for every step of the way, but believes he suffered from repeated misdiagnoses.

She does now wonder if things may have been different if he had been diagnosed earlier, and is sharing their story to urge others to seek second opinions when something doesn't feel right. "What would I tell people now? If something does not feel normal, don't put it off. Please don't put it off." This is Wendy's story.

"Graeme had indigestion for about 10 years. He was taking medication and this worked for about 7 years but then the indigestion came back. About 12 months before he was finally diagnosed, his indigestion got really bad.

It's really hard to explain, but he was burping continually, all day, not just after a fizzy drink.

We went to the local doctor and Graeme was referred for a gastroscopy. It was established that he had a small hiatus hernia and that this was the reason for his ongoing indigestion.

So, we were led to believe there was nothing really wrong and we went to New Zealand for a holiday.

But he was still burping and he was extremely tired. Then he became sick after eating something and was saying he had a pain in his back.

We went to the doctor as soon as we got home and Graeme was hospitalised before being diagnosed with pancreatitis.

They actually did a CT scan and had a look at the pancreas but said it was clear. It was difficult to detect and the fine print on his scans noted that there was an 'obstructed view'.

Weeks later, he was still not well and further blood tests and scans were done.

When the results came in, we were told 'you have got pancreatic cancer'. We were stunned because only three weeks earlier we were told there was nothing there.

We came home shell-shocked. We cried all night. Graeme tried to put on the brave front.

It was five weeks after diagnosis that he had the Whipples operation. His tumour was huge but was contained to the pancreas. During surgery they found it had attached to the portal vein. His surgeon was fantastic and they did a resection of the vein.

Wind chimes

“The week before he was admitted to hospice, I found a gift voucher in one of Graeme’s tops for a local nursery. We knew the end was coming. He told me to buy a plant and plant it in his honor. But when I was at the nursery the girl showed me some wind chimes and so I bought one. I showed it to Graeme and he loved it so much that he said to me, ‘when I go I am going to come and talk to you through that thing!’.

It was a joke; I am a Christian so I don’t believe in these weird and wonderful things! But the day after he passed, one of the grandkids was crying and saying he wanted to speak to Pa. I told him to go outside and sit with the wind chime and remember him. Not a word of a lie, there was not a puff of wind, but the wind chime rattled. Now I find it comforting and I talk to it all the time. It brings me comfort.”

Wendy Maher, whose husband Graeme passed away in 2017 after a two-year battle with pancreatic cancer.

Surgery does give you the best chance of beating pancreatic cancer if you are eligible.

His doctors wanted to do chemo after surgery to mop up any single cells.

But Graeme had a lot of complications from the operation and could not get on to chemo for 11 weeks.

Graeme got to within a month of completing this first chemo, then he got the niggle in his back again.

The tumour markers started to go up and a scan revealed he had another tumour growing in the remaining part of the pancreas. So he was back on the table for another big operation. It had been growing the whole time he was on chemotherapy.

Six weeks after his second operation he started another round of chemo. But then some spots were found on his liver. After this he was changed onto his third type of chemo, which actually held the growth of the tumours for about 6 months. But, as is normally seen with this cancer, the chemo stops working. His chemo was changed again but sadly this one did very little.



IMAGE SUPPLIED: GRAEME AND WENDY MAHER

Graeme passed within six weeks of stopping chemo. He was true gentleman who loved his family and his horses. He was a very well respected businessman, who had time for everybody. We have so many great memories.

I am telling our story now because we want to get the word out to other people about early diagnosis.”

*** Wendy Maher shared Graeme's story in March 2018.**

Why *me*

South Australian oncologist Dr Chris Karapetis has devoted his career to cancer patients and says this is one of the questions he hears most frequently. But really, there are no definitive answers.



IMAGE: DR CHRIS KARAPETIS

"In the majority of cases, we really don't know why pancreatic cancer develops. In most cases, there is not an easily identifiable risk factor. Most people don't have a family history. They don't have a lifestyle pattern that would increase risk. It just happens and we don't know why. That's a source of frustration and disappointment for everyone involved. We do know the incidence is slightly higher in men, but there is no striking difference in gender. Pancreatic cancer is definitely more common in older people (over 70). Having said that, we see it in some very young people as well, for no obvious reason.

There are not any real predisposing factors that come out as being particularly strong. We do know that smokers are at greater risk, but we see it develop in non-smokers. It is not as though not smoking protects you from pancreatic cancer. People with a history of chronic inflammation (a type of swelling and irritation) of the pancreas might be more susceptible. This inflammation can occur as a result of various immune conditions or alcohol, or other irritants like gall stones – anything that makes the pancreas become chronically swollen or inflamed or scarred can lead to cancer. But again, the majority of patients have no history of this kind of inflammation and pancreatic cancer just develops out of the blue.

Often a person comes along and they are the only person in that family with pancreatic cancer. There are some rare types of pancreatic cancer that can be more familial, including neuroendocrine tumours, or NETS, and they can be part of a syndrome of tumours that can run in families. But the vast majority of pancreatic cancers develop in patients without a family history."

*** Dr Karapetis shared his insights in March 2018.**

Screening Study

Do you have a Family History of Pancreatic Cancer?

Patients with a strong family history of pancreatic cancer, with two or more close relatives diagnosed or with specific genetic conditions associated with an increased risk of cancer, are eligible for an early screening test as part of a research study.

The Austin Hospital in Victoria and St Vincent's Hospital in NSW are the first Australian centres to establish a formal, ethically-approved pancreatic cancer screening program. This program is supported by the Pancare Foundation.

Around 90 people are currently being screened in Victoria with a further 18 subjects set to begin. In New South Wales, more than 100 people have been enrolled. All those enrolled will have a series of blood tests and endoscopic ultrasound examinations over five years.

An early tumour has already been detected in one trial participant.

Mother-of-two Carmel joined the trial after losing her father, grandmother and great-aunt to pancreatic cancer. Tests revealed a cyst on her pancreas which is now being closely monitored. She says now: "It doesn't worry me anymore because I know that I'm in a good position and if I was to develop it they would catch it very, very early, so I consider myself very lucky."

A Pancare spokesperson said: "Ideally, our aim is to develop methods to identify patients who are at high risk of developing pancreatic cancer (those with high-risk pre-cancerous changes in the pancreas) or identify very early cancers, when surgery can provide a potential cure."

Initial patients enrolled in the study are expected to complete follow up later this year.

For more information please call the Pancare Foundation on 1300 881 698, email info@pancare.org.au or visit pancare.org.au.





“While
there
is life
*There
is hope*”

Linda Wilson is a wife, mother, grandmother and registered nurse who was diagnosed with pancreatic cancer in June 2012 after feeling ‘not quite right’. Linda remains on chemotherapy, is still working as a nurse three days a week and has defied all odds to reach six years post diagnosis. When she was first diagnosed, her son was in medical school. She thought she may not live to see him graduate. But, not only has she watched him receive his medical degree, she has seen him become engaged, married and now, is delighting in his baby boy, Oliver. Linda says now, “I don’t consider I am dying from pancreatic cancer. I am living with pancreatic cancer. Every day is a blessing. While there is life, there is always hope.”

"I am a mother, wife and grandmother. The kids call me Maddie and not grandma or granny. Apart from my family, my passions are definitely fishing and nursing. I just ... I actually just love socialising and enjoying my life. I do love my life.

I was diagnosed in 2012. I had reflux that didn't settle with over-the-counter medication and I had a dull ache in my upper left abdomen. I felt 'NQR' – not quite right. So I went to the doctor and I had an ultrasound.

I had that done on the Friday. I went to work on the Monday but during a break I saw a lot of missed calls on my phone. It was the local GP's number and then I knew I was in trouble.

I was devastated, but the hardest part was seeing the effect it was having on my family. They were just crying.

I then underwent a distal pancreatectomy and a splenectomy, which took away the bottom half of my pancreas, leaving the pancreas head in place. In the section that doctors removed, there was a three centimetre tumour with no lymph node involvement.

These were positive results and I went on to have six months of chemotherapy. In follow up scans soon after this, my tumour markers were all clear.

And so it was looking hopeful. I was hoping I had beaten the odds.

But a few months later my tumour markers started going up and a node lit up on a scan. I asked doctors what this meant and I was reluctantly told I had between 6 and 12 months if I was lucky.

Around the middle of 2013 I began a new type of chemo. I tapped into my superannuation because it was time to enjoy some fun times with my family and friends. I had always wanted to visit Kakadu so I went there. I've also had some great fishing trips chasing that elusive Barramundi – it's still elusive!

I was on the treatment for some time, but at the end of 2014, my white blood cell counts were low and my tumour markers were rising. I was advised my treatment was being stopped because I wasn't considered curable.

After further discussions, including another oncologist, I recommenced chemo with the addition of injections to help my blood cell counts recover. I was also told it was time to change to a different chemotherapy.

I tolerated chemo well but my tumour markers would rise if I had a break in treatment.



IMAGE SUPPLIED: LINDA WILSON WITH HER FAMILY

By December 2015 my blood tests and scans were clear. But again, whenever I stopped treatment my tumour markers would rise. So I was referred to a radiation oncologist and in January 2016 I began 30 rounds of radiation therapy to the lymph node area that had lit up in 2013.

I am now on chemotherapy again and my tumour markers have gone down.

I know I am really lucky to still be here. I have seen a new granddaughter born and now a new grandson.

I have watched my children's families grow, I have seen my youngest son become engaged – when I was first diagnosed I was worried I would not see him even graduate.

I have been really lucky to see all of that. I don't consider I am dying with pancreatic cancer, I consider I am living with pancreatic cancer. I wake up every morning and I am thankful I am still here. I am determined to make the most of every day. I say 'yes' to a lot more these days!

My feeling is, that while there is life, there is hope. If you hang in there long enough, there might be something just around the corner that might be able to help you."

*** Linda shared her story in April 2018.**

What's the prognosis

South Australian medical oncologist Dr Chris Karapetis says this is another question he hears frequently from patients diagnosed with pancreatic cancer. But he says there is still much to learn about cancer, and believes a national tumour biobank could help to reveal important answers, about why some patients respond to treatment better than others.

"One of the first things people say to me is 'well Doc, what's the prognosis?' That's when we have a discussion about the extent of their cancer, how big it is and whether it has spread.

It's great if surgery is an option, but I often see patients with a cancer that can't be removed. And that's when we start talking about treatments like radiotherapy and chemotherapy. The benefit of these treatments can be modest and we can extend survival by a number of months, but not generally by a number of years.

The reality is that 50% of (metastatic) patients will die within 12 months and that is why research is so important – we must find new therapies.

Having said that, we do see some impressive responders who have gone against our expectations.

The problem is, we don't have a good way of predicting who is going to be that exceptional responder or who is going to be the non-responder.

Patients are drawn to stories of impressive responders and I have had a few of them.

One of my patients, Dale, was in his late forties when he was diagnosed with locally-advanced neuroendocrine carcinoma.

When doctors opened him up to operate, they decided not to remove anything as it seemed his cancer had spread so extensively.

At that time, we expected he would live about a year and gave him a course of chemotherapy and radiotherapy.

Turns out, he has had the most amazing response. While there is still evidence of a lesion, the treatment did eradicate most of the tumour.

Dale is not cured, but it is five years now since his diagnosis. The cancer remains under control (no growth for 5 years). He is back at work full-time and managing remarkably well.

With all cancers, there is still a lot we don't know. I would like to see a national tumour biobank. This is a bank where thousands of samples of tumour tissue are ethically collected with patient consent. Some hospitals and researchers have their own systems, but a nationally co-ordinated approach would be fantastic.

What it would do is help us find out more about the underlying biology of the cancers and find out more about what sets some of these impressive treatment responders apart."

*** Dr Karapetis shared his insights in March 2018.**

"Throughout the past year, there has been a notable shift in the zeitgeist around awareness and support for pancreatic cancer. This shift in our community augurs well for the future development of clinical trials and research into better treatments for patients with pancreatic cancer.

On 29 November 2016 the Senate established the Select Committee into 'Funding for Research into Cancers for Low Survival Rates'. I appeared as a witness together with members of our Consumer Advisory Panel at the Senate Inquiry hearing on 18 May 2017. The Committee found that identifying low survival rate cancers was a high priority area and called for more funding and better access to clinical trials. This acknowledgement was a significant step forward in regards to public awareness of pancreatic cancer and other low-survival cancers.

from the GI Cancer Institute



BY RUSSELL CONLEY
CEO GI CANCER INSTITUTE

The GI Cancer Institute is conducting research and clinical trials in much needed areas for patients with pancreatic cancer. One of these is the DYNAMIC-Pancreas trial ('Circulating Tumour DNA Analysis Informing Adjuvant Chemotherapy in Early Stage Pancreatic Cancer: A Multicentre Randomised Study') currently in start-up. This trial aims to investigate whether testing for the presence of circulating tumour DNA (ctDNA) in the bloodstreams of patients can help identify more targeted treatment options for patients.

Our other recent clinical trials in pancreatic cancer have shown promising results. The GAP trial, currently in follow-up, tested the effectiveness of treating patients with chemotherapy before surgery (neoadjuvant therapy) rather than afterwards. The trial found that early chemotherapy was safe and feasible. Patients were more likely to be well enough to continue this treatment if they had it first than having it only after the operation. Some patients were also spared having to undergo surgery that would not have helped them.

This research is part of a larger global shift, where the community is rallying, a change is happening and the momentum to focus on underfunded cancers like pancreatic cancer is growing. There is a sense of optimism in our medical community for advancing the treatment of pancreatic cancer. However, none of this possible without the support of our community of medical professionals, patients, families, survivors, carers, donors and supporters. With your continued support we will harness the momentum to further improve the lives of people with pancreatic cancer and their families."



NETS

NEUROENDOCRINE TUMOURS

“Neuroendocrine tumours (NETS) are in fact, a completely different disease. The pancreas is just one of the places in the digestive tract where they can appear. NETS have their own distinct issues, they have a vastly better prognosis and a completely different treatment.”

Professor David Goldstein.

“My attitude changed
for the better”

Prison officer Ron Gibson considers himself both the luckiest and unluckiest bloke. His luck took a downturn when he was diagnosed with pancreatic cancer at just 46 years old. But then, his fortunes changed for the better. A tumour initially thought to be inoperable was able to be surgically resected. Then, his cancer returned twice. Both he and his doctors say he will never be in the clear, but he regards each day as a blessing and says the whole experience has changed his attitude for the better. This is his story.





IMAGE SUPPLIED BY PANCRE: RON GIBSON WITH HIS WIFE

"I am a prison officer in Ararat, which is a country town in Victoria, about three hours drive from Melbourne. This job certainly has its moments. Sometimes it is probably one of the funniest places I have ever worked; at other times I think it is one of the most miserable places on earth.

My wife and I have four kids between us. In November 2010 when the youngest was about 12, I was feeling a bit ill at work one day, with abdominal pains that got worse as the day progressed. I drove to the local hospital but they thought I had gastro and was constipated. I knew it was something else – the pain was excruciating.

I did get better after a few days, but then I went and had a CT scan. That was when the surgeon told me I had a cancer in my pancreas. I knew nothing about it and the whole thing was a bit surreal. There was no rhyme or reason to it, no family history, nothing.

The outlook was pretty grim at that stage and I went into 'tidying up my affairs' mode, making sure the will was in place and my financial affairs were in order.

Then a surgeon in Melbourne ordered me to have a second scan. He still didn't like the look of it, but thought he might be able to do something.

Basically, my tumour had blocked the portal vein, which meant the vein was not working. This was a good thing because I had basically 'replumbed' myself and the blood flow between the pancreas and the liver was disrupted.

It meant my tumour was operable and I had a 50/50 chance of surviving surgery.

I underwent an 11 hour operation and I ended up in intensive care; I was so sick.

My cancer was a pancreatic neuroendocrine tumour, which is not your regular pancreatic cancer but pretty nasty nonetheless.

I spent 2.5 months in hospital and I lost 25 kilograms. But I did not have to have chemo or radiation.

Then in 2013 during a regular check, the doctors found two spots on my liver. I thought I was stuffed, but the doctor thought he could operate. Six months later, they found two more liver spots. Again, they were able to operate. I later developed septicaemia and spent five days in intensive care and a further five weeks in hospital.

It's been a long and slow road back to health. I am pretty lucky to still be around. The surgeon has said he is never going to give me a clear.

How have I changed? I don't take things for granted any more. You appreciate what you have got. I think I am probably a bit more caring. I enjoy simple things, like camping and seeing the countryside. I like to keep things simple and just keep ticking along."

*** Ron Gibson shared his story in March 2018.**



“I want to go scuba diving”

Tareanna Dunn has a simple way of explaining her type of pancreatic cancer to family and friends. “I tell them that I have got the Steve Jobs type, which is a pancreatic neuroendocrine tumour (NET) and they tend to be more slow growing. The other type is typically more aggressive and that is the Patrick Swayze type,” she says.

It is 3.5 years since Tareanna was initially diagnosed and two years since she learned her cancer had unfortunately metastasised to her liver. While Tareanna knows she will never be cured, she hopes treatment will enable her disease to be put on pause for as long as possible. This is her story.

“Just after I had my second child in 2012, I had intermittent occasions where I did not feel quite right – I had ongoing tummy aches and a sore back but there would be months in between each episode. I put it down to being a busy working mum.

Then in late 2013 I was experiencing what I thought was really bad indigestion. Sometimes I would even have days on the couch where I was just in pain with bad cramping and other tummy issues. My intuition told me there was something wrong and I went to the doctor, but I was prescribed tablets for indigestion.

After another episode, it was back to the doctor and I was sent for an ultrasound. Following that, the doctor ordered other scans to be done.

I was called in to get the results and they told me they had found a growth and it did not look good. I had a meltdown in her office; I was in complete shock. I was only 38 at the time and my kids were two and five.

My case was reviewed by a multidisciplinary team they told me it was a NET (neuroendocrine tumour). The primary tumour was in the head of my pancreas and I had 16 tumours throughout the abdomen. There was a tumour the size of a tennis ball in the lower left side of my gut.

Everything happened pretty quickly after that. Following some deliberation and different opinions, it was decided I should have the whipples procedure, because this would give me the best chance of having it all cut out.



...and see my girls *grow*"

IMAGE SUPPLIED: TAREANNA DUNN WITH HER DAUGHTERS

The surgery is huge and I did pretty well. In fact, I hold the record for the quickest hospital exit – I was out of hospital five days after surgery.

But the recovery is horrible – it is long and slow. My mum lives in New Zealand and she moved in with us for six weeks to help.

I would be really honest if I was speaking to other patients having a whipples. I would tell them it is hard and you need support. It takes a long time to recover. I dropped down to 48 kilograms.

I had my fingers crossed that I was clear of cancer, but after 18 months, I was having one of my regular check-ups and it was discovered I had spots on my liver.

These spots were not able to be surgically removed, so I have had chemotherapy and radiation to try and shrink the tumours. I had a treatment cycle of PRRT – Peptide Receptor Radionuclide Therapy, which is basically a course of radiation administered intravenously in combination with oral chemotherapy. This is designed to shrink existing tumours and stop further spread.

I have coped pretty well with this. My hair has thinned and I have developed some pigmentation on my face. And I have been so fatigued – just bone-weary tired, something that is very hard to explain.

I finished this treatment last year. My life has changed. I don't take things for granted anymore and I don't get bogged down by things. I also make an effort to stay in touch with family and friends.

I am not working at the moment, but I would like to go back to work part time if I can.

I have other goals on my bucket list as well: I want to go scuba-diving in Papua New Guinea, which is where I am from. My goal for this year is to get fit enough so I can manage to dive.

I am a positive person and I try to keep my chin up. I have got cancer and there's nothing I can do about it. If the treatment can keep my cancer on pause so I can see my girls become young adults, that would be great.

I owe my strength, resilience and will to fight to the amazing army of support I receive everyday. My support team comprises not only my amazing husband, daughters and extended family and friends but also amazing professionals that have assisted me every step of the way, including surgeons, nuclear medicine specialists, dietitians, nurses, Pancare and The Unicorn Foundation. To know so many are invested in my welfare makes me feel both blessed and loved, and there is no better feeling to have."

*** Tareanna shared her story in March 2018.**



Pancreatic
Cancer
+

exercise

Dale Ischia is an accredited exercise physiologist and an ACSM cancer exercise specialist. She says that two of the most common side effects of pancreatic cancer and its subsequent treatment are deconditioning (a loss of physical condition and fitness) and fatigue. “We know that twelve weeks of chemotherapy creates a similar physical decline as seen in a decade of ageing,” she says. “The good news is; exercise has been proven to be the most effective treatment for cancer related fatigue^{1, 2} and for halting or even reversing this deconditioning process. Maintaining strength, cardiovascular fitness, balance and mobility throughout treatment is imperative to quality of life,³ but we also know that exercise has other benefits. Recent research has further indicated that exercise can help to improve treatment tolerance and effectiveness.”^{4, 5}



IMAGE: DALE ISCHIA



Pancreatic Cancer + *exercise*

What kind of exercise is best?

Exercise should be prescribed according to your treatment side effects, other co-morbidities and assessment findings. But in general, it should:

- Reflect your goals
- Be enjoyable
- Be done with a friend or group
- Cover all components of fitness, including cardiovascular, strength, balance and flexibility.

Walking outside is one of the simplest exercises you can do. It gets you in the fresh air, is free, can be done anytime and helps your cardiovascular system as well as the health of your mind.



When is the best time to begin exercising after diagnosis?

As soon as possible. The more active you are the better. It is safe to exercise during treatment – provided you allow yourself time to recover from treatment and exercise.

Exercise helps ensure you are in the best possible physical condition when you undergo surgery. This will enhance recovery post surgery. Exercise during chemotherapy is also safe.

What are your key recommendations?

It is well established that people diagnosed with cancer should avoid inactivity.

As a benchmark, patients should aim to perform 150 minutes of moderate intensity cardiovascular exercise per week, as well as two sessions of resistance exercise per week.⁶ This is a goal to work towards, and can be broken down into small chunks of 10-minutes, such as walking.

It is also advised that patients seek the advice of a qualified exercise professional such as an Accredited Exercise Physiologist who specialises in oncology. This practitioner will work out the best exercise program based on individual patient needs.

Go to www.ESSA.org.au and click on Find an Accredited Member, type in your postcode, click 'Cancer' under speciality and click search.

What should patients consider before starting an exercise program?

- Loss of muscle mass and strength. Go easy on yourself, you may not be able to do what you used to be able to do. Build up gradually.
 - Are you absorbing enough nutrients to fuel your exercise program? You need enough fat, carbohydrates, proteins and vitamins and minerals.
 - Check that your blood levels are with a safe range.
 - If red blood cells are low, and this is causing you to be fatigued, you should only exercise at a very low level as tolerated.
 - If neutrophils are low, resulting in suppressed immune systems, you avoid exercising in a public place.
 - If your platelets are low, you should avoid any impact exercises.
- If you have a central port, there aren't many limitations except when it is attached to chemotherapy – please speak with your nurse, exercise physiologist or oncologist.
 - You must allow adequate time for your body to heal after surgery. Your surgeon will guide healing time.
 - It is strongly recommended to improve your condition prior to surgery. Try to perform aerobic exercise every day, such as walking, swimming, bike riding, leading up to your surgery.
 - Your body needs to recover from chemotherapy sessions, or radiation sessions, and it needs time to recover from exercise. How you respond to treatment is very individual and depends upon many factors. You may find there are times in your cycle where you can't manage much more than a walk to the bathroom.



PHOTOGRAPHY by RUSSELL BRIDGER

JUNE 2018

- Cramps may be a sign of something else and you should check with your doctor. But they can be common and are best managed by hydration (drinking 1.5-2.5L of water per day), stretching the affected area, and good nutrition, i.e. the correct sodium, potassium, calcium, and magnesium for smooth muscle function. A healthy diet will provide all of these nutrients and supplements are not required if your nutritional intake is sufficient.
- Peripheral Neuropathy is a common side effect of chemotherapy. It will not be worsened by exercise. It can reduce your balance, especially your proprioception. Moving your feet and hands can help with your proprioception. Massage can also help reduce the feeling that your foot is one block, and make it feel like individual bones and joints again.

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6. Schmitz KH, Courneya KS, Matthews C, et al. American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Med Sci Sports Exerc* 2010; 42(7):1409-26.

Pancreatic Cancer + exercise

What about exercising post-surgery?

- It is recommended to get up and walk as soon as possible after your surgery to prevent blood clots in your legs. Going for a short walk every 2 hours is ideal. If this is not possible, pumping your feet up and down is a good alternative.
- You should avoid lifting anything heavier than 2kg for around 6 weeks – but check with your doctor. After you are given the all clear from your doctor that it is safe for you to commence more strenuous exercise and lift heavier things, ensure you gradually increase the load and intensity of your exercise over a number of weeks. Don't do it all at once. Your body needs time to adapt to new loads.
- You will need to regain your overall strength, but areas to focus on are your abdominal strength and leg strength in order to keep you as functionally independent as possible.

Is exercise safe during chemotherapy?

- Exercising during chemotherapy is recommended. It should be performed to tolerance, keeping all the considerations above in mind.
- Your ability to exercise will fluctuate throughout your chemotherapy cycle. Perform a gentle range of movement exercises lying down, if that is all you can tolerate. Keeping active in some capacity is important. Do several short walks in a day and a longer walk on days you have more energy.
- Be guided by your own perceived rate of exertion. Aim to keep your effort light to moderate.



- Always breathe throughout all types of exercise – do not hold your breath.
- If you had surgery involving any of the main blood vessels in your abdomen you should avoid straining, breath holding and heavy weights until your doctor tells you it is safe to do so.
- You may develop diabetes as a result of your surgery as your remaining pancreas isn't making enough insulin, so your blood sugar becomes too high. If so, your diabetes needs to be appropriately managed in order for you to exercise safely.
- An Accredited Exercise Physiologist specialising in Oncology is the best person seek advice from if you have any further questions regarding exercise.

When should you stop exercising and consult your doctor?

You should stop exercising and consult your doctor if you experience any of the following:

- Dizziness or fainting while exercising
- Swelling in your ankles, neck, face or arms – seek immediate medical help
- Shortness of breath with only a small amount of exertion
- Chest pain or palpitations
- Sudden onset of nausea during exercise
- Chills/shaking during exercise
- Severe diarrhoea or vomiting.
- High temperature

Ideally, you should see an Accredited Exercise Physiologist who can safely prescribe the correct exercises for you, taking into account your current treatment, the side effects you are experiencing, and other health or joint issues you may have.

Cardiovascular/ Aerobic Exercise

- Aerobic exercise helps maintain your cardiovascular system (heart, lungs, muscle and blood)
- Aim for at least 150 mins of moderate activity per week (30 mins/day)
- It is okay to begin in 10-minute blocks and progress as you improve.
- Start low, progress slow.
- Have exercises planned for low energy days after chemo. For example, stretching or walking slowly for 5 minutes.

Definition of 'Moderate Intensity Exercise'

- 50-70% of maximum heart rate (Max heart rate is 220 minus your age).
- Talk test. Breathing rate is such that you can talk, but not sing.
- Examples of moderate exercise include walking, hiking, biking, swimming, dancing, gardening, housework.

Exercise guidelines

Strength Training

- Strengthening exercise increases your muscle mass. Your muscle mass is a good indicator of survival; the more muscle mass the better.
- Resistance exercise increases your muscle mass. This includes body weight exercises, free weights, and machine weights.
- If you have recently had surgery you must get the okay from your surgeon before lifting heavy weights.
- Aim for 2 -3 strength sessions weekly for major muscle groups.
- Begin with 1 set of 10-12 reps of 8 different strength-training exercises.
- Build to 2-4 sets of 6-8 reps and increase load.

Balance Exercise

- Poor balance is a common side effect of chemotherapy.
- Having surgery through the abdominal wall can also have a negative impact on your balance.
- Working on your balance will help maintain and improve your balance and prevent you from falling.
- Simple balance exercises such as standing on one leg will help challenge and maintain your balance.

Flexibility/Range of Movement Exercise

- Range of movement exercise allows you to move more freely.
- It is important to include stretching after your strengthening exercises in order to assist in recovery and minimise muscle and joint pain.

The future

In 1985, in his first week as a young intern, Dr Andrew Dean looked after a man called Peter who, in his early 60s, was in the late stages of pancreatic cancer. Peter was a shadow of the proud man he had been and palliative care as a specialty was still very much in its infancy.

“I just remember a complete inability to treat him with anything,” Dr Dean says today. “The memory of that man is still with me. I have absolutely no doubt that this experience in my first week ever as a doctor, has played a significant conscious and subconscious influence in my decision to train in palliative care and oncology. I suspect it is one of the drivers that has led to my interest in pancreatic cancer research. I am pleased to say that things have changed dramatically in the past couple of decades, in terms of how we manage pancreatic cancer patients. But I will always be grateful to Peter for the privilege of looking after him and the influence this experience had on my career and the choices I have made. Looking ahead, I expect the next couple of decades will bring even greater change.”

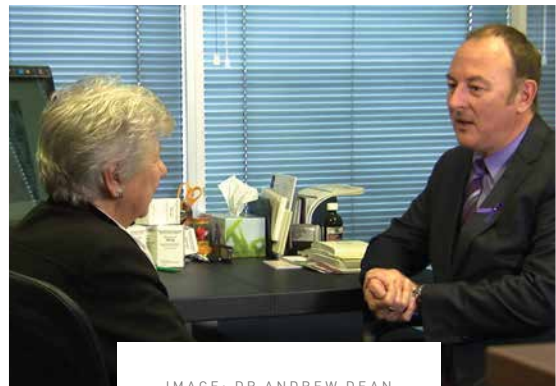


IMAGE: DR ANDREW DEAN
WITH A PATIENT

Dr Andrew Dean's *vision*

Immunotherapy drugs are playing a role in other cancers, particularly melanoma. What about pancreatic cancer?

Immunotherapy is rapidly becoming a treatment option for many different cancers and there are some cancer immune therapy 'poster children' like melanoma, and to a lesser extent renal and lung cancers.

We have not had great success so far in pancreatic cancer, but I predict that in the next few years we will understand why some diseases respond and some don't. I also hope that we will see advances in our ability to understand why some cancers develop a much stronger 'immune signature', which will enable an immune reaction from a patient's own immune system in conjunction with immune delivered therapies.

For example, at the moment with colorectal cancer approximately 5% of patients respond to immune therapy and you can predict with 50/50 certainty who are going to be the responders. Colorectal cancer is way more common than pancreatic cancer, so the research is further advanced.

What is your hope for the future of pancreatic cancer by 2030?

My hope is that in 2030 we will have an effective screening program for pancreatic cancer, based on circulating tumour DNA, possibly being used in conjunction with endoscopic ultrasound.

We would like to see a simple blood test available that is looking for DNA patterns in people at risk.

I further predict that when patients develop pancreatic cancer, biopsies taken from tumour tissue will all undergo molecular profiling to show the molecular and genetic make-up of that particular persons pancreatic cancer. I think we will then tailor individual treatments to deliver the best chemotherapy, probably in conjunction with biological agents such as PARP inhibitors for those patients who have tumours with DNA repair deficiency.

I also expect that by 2030, we will be predicting with a great degree of certainty, the patients who are going to benefit

from immune therapies and also applying treatments to those without the correct immune signatures to help them develop the correct immune signatures.

What would you like to say to patients who are newly diagnosed with pancreatic cancer?

There is great hope for the future treatment of pancreas cancer and patients need to know that we are trialling new agents all the time.

Having said that, surgery is always going to be the most certain way of removing a pancreas tumour. But if my predictions for the future of pancreatic cancer treatment hold true, then in the next decade we will see every patient receiving neo-adjuvant chemotherapy, (which is chemotherapy prior to surgery) integrated with biological agents with or without immune therapy.

I also expect we will also see a very high degree of tumour response and a very high degree of operability with curative intent. Obviously, the holy grail would be to make some huge advances in metastatic disease so that it will be treatable with tolerable chemotherapy regimens, alongside biological therapies and immune therapies. All these advances will help make pancreatic cancer more of a chronic disease, rather than a terminal illness.

In Western Australia, the reality is that we have more than doubled the survival duration for pancreas cancer. Our median survival for metastatic disease is currently 19 months. Median survival for patients who have been diagnosed with locally advanced pancreatic cancer is now more than two years.

We have people with metastatic disease who are surviving three, four and even five years post-diagnosis.

What I would like patients to know is that there is always hope for something better and our ability to treat pancreas cancer is getting better all the time."

*** Dr Andrew Dean shared his insights in March 2018.**



Quality of *life*

West Australian oncologist Dr Tom van Hagen wants his pancreatic cancer patients to know that it is possible to maintain a good quality of life while undergoing chemotherapy.

“People often make the assumption that chemotherapy will lead to a terrible quality of life, which thankfully is usually not the case at all. In fact, many pancreatic cancer studies have shown that people’s quality of life is actually improves while on chemotherapy. This may sound counter-intuitive, but is often due to the fact that it is actually their cancer that is the driving force behind the awful symptoms (such as pain, nausea and vomiting, weight loss and general malaise) that many people feel when first diagnosed. When you are controlling the cancer, those symptoms can often be diminished. People often live very well while on chemotherapy and my philosophy has always been that if we are giving patients a treatment that makes their quality of life worse, then we are not doing them a service at all.”

Can you tell us about a patient who has had a particular impact?

One of my patients is a 68 year-old chap called Kerry. He is a metastatic pancreatic cancer patient and we gave him just 24 hours to live 18 months ago, when he was in intensive care with severe pneumonia. He’s significantly better

now! Kerry was initially operated on with curative intent followed by chemotherapy, but sadly had a recurrence in his liver and lymph nodes a year later. After further chemotherapy treatment (which led to significant tumour shrinkage), he developed bilateral pneumonia which very nearly took his life. His mental and physical strength helped him to survive against the odds and he

“People can live well on chemotherapy”



IMAGE: DR TOM VAN HAGEN

has spent the last 18 months both recovering, but also responding again to a combination chemotherapy and enjoying life once again. There is not really a secret, we simply try and offer people the chance to live a good (and as long as possible) life, while managing symptoms. We have increasing access to new, wonderful medicines that have been recently developed to help people live longer.

What inspires you to work in this area of oncology?

I have been a specialist consultant for about 10 years and there has been quite a dramatic change in that time. When I began, we were really just offering a single chemotherapy agent. For decades, researchers had been trying to make a difference with additional chemotherapy but nothing extra was really improving patient outcomes. Now, we are able to offer patients different drug combinations and different therapeutic combinations. This means our chances of being able to improve survival and even downstage somebody's cancer (where we can change a cancer from incurable to curable by shrinking tumours via chemotherapy with or without radiotherapy

before operating) are much higher. Still, I estimate that only 10-20% of patients that I see are able to have their cancer resected (removed via surgery). Early detection would improve these statistics of course, but currently there are no good screening tools, and patients often present with advanced disease. This is another area of ongoing research and hopefully will improve in time as it has for our patients with metastatic disease. In Kerry's case, there are treatments available to him now, that a decade ago would not have been available. He thinks every day, every month and every year is a bonus. I would say that patients like him do have a chance of living well for a lot longer now than people diagnosed 10 years ago. My philosophy as an oncologist is to keep people 'well' for a long time, not just keep people 'alive' longer. There is still a long way to go, but we feel blessed that today, we are able to help people significantly better than was previously possible.

*** Dr Tom van Hagen shared his insights in March 2018.**



IMAGE: PROFESSOR
EVA SEGELOV

“Clinical trials will make a difference”

Professor Eva Segelov explains the importance of clinical trials and how you can participate.

When Eva Segelov was a medical student, her view of oncology was that there were minimal options for cancer patients and that treatment offered little other than side effects.

But, as an intern caring for patients, she realised what could be done with patient-centered care and had no doubt this was where she wanted to build a career.

More than 20 years on, she has overseen the care of thousands of cancer patients and is regarded nationally and internationally for her work in gastrointestinal cancers, including pancreatic cancer, as well as breast cancer. In her mind, it is clear that the survival statistics for pancreatic cancer need to change. “And the only way they will change is through research,” she says. “That is, the whole pathway of lab research linked to clinical research. And the link is clinical trials. Just as the situation has changed dramatically for some cancers, like melanoma, we are waiting in pancreatic cancer for our turn to witness paradigm shifting changes.”

Why are clinical trials so important in pancreatic cancer?

Unfortunately, pancreatic cancer remains one of the most challenging cancers for patients. Although some new therapies have come into standard practice through rigorous testing in clinical trials, there is still a huge need to find better, more effective and less toxic treatments.

Clinical trials are increasingly being recognised as important, as the only way that advances are made in clinical medicine. The Government, through initiative such as the Medical Research Future Fund (MRFF), is looking to fund more trials than previously, recognising that you can have the exciting results in the laboratory and then in animals, but until treatments are properly tested in humans, those results are meaningless.

For patients, the chance to participate in trials can provide access to new drugs that are undergoing testing, or new ways of using existing treatments. Increasingly trials are looking at therapies in combination with other anti-cancer treatments, such as radiotherapy or surgery.

Furthermore, in this era of personalised medicine, we are focussing on the fact that not all drugs work for all people and that cancers differ between individuals sometimes as much as faces do! One of the major aims of undertaking a trial is to collect multiple samples of blood and tumour tissue, to work out whether there is a biomarker that shows the specific population where that trial therapy is working. And that is the whole future of cancer treatment, the so-called 'personalised therapy'. So, when a patient enrolls in a trial, as well as helping them, it usually provides great insights that can help other patients down the track.

Should patients worry that if they sign up for a trial that they might somehow miss out on receiving the therapy they would otherwise have been treated with – ie - standard of care therapy?

All clinical trials go through a rigorous process of review by ethics and governance committees, exactly for this reason – to ensure that no patients miss out on standard care. So, patients who are enrolled in a trial can be assured that they will get at least what would be offered to them if they did not go on the trial.

Many trials are offered when there is no further standard treatment. This is where evaluating new treatments comes in to play. Patients on clinical trials are monitored carefully and all of their other supportive care needs (pain and other symptoms, social work, psychological support etc), are also attended to.

Sometimes, being on a trial means there is more travel required or more appointments or blood tests. We at Monash, as well as other centres, are trying to redistribute the availability of trials particularly to address equity of access for rural and regional patients, through initiatives such as tele-trials.

Should patients proactively seek out trial information?

Patients should be proactive – absolutely. Patients and families should probe to see what trials are open not only at the centre that they are currently being treated at, but if there is a suitable trial open at another centre, particularly nearby, the patient

should request to be referred to that trial. This is something where patients can be very active, otherwise their oncologists may assume that they want to stay in their original treating centre. Some patients will choose to do that, for continuity of care, but other patients don't want to miss out.

There are some circumstances where patients may wish to encounter trials overseas, but generally that would be at their own cost and that would be expensive. We work very hard in Australia in academic, not for profit organisations like the AGITG (Australasian Gastro-Intestinal Trials Group), to make sure we have as large a range of trials as possible, including access to new drugs being tested overseas.

Are all patients eligible to take part in a clinical trial?

Not every patient can go in a trial and some people are simply not fit enough, or may have other medical problems or abnormal blood tests. There has to be strict criteria to run trials, so that when the results are delivered, we can make sense of them – both in how well the treatment worked and in what side effects were seen. Increasingly, however, we are undertaking methodologically strict trials comparing models for best care delivery by different health systems models, or the best kinds of treatment in the very end stages of life, so that even patients with advanced cancer might be suitable to participate in these sorts of studies.

How can rural and regional patients take part in clinical trials? Aren't they usually run only in big centres?

One of the challenges of clinical trials is offering access to rural and regional patients. One of the initiatives we have launched is the Tele-Trials initiative. This platform works by using video conferencing, so that patients can attend the trial centre 'virtually'. We are also heavily involved with clinical trials capacity building in regional centres.

*** Professor Eva Segelov shared her insights in March 2018.**

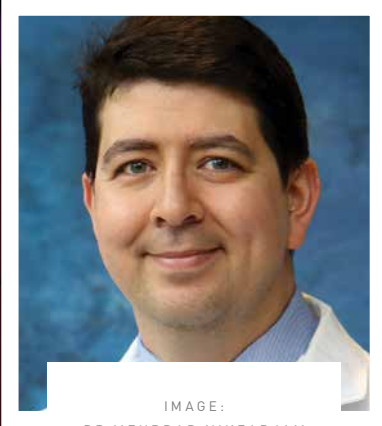


IMAGE:
DR MEHRDAD NIKFARJAM

Are you eligible for
surgeries?

Highly regarded surgeon Mehrdad Nikfarjam estimates that only about 15% of people diagnosed with pancreatic cancer are considered eligible for surgery upfront.

Up to 25% of others may become eligible for surgery following treatment. And surgery, he says, still offers the only chance of a cure for this cancer and more patients are being offered the chance of surgery than ever before. But removing part or all of a pancreas and associated organs is a complex operation and brings other health issues. In this piece, Dr Nikfarjam discusses who is eligible for pancreatic cancer surgery, and what it involves.

Which pancreatic cancer patients are eligible for surgery?

Surgery does offer the only chance of a cure. But up front, only about 15% of patients are eligible for surgery. The first thing we do is to assess whether surgery is an option and it's only an option when the cancer has not spread. Unfortunately, that has already occurred in 50 – 60% of cases by the time it is diagnosed.

When the cancer has not spread, patients have either operable, borderline operable or locally advanced /locally inoperable cancer. This is generally determined based on the relationship of the cancer to certain blood vessels seen on CT or MRI scans. For cancers involving the pancreatic head, the main blood vessels of interest are the superior mesenteric/portal vein and the superior mesenteric artery.

Patients who are initially classified as having borderline operable or locally advanced cancer generally have chemotherapy or chemotherapy plus radiation first-up and are later reassessed for surgery. Depending on whether their tumours respond to such therapy, they may be offered surgery with the possibility of cure. This approach maximises the chance of removing the cancer completely without leaving some portions behind.

Patients with locally advanced cancers involving the pancreatic head, usually have cancers that encase the superior mesenteric artery. We are now getting better results with chemotherapy, and even even some of these patients who were initially considered clearly inoperable, may respond so well to chemotherapy, that they may become eligible for surgery.

Overall, about 40% of patients may be eligible for surgery at some stage.

Does pancreas tumour location impact the chance of surgery being an option?

Patients with a tumour in the head of the pancreas are more likely to be operable, because they tend to present earlier than patients with a tumour in the tail or body of the pancreas.

That is because when a tumour is in the head, it might be pressing on a bile duct and the patient can present with jaundice. They go to the doctor not because they are feeling unwell, but because their skin colour is turning yellow.

When the tumour is in the tail or body of the pancreas however, there can be few symptoms and patients often don't present until the cancer has spread to other organs or has locally grown, often encasing major blood vessels and causing problems like severe backache. Patients with pancreatic tail or body tumours are rarely eligible for resection because of these factors.

Does the chance of survival increase with surgery?

If surgery can remove the tumours whether they are operable or borderline, you are looking overall at a 15-20% five-year survival rate.

Unfortunately, if you have a tumour that has spread (metastasised) to other organs when it is diagnosed, then the likelihood of reaching five years is remote - less than 1%.

What are the main surgery options?

Most of the operations we do are when tumours are located in the head of the pancreas.

In these patients we do what's called a pancreaticoduodenectomy, or the Whipple procedure.

This involves removing the head of the pancreas, part of the intestine, part of the stomach, the bile duct and gall bladder and then reconstructing.

The reason we remove all those associated organs is because they surround the head of the pancreas. The cancers often grown into these surrounding organs or the surrounding lymph glands. If you remove just the pancreatic head you would compromise blood supply to all the other organs and are likely to leave cancer behind, so essentially the whole area needs to be removed and re-plumbed.

If the tumour is in the tail, we would perform a distal pancreatectomy and we often remove the spleen as part of this operation.

Are you eligible for surgery?

Is there a risk of complications with the Whipple procedure?

Between 30 and 60% of patients will have some kind of complication, but few will have a major complication.

This surgery, in top centres, should have only a 1-2% mortality rate – so there should be only 1 or 2 patients out of every 100 who die as result of a major complication.

Previously these rates were as high as 5 to 10%. I would still say it is important that these operations are done by experienced surgeons.

If you have to remove all of the pancreas, called a total pancreatectomy procedure, a patient instantly becomes an insulin dependent diabetic. This is very rarely required and most commonly is done for multifocal cancers, cancers involving the head and body of the pancreas and as a salvage procedure, when major complications have arisen during or after surgery.

This is not the case for Whipple operations, where only the head portion of the pancreas is removed. Long-term however there is a higher risk of becoming an insulin dependent diabetic, but for the majority this does not become an issue. These patients generally function quite normally. The plumbing might be a bit different, but they often do quite well.

The most dreaded complication of surgery is leakage of juices from the pancreas where you have joined it to the intestine. This is a relatively common and occurs in 10 to 15% of cases. The majority of the time however this heals itself without major issues.

Rarely the pancreatic juices leaking can damage blood vessels and can cause bleeding and infection. Leakage from the joints such as the bile duct and stomach such be uncommon .

It is however not uncommon for patients to experience delays in gastric function post-surgery, where the stomach does not empty at same rate as before. This happens in about 20% of cases, but generally, comes good within 4-6 weeks.

General complications related to major surgery, such as chest and wound infections also occurs with pancreatic surgery, but generally don't cause major long-term problems.

You founded the Pancare Foundation in 2011. What was your motivation?

Sometimes we think it us up to the doctor and the hospital to support patients and direct them to the best treatments, but in reality it often doesn't happen. I could see there was a need for an organisation that supported patients as well as carers ... we often forget about carers and they have a really important role in pancreatic cancer. I could also see that improving outcomes was dependent on better research, so Pancare is dedicated to supporting research, particularly novel therapies and early cancer detection. We set up officially in 2011 and so far, we have supported hundreds of patients and their families, as well as providing several research scholarships. Supporting large trials requires a very substantial investment, so up to this point we have support smaller and novel studies. We would like to support large clinical trials in the future.

What continues to inspire your work?

There is a so much negativity about cancer and rightly so, particularly with pancreatic cancer.

Even when patients have a dismal prognosis, you can always do things better and there are always patients who defy expectations. There is hope.

We do see patients defy the odds. Research will help us to identify them, learn from them and do things better for new patients.

I hope that by 2030, no patient with pancreatic cancer is denied surgery when appropriate and all patients have access to new clinical trial information. I also hope there will be improved therapies. We have had major improvements with chemotherapy combinations, but there is still a long way to go."

*** Dr Nikfarjam shared his insights in April 2018. To support Pancare visit www.pancare.org.au/donate**

Call to screen Type 2 diabetics for

pancreatic cancer



IMAGE:
DR LORRAINE CHANTRILL

Dr Lorraine Chantrill has been a medical oncologist for 10 years, with a particular focus on pancreatic cancer “because it is so terrible and there is so much room for improvement”.

She notes that average survival rates for pancreas cancer have improved but remain abysmal (only 7% of patients survive five years post diagnosis) “and we need to do a lot more work in the prevention space”. She is also calling for screening studies of patients who are newly diagnosed with Type 2 diabetes (possibly via ultrasound) to potentially assist early pancreas cancer detection in some patients. While no link between these two diseases has been established, Dr Chantrill says tumours can affect normal insulin production and a surprise diabetes diagnosis may sometimes be an early cancer warning.

What is your rationale for potentially screening patients who are newly diagnosed with Type 2 diabetes?

“We know that probably about 25% of pancreas cancer is cigarette smoking related. Maybe up to 10% of cancers might be linked to inherited changes but that leaves two-thirds with no known cause. What we do know is that there are some associations. There is an association - and I say that carefully - between new onset Type 2 diabetes and pancreas cancer. **There is a reasonable rationale to do screening of the pancreas gland in people who are diagnosed with Type 2 diabetes who do not have other risk factors for diabetes.**”

It’s quite simple. If you have a tumour in the gland, it may become dysfunctional so you might not be able to produce insulin as efficiently. As an oncologist I hear the story so frequently: ‘I was diagnosed with Type 2 diabetes only a year ago’ -- so it is a very common story. But it just so happens that this is an age group of people where that can happen anyway. The median age for a diagnosis of pancreas cancer is 67 for primary disease and for metastatic disease it is 71 years old. That is also the age people are commonly diagnosed with diabetes. It is very hard to prove this connection, but I think it might be a place to start. Let’s face it, we don’t have a screening test for pancreatic cancer. At least start a discussion.”

Social + Emotional Care

is

vital

Twelve years ago, Dr Helen Gooden was working for the NSW Cancer Council when the organisation was awarded a Federal Government grant to put together an information package for newly diagnosed pancreatic cancer patients.



Helen put up her hand to be involved. Only two years earlier, her uncle had died from the disease, only six weeks post-diagnosis. “And that was a fairly typical,” she says. “So I was very much aware of how difficult the situation was.” Embarking on her project, she began researching to see what information was already available. “There was nothing in Australia. So, I decided we need to hear from the people themselves and find out what their needs were.” Helen’s research led to her completing a PhD on the ‘Psycho-social and supportive care needs of people affected by pancreatic cancer’. These are some of her insights.

What is a typical reaction when people are diagnosed with pancreatic cancer?

A diagnosis of pancreatic cancer is not just physical. It is emotional and life-changing. People can experience an existential crisis. Some people can feel distressed and unable to move forward in any way. We know that when they are in this state that they don’t respond as well to their treatment or are at risk of not continuing with their treatment. It is so important people, both those diagnosed and their caregivers get help to support them through this phase.

Psycho-social support can range from something as simple as talking to somebody else who has been through the same experience, as this can

help normalise it for people newly diagnosed or just starting treatment, to seeking specialist help. It is not a ‘one-size fits all’ – different people have individual needs. Some people may need to have a psychologist involved to help them with their feelings of despair.

Generally, the person who is newly diagnosed is in a state of shock.

What would you advise newly-diagnosed patients?

- I would advise them to speak up. Patients need to acknowledge the emotional and psycho-social effects of this disease.
- Talk to your doctor and ask for a referral to a psychologist/counsellor or social worker. Patients and families need to know that they are not alone. Booklets are available via the Cancer Council called ‘Understanding Pancreatic Cancer’. Understanding the language of pancreatic cancer demystifies the disease.
- I would also advise patients to always have somebody with them at all appointments. Another set of ears that can hear the information really helps. And take a checklist to your doctor so you don’t forget to ask anything.
- Exercise is really beneficial. It helps people feel connected and can help their physical recovery. **(See Maggie’s story – right).**

Do physical symptoms impact well-being and what can be done about them?

A major incidental finding of my research was that a lot of patients were putting up with physical symptoms that we can do something about. Patients often experience socially-debilitating symptoms either post-surgery or when they have treatment for advanced cancer. It is all about the pancreas not being able to function properly and produce the digestive enzymes that help the gut work normally. Symptoms like dreadful diarrhoea, foul smelling stools, feeling unwell, not being able to eat much – these things can easily be managed by enzyme replacement therapy.

A diagnosis of pancreatic cancer often creates great financial turmoil. Where can patients get help?

We see a lot of younger people coming through. They are still in the workforce, running their own businesses and living life full steam ahead. And then this full stop comes into their life.

The Cancer Council is able to provide pro-bono financial and legal assistance that is tailored to an individual. This does not mean the Cancer Council is going to pay the mortgage for you or anything like that, but they can point people in the right direction for financial assistance and help you to navigate the system.

A lot of people don't know you can access your superannuation, for example. The Cancer Council will help you to navigate the paperwork, which can be quite onerous.

Where can people go now for help?

Information about pancreatic cancer, treatment and care, as well as a range of support services to help you and your family/caregiver manage the emotional, social and financial impact of pancreatic cancer are available through Cancer Councils around Australia. You can access these easily by calling 13 11 20 or going online.

Other organisations such as Pancare and Pancreatic Cancer Support Australia - at the Centre for Community-Driven Research also offer support services.

There is no doubt that this is a tough time and we know now from research and experience that people who reach out for help for both physical, emotional, and social care, after a diagnosis of pancreatic cancer, can achieve good quality of life and better outcomes.

"Exercise + Animals helped me"

SUPPORTIVE CARE



Maggie South says "exercise and animals" have been critical to her long term recovery from pancreatic cancer.

Now 63, she was diagnosed in August 13 years ago. Originally told her tumour was inoperable, she was given just weeks to live. One doctor told her, "If you haven't bought Christmas presents I suggest you buy them now because you are not likely to see Christmas."

Maggie sought a second opinion and ended up having a Whipples procedure. On her discharge from hospital, she began walking daily. She lived close to the beach, but walking even 200 metres was exhausting.

The first few times, she caught a cab home. Eventually, she managed the round trip, building up a little bit each day.

Eighteen months post-surgery, Maggie adopted a rescue labrador, Jed. Walking him daily was her motivation to keep moving and six months after that, she adopted Elly-May.

"A lot of times I would not have gone out for a walk, but because I had them, I had to go," she says. "It was the most important thing. Pancreatic cancer is not easy, it is a very long recovery period and it is very easy to wallow in self-pity. You have got too much thinking time. When you are out you are not thinking, and you are out in the fresh air. Interaction is very important."

*** Maggie shared her thoughts in July 2018.**



Marrowfat diet

“Eating well is an important way for cancer patients to ensure that they are healthy enough to cope with treatment,” explains dietician Katie Benton. “This can be challenging for pancreatic cancer patients in particular, as their pancreas may not be functioning normally and the digestion of key nutrients can be affected. Pancreatic cancer and its treatment can also lead to symptoms like nausea, lack of appetite, and diarrhoea, which can make it really difficult to eat and maintain a healthy diet.”

“I would really impress upon patients to try and eat well,” says dietician Belinda Steer, “Because it can really make a difference to their overall wellbeing and quality of life.”

Dieticians Katie Benton + Belinda Steer *discuss the importance of diet*

What's a general message for pancreatic cancer patients regarding their diet?

With pancreatic cancer patients, it's really vital they avoid unintentional weight loss. Often, a patient's diet needs to incorporate foods higher in calories and protein which may not represent the typical healthy eating picture. In general we advise a high-energy, high-protein diet. Patients should be eating full-cream dairy, meats and meat alternatives. They need the protein from foods like eggs and meat to build and repair cells, and they also need the high energy foods, which contain fats, carbohydrates and sugars, to provide fuel for their bodies and maintain or gain weight.

When people are diagnosed, it is common for them to change their diets drastically and cut out certain types of food. This is often not beneficial in terms of maintaining a healthy weight, which is important for treatment. We would really like patients to have an awareness of the risks associated with self-managing diet. Implementing dietary restrictions, like gluten-free, dairy-free, or sugar-free diets is not recommended as this can escalate weight loss.

What if patients are affected by loss of appetite and nausea?

Loss of appetite and nausea can affect pancreatic cancer patients, so we recommend eating at times when they are hungrier or eating frequent small meals throughout the day.

They should also be monitoring bowel motions for signs of loose, pale, floating stools. This is really important, as it can indicate malabsorption – a common problem for this group of patients.

There are several other symptoms of malabsorption, including more frequent or loose bowel movements and bloating or pain, because the large bowel is not used to dealing with these nutrients. Other signs may be excess flatulence, oily stools, stools that are difficult to flush or may stick to the toilet bowl, weak muscles or weight loss.

It is recommended that patients do not skip meals entirely, even if patients do have a reduced

appetite. Meal planning and using convenient meal options, such as cooking meals in large portions and freezing, accepting help from friends and family, or using ready-to-go meals is one way to avoid skipping mealtimes.

Nutritional supplement drinks and powders can also be a good source of energy, protein and nutrients, particularly if loss of appetite is an issue. Depending on their situation, patients can choose to implement strategies that work best for them and are most effective in managing their symptoms, with the aim to optimise their nutritional intake.

Every patient is different and their diets may also need to be tailored to their specific treatment and symptoms. We recommend meeting with an accredited practicing dietitian when they are commencing treatment, in order to establish a specific plan customised to their own situation.

Working with a dietitian and being aware of the importance of maintaining a nourishing diet throughout treatment can enable patients to cope with the disease and their treatment more effectively.

How can patients manage changes in taste or smell?

These symptoms are common during cancer treatment and particularly during chemotherapy. If food is too sweet, add small amounts of lemon juice or even instant coffee granules. Plain breakfast cereals without any sugar are another option.

Some patients find that using a straw is helpful with some foods, as it helps to bypass the taste buds.

If you have a bitter or metallic taste in your mouth, eat fresh fruits. Sometimes sucking on a lolly can help.

We also find that cold foods don't affect smell as much as hot spicy foods. There are lots of strategies we use with patients to try and ease their particular concerns. Again, it is about tailoring treatment to individual patients and working with them for the best outcome.

The Pancare Dietary Handbook can be downloaded for free at: www.pancare.org.au or call 1300 881 698 to request a copy.

Supporting Research

In 1991, a handful of medical oncologists started a conversation about how to deliver improved results for their patients with gastro-intestinal (GI) cancer. Out of this discussion the GI Cancer Institute was founded - a not-for-profit organisation that conducts research to improve patient care and medical practice in the treatment of gastro-intestinal (GI) cancers, including pancreatic cancer. There are a number of ways to get involved and support our organisation.



GI CANCER
INSTITUTE

GASTRO-INTESTINAL CANCER RESEARCH

Get

Clinical Trials

Clinical trials can offer access to new treatments as well as the standard treatment, and offer a high quality of care. If you would like to find out about clinical trials relevant to you, ask your oncologist if any are available, or go to:

- **GI Cancer Institute:**
www.gicancer.org.au/community-clinical-trials
- **Australia and New Zealand Clinical Trials Registry:**
www.anzctr.org.au
- **Further trials may be found at:**
www.australianclinicaltrials.gov.au

Donate

Donating to clinical trials enables real benefit to be realised by real people – including immediate benefit for the people who take part. It is a meaningful way to support pancreatic cancer research. You can make a single donation or make a regular gift at:

www.gicancer.org.au/donate

involved

Fundraising

Pancreatic cancer can be very difficult for everyone affected. Family and friends can make a real difference by taking on a Gutsy Challenge and raising funds for pancreatic cancer research. By running, cycling or hiking, our fundraisers raise awareness and provide much-needed funds. All of these donations contribute to research and clinical trials.

Workplace Giving

For family or friends who want to support pancreatic cancer research, setting up workplace giving is a simple, convenient and tax-effective way to donate. All Australian workplaces can facilitate Workplace Giving donations. To set up Workplace Giving you can nominate the GI Cancer Institute as your charity of choice to your payroll department.

FOR MORE INFORMATION:

1300 666 769

info@gicancer.org.au

www.gicancer.org.au

Letter from

Specialised Therapeutics



IMAGE:
CEO CARLO MONTAGNER



Specialised
Therapeutics®

We trust that stories in this publication have provided you with relevant, up to date and useful information about the pancreatic cancer experience.

The idea for our magazine came about after patients told us they wanted to hear full and frank conversations from other people who had been similarly affected. They also wanted hope.

We trust that the people who generously agreed to share their stories have inspired you with their courage, resilience and endurance while living with their own devastating diagnosis.

We would also like to thank all the oncologists who agreed to be interviewed for this publication and have shared some terrific insights, as well as the GI Cancer Institute and the Pancare Foundation, who have worked closely with us to ensure that this is the information pancreatic cancer patients are seeking.

As a company, Specialised Therapeutics is particularly passionate about making a difference to pancreatic cancer.

Despite some inroads, statistics tell us that only 7% of people diagnosed will survive five years post-diagnosis. New therapies and technologies are desperately needed.

Our promise to patients and their families, is to continue seeking, developing and providing specialist medicines that may one day, make a difference.

Warm regards,

Carlo Montagner,
Chief Executive Officer,
Specialised Therapeutics.



Support for you

It may come as a shock to hear that you or a loved one has been diagnosed with pancreatic cancer.

We have a range of services to support you and your family in dealing with your diagnosis.

We also provide financial aid, support groups, patient and dietary handbooks plus a dedicated community care program.

Founded in 2011 by prominent liver, pancreas and biliary surgeon Mehrdad Nikfarjam, The Pancare Foundation aims to increase survival and provide support to people affected by pancreatic cancer and other upper gastrointestinal cancers. They do this by investing in research and providing support to people living with these cancers.

1300 881 698
info@pancare.org.au
www.pancare.org.au



Purple

PANCREATIC
CANCER
CONVERSATIONS

Peter McDonald was 53 when he was diagnosed with cancer completely out of the blue. As he says now, "cancer does not play favourites".

That was back in 2012. Doctors had found a neuroendocrine tumour (NET) in his pancreas. He found the following months of treatment and surgery particularly gruelling, and while he had always been sporty, it took five long years before he felt able to return to physical activity. "The body was not really ready before that."

These days, Peter exercises almost every day and says it's been terrific for his mindset. His goal is to return to competition cricket by the end of 2018. He has some spots on his liver, but notes that at the moment, his cancer is dormant.

He says of his pancreatic cancer experience, "It's important to stay positive, worry only about what you can control, and appreciate what's around you more."

IMAGE:
PETER McDONALD