

CULTURE CANCER CARING

Inspiring stories for our mob





ABOUT THE ARTWORK

BLUE DUSK

This artwork was dotted using a magpie feather. The colours in the artwork are dominated by shades of blues. The colour blue is associated with calmness, tranquillity, healing and health. This painting depicts a plant that I fell in love with as a child: shivery grass. It grows in abundance on the hill opposite my childhood home, and I will always remember the way it almost glowed with shades of gold and bronze in the setting sun. Shivery grass reminds us to stand strong even when we are shaking on the inside. It is a symbol of courage and strength in the face of fear. Also depicted are fireflies. They often make an appearance just on dusk and their flashing backsides are a welcome light in the approaching darkness: a symbol of hope.

ABOUT THE ARTIST

LAURA BOWEN

Laura is an Artist, writer and nature lover; her Indigenous connections are to the Worimi and Biripai people of the Manning River area of NSW.

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Thank you to all the communities, organisations and individuals who shared their inspirational stories. Without you this book would not be possible.

Central West (Dubbo)

Hunter New England (Tamworth)

South Coast (Nowra)

South Coast (Illawarra)

North West (Bourke)

North Coast (Grafton)

Riverina (Wagga)

Western Sydney (Airds)

Aboriginal and Torres Strait Islander readers are advised that this book may contain images of deceased people.

The Aboriginal Health & Medical Research Council of NSW, Cancer Institute NSW and Cancer Council NSW are working together, in partnership with communities and health professionals, to implement the Aboriginal Cancer Partnership Project funded by NSW Ministry of Health. This resource is an outcome of this project.

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FOREWORD



I am proud to present this collection of inspirational stories to highlight the great work being done in communities to reduce the impact of cancer in NSW.

This booklet, Culture, Cancer, Caring – Inspiring Stories for our Mob, highlights the activities of Aboriginal Health Workers, Aboriginal Community Controlled Health Services and mainstream health services to reduce the impact of cancer in Aboriginal communities in NSW.

The stories in this booklet feature innovative and locally designed programs that emphasise the importance and effectiveness of culturally appropriate cancer support and screening services for Aboriginal people. You will read about the experiences of Aboriginal people in developing these initiatives, as well as some practical solutions for Aboriginal people, health professionals and organisations wanting to improve or set up cancer support services within their own community.

I would like to acknowledge and thank all those people from urban, rural and

remote areas of the state who have shared their insights and journeys. Thank you also to the Cancer Institute NSW and the Cancer Council NSW for their commitment to working in collaboration to address cancer as a significant health issue for Aboriginal communities. I would also like to acknowledge the NSW Ministry of Health for funding the project.

We sincerely hope this booklet, Culture, Cancer, Caring – Inspiring Stories for our Mob, will not only be a source of motivation for communities, but also provide practical solutions for Aboriginal people, health professionals and organisations wanting to improve or set up cancer support services within their own community.

**Sandra Bailey, Chief Executive Officer,
Aboriginal Health and Medical
Research Council of NSW**

TACKLING EARLY DETECTION USING SOCIAL MEDIA

Mark Saddler is a Wiradjuri man who is trying to make cancer information accessible online. Mark set up a Facebook page to educate people about culture and is now also using the page to provide easy to understand information about cancer.

"I'm just trying to get simple information back to remote communities. When you find out you have cancer, the last thing you want is your doctor throwing brochures and links to all sorts of websites at you and telling you to read all that."

Mark's Facebook page provides step by step, practical information for Aboriginal cancer patients.

"If you've got bowel cancer and you're in a remote community the first thing you want to know is what to do next. Firstly you'll need to work out where you will be having treatment, then you'll need to know how to get there and where to stay and finally you'll need to know about money."

Mark said his Facebook page, Wiradjuri Mob, is accessed by around 25,000 people a week and has had around



7000 'likes'. In order to keep people engaged, Mark spends hours being active on the page and doing regular posts.

"If you have a Facebook page it's a good idea to set the ground rules at the start. I have a simple rule on my page: come here respectful and leave respected. I'm extremely active on the page and I make it exciting and keep it fresh. I look at everybody's comments and like them. At first I didn't have anything about myself on the page but then people started wanting to know who was running the page so I wrote a little bit about myself to let them know I'm no one special and that I'm not an elder and I'm not speaking on anyone's behalf."

Mark admits that writing about cancer doesn't necessarily win you more friends on Facebook but he says that if he can save even one life it will be worth it.

"I'm not doing this page just to see how many friends I can get. Cancer has no friends – it doesn't care who it takes. I know what people like to look at, but I also insert things people don't like but have to know about because it's about their health. My posts about what I've been doing on country get thousands of likes, but when I write about cancer most people don't want to know about it. But if I can get one or two people to get a test then all my time has been worth it."

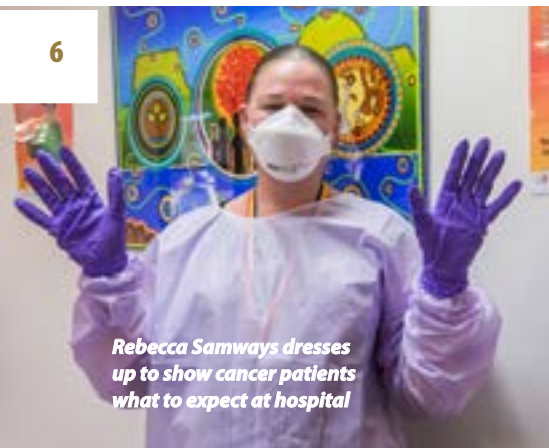
ARTWORK HELPS PAINT THE EARLY-DETECTION PICTURE

Mark uses artwork online to help provide information in a culturally appropriate way.

"Artwork is really useful as for thousands of years it has been our language. If the artwork comes from the heart then people can see the message and are more

likely to want to read a simple brochure. I'm not a trained artist so my artwork for bowel cancer just shows the bowel with some polyps in there with a couple of spears pointing at it. The message is, if something goes wrong in your gut, there's someone out there to fix it."

**ABOVE Artwork
by Mark Saddler,
depicting bowel
cancer. To visit the
Facebook page visit
www.facebook.com/WiradjuriMob**



Rebecca Samways dresses up to show cancer patients what to expect at hospital

The Illawarra Aboriginal Medical Service's (IAMS) Cancer Care Team has only been in operation for just over 10 weeks yet they are already helping make cancer treatments less scary and more culturally sensitive.

The Cancer Care Team is the first of its kind with ongoing funding from the NSW Rural Doctors Network. The team includes an Enrolled Nurse, an Aboriginal Health Worker, a Counsellor Support Worker plus six hours of dedicated cancer care each fortnight from their IAMS doctor.

Setting up the new program has involved extensive networking with not only the local community, but also with the local hospital to try and ensure a better service delivery for the mob.

Rebecca Samways, the Cancer Care Team's Enrolled Nurse, said for most Aboriginal people hospitals can be a scary and culturally insensitive environment.

"One of the first things the team did was to

RIGHT The Illawarra AMS Cancer Care Team launch their services at Australia's Biggest Morning Tea

FAR RIGHT Putting on a good spread helps to spread the word about cancer



MAKING CANCER LESS SCARY



Liz Dwyer shares her journey with the Cancer Care Team at Australia's Biggest Morning Tea at the Illawarra AMS

spend time at the hospital. We spent half a day in the chemo suite and time in the radiation suite and all the different wards and found out why our patients would be put there. We wanted to go through the whole process they will go through so we spent time talking with people in the

cancer unit and clients that were cancer survivors and discussed their journey and what was important to them and what they felt was lacking," said Rebecca.

Understanding the process and getting familiar with the hospital where you will be treated is vital, according to Rebecca,



who said even the way nurses dress can be overwhelming and frightening if you are not prepared for it.

"We have a kit in here at the IAMS that shows people what the nurses will be wearing when they go in for treatment. I tell them, 'If you go for treatment the nurse will be wearing these purple gloves and this purple gown and she'll have on a mask and goggles and some have a full face shield.' I explain that they wear purple because in the hospital purple means chemo which goes into a purple bin and is disposed of. Then I also explain to them that the nurses have to wear this for all patients because even though you need that treatment to kill your cancer, for a nurse who doesn't have cancer if they're touching it every day it could make them sick."

While being prepared and understanding your treatment definitely helps ease the anxiety for cancer patients, according to Trish Levett, the Aboriginal Health Worker with the Cancer Care Team, it is also essential that health care is culturally appropriate.



"I decided to take photos because I love photos, so I got myself a little book and I put in all my reports, my scans, my biopsies and my mammograms. It just reflects the journey and I'm quite happy to share it because I like to raise awareness." *Liz Dwyer*

"We're in the process of trying to make the hospital feel more culturally safe. A lot of our mob are scared of the hospital. They think 'We go to the hospital and we die'. The moment when you walk in, the hospital is a very sterile environment, but they are working towards making it more culturally appropriate for our mob to go there. They're actually looking for artists to start putting artwork in there."

Trish believes that getting to know your local hospital is vitally important for cancer support services so you can not only better understand medical processes, but also gain insights that may help improve patient care.

"We've done a lot of liaising and while we were at the hospital we found a glitch in the system which meant when our mob were going to see the doctor, the doctor was unaware they were of Aboriginal descent. It was being ticked off at reception but on the specialist's or professor's system they weren't being identified, so now they're going to correct that and mark files possibly with a little Koori flag so everyone in the system knows if a person is of



"I work at Shellharbour Hospital at the Aboriginal Maternal Infant Child Health Service alongside the midwives. I'm an Aboriginal Health Education Officer. I'm a pretty confident person when it comes to liaising with specialists but it doesn't matter how much experience you have when you hear that word 'cancer' everything goes. Knowing the girls at the AMS will take the time to sit down and yarn with you and that they are there, not just for me, but for my family has been so important." *LIZ DWYER*

"I only wish they had these cancer support services before my twin had her cancer journey. She refused to have chemo because she was travelling backwards and forwards to have her treatment mostly on her own or with somebody she didn't know. If she was with the IAMS she would have been more comfortable and felt she was going to be taken back to a safe place. Nothing bad about the mainstream but she was terrified being driven off to some place she didn't know because it was very much like what happened with us in the stolen generation. To have these new cancer support services now is fantastic. It's very secure here, people know each other and because most of the people that come here are related it's one big family." *AUNTY BETH SINCLAIR*

Aboriginal descent and to treat them in the ways they need to be treated that are culturally appropriate."

FAR LEFT Aunty Lindy Lawler celebrates the launch of the Cancer Care Team

LEFT Rebecca dishes out cake and information about the Illawarra AMS's new Cancer Care Team

WEARING THE CANCER MESSAGE PROUDLY



Tharawal staff celebrate the launch of their new cancer t-shirts

For most cancer support services, getting the prevention and early detection message out into the community is a high priority. Tharawal Aboriginal Corporation in Airds, South Western Sydney, recently came up with a unique way to not only spread the word about breast cancer screening

but also provide a great incentive to get the community accessing services.

Vickie Connolly, the Indigenous Outreach and Health Worker from Tharawal, explains.

"I ran a two-day workshop on cancer awareness during NAIDOC week when the breast screen van was on site. From

that we designed a t-shirt and the 30 ladies that got screened on the day each got a shirt. We did a backpack as well and inside that was a women's health diary, which covers everything from your menstrual cycle through to having a place to write in all your health appointments."



One of the participants in the breast screening program, Melissa Ruttley, who was a carer for her father before he died of throat cancer and who has also lost relatives to breast cancer, came up with the slogan and helped design the t-shirt.

"We yarned about different cancers and how they impacted people and then Melissa came up with the slogan for the t-shirt after the screening and workshop," said Vickie.

The slogan, "Big or small it doesn't matter at all, come on sisters let's learn some more," was then printed on the t-shirts along with the Koori flag and the breast screen ribbon.

"I like writing poems but I am also pretty straightforward so I wrote a slogan that just got to the point. My first design was actually going to be more aimed at women with just the Aboriginal flag and I was going to draw a ribbon in between the breasts but then my husband reminded me that men get breast cancer as well and also that men sometimes find the lump," said Melissa.

While programs for breast cancer awareness are primarily focused on women, Vickie said that after seeing the t-shirts, the men in the community also wanted to step up to show their support.

"The men decided to have a t-shirt as well

"I'm stubborn when it comes to getting women in here to get their checks, sometimes you can talk til you're blue in the face but I just keep at it and I chase up, chase up, chase up."

with the slogan "Brothers who support sisters." Our CEO liked the t-shirts so much that now all our staff wear them. Now there's people in the community wanting to buy them as well so we're looking at making more t-shirts to keep raising awareness but also to hopefully raise much needed funds. We've also turned the slogan and artwork into a poster to send through to all the AMS's in Australia."

Vickie believes it is important to not only offer incentives but to also make it as easy as possible for people to have their cancer and general health screenings.

"This is the fourth year the breast screen bus has come here. We always do a

mail-out to all the ladies over 40 in the community, but we also recall women who have been screened before. I'm stubborn when it comes to getting women in here to get their checks, sometimes you can talk til you're blue in the face but I just keep at it and I chase up, chase up, chase up. Aboriginal women are busy, they often have a lot of kids, so if we're doing anything in the school holidays we make sure we have activities for the kids and the staff will even yarn with the kids while Mum and Dad are getting their checks."

As a member of the local community Vickie understands how important it is for outreach workers and health workers to get out into the community.

"I spend one day in the clinic and four days in the community. It's quite an honour for me to work here; my mum opened up the first building at Tharawal with Gough Whitlam. I lost my dad when I was 12 and have also lost a lot of siblings through cancer and chronic health disease. That's why I try and educate the best I can. It's a passion for me, that's why I'm here – if it wasn't for the community I wouldn't have a job."



FAR LEFT Men show their support for breast cancer

MIDDLE Melissa shows off the t-shirt she helped design

LEFT Vickie and Melissa with poster ready to go to every Aboriginal Medical Service around the country

YARNING TO MAKE THE CANCER JOURNEY EASIER



Robin Payne, Brooke Sullivan and MaryAnn Seymour talk about their yarning group in Dubbo

“Sometimes people just want to come in and listen,” said Robin. “We don’t just dwell on the cancer, we focus on the person themselves and we yarn about other things too.”

Three years ago a group of volunteers in Dubbo set up a yarning group to help support Aboriginal cancer patients and their families. Now the service is helping show the way for other communities who want to support their mob.

“There was nothing here for Aboriginal people,” said Robin Payne. “We wanted to do something because we realised that just about every second person we talked to either had cancer or had been affected

by it. I’m a cancer survivor, my sister died of breast cancer and my father died of lung cancer. Cancer doesn’t only affect the client, it affects the whole family. Yarning just eases the burden as they know they are not going on that journey alone. It helps to know there are other people out there and other support services out there.”

The idea for the support group which was born over a cup of tea and a yarn, is all about just that, providing the space

for people to get together and talk about cancer in a supportive environment.

“We just approached the Cancer Council and asked if we could start up a support group and they took us through it and we went from there. We support people from as soon as they are diagnosed and assist them right through their cancer journey. We have meetings every two months but we offer support anywhere and everywhere. If they don’t want to come to us, we’ll meet them wherever they choose – whether that’s on a riverbank or under a tree – and talk with them or point them in the right direction if they need help.”

The group is run entirely by volunteers in a hall donated by the local church. To get the service off the ground, Robin said she not only consulted with the

community, but also used the local media to spread the word.

“I spoke on the radio on ABC and SBS when we first started, as well as doing an interview with the local paper. We also let people know we were here by word of mouth and going around offering support to people in the community who we knew had been affected by cancer.”

The group also have a volunteer publicity officer, Brooke Sullivan, who is a member of the yarning group and has been helping them with their work.

“They took a vote when I was away on holiday and then I got a phone call saying. ‘You’re our publicity officer,’ laughs Brooke. “Oh, thanks,” I said. So after that I did up posters and flyers to try and get the word out there. We’ve got our own logo now, which one of Aunty Robin’s nieces did, and we got free printing just by asking people. As soon as they know what it’s for, people are happy to help out because on some level they’ve all been affected by cancer.”

Apart from just providing a listening ear and a place to talk about cancer, the group also regularly supplies guest speakers to help keep their mob informed about cancer services. MaryAnn Seymour, a member of the support group who is also on the Dubbo Health Council, explains.

“We have a variety of guest speakers from pharmacists, to Medicare Local, to the social

worker from the hospital and other local agencies. Our people pick out who they want to talk to and then we just try and get them here. The pharmacist was particularly good as she was talking about checking medications and making sure you’re not over-prescribed. It helps for our mob to have things explained, as the doctors and nurses will tell them something, but if they don’t really get it they won’t necessarily ask questions. When they come here it’s a shame-free environment where they can ask whatever questions they like.”

While some people come to the group to yarn, Robin said, others simply want company or to provide a listening ear.

“Sometimes people just want to come in and listen,” said Robin. “We don’t just dwell on the cancer, we focus on the person themselves and we yarn about other things too.”

For the yarning group at Dubbo, it’s all about making people feel comfortable, relaxed and of course – giving them a cuppa tea!

“I recently spoke to some people in Adelaide who wanted to set up a similar group to ours. I told them that the Cancer Council offers support and advice but that with our mob it’s really important that it’s a comfortable, friendly, relaxed environment. Having a laugh really makes a difference and, of course, you always gotta give a black fulla a cuppa tea,” laughed Robin.



TOP Logo designed by a volunteer for the Dubbo Aboriginal Cancer Support Group

ABOVE LEFT As a cancer survivor, Robin understands the need for information and support

LEFT Robin and Brooke share a story at Dubbo's cancer support group

SUPPORTING OUR MOB WITH MINIMAL FUNDING AND BASIC TECHNOLOGY



The Taylor Family have experienced cancer through the generations and been part of the development of A Cancer Journey resources, through sharing their stories of culturally safe care

“To make it localised we have used local artwork, language and people’s journeys.”

Rose Wadwell is definitely strong, and is considered a proactive kind of a woman. Despite having limited funding and only having access to Microsoft Word, Rose with the help of local communities, has created a whole suite of culturally safe cancer resources.

As part of her role as Aboriginal Cancer Project Officer, Rose has developed localised booklets, posters and DVDs

for community members who have been diagnosed with cancer.

“We’ve got three booklets and DVDs, which cover all of the Hunter New England areas,” said Rose. “In 2013, our steering committee, realised there was a gap in culturally safe resources at all three oncology sites so over the past twelve months we’ve developed resources for all three centres.”

RIGHT Norm Allan at the launch of A Cancer Journey resources with some other community



RIGHT (L-R) Attending the Launch of A Cancer Journey Resources: Uncle Len Waters, Jill Lack, Leonie Donovan, Tony Martin, Dr Tony Proietto, Norm Allan, Robyn Haack, Donella Waters, Brad Hansen, Rose Wadwell and Dave Willis.

CANCER IN THE HOME OF COUNTRY MUSIC

Tamworth is famous for being the home of country music, so much so that now even their cancer ward pays homage to the Aboriginal king of country Troy Cassar-Daley.

The new hospital, which was built completely in consultation with the local Aboriginal community, features an oncology ward where the main piece of radiation equipment is called ‘Troy’ after the ARIA and Deadly Award winning artist. After completing their radiation treatment, all patients receive a guitar pick which they can use to strum one of Troy’s very own guitars.

The radiation suite also features a painted-up carved artwork in the shape of a tree that the patients lie under and look up at to give the feeling of still being connected to country.

Rose said it was very important when developing the resources to engage the elders of the local communities and that they were specific to each area. The resources cover the Greater Newcastle Sector, the Peel Sector which includes the North West Cancer Centre in Tamworth, and the Great Lakes Area.

“To make it localised we have used local artwork, language and people’s journeys,” said Rose. “They are very informative and tell the story of a typical journey through each of the cancer centres. For example, if you need radiation, the booklet will tell you who to contact and what happens during that process. This is important as in some places, such as the lower mid north coast, you may have to go off to another location for treatment, so the booklet

outlines what support circles there are for you while you are away from home.”

While Rose’s position is funded in partnership with three bodies, including the Hunter New England Local Health District (HNELHD) Aboriginal Health, the HNELHD Network Directorate and the Cancer Institute NSW – there was limited funding for the development of resources. The Hub of DVDs were developed by Rose and Dave Willis, Chief Radiation Therapist at North West Cancer Centre. The majority of his work was voluntary.

“All we have here is Microsoft Word, and I had to develop the booklets with the resources we had. When it was all finished we had a graphic designer finalise it and at that point she told me that all the photos I had needed to be 300 dpi (dots per inch) to be of a printable quality. So I had to go back and re-do it all and it was a lot of work. So my advice to anyone wanting to do something like this is that it’s really important that you index everything and have good quality photos.”

To work around their limited funding, Rose said that they have mainly distributed the resources online. On the HNELHD intranet Aboriginal Health Unit, HNELHD Cancer Services, the Hub of DVD’s will be uploaded on these sites plus HNELHD Utube site.

“What we’ve got is a soft copy on a link on the Aboriginal Health intranet site for staff, so they can print it up as they need

it, which is especially important if they are in a remote area. We also printed 200 copies for each site which we gave out to the community, the Aboriginal Medical Service, the Oncology Department, the Elder’s group, people involved in the launch and significant people in the community.”

To raise awareness of the resources Rose said she issued press releases to mainstream media outlets.

“When we launched the first booklet in Taree, I wrote a media release myself and put it through our communications team. NBN media, which is the local television station, were the only mainstream media who turned up to our launch, but they did a great story. That story’s now on our intranet. ABC radio North West in Tamworth also did a live cross to Director Aboriginal Health Tony Martin who also provided valuable feedback relating to the resources and the project in general. The story was also covered by Koori Radio. It’s very rewarding to get it out there in the community because we’re showing that it’s ok to talk about cancer. Our mob has a 1.3 times lower survival rate because of late diagnosis because there’s a lot of shame in talking about cancer, but a lot of cancers are curable if detected early and if we have the proper treatment. For me doing these resources were all about ensuring there’s culturally safe information out there.”

BELOW Dave Willis and Rose Wadwell with the radiation equipment called ‘Troy’



WALKING THE CANCER JOURNEY TOGETHER

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ABOVE Remembering those who have lost their lives to cancer

RIGHT Putting one foot in front of the other to raise money for cancer research



Ever wonder what one little town can do? Well Sarah Lovett, the Access Co-ordinator for the Bourke Aboriginal Health Service, knows that even the smallest outback community can make a difference if the whole town works together.

Ever since she was a child, Sarah wanted to work supporting kids with cancer and now she is doing just that, by co-ordinating a team of volunteers to raise money for cancer research and services.

"We wanted to do the Cancer Council's Relay for Life, but because we're such a small community we weren't able to, so we decided to do what we could and have organised a six-hour walk for cancer around our local footy oval. The whole town is coming together for cancer," said Sarah. "We will have people walking in groups of 10 in t-shirts and caps that have been donated by the Cancer Council, and after dark we will light candles in memory of people who have passed from cancer or for people who are currently fighting cancer."

Sarah said that getting both Indigenous and non-Indigenous volunteers on board was easy as the town has a very strong culture of helping each other when times are tough.

"Whether people are black or white they all come together. When there is anyone in need the whole town is there to support them," said Sarah. "Because

everyone's been touched in some way by cancer, this is a very generous town when it comes to donating for cancer."

Sarah said in order to bring the town together it was essential to have a committee which represented the whole community.

"We formed a committee in the town and we started from scratch and we asked all of the other health services to combine with us. There are about twenty of us on the committee."

The aim of the walk is to not only raise awareness about cancer, but also raise funds for the Cancer Council.

"Businesses have donated prizes to raffle off and we also have committee members who are going to shave their head or dye their hair a crazy colour – they're willing to do anything to raise money," laughed Sarah. "People will also pay for the t-shirts and caps they walk in – \$20 an adult and \$10 a child. We will have stalls around the oval with each stall holder paying \$50. We'll also have live music, face painting, a BBQ and lots of other fun activities to keep the kids occupied.

"Because everyone's been touched in some way by cancer, this is a very generous town when it comes to donating for cancer."

"The more money we can raise for research, the more likely we are to find a cure for cancer."

While this year's walk will be supporting research, fellow volunteer Susanne Hand, the Diabetes Co-ordinator with Bourke Primary and Community Health, said that funds from future events will go directly to the Bourke community to help patients with the costs associated with their treatment.

"A lot of people have to go to Dubbo or even to Orange or Sydney for treatment for up to six weeks at a time. It's not just about getting there, there's also the cost of the treatment, which isn't cheap, as well as the cost of supporting their

family at home while they are away. We have Connected Communities and Close the Gap funding as well as Blue Robinson money from a local benefactor, but it's just not enough," said Susanne.

Lack of funding can not only mean added financial burdens during what is already a stressful time, but can also mean people fail to follow through on their treatment.

"You hear some people saying they're not going away because they can't afford to," said Susanne. "That's the sad part about living in a country area."

The walk, which is scheduled for the later this year, was originally planned for March but, despite all their best laid plans, it had to be postponed.

"You don't realise what's involved in an event like this until you start," said Susanne. "We were all set for our walk in March and then we had four days of extreme heat where it was over 44°C and we had to cancel it because it was too dangerous to have people walking in that heat."

Sarah agrees that you can't always foresee every eventuality, but that you just have to stay focused on solutions.

"The most important thing is that we raise funds and get the message out there that if you get checked and get cancer diagnosed early there is still hope out there."

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LEFT Lighting candles to help bring hope to Bourke cancer patients and their families

Gloria who is in remission from lymphoma attends Waminda's pamper day. "It's great to have a laugh and a joke with the girls. They really respect me and what I need. Without them I would not have healed the way I have"

Let's face it, none of us likes the idea of invasive or even non-invasive cancer screening – however the thought of being pampered for the day... well that's another story.

Kristine Falzon, the Project Manager from Waminda South Coast Women's Health and Welfare Aboriginal Corporation (Waminda) in Nowra, knows just how important it is to make health screening as enjoyable as possible.

To attract participants, Waminda's pamper days include haircuts, waxing, tinting, nails and facials. They are also an opportunity to not only raise awareness about cancer but also conduct on-site health checks. In between pamperers, Waminda staff offer pap smears, referrals for breast screening,

sugar tests, advice on quitting smoking and consultations with the health and wellness team. Women who do their pap smears on the day also receive a \$20 Woolworths card.

While incentives are essential and definitely assist Waminda to regularly attract around 60 participants to their Nowra/Bomaderry pamper days Kristine admits that their health screening would not have been so successful without meaningful community consultation.

"Everything we do is through consultation with the community and they really are our

guide. If I'm doing a pamper day at Wreck Bay, for example, I will always ask 'What do you want to see happen?' Consultation should not just be about doing surveys and getting information – it's really important that the community can see that what they're saying is being taken on. Make sure you are accountable – if you say you are going to do something, do it."

While Waminda are committed to delivering on their promises, Kristine also recognises that you need to balance follow-through with cultural awareness.



RIGHT Getting pampered helps South Coast women feel better about cancer screening



WORKING WITH AN UNCERTAIN FUTURE

Despite the success of the program, Kristine said ongoing funding is currently looking unlikely, however she is determined to continue to make sure her community are not only looked after but pampered as well.

"I'm not just going to settle for no funding," said Kristine, "My aim was always to get one of the health workers trained up enough to do the joint roles, so before my position ends that will be my main aim. I want the project to keep growing and expanding. Our community want us to do that too because we have nothing without it."

in building awareness and raising screening numbers, Kristine said the Cancer Care and Wellness Project relies on the collaboration of partner agencies to fully service their community.

"Our success wouldn't be possible without our partner agencies – whether that's the Illawarra Shoalhaven Local Health District, Medicare Local, the Shoalhaven Women's Health Centre or the local Aboriginal Medical Service. It's really important that we continue to work in collaboration, as a large part of our role is to be a conduit between our community and other mainstream cancer care providers."

BELOW The hair-styling session was a big hit at Waminda's cancer pamper day



and diverse area that includes remote and urban communities, Kristine said it is important to be flexible and to avoid a one-size-fits-all approach.

"Because it's such a massive area, you need to recognise there are going to be barriers when engaging with some members of the community and that is why it is vital to have the right people involved in the process to support and guide what you do. We are also guided by seven local Aboriginal women on our board. As a service we really listen to any negative feedback we receive from the community so we can stay open to everyone, rather than just doing what we think is best."

"Consultation should not just be about doing surveys and getting information – it's really important that the community can see that what they're saying is being taken on."

It is for this reason that the cancer support services at Waminda have been active in gathering the support of local cancer champions to talk at their programs.

"Having local women who are willing to talk about their experience is so important because if local people get to see a local face then they

think to themselves, 'If she can have cancer anyone can have it.'"

While the program has been successful

"We've had sorry business in the community and so we've had to cancel our yarn-up days twice. When something like that happens you need to let people know, especially in mainstream services, that it's important protocol for the day to not go ahead, so they understand why it has been cancelled."

With Waminda servicing an expansive



BELOW Good tucker is a good incentive to turn up and learn more about cancer



MORE TO SCREENING THAN JUST GETTING A MAMMOGRAM



Bulgarr Ngaru Medical Aboriginal Corporation is working with their local mob to ensure women understand the whole process when it comes to being screened for breast cancer. Located in Grafton NSW, Bulgarr Ngaru started offering breast screening with the Breast Screen NSW mobile van four years ago after they were offered a group booking for their clients.

"If people had to visit the bus on their own they probably just wouldn't go. Now instead of going on their own to have their mammograms, the women can go as a group. Before the screening we have morning tea in the park and then after the screening we all go to lunch together," said Lea Clayden the service's Women's Health Nurse. "Because we make

it a really enjoyable day we are getting far higher numbers coming for screening."

Lea said it is important to ensure our mob are informed not only about the initial mammogram test but also about reasons why they may be called back for further testing and the process if that happens.

"So far no one has been diagnosed with cancer during the four years of our Breast Screening program, but we did have a few younger women who had to go on and have further investigation. When these women realised they had to go for more tests they just thought, 'Oh no, I've had my mammogram and my results said I have to have further treatment - I must have breast cancer'. We explained that they just needed a different sort of mammogram than what the bus could offer and that they may also need a biopsy. All three women were cleared after they completed their tests."

To make sure no more patients are worried about positive diagnosis and to ensure all women are kept well informed, the team from Bulgarr Ngaru now have yarnning circles on the screening days.

"We usually do education on the day. We sit around in a circle and yarn about it, and the ladies who have had a mammogram before will often speak about their experience and say things like 'it doesn't hurt' or 'I'm glad I got tested.'"

Apart from the obvious reasons why people may be reluctant to have a mammogram, Lea said there can also be things as 'simple' as paperwork that can make the process more overwhelming that it needs to be.

"When you go to the bus there's a fair bit of paperwork that needs to be done. The first year this took up a lot of time so now I get Breast Screen NSW to send the paperwork through to the clinic ahead of time and we try and fill in as much information as we have on file, such as Medicare numbers or who their doctors are, before the actual day."

Lea believes that the easier and safer you make it feel for women, the more likely they are to come back for important screening tests that can detect cancer well before it can be felt or noticed. Screening increases the likelihood of early detection, and early diagnosis greatly improves the chance of survival.

"That's also why we take them out to lunch to try to do something a bit special and it works because they tell all their family. Last breast screening day we actually had three sisters come along from the one family!"

For more information about breast screening, visit

www.bsnsnsw.org.au/having-your-mammogram/screening-centres



ABOVE Helen Brown, Thelma Davis, Andrea Brown and Joy Langton, Bulgarr Ngaru Health Worker, at the Breast Screening Day in Yamba

RIGHT Joy Langton and Kim Ferguson

Contacts

Aboriginal Health & Medical Research Council
www.ahmrc.org.au
 Phone: (02) 9212 4777

Find your local Aboriginal Community Controlled Health Service
www.ahmrc.org.au/index.php?option=com_content&view=article&id=121&Itemid=76

Breast Screen NSW
www.bsnsnsw.org.au
 Phone: 13 20 50

Cancer Australia
www.canceraustralia.gov.au/
 1800 624 973

Cancer Council NSW Helpline
www.cancercouncil.com.au/
 Phone: 13 11 20

Cancer Council NSW ABORIGINAL PORTAL
www.cancercouncil.com.au/aboriginalcancer
 Phone: 13 11 20

Cancer Institute NSW
www.cancerinstitute.org.au
 Phone: (02) 8374 5600

Carers NSW
www.carersnsw.org.au
 Monday to Friday 9am to 5pm 1800 242 636
 Carers wanting emergency respite 1800 052 222
 After hours' service: call Lifeline 13 11 14

Chris O'Brien Lifehouse
www.mylifehouse.org.au
 Phone: 1300 852 500

Department of Human Services Centrelink and Medicare for Aboriginal or Torres Strait Islander people

www.humanservices.gov.au/customer/themes/indigenous-australians
 Indigenous Helpline 1800 136 380
 Carers 132 717
 Financial Information 132 300
 Medicare Access Helpline 1800 556 955

Health Info Net
www.healthinfonet.ecu.edu.au

National Indigenous Cancer Network (NICaN)
www.nican.org.au
 Phone: (07) 3309 3420

NSW Rural Doctors Network
www.nswrdoc.com.au
 Phone: (02) 4924 8000

Palliative Care NSW
www.palliativecarensw.org.au
 (02) 9206 2094

The Leukaemia Foundation
www.leukaemia.org.au
 Phone: 1800 620 420

