Walked the walk to talk the talk:

yarning about cancer

Cancer Conversations
in Aboriginal Communities
with cancer survivors

Too many Aboriginal people are affected by cancer.

People don't often talk about cancer.

What can be done so less Aboriginal people suffer from this disease?

A report on 'Cancer Conversations in Aboriginal Communities" by cancer survivors from Cancer Voices South Australia, from February 2010 – December 2011.

Cancer Voices South Australia received funding from the Australian Government through Cancer Australia to conduct "Cancer Conversations in Aboriginal communities".

Australian Government
Cancer Australia

cancer voices sa
RAISING A VOICE FOR THOSE AFFECTED BY CANCER

Cancer Voices SA is an independent, incorporated organisation of volunteers representing South Australians affected by cancer.
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Contents

This report, 'Walked the walk to talk the talk: yarning about cancer', describes the cancer conversations we conducted and includes a 'Cancer Conversations toolkit' to assist others to also conduct a 'cancer conversation'.

It is the culmination of

- Work funded from the Cancer Australia 'Building Cancer Support Networks' grants program (Feb 2010-Dec 2011), which enabled us to also fulfill a pledge,
- a 'Commitment to Action' to conduct more Cancer Conversations in Aboriginal Communities. This pledge was made by Cancer Voices South Australia to the LIVESTRONG Global Cancer Campaign in June 2009.

WARNING: There are images of Aboriginal people in this report.

Introduction

We are cancer survivors and volunteers. We don't want others to go through what we have. Our 'expertise' is from having 'walked the walk' as people affected by cancer.

We believe there's a stigma and silence about cancer that is contributing to poor cancer outcomes in Aboriginal communities. By breaking the silence and having a normal sort of conversation about cancer, we hope that we can share our experiences, ideas and suggestions to change things.

We've 'walked the walk' to 'talk the talk'. We don't give a lecture. We aren't health professionals or have clinical training. We're people affected by cancer, just like many of you.

This isn't just 'talk' then no action. These conversations are different! Let's talk about what has worked, what will work, what needs to change in your view, in your community, to make a difference around cancer?

In addition to yarning about cancer, we've developed a 'Toolkit' to help keep these conversations going. We hope this will ensure Cancer Conversations are sustainable.

About us: We are members of **Cancer Voices SA** and we are serious about **"raising a voice for those affected by cancer"** in Aboriginal communities.

We are all cancer survivors.

Ashleigh Moore (centre): Head & Neck cancer diagnosed 2005, Lung cancer diagnosed 2010.

Sandy Miller (right): Breast cancer diagnosed 2005.

Julie Marker (left): Colon cancer diagnosed 2001, liver secondaries diagnosed 2005, 2006.

Background - About 'Cancer Conversations'.

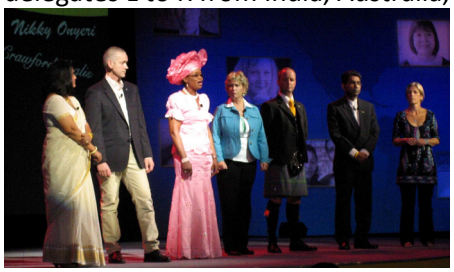
"Cancer doesn't affect just one person, it affects the entire community around them".
LIVESTRONG

Cancer Voices South Australia (volunteers, people affected by cancer) held 'Cancer Conversations' in early 2009 as part of an international 'Go Public'[1] initiative established in Canada. GoPublic provided templates for organising, conducting and reporting 'cancer conversations'. We had conducted 12 Cancer Conversations by June 2009, 3 with Aboriginal participants. The clear message to us was:

'you've got to keep doing these Cancer Conversations in the Aboriginal community',

We made this a 'Commitment to take Action' within the LIVESTRONG Global Cancer Campaign. Cancer Voices SA members Sandy Miller, Ashleigh Moore and Julie Marker (see photo, right) were invited to attend the LIVESTRONG Global Cancer Summit[2] in Dublin, Ireland in Aug 2009.

Ideas were exchanged at the Global Cancer Summit, with opportunities to talk with 500 delegates from 65 countries including Africa, India and Alaska . A number of connections with these delegates continues to form a valuable network. Similarities in the issues for Aboriginal peoples in many nations means the international linkages can provide useful insights and ideas. (Photo below: Ashleigh – 2nd on left, a speaker at the Global Cancer Summit with delegates L to R from India, Australia, Nigeria, USA, Scotland, Sri Lanka and USA).



Ashleigh was also invited to attend the GoPublic Conference in Ottawa, Canada in Sep 2009 (photo, above right), where our 12 Conversations contributed to the 'Global Focus Group' results of 201 conversations held around the world. Productive relationships with the GoPublic Campaign to Control Cancer[3] initiative have also been maintained.

The GoPublic initiative discovered that

- **cancer conversations were an effective way to engage people in developed as well as developing countries.**
- **The conversations proved to be an important delivery channel for awareness, education and action.**
- **Participants were encouraged to talk to others about their experience.**

[1] http://gopublic.squarespace.com/about-the-c2cc
[2] http://www.cancervoicessa.org.au/involvement/livestrongglobalcancercampaign/livestrong-global-cancer-summit
[3] http://www.controlcancer.ca/

- **This 'grassroots army' to promote change tends to be sustainable, enduring and engages personal commitment.**
- **Personal experience, either direct or indirect, was a key driver of engagement and action.**

In late 2009, Cancer Voices SA commenced discussions with the Aboriginal Health Council SA, to develop a plan to conduct Cancer Conversations in Aboriginal communities.

A 'Building Cancer Support Networks' grant proposal titled '**Cancer Conversations in Aboriginal Communities – a pilot study'** was successful. (Photo: Julie & Sandy at the **Cancer Australia** grants announcements, 4 Feb 2010).

The **'Cancer Conversations in Aboriginal Communities – a pilot study'** commenced in February 2010 and was expected to be completed in 12 months, with 3 'conversations' to be held in 2 rural locations and an urban setting.

This project proposed to:

- pilot and refine the methodology for Cancer Conversations in Aboriginal Communities, and
- engage with Aboriginal leaders, groups and organisations to develop a funding proposal around 'Cancer Conversations' to submit to the next Cancer Australia funding round.

Cancer Conversations would aim to

- reduce the stigma around cancer by encouraging communities - men and women - to talk about cancer in small groups in a relaxed and conversational way.
- raise awareness about cancer through these conversations
- encourage Aboriginal people to attend health clinics for cancer check-ups so cancer can be prevented or detected earlier.

Cancer Voices SA (CVSA) will use the innovative approach from the international 'Go Public: Campaign to Control Cancer' methodology for Cancer Conversations. We will pilot and refine this, and develop a plan to work in collaboration with Aboriginal organisations towards a sustainable model to conduct Cancer Conversations in the broader Aboriginal community in future. Working in collaboration with Aboriginal Health Workers will provide avenues for appropriate and timely referral to care pathways following issues revealed or arising from Cancer Conversations.

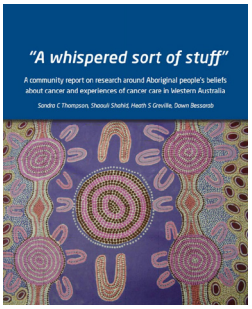
The project was delayed when Ashleigh's new diagnosis with lung cancer put everything 'on hold' for awhile. Thankfully Ashleigh has recovered after 'time out' for surgery, radiotherapy and chemotherapy, and with Cancer Australia's agreement to an extension of the timeline, we completed the pilot study in December 2011.

Two other significant projects emerged during June 2011, which are relevant to our **Cancer Conversations in Aboriginal Communities** pilot study.

In June 2011 a West Australian report into beliefs about cancer and the experience of care in Aboriginal communities 'A whispered sort of stuff[4] made the following **Recommendations**:

[4] www.cancerwa.asn.au/.../2011-06-14-A-**whispered-sort-of-stuff**.pdf

- Community education –more information in the community about preventing cancer, early diagnosis, sharing positive stories about treatment and recovery.
- Support systems - transport, accommodation and hospital liaison services
- Health system & staff to be more sensitive, responsive to Aboriginal needs



These report recommendations reinforced the need for the 'community education' aspect of the Cancer Conversations, and we heard similar support system and health system issues raised.

In June 2011 an international 'Break the Silence' program was launched by LIVESTRONG . The aims of this program are around addressing the stigma of cancer:

"For too many people, the stigma of cancer prevents them from getting the

- information,
- treatment and
- support they need."

The powerful example below demonstrates the international dimension and importance of cancer conversations to 'break the silence':

"I'm not ashamed. Break the silence

*When I was diagnosed with cancer of the larynx, I worried about losing the power of speech. But my voice remained—and LIVE**STRONG** helped me use it to reach fellow cancer survivors in my community of Soweto, South Africa.*

*Here in South Africa, people don't openly talk about cancer. By working with LIVE**STRONG**, I am able to share my story on the radio and in clinics across the country to let people know that cancer is nothing to be ashamed of.*

Today, people stop me in the streets to talk about their own struggles with cancer.
I've felt the stigma of cancer. When I told my friends and family about my diagnosis, some of them thought I was bewitched. It's a widely-held belief that cancer is something that only affects westerners.
But in truth, cancer knows no boundaries.
Person by person, family by family, community by community, we're getting the message out that cancer survivors don't have to stay silent.

*David Mfeka, Cancer survivor and LIVE**STRONG** volunteer*
28 Jun 2011"

This network via LIVESTRONG aligns well with our Cancer Conversations in Aboriginal communities.

Cancer Conversations – Our methodology

The **"Cancer Conversations in Aboriginal Communities – Pilot Study"** was conducted by Cancer Voices South Australia from Feb 2010 – Dec 2011 with funding from the Cancer Australia "Building Cancer Support Networks" grants program.

Our Aims:

- To reduce the stigma of cancer, by encouraging communities to talk about cancer in a relaxed and conversational way
- To raise awareness about cancer through these conversations
  - Cancer need not be a death sentence
  - Awareness of different cancer types, possible cancer signs or symptoms, the need for check-ups for prevention, screening and earlier detection, treatment and beyond
- To encourage Aboriginal people to attend health clinics for cancer check-ups (prevention, earlier detection)

Outcomes sought:

- Determine what are 'the problems' and to encourage problem solving or ways to look after health that are proposed by Aboriginal people affected by cancer eg. through healthy eating, traditional foods, not smoking, physical activity etc.'
- Can Aboriginal people, by sharing their stories, motivate themselves and their community to take action eg.
  - make healthy life changes,
  - have confidence to 'take on' and fight cancer?
- Conversations to inform, inspire and encourage people (not be 'victims' of cancer)

This Pilot Study also proposed to:

- Pilot and refine the methodology for Cancer Conversations in Aboriginal communities, and
- Engage with Aboriginal leaders, groups and organisations to develop a funding proposal around 'Cancer Conversations' to submit to the next Cancer Australia funding round

What we did:

Cancer conversations were held in
Coober Pedy - Aboriginal Umoona Tjutagku Health Service (Aug 2010),
Port Lincoln - Aboriginal Health Service (Sept 2011) and
Port Adelaide – Tauondi Community College (Nov 2011).

Networks and planning

We have worked with the Aboriginal Health Council SA throughout this project, to develop the original proposal, for guidance on the locations for our 'pilot' conversations, and for advice on key contacts in these locations.

The grant proposal was premised on the notion that transferring 'Cancer Conversation' skills to Aboriginal Health Workers would be appropriate and sustainable. Contact people in Health Service

sites were determined in consultation with Alwin Cheung and Richard Nelson at the SA Aboriginal Health Council (until Dec 2010) and with Shane Moher (June 2011).

We presented a summary of the project to the Chair of the Aboriginal Health Council SA Board in Feb 2010, and presented to the whole Board in May 2010. They were supportive and helpful.

Liaison with each site was established 6-8 weeks in advance of our visit, to make connections in the community and to set a date and venue for the conversations. Details of the aims and objectives were sent.

See the Appendix Toolkit 2, 3 & 4 for examples of the letter sent describing 'Cancer Conversations', a brief slide presentation and draft flyer that could be adapted for each location.

Despite careful preparation, things don't always go to plan. We learnt to be ready to respond to a new and unexpected situation whenever we arrived for a cancer conversation.

Grant funding of $20,000 covered travel, catering and expenses related to the Cancer Conversations, as well as payment for some of the time taken to develop, report and evaluate these Cancer Conversations.

Organisational 'matched funding' was a requirement of the Cancer Australia funding, so for Cancer Voices SA, a 100% volunteer organisation, this meant we contributed the majority of our time and effort as volunteers.

After each conversation, by reflecting on the issues raised, the questions people asked us and the things we were told, we revised the questions we asked.

Coober Pedy

Coober Pedy has an Aboriginal community of about 700 people. We'd been told that Bowel Cancer Screening was a program the Health Service was trying to promote, so our assistance to encourage participation would be particularly appreciated.

We had originally intended to visit Port Augusta, but an Aboriginal Health Council Board member from Coober Pedy was very persuasive that we should go to Coober Pedy.

We arrived to find the Health Service flags half-mast. There had been 3 deaths in the community and many people were away at funerals.

In Coober Pedy

- On arrival we met with Aboriginal Health Workers to discuss final details for a Cancer Conversation, given the difficult circumstances of the community bereavements.
- Organised catering
- Held a Cancer Conversation - 5.30pm – 7pm in the Umoona Tjutagku Health Service, with food we provided. This was attended by 11 people: 3 Aboriginal women from the community, 5 Aboriginal Health Service staff (2 agency nurses and 3 long-time Coober Pedy Aboriginal Health Workers (2 women, 1 male Aboriginal nurse)) and 3 Cancer Voices.

- Met with Aboriginal Health Service staff the following morning for feedback on the Cancer Conversation. We heard a number of additional issues from staff who had not been present at the Conversation.

Feedback:

- Very good to have this relaxed conversational method. Heard a lot of experiences of cancer that staff were not aware of.
- Many people heard about it afterwards. Would have come if they'd known about it and known what it was.
- Our flyer was posted on the Health Service noticeboard. It didn't 'stand out' as an event amongst the wall full of other notices.

Port L:incoln

We had arranged the dates of our visit so we could attend a monthly Health Service Board meeting.

In Pt Lincoln

- We met with Aboriginal Health Workers. They wanted help to get Aboriginal people to do screening for prostate, bowel and breast cancer.
- Met with the Home and Community Care Coordinator and discussed issues.
- Visited the Community Centre
- Organised catering
- Gave a presentation to the Aboriginal Health

Service Board about Cancer Conversations, 10-11am,

- Held a Cancer Conversation, 12.00 noon – 2.30pm in the Pt Lincoln Aboriginal Health Service with a healthy lunch that we provided.
  This was attended by 21 people, 14 Aboriginal community members, 4 Aboriginal Health Workers and 3 Cancer Voices.

Feedback:

- Excellent. Really 'broke the silence'

Tauondi College Elders Group, Port Adelaide

At Tauondi College we met with the Elders group who meet regularly, twice/week.

- We held a Cancer Conversation, 10.30-12.30pm with healthy food provided.
- This was attended by 10 people: 5 Elders (women), the Tauondi College Elders Group Coordinator, 2 Aboriginal SA Dept of Health Aboriginal Health staff and 2 Cancer Voices.

Feedback:

- Come to our Grannie's group.
- You should contact the men's group.
- That was really good. We all learnt something.

Cancer Conversations – The questions we asked

1. Anyone here who's known someone who's had cancer?

   We'll start by telling you a bit about us:

   What type of cancer?
   How old/ how long ago when diagnosed; what symptoms; how diagnosed?
   Briefly your personal/ family situation eg 2yr old, breadwinner for a young family
   Risk factors? Cancer in family?
   Treatment we've been through eg surgery, chemo, radiotherapy?
   Where are we now re: cancer?

2. What do you think when you hear the word cancer?

3. Cancer is not talked about much. Shame – is that a reason it's not talked about?

4. What are the problems you see for people with cancer, or people caring for someone with cancer?
   Tell us some of the things that happened?
   Anything bad …how could it have been done better? What needs to change?

5. Can anything good come out of a cancer experience?
   Those people who have been close to someone with cancer, what helped you get through?

6. Did you know that Aboriginal people are dying from cancers that white people are surviving? Why is that?

7. How to get more people to talk about cancer?

8. What services are there around for cancer?
   What works well. What doesn't work so well. What services are missing. What needs to change?

9. What are the biggest challenges or issues around cancer in your community?

10. What can you do, or your community do to 'make a difference' around cancer?

These questions have evolved over time, and we used them as a rough guide. (See the appendix: Toolkit 1 Reporting sheet).

Our Cancer Conversation key messages:

- As cancer survivors, we don't want others to have to go through this.
- The stigma/ silence/ taboo about cancer - could that be killing Aboriginal people? If we 'break the silence', could that make a difference?

- We want to raise awareness for earlier detection, prevention, and to encourage people diagnosed with cancer that it is possible to survive cancer
    - Earlier detection means less people die
    - Screening tests aim to pick up cancer earlier, before symptoms develop. You can't wait for the symptoms, or delay in getting symptoms checked (Bowel, breast, cervical, prostate screening tests are available)
    - It's not shameful to do the screening tests or go to get symptoms checked
- **Cancer need not mean a death sentence**
- **What can you do to 'make a difference' about cancer?**

- **Aboriginal people are dying from cancers that white people are surviving - Why is that?**
    - A similar number of Aboriginal people get cancer compared to the rest of the population, but more Aboriginal people die and don't recover from cancer.
        - Diagnosed/ detected too late – cancer already big or spread around the body
        - Don't get offered/ accept/ have all the cancer treatments

Different types of cancers more common eg lung, liver …more lethal and difficult to treat even in white people

Cancer Conversations - What people told us

Cancer conversations were held in Coober Pedy, Pt Lincoln and Pt Adelaide, and all generated a lot of discussion. We gratefully acknowledge the openness and generosity of those who shared their experiences. People generally hadn't talked about cancer in this manner ever before. Many expressed a sense of release to have talked about cancer. We hope these observations can contribute to building a better system. The comments were captured in notes jotted during the conversations.

1. Do you know someone who's had cancer?

Most conversations started with people saying they didn't know too many people who'd had cancer, but after yarning for a bit, it was apparent that cancer had touched the lives of most participants many times.

2. What do you think when you hear the word cancer?

You hear the word 'cancer' and think you're gonna die.
Just see death at the end of it. Think - no-one survives.

You worry about your family, the treatment, chemo. It's frightening. Cancer eats your body away. There's pain; and the drugs you've got to take. The treatment damages your body. At the back of your mind you know its going to be a terrible thing.

Remember seeing them in agony, in terrible pain.

Some accept it and get on, do the treatment. Gotta be a strong person, brave and strong. Everyone needs to make their own decision.

Fear, anger, resentment. 'Why me'. Shock.

Mother accepted it but the family couldn't. In the same way people deal with grief - some do, some don't.

3. Cancer is not talked about much. Shame – is that a reason it's not talked about?

"Any other gossip gets around but not about cancer. Don't hear about cancer on the grapevine."

Cancer is often seen as a very private topic. Even close family may not know what sort of cancer someone has, or what treatment.
By not talking, sometimes even the kids don't know exactly why someone died, or what sort of cancer.

There's a lot of emotional distress amongst family and friends, and people are often afraid to talk for fear they'll show they're upset if they start talking about it. Hard when you've got the distress but don't know enough about what's going on.

People don't want to talk and lock themselves away. There's shame, maybe visible changes to the body.
Shame? More embarrassed, 'ashamed'.
Guilt? Blame? What did I do to deserve this?

Males 'shut down' and don't want to know. They need to talk about it.
He was afraid it was cancer and hid it from everyone, but eventually found out it was diabetes.

It's taken 25 years to be able to talk like this.

4. What are the problems you see for people with cancer, or people caring for someone with cancer?
Tell us some of the things that happened?
Anything bad …how could it have been done better? What needs to change?

Elders don't want to impose on their kids to look after them when they're having treatment.
Relationships can break up. Friends turn away.
Drs didn't tell us what was going to happen.

Need networks here. Want to talk to someone here (locally) who's been through it.

No money to go on the bus to visit someone, and can't stay with them. Would be good to be met at the bus and not have to worry about getting to places you don't know.

Lack of privacy, confidentiality – Angry at the way the diagnosis was given. Care factor ZERO. Pulled a curtain around but everyone in the whole big room could hear him being told he had cancer. Dr's have a responsibility to have compassion.

Does cancer spread when they open you up? Does surgery make it worse?

There are practical things to learn by talking to others. The bowel cancer bags, the smell used to go through the whole house. People need to know that charcoal tablets help that.

She had Faith; very strong Faith; didn't have treatment; put her trust in the Lord.

5. Can anything good come out of a cancer experience?
Those people who have been close to someone with cancer, what helped you get through?

Very good seeing this inspiring person. Good attitude, very brave and strong. Changed her eating, took up a healthy lifestyle and looking really good now.

Hearing positive talk about cancer is good. People go and talk to other people.

6. Did you know that Aboriginal people are dying from cancers that white people are surviving? Why is that?

It's not fair. Died at 39yrs. Didn't smoke or drink. What can you blame the cancer on?
A body builder. Died at 56. Didn't smoke or drink. Cancer just ate him away. So terrible to see.
You don't see too many survivors or people surviving well.

7. How to get more people to talk about cancer?

I used to be real scared to talk about it. Got to trust one another to heal, and talking is a healing part of cancer.
People don't know how to talk about cancer to each other.

Scared to get the symptoms checked. Do you feel pain if you've got cancer? Do you know you've got it because you feel pain?

Aboriginal Health have been doing a marvelous job with diabetes, and did something on sex, HIV, when a nice young lady came and talked. That was very enlightening; but this is the first time we've heard cancer being talked about.

Need to have these conversations regularly, with topics to keep talking going with all different age groups. Closing the Gap has the Aboriginal family wellness programs with funding. Youth groups could focus on how to engage in prevention. You need the right activity for the group, like. art, filming, IT. We definitely need more in prevention.

8. What services are there around for cancer?
What works well, What doesn't work so well. What services are missing, What needs to change?

Don't hear much about cancer screening here. Hear about diabetes but not cancer. There's the 'Closing the Gap' smoking program starting up, on tobacco control.

Good staff at the Health Service

We need community meetings, round table discussions on how to tackle this.
Not just for the Health Service, needs to go into the wider community, maybe at the footy club.

Need education to know about our bodies. Anxiety and fear of getting cancer, diabetes ... used to think you could catch them from others (contagious). You get education from talking.

Auntie had breast cancer. Am I at risk? How do you access breast screening? Do you have to pay?

Men don't want to participate in screening.

There's very high Health Service staff turnover. Rely a lot on agency staff. People don't know new staff. Staff say it's hard enough to get a blood pressure let alone anything more invasive like screening.

A Health Service opened up for wellbeing as well as medical treatment. Good ideas, but high staff turn-over. Need consistency, coordinated, old fashioned sort of care.

A step-down care unit is needed in the local community, for those with no support at home.

9. What are the biggest challenges or issues around cancer in your community?

Getting people to do screening tests. Need community leaders to come in and help so a group all support each other and go through the screening together.
Need to get to the kids at high school – need more workers out there educating.

People get diagnosed late and want to be at home to have their last days with family.
Complicated system - between community health, hospital, drug & alcohol etc. Lots of hand-balling, things not being treated.

Having treatment in the city – need interpreters. People don't listen to the patient. Health service staff can't get discharge summaries or correspondence. Services in the city are Inflexible, rigid rules or services not connecting with the people's needs.

** There's a real problem with many people having the same name, and mix-ups where the wrong information and diagnosis is given to the wrong person. Someone might be told they have cancer, but they don't have it. Worse still, someone does (have cancer) and doesn't get told..*

** People at all 3 cancer conversations (Coober Pedy, Pt Lincoln and Pt Adelaide) told us they were worried about cancers caused by the Maralinga nuclear bomb test. Cancer is a lot more common now, and especially in relatives who lived over that way years ago. Bush medicine saved more people from getting cancer, but when you get cancer, the bush medicine isn't strong enough. Need something stronger.*

Problems with uncoordinated and inflexible systems. A man with pancreatic cancer got struck off the follow-up list of a city hospital because he missed appointments due to problems with transport, distance ... and got struck off after 3 missed appointments

What can you do, or your community do to 'make a difference' around cancer?

People don't know what to say if someone is upset about cancer.

Like in Diabetes Education, education can make you think differently about how you live. The Community Garden – it shows what can be done, using less chemicals, eating fresh vegies, natural and healthy food, avoiding preservatives.

You need to be aware if cancer is in your family.

Port Lincoln jetty

Cancer Conversations – Are they useful?

In addition to the invaluable information we heard about the actual experiences of cancer in Aboriginal communities, after each Cancer Conversation we asked participants for advice and feedback on the 'conversation' as a communication method.

Was this useful? Should we keep doing Cancer Conversations?

- YES. Come to our Grannie's group, and the Men's Group.
- Thank you for coming. You are very brave to come and talk to us about your cancer.
- It takes courage to come along to a 'cancer conversation'. "Scary, frightening to think about". I expected it to be harrowing and I'd only be listening, but surprised myself that it was so very interesting and I got involved!

Who should run Cancer Conversations?

Outsiders? / survivors? People like us? If survivors, do they all need to be Aboriginal people or OK to have a group like us? Is it better to have people you know, or easier to start with 'outsiders', provided they're cancer survivors? Could/ should Local health workers try to start these conversations? Anyone else in the local community who could do it?

- "You people have walked the walk to talk the talk. You've got credibility.. Others come and talk and you think 'What do you know? What do you care? You guys who've been through it, you are doing it from the heart'."
- It's important for survivors to talk about what they did to beat cancer. Talk about what action people can take.
- Easier for people from outside the community to 'break the silence'
- Good to have an Aboriginal face in the team, especially a survivor, as good outcomes are not often heard of. "Good to see there are survivors. Gives us hope".
- Need Aboriginal survivors to become champions for the conversations. People who will talk and who are committed to make a difference. People connected in the community.
- Better to have someone who is not from the community to start with. Feel shamed if an aboriginal person you know started talking about cancer like we have. Kid's would be embarrassed if Auntie talked about her breast cancer at the school. Easier for outsiders.
- Do men only talk with men? Women with women? Hold separate cancer conversations? Maybe for some discussions it's better to be separate.

Re: Aboriginal Health Workers

- Health workers have to be trained on these topics.
- It's too big an ask. Too much expectation. Trying to be' everything to everybody'. Too emotional for them to start cancer conversations. Outsiders can come in who are OK to talk about it.
- Health Workers know about cancer, but haven't had it to be able to talk about it.

Where is best to hold Cancer Conversations? Community venues?

- Hold them in a place people are familiar with, and a time that suits. We were advised by Health Workers to do it in the evening, but were told afterwards it was strange to hold it in the evening at the Health Centre. People don't usually come there in the evening.
- Go where there is an established group, especially for men, where there is already trust and openness to speaking about personal things.

What made you come along today?

People came because a trusted local told them about us, and asked them to come.

Should we do these as a 'one off' and leave it with you to follow on with, or come back and do more sessions like this with you?

- Need to spread the word so more people would come along if we did another session. Now we know what it is you do, others would come. There's more to talk about.

Any resources that would be useful to have at these session, or any we've shown you that you think are good?

People were keen for information. We handed out:

Magazines: LIFESUPPORT, from the LifeHouse Cancer Centre (People really liked the photos and stories of others, and especially seeing photos of Ashleigh's wife and children to put his family in context after hearing his story).

Cancer Council NSW resources:

Booklet: 'Aboriginal Cancer Journeys. Our stories of kinship, hope and survival'

Brochures: Talking about cancer,
Cancer Treatment,
Practical information for people having cancer treatment,
What is Palliative Care.

Any other comments/ advice for us, or to help us do better Cancer Conversations in other Communities?

- Keep doing these.


Coober Pedy landscape

Cancer Conversations – What we have learnt

Key recommendations:

- **It is vital to have an Aboriginal person in the team** who has personal contacts and knows how things work at the local level.
- There's **a unique role for cancer survivors to run cancer conversations**. We have **credibility, having 'walked the walk' to 'talk the talk'** with personal knowledge and understanding of the 'everyday' impacts and reality of cancer. Personal stories are engaging to listen to.
- It's good to have male and female survivors, and 3 different cancers that are all quite common in the Aboriginal community.
- Relaxed conversational style raised issues not voiced before. Locals and health professionals thought it worked well.
- 'Outsiders' are needed to start these conversations and 'break the silence'.
- It was very useful to have a Cancer Conversation with Aboriginal Health Workers separately from the community Cancer Conversation. This allowed Health Workers to understand what we were doing, and even those who had worked together for years had never discussed many issues raised in the Cancer Conversations. Staff perspectives and system issues raised here are often very different to the personal impact issues raised by the community.
- Re: Aboriginal Health Workers, it is valuable for them to be involved, but 'too much' to expect of them to lead or run 'Cancer Conversations'. It's important to have one or two senior people present who can take some of the issues of concern to be addressed.

Realisations

Cancer Conversations scope is broader than a health issue
The impact of cancer is broader than a health issue, so we now suggest it is not sustainable or appropriate to restrict this to the model within an Aboriginal Health Workers role as originally proposed. Community settings as well as health service settings are important, across the age spectrum, wherever people meet, such as schools, sporting groups, elders, men's groups, women's groups.

Aboriginal Health Workers role.
The grant proposal was premised on the notion of transferring 'Cancer Conversation' skills to Aboriginal Health Workers. During the course of this Pilot Study we realised that this needs a re-think.

- We were naive to believe that people would understand what a 'Cancer Conversation' was, and would organise anything for us in advance. Aboriginal Health Service staff are very busy, and probably don't often organise community meetings. Although they said 'yes, things were in place', in reality that wasn't usually the case. In hindsight, it is not surprising they were cautious about 'setting up a meeting' when they didn't know us.
- Many Aboriginal Health Workers have no close experience of cancer, don't feel qualified to speak about cancer, and don't appreciate that cancer is a big problem in the community.
- Communities are very grateful for the Aboriginal Health Services and don't wish to be critical of them. It is difficult when we ask 'What was not done well, or what could be done better?' when Aboriginal Health Workers are present.
- Aboriginal Health Workers are 'flat out' with many new initiatives around 'Closing the Gap', as well as accreditation for some, which is all on top of their routine role tasks.

We now believe it is not realistic or reasonable for Cancer Conversations to be an Aboriginal Health Workers role. However, it is valuable to involve the Aboriginal Health Service in the planning and conduct of these community events, particularly in rural communities.

Unique role for cancer survivors
Survivors who are 'yarning about cancer' need to build up their credibility through direct personal contacts, so the word gets around that these conversations are a good thing.

In addition to being cancer survivors we are also experienced cancer advocates. This means we have avenues to take issues further; we meet with the SA Minister for Health (Hon John Hill), we can raise issues at the SA Cancer Clinical Network where they can be taken forward and addressed to change pathways for cancer care.

Engagement, Promotion, and getting people to come along.
We didn't appreciate that people could be reticent to come along for a yarn if they thought we might be telling a harrowing tale about cancer. They didn't know that our aim was to give hope, that cancer need not be a death sentence, and our focus would be on positive actions towards tackling cancer problems.

Word-of-mouth recommendation is far better than posters or flyers to encourage people to come to a Cancer Conversation. Noticeboards in Health Services are crammed with posters. How do you differentiate an 'event' from an 'information' poster. We decided not to spend effort and money on developing posters.

When we arrived and people met us in person, people did go out of their way to help us organise the Cancer Conversations; they did believe that we were sincere and that we could make an impact.

Perhaps a better title, instead of 'cancer conversations', is to describe what we do. We've '**Walked the walk to talk the talk – yarning about cancer'**. These words were suggested by Aboriginal Elders.

Funding, food and travel expenses
Funding will be needed to sustain this.
Hearing that 'outsiders' are needed to 'break the silence' means the cost of travel to rural and remote places will need to be 'factored in' to future Cancer Conversations in Aboriginal communities. We only made one visit to each community, but felt at least a second follow-up visit would have been very beneficial. Having 3 survivors working as a team was good, as it shared the workload, increased engagement and provided different perspectives and understanding to address issues raised.

Starting the meetings with food and chatting informally was an important component to relax everyone ready for a conversational style meeting and was especially important if participants didn't all know each other.

Funding for reimbursement of 'out of pocket' travel expenses such as mileage, carhire, accommodation and meals was also vital.

Payment for some of the time contributed to this work is important. The tasks, reporting and evaluation of a grant funded project should not be substantially more onerous than accountability required of a sustainable program. However, the effort, responsibility, stress, disruption and workload of organising and conducting a Cancer Conversation in distant locations should not be taken for granted or expected as a voluntary task. Employment on a casual consultancy basis may be suitable.

Challenges

"Cancer may leave your body but it never leaves your life ....." A cancer relapse is a risk for all cancer survivors, and it hit our team suddenly and unexpectedly. We were lucky to be able to continue, after 9 months 'time out'. The risk of illness and need to monitor and nurture cancer survivors health and wellbeing must be kept in mind.

High staff turnover and organisational upheaval in Aboriginal Services was a challenge for us. We had to delay then re-establish contact and brief new staff with details of our plans.

The way forward

We aim to continue 'yarning about cancer' in Aboriginal communities, and build our capacity to do this by mentoring other cancer survivors to conduct these conversations. We are actively seeking additional Aboriginal cancer survivors to join our team.

We need a 'men's group' Cancer Conversation team.

We will continue to review and reflect after each Cancer Conversation to determine if the ToolKit needs further refining.

We will continue to review the issues raised to determine if advocacy action needs to be taken.

We will continue to network with Aboriginal Health Services and community organisations.

Funding is an issue, as it is required airfares, accommodation, mileage and incidental expenses to conduct this work. Some payment of cancer survivors time to report and evaluate 'Cancer Conversations' in a consistent way would be valuable. Employment on a casual consultancy basis may be suitable for cancer survivors. Collating of reports and evaluations should be continued.

'Outsiders' may be needed to start these cancer conversations, but we expect the local capacity to build, and resources within the community to be established to take over this role in time. We want to start the conversations, and our work will be a success when we are no longer needed.

A summary version of this report will be widely disseminated through our local, national and international networks, to share the experiences from these cancer conversations.

Summary/ Conclusions

There's a perception that cancer is not a big issue in the Aboriginal community. We believe that is a misconception. Because nobody talks about cancer, there's a lack of awareness of the true dimension and impact.

- **We should continue these cancer conversations led by cancer survivors.**

Key recommendations:

- **It is vital to have an Aboriginal person in the team** who has personal contacts and knows how things work at the local level.
- There's **a unique role for cancer survivors to run cancer conversations**. We have **credibility, having 'walked the walk' to 'talk the talk'** with personal knowledge and understanding of the 'everyday' impacts and reality of cancer. Personal stories are engaging to listen to.
- It's good to have male and female survivors, and 3 different cancers that are all quite common in the Aboriginal community.
- Relaxed conversational style raised issues not voiced before. Locals and health professionals thought it worked well.
- 'Outsiders' are needed to start these conversations and 'break the silence'.
- Cancer Conversations scope is broader than a health issue, and should be conducted with community groups in a variety of settings.
- It was very useful to have a Cancer Conversation with Aboriginal Health Workers separately from the community Cancer Conversation. This allowed Health Workers to understand what we were doing, and even those who had worked together for years had never discussed many issues raised in the Cancer Conversations. Staff perspectives and system issues raised here are often very different to the personal impact issues raised by the community.
- Re: Aboriginal Health Workers, it is valuable for them to be involved, but 'too much' to expect of them to lead or run 'Cancer Conversations'. It's important to have one or two senior people present who can take some of the issues of concern to be addressed.

Our experience confirms that

- **Cancer conversations were an effective way to engage people in Aboriginal communities.**
- **The conversations proved to be an important delivery channel for awareness, education and action.**
- **Participants were encouraged to talk to others about their experience.**

Acknowledgements

Thank you to the people who came along to a Cancer Conversation with us.

Sincere thanks to people who assisted us, especially:

Margaret Brodie (Tauondi Aboriginal College, Pt Adelaide)
Alwin Cheung (SA Aboriginal Health Council)
Warren Clements (Pt Lincoln Aboriginal Health Service)
Jo Tappin (Umoona Tjutagku Health Service, Coober Pedy).

Thank you to Cancer Australia

Cancer Australia ' Building Cancer Support Networks' grant funding

- enabled us to travel to the rural and urban communities to conduct these conversations,
- covered catering and refreshments for the people who attended, and
- reimbursed some of our time to develop networks, document, evaluate and report on this grant. The majority of our time was volunteered.

Toolkit 1: Cancer Conversations Reporting Sheet

Total number of people attending: _____

Anyone know someone who has had cancer - or may have it themselves?

Approx number/ proportion of people 'affected' by cancer _____

1. **Participants names (first name will do) and any cancer 'experience' eg. breast ca - self,**

Name	Cancer details

2 What do you think when you hear the word 'cancer'?
or hear that someone you know has cancer?

3 Cancer is not talked about much?.
Would you hear 'on the grapevine' that someone has cancer, or is it something people don't talk about?
We've heard people mention 'shame' in relation to cancer.

Is it 'embarrassment' about cancer in a certain parts of the body like breast or prostate, or
Is 'shame' associated with any cancer?
'shame' meaning you don't like to talk about it?
'shame' like guilt or blame; could people be thinking 'what did I do to deserve this?'

4 What do you see are the problems for people with cancer, or for the people close to, or caring for someone with cancer?

5 Has anything good come out of cancer?
Anyone, anything inspiring? Anything positive eg closer family?

6 Those people who have been close to someone with cancer, what helped you get through it, eg particular people or services helped?

7 What didn't / doesn't work well ? What needs to change for cancer 'experience' to be better for patients and the family or people caring for them ?
What are the biggest challenges or issues around cancer in your community?
Eg Travel? Cost? Pain? Fear? Isolation? Time/Distance away from family ?

8 Did you know that Aboriginal people are dying from cancers that white people are surviving? Why is that?
To make things change, Who/ what needs to make the changes?
Eg. people doing screening. Earliest possible diagnosis for better outcomes. We've survived because the cancer was diagnosed early enough. Know your risk. Know your family history of cancer – what type, what age.

9 What would you do to make a difference? What commitment will you make?
Eg Talk about cancer? Stop smoking?

10 How could you get more people to talk about cancer?

Conversation Evaluation Questions:

- **Key questions:**
  - Do Aboriginal people think these conversations are useful?
  - how best to achieve engagement in the community to participate in these Conversations?
  - do Cancer Conversations work better with 'external people' coming in?
  - the importance and impact of 'cancer survivors' to run the groups,?
  - how to keep the Conversations going after we leave?
  - how to measure the impact of the Cancer Conversations?

Questions to ask the Group

- Was this useful? Should we keep doing Cancer Conversations?

- Who should run Cancer Conversations?
  Outsiders? / survivors? like us? If survivors, do they all need to be Aboriginal people or OK to have a group like us? Is it better to have people you know doing this, or easier to start with 'outsiders', provided they're cancer survivors? Could/ should local health workers try to start these conversations? Anyone else in the local community who could do it?

- Where is best to hold Cancer Conversations? Community venues?

- What made you come along today?
  How could we promote this better so more people would come along, or does it need people like you to spread the word so more people would come along if we did another session?

- Should we do these as a 'one off' and leave it with you to follow on with, or come back and do more sessions like this with you?

- Any resources that would be useful to have at these session, or any we've shown you that you think are good?

- Any other comments/ advice for us, or to help us do better Cancer Conversations in other Communities?

Thank you everyone for sharing your experiences with us. We really appreciate it.

Toolkit 2: Sample letter

Dear

As discussed with you recently, we would like to hold a 'Cancer Conversation' with the Elders and others affected by cancer. It needn't be just the elders.

We know that 'cancer' is not the most sexy topic to draw a crowd. This isn't a lecture or 'presentation' about cancer. This is a community conversation to try and exchange ideas and together work out some ways to manage the impact of cancer on individuals and in the community. We don't have solutions, but through our cancer and advocacy experiences, maybe we can give people the confidence to begin talking and making a difference at the local level.

Please find attached a flyer that could be used or adapted to promote the conversation. Can you modify it to let people know that we are coming, and why. We'll be guided by your experience on how best to do this and how much advance notice would work best.

A dozen or so participants would be an ideal number.

The plan is for us to come over on Tuesday 22nd November 2011, have a chance to meet the elders and others over morning tea then hold a 'Cancer Conversation'. The conversation would probably last about 2 hrs.
We'll provide lunch for the participants after the Cancer Conversation, with the opportunity for individuals to chat some more to any of us, aside from the whole group.

Re: the actual Cancer Conversation

- We are volunteers and cancer survivors, not health professionals.
- **We won't be talking about clinical details**.
- We want to get people talking openly about their thoughts, emotions and experiences of cancer. It's a community focussed thing, getting people telling their stories.

- From these conversations, we want them to tell us the problems they see around cancer, and also ask them what they think they can do to change things.

- What things would they like others to do? We can help pass on to decision-makers the things the community want to happen, but it also requires a commitment from individuals and the community themselves to make changes.

- If it's beneficial for the community, then this could lead to further group conversations.

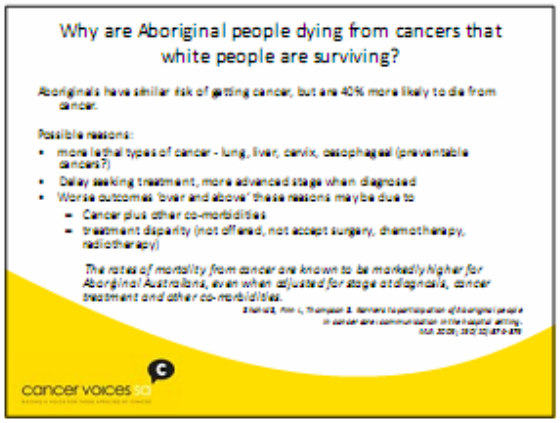
Many thanks, we really appreciate your advice and assistance with all the arrangements. We have some grant funding from Cancer Australia to cover the 'out of pocket' costs such as catering for the Conversations, but most of our time is volunteered.

I've also provided a brief powerpoint describing what this is about, just for your information. We won't do a powerpoint presentation on the day.

Please don't hesitate to get back to us to discuss any issues or aspects to help ensure this goes as well as possible. Please phone Ashleigh on 0403 925 599.

Kindest regards
Ashleigh Moore, Sandy Miller* & Julie Marker

Toolkit 3: Slide presentation



What can Cancer Voices do?

- Raise awareness
  Cancer need not mean a death sentence.
- Aboriginal Cancer Conversations - not a research project.
  Genuinely listening to Aboriginal people:
  - how affected by cancer,
  - seek their suggestions and solutions.
- We want to start the conversations & unlock the silence
- We recognise the importance of involving Aboriginal Health Workers, but don't want to burden them;
  How best to work with them?
- Ensure suggestions, solutions go somewhere, & get implemented!

As cancer survivors, we don't want others to have to go through this.

cancer voices

Cancer Conversations – Pilot Study

- Refine the methodology for Cancer Conversations in Aboriginal communities
- Meet with Aboriginal leaders, groups and organisations to assist, advise and community engagement
- Outcomes required from Pilot
  - to develop an effective and sustainable model
    identify key elements critical for success
  - draft future funding submission...
  - develop effective procedures to 'action' issues (individual and system)

cancer voices

Cancer Conversations – we know they work

CVSA held 12 Cancer Conversations in May 2009
including 3 groups with Aboriginal people – who urged 'do more of these'.

Questions:

- "Cancer experience - What, who was inspiring?
- what went well, what didn't work well?
- what needs to change?
- who needs to make this change happen and how?"




cancer voices

Break the Silence

•a campaign to empower communities across the globe to fight cancer head-on.

For too many people, the stigma of cancer prevents them from getting the
•information,
•treatment and
•support they need.

'Break the Silence' is an international program launched in Jun 2011 – and aligns well with Cancer Conversations.

cancer voices

Who are Cancer Voices SA?

'Raising a voice for those affected by cancer',
through

•Advocacy
•Involvement
•Awareness
•Information

Cancer Voices SA is an independent, 100%volunteer consumer organisation.
Membership is free and open to cancer patients, their family, friends, carers and supporters.

cancer voices

cancer voices sa

"RAISING A VOICE FOR THOSE AFFECTED BY CANCER"

www.cancervoicessa.org.au

Contact us:
email: info@cancervoicessa.org.au
telephone: 0403925599

cancer voices

Toolkit 4: Advertising Flyer – Pt Adelaide example

Yarning about cancer

Too many Aboriginal people are affected by cancer.

People don't often talk about cancer.

What can be done so less Aboriginal people suffer from this disease?

Tell us your stories, and what needs to change.

This won't be 'just talking' and no action.

Talking is just the beginning.

Come for a yarn and some good tucker.

When: 10.30am, Tuesday 22nd November 2011

Where: Tauondi College

Who are we?

Sandy Miller, Ashleigh Moore and Julie Marker – **we are volunteers, all 3 of us have had cancer**.

We are members of **Cancer Voices SA** and we are serious about **"raising a voice for those affected by cancer"** in Aboriginal communities.

For more information about Cancer Voices SA, visit the website at www.cancervoicessa.org.au or ph: Ashleigh Moore on 0403 925 599. Cancer Voices SA is an independent, 100% volunteer organisation.

Cancer Voices SA received funding from the Australian Government through Cancer Australia to conduct "Cancer Conversations in Aboriginal communities".

Australian Government

Cancer Australia

cancer voices sa

RAISING A VOICE FOR THOSE AFFECTED BY CANCER