

# Aboriginal cancerjournneys

*Our stories of kinship, hope and survival*



**Thank you** to the Aboriginal people and their families who shared their stories for this project. We hope their experiences of cancer will encourage other Aboriginal people who have cancer or who are caring for someone with cancer. Names have been changed to protect people's privacy.

**Note to readers**

Always consult your doctor before beginning any health treatment. The information in this book is intended as a general introduction to other people's experiences of cancer. It should not be seen as a substitute for your own doctor's or health professional's advice. However, you may wish to discuss issues raised in this book with them. All care is taken to ensure that the information in this book is accurate at the time of publication.

Readers are also advised that this book contains stories from some people who are now deceased.



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## Foreword

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

Cancer is a major cause of disease and death in Aboriginal communities. In writing this foreword, I am mindful of the gravity of the topic, the trauma associated with cancer at all its stages, and the courage of those who must confront the disease and its impact on their lives, their families and their friends.

I therefore acknowledge and thank all those Aboriginal people who have shared their unique insights – from an Aboriginal perspective. The journeys experienced by the people interviewed – from urban, rural and remote areas of NSW – highlight many issues, including late diagnosis, denial, family concerns, palliative care, and grief and loss. They reinforce in a very real way the importance of providing information about cancer.

As Aboriginal people, we need to be able to talk openly about these issues and develop strategies to assist our families and communities to cope with this devastating disease.

*Aboriginal Cancer Journeys* and eight fact sheets have been produced by the Aboriginal Health and Medical Research Council, in collaboration with Cancer Council NSW, to begin the process of developing resources that meet the needs of Aboriginal communities. This work is important to raise community awareness for all to take urgent action to reduce the impacts of cancer on Aboriginal peoples.

We express our appreciation to Cancer Australia for their funding and support to produce these important resources.

# Introduction

*by Rodger Williams, Chief Operating Officer,  
Aboriginal Health and Medical Research Council of NSW*

Cancer is something that can sneak up and grab any of us. This happened to my father when he was 69. Dad had several different forms of cancer over the two-year period until he died in 2008.

Dad – who was born in Mudgee of Aboriginal heritage, the Wiradjuri people – was always positive despite everything he went through. He had lots of treatment and he had lots of side effects.

Eventually, the doctor said there wasn't much else they could do for him. Dad decided to stop treatment because it was making him feel worse than without it. He wanted to stay home to die, so my stepmother – a nurse – looked after him. Dad ended up passing away through the night in his bed with family around.

Because we knew Dad was going to pass away, we were able to talk to him about his funeral wishes and other practical things. The opportunity to get his house in order helped my father. To honour his wishes was important for us.

Like me, there are many people who have a personal or family story about cancer. Some are sad, others are inspiring. This book shares a few of these stories.

One thing I learnt when Dad had cancer was how important it is to talk – and to listen – not only to your health care team but also to your family and friends. I hope the stories in this book encourage you to tell your own story and to hear other people's too.

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# Belinda

*Determined to survive for her family*

“ I was diagnosed with a rare sarcoma. The tumour was on the back of my knee and very large. I’d been slack and let it go for a while, but then I started losing a lot of weight in my leg. It got worse and sorer. The doctor took a bit off and sent it to pathology. He rang me and told me it was a tumour and we’d have to do what we can as soon as possible.

In one year I ended up having three operations. The tumour was removed, along with some bone. I’ve got a huge scar on my leg. I also had radiation

treatment. They were worried the tumour could come back aggressive, so it happened very quickly and changed my life over a few months.

When I was diagnosed I was only 32. I’ve got three kids. So that was scary, thinking you’re going to die. When the doctor told me, I got drunk, smoked, couldn’t face up to it. Later I cried my guts out.

Then I thought, “I’m not going to let this get me. I’ve got to show these kids my inner strength.” So I’m still sitting here

Get all the help you can.  
Don't think you're going to die.

now. I feel lucky that I’m here. I’ve got my kids and I can watch them grow up.

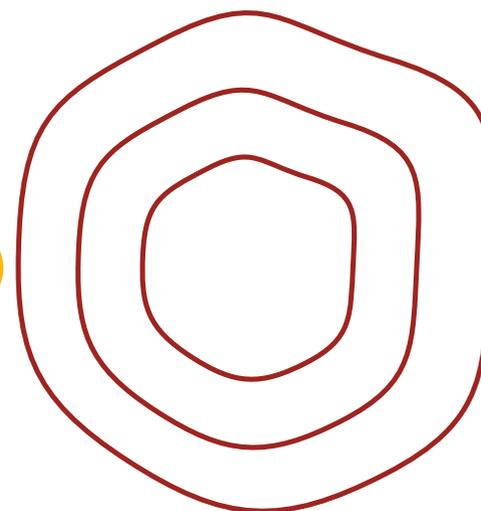
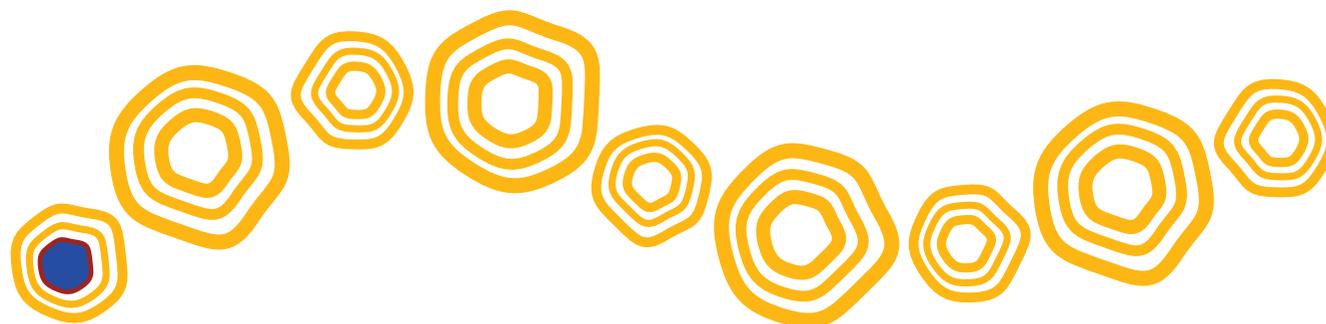
There’s a risk the cancer can come back, but it hasn’t. I go to the doctor once every year to have x-rays, unless I have problems myself. It’s scary waiting for test results to come back because you don’t know. But it’s been six years now.

I’m grateful that I’ve had strong mind power. I see a naturopath and we go through meditation so I don’t stress out. I feel better about myself and

know things are going to be all right.

I got a lot of support. The doctors and people in the radiation unit were wonderful. But they didn’t tell me what I know – I found that on the Internet.

It would be good to have information about how you’re going to feel and how to manage it with your family. A lot of the family won’t even talk about it. People hear the word ‘cancer’ and they put ‘death’ straight to it. The more they know, the more they would understand, and the easier it would be.



## More information

● Cancer Council  
Helpline – 13 11 20  
Free cancer support  
and information,  
including relaxation  
and meditation CDs

# Tom

*Cancer brings a family together*

## **Q. How did you get diagnosed with testicular cancer?**

**A.** I was having a shower and found a lump. My wife encouraged me to get it checked out with my local doctor. Within a couple of hours of the test I found out I had cancer.

## **Q. What emotions did you feel?**

**A.** I thought more about how it would affect everyone else. People were more upset than I was.

We have a son and a daughter. Our son was in and out of hospital all the time, so I had a good relationship with the doctor and the hospital staff. I just thought we had to do what we had to do to get over it and look after our little boy.

Work colleagues and friends were more shocked. Many of them had checkups to make sure they were all right – if it can happen to Tom, it can happen to anyone!

## **Q. How did you find the treatment?**

**A.** At first I came home on weekends, but after three weeks I was just too tired, so I stayed in Sydney. My wife couldn't visit, as our son was sick.



## **Q. What about side effects?**

**A.** The hair was the worst thing. It made it obvious that I had cancer. I had thick, black, wavy hair and I used to really look after it. When it started to fall out I got the clippers and started at number 4, then 3... Now I just keep it shaved.

I used humour to keep the spirits up of the other blokes being treated.

## **Q. How did you find dealing with the doctors and nurses?**

**A.** They were pretty good but it was very embarrassing at first. Easy to see why people would not go to doctors with really personal stuff. After a few weeks I gave up worrying about it.

## **Q. How did you cope with the other areas of your life?**

**A.** Everything else just keeps going on. Money was the hardest thing. We got some help from Can Assist. Work were really good – lots of support and I had enough leave. It was tough not having more family contact.

## **Q. Do you have any advice for your family and community?**

**A.** Ask lots of questions. Find support from wherever you can. Cancer doesn't discriminate. Figure out what is important – your health is important if you want to be able to look after anyone else as well.

## **Q. Has having cancer changed your outlook on life?**

**A.** Not just my cancer, but my Mum having cancer has made a big difference. It helped us fix some stuff that had not been right for a long time and helped me back to my family. A really bad thing has turned up some good stuff as well.

### **More information**

- ☎ *Can Assist – (02) 8217 3400  
Accommodation and financial assistance for cancer patients from rural NSW*
- ☎ *Cancer Council Helpline – 13 11 20  
For practical assistance in other states*

# Max

*The cost of cancer can be huge*

## Diagnosis

I'd been taking antacids for acute stomach pain. I think they masked the problem. So I had a gastroscopy to find out what was wrong and they found the cancer.

## Reactions

I was hurt, felt a lot of fear, and worried about how the family would get on. I have a young grandson and I want to be around to see him grow up.

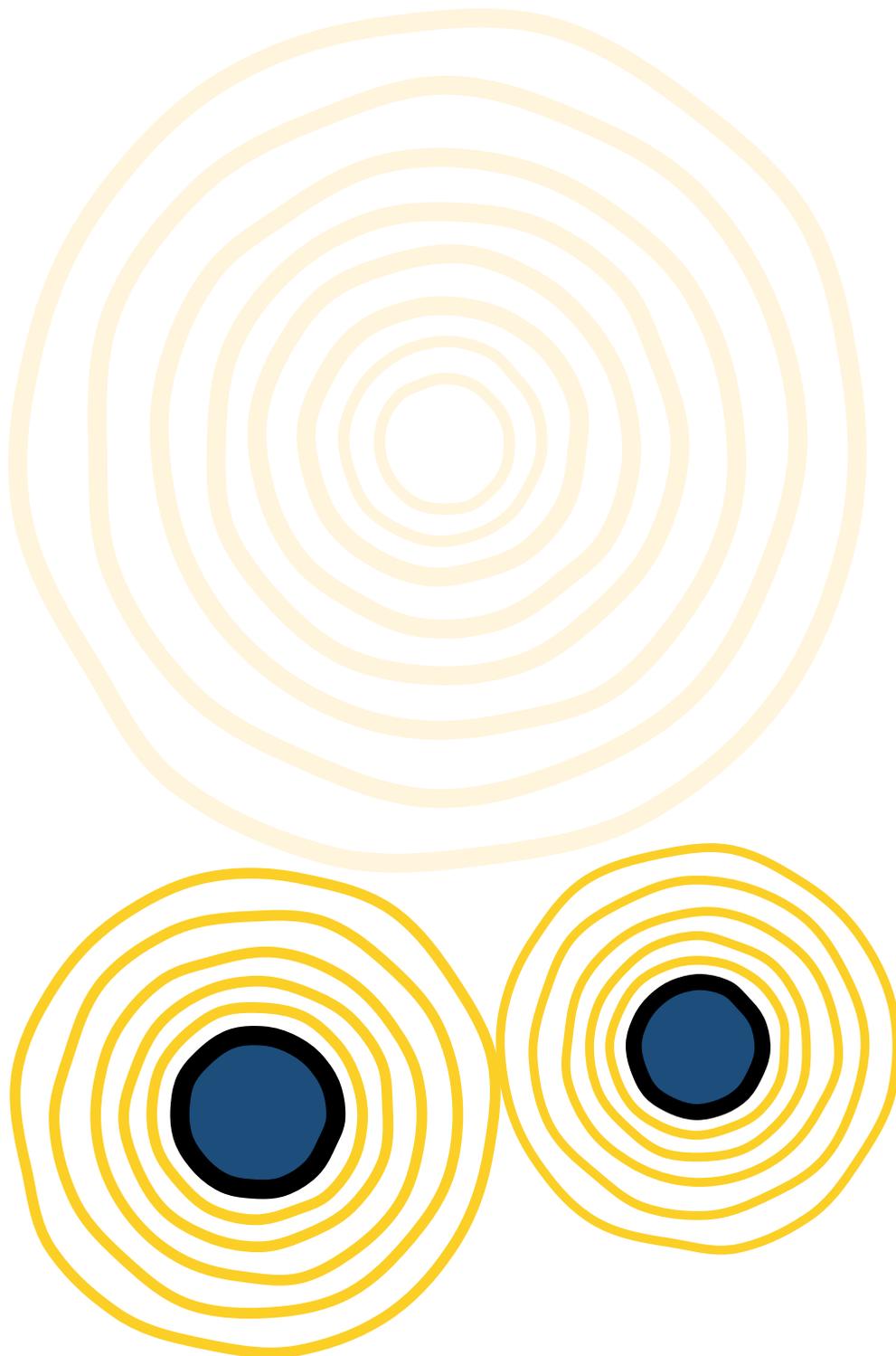
Waiting three weeks for the first stomach surgery – that was the toughest time – and not knowing what was going to happen.

## Treatment

I had surgery, chemotherapy and radiotherapy the first time. When the cancer came back, I just had surgery. Hopefully the cancer's gone for good.

## After treatment

When I got back home I got back to being well pretty quickly. I was back to work in 12 months and back to golf in eight months. Put the weight back on!



## Support

The hospitals were good. My wife was there a lot, and my sons visited and were very supportive.

My faith in the Lord has also helped me get through the last six years.

## Regrets

Two years later when I had surgery again, I made some pretty rash decisions. I spent my superannuation and any savings to have the treatment the second time round. It has meant that my wife now has to work. It has changed our life in that way. We used to rent privately. Now we have a house through Aboriginal housing.

## Words of wisdom

Don't give up. Stay positive. Get regular checkups. Ask questions.

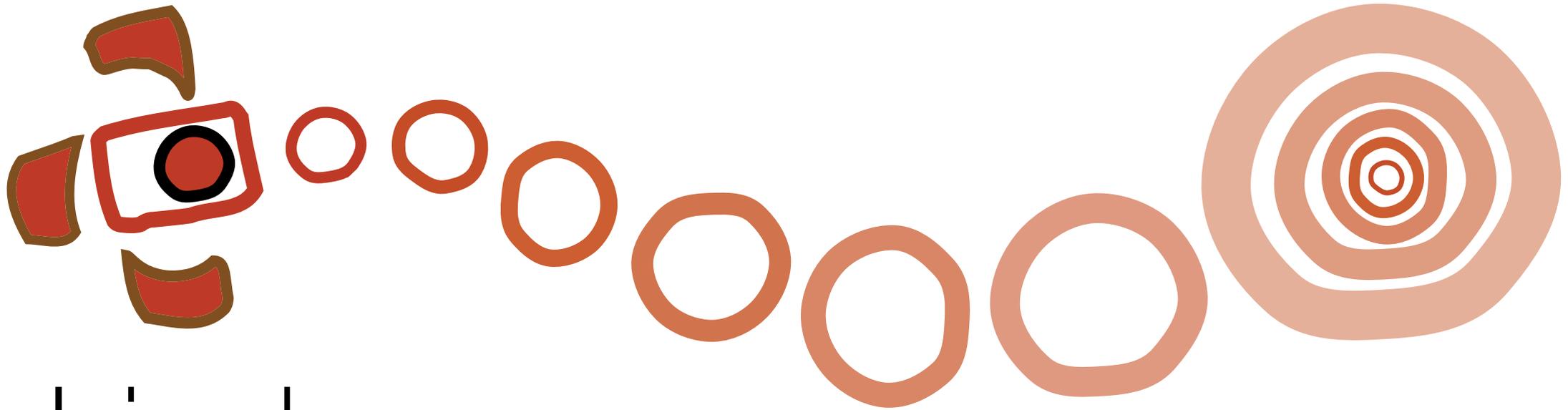
## Tips for others

Get good quality information about what's going on. Get some counselling to help you through it. See a financial adviser to help you make good decisions when you're stressed and don't know what's going to happen.

## More information

© Cancer Council Helpline – 13 11 20

*Provides support, including information about financial planning and counselling*



# Linda

*Cared for her husband at home*

## **Q. How was your husband diagnosed with cancer?**

**A.** It started off with a sore back. We went to the doctor, physiotherapist and chiropractor. Then my husband, Steve, was having trouble walking and the pain was unbearable.

## **Q. What tests did he have?**

**A.** We changed our doctor and he sent us to have some scans. A specialist told us the scans showed a mass, and he referred my husband to hospital for further tests and an MRI.

## **Q. What happened next?**

**A.** After he had the MRI, a different doctor at the hospital came in and

said, “You’ve got cancer,” and walked out.

They never found the primary site; they only found the secondary sites on my husband’s spine, in his lungs and in his liver. He had a biopsy on his spine. They said it was inoperable and untreatable.

## **Q. Did he have any treatment?**

**A.** He did have chemo and radiation to relieve the pain. When he was being marked up for radiation I was told – not him – that he only had four months to live if we were lucky. He couldn’t even sit in a chair because he was in too much pain. Soon he was bed-ridden.

## **Q. What support did you get to care for your husband?**

**A.** While I nursed him at home, I had a lot of respite care from my mum – she was my rock.

We also had an excellent palliative care nurse. He came every day; he was like a friend. But when he went on holidays, I had a lot of difficulties with the nurse that replaced him. She didn’t come in the morning.

## **Q. Were you able to say goodbye?**

**A.** When the nurse at the hospital told me it was time, I called everyone in. I never said to my husband not to go, but I said, “The kids and your mum and dad are on their

way. When you’re ready to go, you go.” He went about 20 past six in the morning. Our five children, his parents, my mum and I were with him at the end.

## **Q. How were the hospital staff?**

**A.** I couldn’t have faulted the nursing staff at the palliative care unit. The Aboriginal Liaison Officer at the hospital was really good. We were given permission to do the smoking ceremony, and so I felt really good.

## **More information**

☎ *Commonwealth Respite and Carelink Centres – 1800 052 222*

☎ *Carers Australia – 1800 242 636*

**Cancer does change you**

“When you have cancer, your thinking does change – the way of dealing with life, life situations, people, and issues. I changed my diet. That was all part and parcel of helping my body battle cancer.”

*Mary, woman with breast cancer*

**Believe in yourself and your medical team**

“When I had surgery, all I kept thinking to myself was, ‘I’m not going to die. I’m going to be okay.’ I knew I was in the hands of a good brain surgeon. He told me he was going to look after me and that nothing was going to happen to me.”

*Gloria, woman with brain tumour*

**Connecting with others**

“When I found out there was an Aboriginal support group, I thought it would have been good for Dad and me.”

*Claire, sister of woman who died of breast cancer*

**Information is available**

“When Mum had cancer, I learnt a lot of information from the Internet because it was from all over the world. What I couldn’t find on the Internet, I learnt from brochures in the hospital.”

*Celia, daughter of woman with lung cancer*

# Words of wisdom

**Early detection can make a difference**

“You have to be prepared to listen to your body and be prepared to take notice of your body at the same time. Don’t just wait. Go and get it checked out now.”

*Ethel, woman with lung cancer*

**Support is there for you**

“I’m a carer. I lost my daughter to cancer. The most important thing is to get all the information you can, and once you get that, you know where to go for help.”

*Will, father of young woman who died of breast cancer*

**Dying at home is possible**

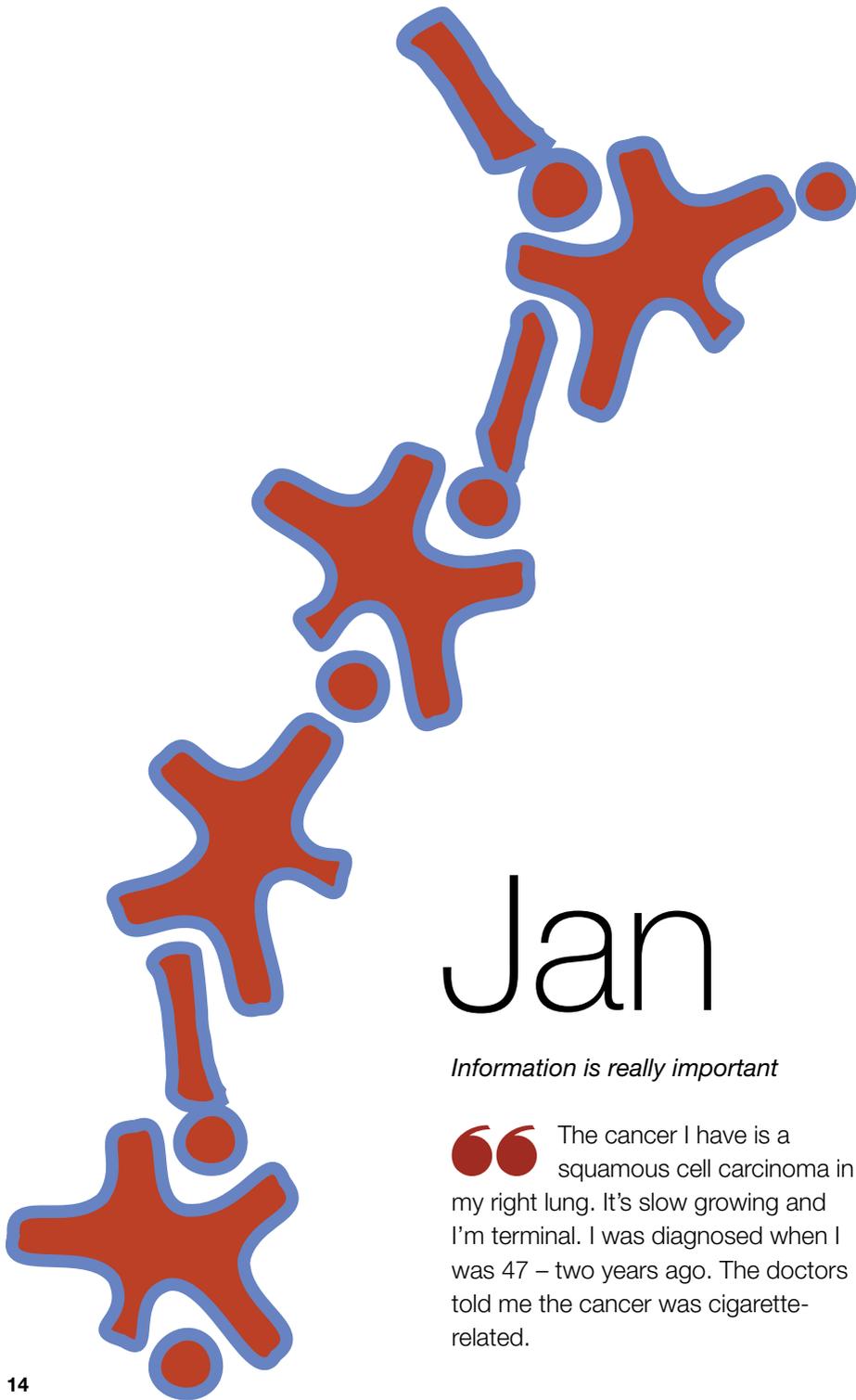
“Two people I know died in familiar surroundings. Their family was there the whole time taking care of them. To me, that is really important that people have that opportunity, as well as the support and care and resources to die – if they choose – in their own home.”

*Martina, friend of people who had cancer*

**Take time to deal with a diagnosis**

“When I found out my mum had cancer, I stopped talking to her and I got angry with her. My partner said, ‘If you don’t talk to her now, if anything happens to her, you’re never going to forgive yourself.’ I thought, ‘Yeah, he’s right.’ So I started talking to her.”

*Vicky, daughter of woman with lung cancer*



# Jan

*Information is really important*

“ The cancer I have is a squamous cell carcinoma in my right lung. It’s slow growing and I’m terminal. I was diagnosed when I was 47 – two years ago. The doctors told me the cancer was cigarette-related.

## **Diagnosis**

By the time I was diagnosed, the cancer was inoperable. They told me, then walked out of the room!

I went home thinking, “Is that it?” I was shocked. From diagnosis, I didn’t know what was happening.

## **Treatment**

A month later, I started treatment – radiotherapy and chemo. The doctors never explained what they wanted these treatments to do.

## **Side effects**

After chemo I was sick. I couldn’t sit up. I didn’t eat or drink for three days. I had to go back to hospital. When I started my next course of chemo, I was weaker and sicker than before.

They don’t tell you how demoralising it is having treatment, or about the depression – and that your family is going to have that too. I was also in a lot of pain.

## **After treatment**

The doctors told me the chemo wasn’t working and they could only treat the symptoms of the disease. I only go back to the hospital for respiratory problems.

When they told me they couldn’t help me, I was suicidal. I was that bad. It would have been much quicker to have died then.

## **Other therapies**

I have a lot of fruit and vegetable juices. I’ve also tried some herbs. I felt that they did a lot of good for me.

## **Family**

At first my family wasn’t really there for me. I felt unimportant, unloved. That didn’t help. Since then, I’ve realised they weren’t there because they didn’t know how to be – they were afraid, they didn’t understand. But they love me very much. My mother and daughter have helped so much.

## **Cancer information**

You need doctors and nurses to explain the treatment available and the steps to take. It’s important to find out about complementary medicines because of how much good they can do. If I’d known earlier what I know now, I would have come out better.

## **Words of wisdom**

Don’t smoke! And we need information early on so that mentally we can prepare our bodies for where they have to be.

## **More information**

☎ *Lifeline – 13 11 14*

*24-hour free telephone counselling service*

☎ *beyondblue – 1300 22 4636*

*Information and referral to services for depression and anxiety*

# Aunty

*Living without regret*

## **Diagnosis**

One day, I was 74 at the time, I started feeling a lump coming when I was in the shower. It started getting bigger and bigger. I had a mammogram and ultrasounds.

## **Feelings before treatment**

I didn't know anything. It frightened me but I just carried on. I talked to Community Care, to a lot of people around here and the hospital, of course.

## **Treatment**

I had the whole right breast removed. I stayed in hospital for a week. I had a beautiful room all on my own. I had visitors galore! The doctor talked to me about what we should do before the operation. He talked about chemo and radiation, and I said I didn't want that. He said, "Well, we'll take it all off," which he did.

## **Follow-up treatment**

The doctor wanted me to have radiation, after I had my boob off, but

# Elizabeth

I said, "No, because you said I didn't have to." He said, "Will you listen to the radiation oncologist?" I did, but I had my mind made up not to have it. I'd probably have it if I was younger.

## **Feelings after treatment**

I feel good, really good. If I had radiation, I'd be tired and sick. But I've got things to do. I can't afford to lie around sick. I'm very comfortable.

## **Support**

There has been a lot of support from the hospital. They're lovely people. They can't do enough for you. I've had family support too. I live on my own but I only have to ring them and they are here if I want them to be here. But they've got their own lives. I don't like annoying anybody. I love my life. I live it to the full – my way.

## **Thoughts about cancer**

There are so many here in hospital now. It's terrible, cancer – it's frightening. People don't want to know. They don't want to go to the

doctor. They're frightened. I have told my family to go and have their mammograms and Pap smears. They used to laugh. One young one has died and I have another niece who has cancer of the uterus. They got their sisters and aunts to have the tests.

## **Words of wisdom**

People need to know more about cancer and do something before they get it. They need to have checkups like mammograms and Pap smears.

## **More information**

● *National Breast and Ovarian Cancer Centre – 1800 624 973*  
*Resources about breast and ovarian cancer and lymphoedema, including a DVD for Aboriginal and Torres Strait Islander women*

# Valerie

*Family helped her through treatment*

“ One week after I was diagnosed I went and had the lump removed. They said that they got it all.

When they told me I had breast cancer I didn't feel for me, I just felt for my family. I thought of them straight away and how they were going to take it. I didn't think about me, or dying.

My elder sister came with me when I was diagnosed. After that I went to the doctor's by myself and I asked him questions and he explained everything to me. I knew what was going to happen. As they weren't going through it, my family worried.

Five years later exactly, I got it in the other one. I had another mammogram and they found a lump in the right breast. I had a biopsy and they cut the lump out. I got an infection in my breast. Then they found more little lumps.

I told the doctor I didn't want any chemo or radiation, and I didn't want any more operations later. I asked if they could remove both breasts, and they said they could, so they did.

The nurses and doctors gave me books and information to read up on about everything and all the treatment options available to me.

*I've changed my eating habits, stopped smoking and drinking.*

I also had a day nurse come to visit me for about six months after I was diagnosed. My younger sister became my full-time carer.

Not everyone dies from cancer, but you need to get it early. A lot of people are frightened to go and find out. Even if it is a small lump, it is better to go to the doctor's and get it checked out. I go to the doctor when something is wrong. I'm keeping myself alive – myself – by getting these things checked.

I've given away smoking and drinking. I love fishing. Fishing makes me relaxed and calm, so I didn't go back to the pub.

## More information

☎ *Quitline – 13 7848*

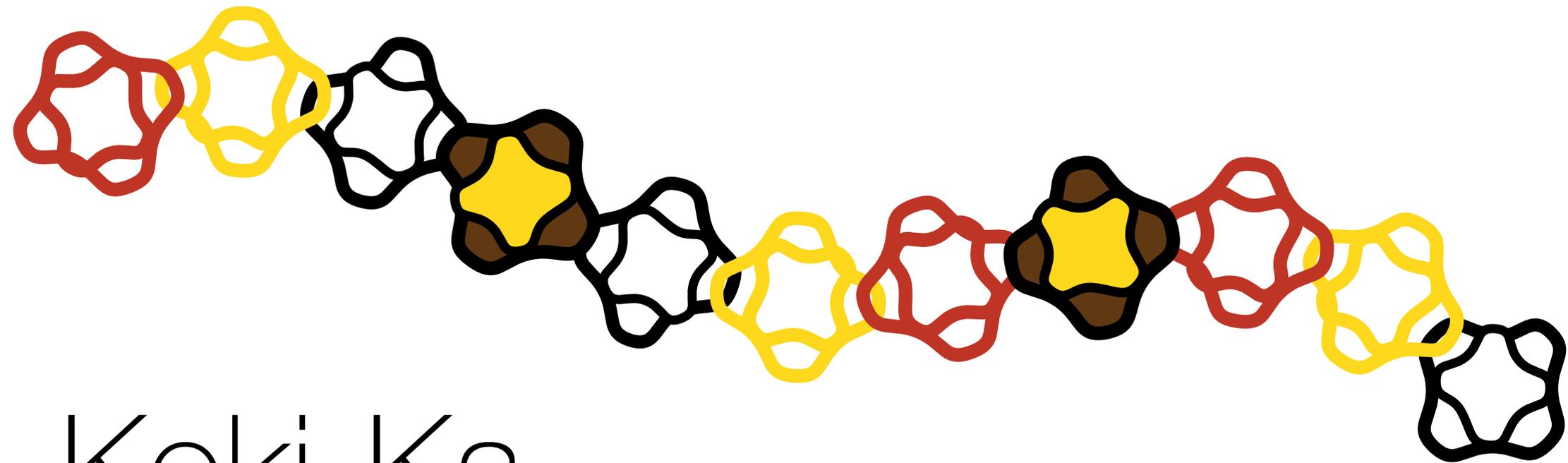
*Free Quit Kit and support to quit smoking*

☎ *Healthy Active Australia –*

*[www.healthyactive.gov.au](http://www.healthyactive.gov.au)*

*Information about eating well and exercise*





# Koki-Ka

*Family history led to regular checkups*

“ I’ve had three close family members who’ve died from cancer. First Dad. He was 60 and had oral cancer for five years. The last 12 months it really affected him. He went from being a really big man to a very frail, thin fellow.

My second experience was with my sister. She was 49 when she died. She had lung cancer. By the time they found it, it was very advanced. It was aggressive. She was diagnosed in June and she died in July. She was a very heavy smoker and a big drinker as well.

The third person was my mother. She died the same year as my sister. She had tumours in her brain. I think she had them for a couple of years.

After my mother died, I went to the doctor. I wanted to have all the tests that you could possibly have to check for cancer. The doctor listened to all my concerns and now I have regular checkups.

I have Pap smears and breast checks. I try to always see the lady doctor because she is aware of my anxious feelings about it, even though she said

I don’t have a lot of the risky behaviour for cancer, like smoking and drinking.

My doctor said I do have a bad family history of cancer, but if I look after myself and have regular checkups, it could be all right. But it is scary.

If I could give a message to people about what I’ve been through it would be to ask lots of questions to any of the health professionals. If you doubt anything, make them spell it out to you. If you want second opinions then get second opinions. Remember that you have a choice.

Make sure you have your checkups – your breast checks and Pap smears – and to ask questions all the time about things you aren’t sure about. Even if you get a little tiny lump somewhere and you think, “Oh, it’s not anything,” always get it checked out because you just don’t know.

## **More information**

- For Pap smears, breast checks and other screening for cancer, contact your local GP or Aboriginal health service
- BreastScreen Australia – 13 20 50  
Free mammograms for women over 40

# Glossary

Here are the meanings of some words relating to cancer. See more word meanings at [www.cancercouncil.com.au/words](http://www.cancercouncil.com.au/words).

<b>aggressive cancer</b>	Cancer that grows very quickly.
<b>alternative therapies / medicines</b>	Therapies used in place of treatment from doctors. Some people try them hoping that they cure cancer, but there's no proof of this.
<b>biopsy</b>	When the doctor removes cells from the body to see if they are healthy or not. This test shows if cancer is in the body.
<b>breast check</b>	Feeling breast tissue to see if there are any changes or lumps. You can check your own breasts or ask your health care worker.
<b>cancer</b>	When unhealthy cells grow out of control and form a lump or cause problems in the blood. Cancer cells are able to spread.
<b>cells</b>	What the body is made up of. There are billions of cells in the body, which form organs, blood, hair, skin etc.
<b>checkup</b>	An appointment with the doctor to check your health and to make sure treatment is working or the cancer has not returned.
<b>chemotherapy</b>	Strong medicine that kills cancer cells.
<b>chiropractor</b>	A natural therapist who works with muscles and bones to help reduce pain, stiffness and other problems in the body.
<b>complementary therapies / medicines</b>	Different natural therapies that some people use to help with the side effects of cancer, e.g. herbs, massage or relaxation.
<b>CT scan / CAT scan</b>	A test that takes pictures of the inside of the body to help the doctor locate a tumour or find out what is wrong.
<b>cyst</b>	A harmless lump in the body.
<b>diagnosis</b>	When the doctor works out what is making someone unwell and gives the problem a name, e.g. liver cancer or depression.
<b>family history</b>	Medical information about your family that can help the doctor understand your risks of getting cancer or other illnesses.
<b>gastroscopy</b>	A test that lets the doctor look at the throat, stomach and small intestine by using a tube with a camera attached to it.
<b>lymph nodes</b>	Small glands (like beads) in the body that help fight infection.
<b>mammogram</b>	A test that takes pictures of breast tissue to show up lumps.

<b>meditation</b>	A way to relax using breathing and imagination.
<b>MRI scan</b>	A test that takes pictures of the inside of the body.
<b>naturopath</b>	A therapist who uses natural medicines, nutrition (what you eat) and bodywork (e.g. massage) to help improve people's well-being.
<b>oncologist</b>	A doctor who has done many years of training to treat people with cancer using chemotherapy or radiotherapy.
<b>palliative care</b>	Treatment and care given to help people feel better and more comfortable without trying to cure cancer. It also helps carers.
<b>Pap smear</b>	Cells are taken from the cervix (top of the vagina) to check for unwanted changes. Women should be tested every two years.
<b>pathology</b>	Hospital department where scientists work out why someone is ill by looking at substances from the body, e.g. blood or urine.
<b>physiotherapist</b>	A therapist who helps you with physical problems after cancer treatment, such as improving walking or your strength.
<b>primary site</b>	Where cancer starts in the body, e.g. the lung.
<b>radiologist</b>	A doctor who looks at scans and x-rays to diagnose disease.
<b>radiotherapy / radiation</b>	Powerful beams that you can't see (called x-rays) that go into the body to kill cancer cells.
<b>respite care</b>	Care given to a sick person to give their regular carers a break.
<b>sarcoma</b>	A type of bone or muscle cancer.
<b>secondary site</b>	Where cancer spreads to, e.g. the liver, bones or brain.
<b>side effects</b>	Unwanted effects of cancer treatment, e.g. tiredness, feeling sick or hair loss. Most side effects go away after treatment.
<b>specialist</b>	A doctor who has done many years of training to focus on one area of health, e.g. surgeon (operations) or haematologist (blood).
<b>surgery</b>	When a surgeon cuts out a cancer during an operation.
<b>symptoms</b>	What people see or feel if they're unwell, e.g. rash, pain, fever.
<b>terminal</b>	When a disease cannot be cured and is likely to cause death.
<b>tumour</b>	A lump in the body that shouldn't be there.
<b>ultrasound</b>	A test that shows where and how big a tumour is.

## Aboriginal Cancer Journeys:

### Our stories of kinship, hope and survival

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The Aboriginal Health and Medical Research Council of NSW (AH&MRC) is the peak body for Aboriginal health in NSW and is comprised of over 60 Aboriginal Community Controlled Health Organisations throughout the state.

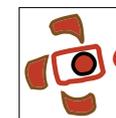


Cancer Council NSW is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.



Cancer Australia is a national government agency, working to improve outcomes for all people affected by cancer and particularly for those people whose survival rates or cancer experiences are poorer.

**About the artist:** Adam Hill is a descendant of Mid-North Coast peoples and is an artist and performer. He has interpreted the experiences of the people interviewed for this book.



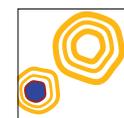
Shows a carer losing their loved one, from the hospital bed to the Dreaming.



The importance and strength of family and kinship.



Exclamation marks represent the shock of a cancer diagnosis.



Finding strength through the journey of life.



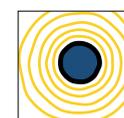
The line of the surgeon's scalpel divides the breasts, which are marked with traditional cicatrices (scars).



A cancer diagnosis brings up many questions for the patient and their family.



Keeping hope and being supported through cancer, and retaining femininity throughout adversity.



Circles (rondels) represent the elements of life, water and place.



Support from the spirits of family members, who have their arms linked together.



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