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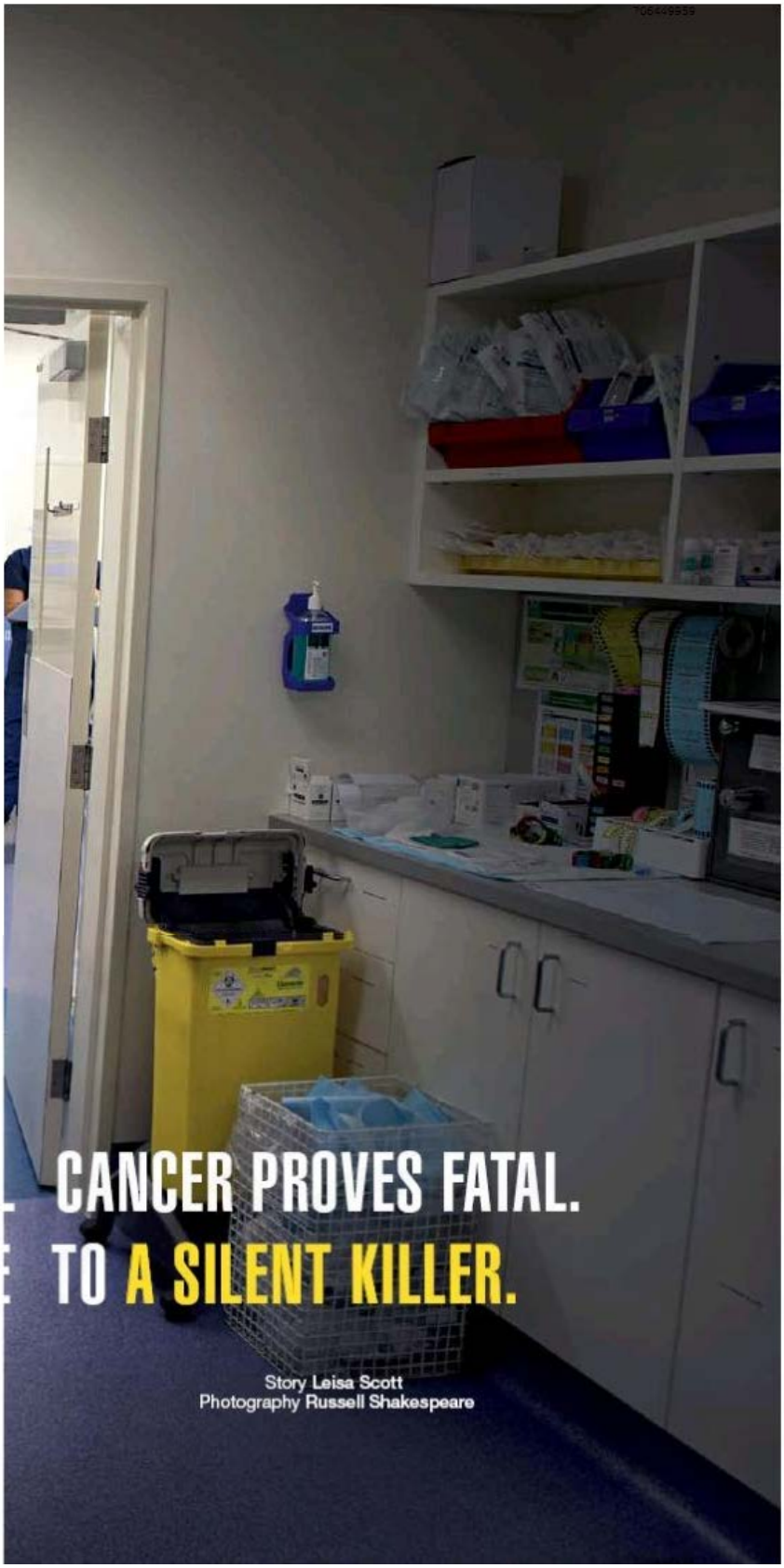

CANCER PROVES FATAL. TO A SILENT KILLER.

Story Leisa Scott
Photography Russell Shakespeare

It can't be easy to relax when you're lying on a hospital trolley about to be wheeled in for cancer surgery, but Judy Philp is managing a good impression of calm. She jokes with the surgeon about the wine she'd like on recovery – "A Marlborough sav blanc, not too fussy about the year" – and chats about Buddy, her latte-coloured labradoodle waiting at home in Eumundi on the Sunshine Coast for her return. At 66, this fit and lively woman knows who she is and what she wants out of life.

And she wants more. More time with Maurice, her husband and high school sweetheart, more travel, more laughs with friends, more Buddy. So when she awoke one morning in October last year to discover blood on her underpants, she didn't muck around. She made an appointment with her GP straightaway. "I had gone through menopause at 57 and I knew that any unexpected bleed should be checked out," Philp says. "I'm the sort of person that deals with things. Don't put it off, just do it."

It's music to the ears of her gynaecological oncologist, Professor Andreas Obermair, who has seen too many women put themselves last. "Women will nurse or care for a husband, a parent or a child and ignore their health concerns. I see this very regularly," says Obermair. He wants that to change. Women, and the men in their lives, need to get over embarrassment and talk freely about gynaecological issues – learn the facts, dispense with myths, act early. Because one in three Queensland women diagnosed with gynaecological cancer will not survive, many because they missed, or failed to heed, the warning signs. "Postmenopausal bleeding is an early warning sign and you need to assume it is cancer unless proven otherwise," Obermair says. "You cannot say, 'It's just a little bit of spotting, she'll be right'. That is wrong."

Philp's GP sent her for an ultrasound, which found what looked like a polyp. An exploratory hysteroscopy followed; a small mass identified. Cell tests showed Philp had endometrial (also known as uterine) cancer. Three weeks since the bleed, Philp's womb is about to be removed by laparoscopic surgery at Brisbane's inner-south Greenslopes Private Hospital, an operation she has allowed *Qweekend* to witness. If the cancer has been caught early, if Philp's proactive approach to her health has paid off, the hysterectomy will be the end of interventions. No chemotherapy or radiation, just a drive back to Eumundi to Buddy and the homestead the Philps call Heaven on Earth.

CERVIX. OVARY. VAGINA. STILL WITH ME?

Uterus. Vulva. Fallopian tube. Just words for body parts. Like lung, leg, spine. All can become cancerous. But for several reasons – prudishness, a sense of "proper" topics, embarrassment – many women recoil from informed discussion about these sex and reproductive organs. It's breeding an ▶

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Early warning ... Ovarian cancer survivor Lisa Roper with daughter Charlotte, whose gestation led to its discovery; (*opposite*) gynaecological oncologist Andreas Obermair.

ignorance that can kill. Obermair, a senior consultant at the Royal Brisbane and Women's Hospital, chair of gynaecology at Greenslopes Private Hospital and a professor of gynaecological oncology at the University of Queensland, gives speeches about his specialty. He talks about the paucity of reliable screening tests for the range of cancers and celebrates the fact that at least with cervical cancer, there is the pap smear and, more recently, through the groundbreaking work of immunologist Professor Ian Frazer, a vaccine. Then he waits for the women to approach him after the speech. "Women come up to me, educated women, and they say, 'I'm surprised you say the pap smear doesn't screen for ovarian cancer'," Obermair says. "An enormous number of women believe the pap smear screens for all gynaecological cancers. Enormous." He notes my sceptical look. "This is not something I'm making up, I know from first-hand experience."

Ovarian cancer survivor Lisa Roper is often alarmed by friends' reluctance to see a doctor over gynaecological issues. She thinks a "cheeky" advertising campaign might be in order to alert women to the nebulous symptoms of ovarian cancer: bloating, abdominal or pelvic pain, frequent or urgent urination and feeling full after eating a few mouthfuls. "If you go to the doctor and it turns out you're just bloated, well, great, fine, I'll just stop eating onions, but don't be embarrassed to go and get something checked out and be told there's no problem," says Roper.

Roper had a lot of changes in her body when she was diagnosed in February 2005, aged 31. She was pregnant for the first time. Her 18-week scan picked up a suspicious cyst. One of Roper's most enduring memories is being pregnant and wheeled into surgery, her husband, Miles, fading into the distance, as surgeons prepared to remove the cyst. "It was awful not knowing how I'd wake up. Pregnant or not pregnant. Cancerous or not cancerous. I could have lost the baby and had cancer."

The baby was safe, but it was cancer and an ovary was removed. The long wait began to deliver the baby at 32 weeks so that Roper could have chemotherapy. On May 16, 2005, Charlotte arrived healthy via caesarean section and Obermair was on hand to check if the cancer had spread. Roper awoke to learn the results were clear but, keen to breastfeed, she started chemo after ten weeks. As a science teacher, Roper, now 42, has a respect for baseline data and asked for a scan of the remaining ovary and her uterus after the chemotherapy.

"It was very much me asking for it, this is what I want," she says. "You've got to be proactive." Incredibly, the scan showed a mass on the other ovary, proven later to be cancerous. "So I had a full hysterectomy. We'd have wanted more children but I wanted to be around for my daughter," adds Roper, who refers to Charlotte, 9, as "our little angel" because her gestation led to Roper's cancer being discovered. Roper remains cancer-free and Charlotte is an active girl who loves swimming and netball.

Ovarian cancer is so insidious that a reliable screening test would be revolutionary, but is a long way off. Genomic research has found ovarian cancer has numerous subtypes, making a one-size-fits-all test unlikely. Tests that exist have limitations – Roper had the biomarker CA125 blood test and it came back negative.

Late last year, the patient-led Ovarian Cancer Australia non-profit organisation launched its first national plan, which declared it would divert its research funding from detection to treatment and prevention. CEO Alison Amos says the genomic research led to OCA's decision that "putting money into developing a population-based screening test to detect the disease is not a realistic target". OCA has pledged $550,000 to two research projects, the main one being the Australian Ovarian Cancer Study based out of Melbourne's Peter MacCallum Cancer Centre in conjunction with other centres, including the Queensland Institute of Medical Research.

So with limited scanning programs, a woman's best safeguard of her gynaecological health is to be proactive – and assertive. The late South Australian Liberal senator, Jeannie Ferris, learned that too late. Her parliamentary colleague and friend, Queensland Labor Senator Claire Moore, remembers Ferris being outraged at the way her concerns about her wellbeing were dismissed by doctors for about 12 months before her diagnosis. By then, the disease was advanced and Ferris died 18 months later, aged 66. "She was a middle-aged woman and she truly felt that she was just dismissed: 'You're tired, you've gone through menopause, you're a bit hysterical, dear'," Moore recalls. "She'd been to several doctors and then got to the stage where because people had told her to just change her diet, rest more, lose a bit of weight, that she let it go on and I think she was angry with herself as well, that she wasn't stronger."

Ferris channelled her anger into action, and with Moore and then Australian Democrats senator Lyn Allison spearheaded a parliamentary inquiry into gynaecological cancers. "Jeannie's position was that if someone as well-educated and well-resourced with networks as her could have not got her diagnosis in time, what chance do others without those advantages have?"

The inquiry produced the 2006 report, "Breaking the silence: a national voice for gynaecological cancers", which Moore says helped put gynaecological cancer on the radar. A key recommendation was the establishment of the National Centre for Gynaecological Cancers, which received $1 million in set-up funding from the federal government and is part of Cancer Australia.

Still, gynaecological cancer is a long way short of having the profile and fundraising power of the breast cancer lobby. "We're the poor cousin," says Obermair. A Cancer Australia report into cancer research released in September last year found that between 2009 and 2011, breast cancer research received $85.9 million; gynaecological cancers received $19.3 million. Obermair talks of the Matthew principle, the concept that where there are riches or fame, more will follow to the disadvantage of other worthy endeavours. "Breast ▶

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Remote control ... Obermair and team perform laparoscopic surgery on patient Judy Philp (*opposite page*), today, and (*opening pages*) just before undergoing her hysterectomy.

cancer people have done very well [at attracting funds]," he says.

There are good reasons breast cancer has attracted more research funding. It affects more people. A 2012 report by the Australian Institute of Health and Welfare found breast cancer was the most commonly diagnosed cancer among women, with 13,567 cases compared with 4534 gynaecological cases. More people died with breast cancer – 2680, compared with 1502 with gynaecological cancer. But there are good reasons why more research needs to be directed to gynaecological cancers. Today, with improved screening and treatment for breast cancer, 88 out of every 100 women are alive five years after a diagnosis. In contrast, ovarian cancer – the second-most diagnosed gynaecological cancer after uterine – has a five-year survival rate of 43 per cent, while the rate for the less common vaginal cancer is 45 per cent. Cervical cancer has a survival rate of 72 per cent while uterine cancer, a generally slow-moving disease (the incidence of which is increasing by 1 per cent every year in women under 40, largely due to obesity), offers the best chance of survival at 82 per cent.

Raising the profile – and, in turn, funding – of gynaecological cancer is not easy. Well-known women will talk publicly about breast cancer; it's not as easy to get them to discuss cancer of their sex organs. Janette Howard is a cervical cancer survivor. The wife of former prime minister John Howard was diagnosed in 1996, soon after her husband took office. Howard's hospitalisation was reported but she did not say she had cervical cancer. Ten years later, after it was widely assumed she'd had breast cancer because of her role as patron of the National Breast Cancer Centre (now Cancer Australia), she decided to clear up that assumption and reveal she had cervical cancer. Howard declined an interview for this story.

"Celebrities don't want to be on [a media organisation's] title page saying 'I had cervical cancer'," says Obermair. But he believes privacy and embarrassment are not the only things that stop women from talking about their gynaecological cancers. He says misinformation about cervical cancer in particular, spread by groups wishing to "push their own political or ethical agendas", has made women feel guilty. That makes him angry.

Obermair says the development of the human papillomavirus vaccine led to a wider understanding that cervical cancer results from the sexually transmitted HPV. That spurred some to suggest the cancer was a result of promiscuity. The truth is one sexual encounter can be enough to contract the virus, which may lead to cancer. But, Obermair adds, if a woman has had a diverse sexual life, what does that matter to her right to live? "There's been so much rubbish about this whole sexual aspect, it leads to an 'it's my fault' thing," he says. "I find that very disturbing. There's this belief that if you have cervical cancer you had, you know, a pretty good life sexually. It's a common belief. And Janette Howard probably does not want to be portrayed as promiscuous.

"A lot of women I treat for cervical cancer are in exactly the same position ... and I think it spreads to other cancers. When I speak to people with uterine cancer, some shut up because they're not quite sure if there was something they've done when they were young that is now the punishment for this. I'm concerned a lot of women feel guilty. And really, they shouldn't. They just should not."

THE BEEPS OF HIGH-TECH MACHINERY punctuate the studied quiet of the operating theatre as Obermair makes the final cuts to free Philp's uterus. Thirty minutes after the first incision, reproductive organs that have helped produce two healthy children (Nicole, 43, and Peter, 41) are released from their anatomical bonds. Against the general order of things, the uterus, fallopian tubes and ovary are pushed through a tube inserted in the vagina and out into the visible world.

Obermair holds the uterus in the palm of his hand. He points out the cervix and tubes and one ovary, the other having been removed in Philp's late forties because of recurring cysts. It's a marvellous thing to contemplate: this uterus, now about the size of a plum, previously grew to the size of a watermelon and held and twice nurtured a baby. It's sobering to remember that somewhere in that small, bloody mass is a tiny amount of cells that have turned cancerous and could kill Philp if not removed.

Obermair sends the sample away to pathology and goes back to Philp to remove some lymph nodes for testing. Watching Obermair and his team is as awe-inspiring as the female reproductive system itself. It's the remoteness of laparoscopic, or keyhole, surgery that boggles the mind. Small incisions are made in points of the stomach to allow the insertion of a camera, a carbon dioxide outlet (to inflate the abdomen for a better view of organs) and instruments. The camera relays the image onto a video screen which Obermair watches to guide the instruments where needed, his hands working outside the body. He looks a bit like Edward Scissorhands, the titular character from the 1990s fantasy cult film starring Johnny Depp, an observation Obermair either doesn't hear or chooses to ignore. He's alert to the surgery phone ringing, though, and listens intently as a nurse holds the receiver to his ear.

"Great. That's perfect. That's really good news," he says. The initial pathology results are back within 30 minutes and Philp's cancer is Grade 1, the lowest of three grades for uterine cancer. If the lymph nodes prove cancer-free, Philp will need no further intervention.

Obermair became an apostle of laparoscopic surgery for hysterectomies after arriving in Australia with his young family from his native Austria in late 1999. At first, it was Brisbane surgeons' drive to remove advanced cancers during open surgery that impressed him. "Honestly, it blew me away what you could do," he says of his early days at RBWH. "In Austria, if they cut the tummy open and saw advanced cancer, they would say, 'This is inoperable'. Here, I saw people tackle it and, at the end of a four-hour operation, the patient was tumour-free. That is the difference."

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He moved to Perth in late 2001 as part of his gynaecological oncology training and worked under the tutelage of the late Tony McCartney, a pioneering laparoscopic surgeon. After watching his first laparoscopic hysterectomy, Obermair was hooked. It was innovative and enabled women to leave hospital within one or two days, compared to the weeks often required for open hysterectomies. "To me, it was unbelievable but it was true.

"When I left Perth [to return to Brisbane] in late 2002, I said, 'We really need to establish this, this is such a beautiful and helpful operation'," says Obermair. "One of the ways to establish it as standard so it replaces the opening of the abdomen is to do a trial, to prove that it is a better operation."

Which is how Obermair became enmeshed in the perennially fraught issue of research funding. At first, he could not secure government assistance so cajoled a surgical equipment company and its rival into donating. With $60,000 in the kitty, the Queensland-led, international LACE (Laparoscopic Approach to Carcinoma of the Endometrium) trial began in 2005.

Over the years, the persistence of Obermair and his colleagues at Queensland Centre for Gynaecological Cancer Research led to grants totalling almost $2 million from a range of sources, including the Queensland Government and various cancer councils. The biggest grant of $775,000 came from the National Health and Medical Research Council, Australia's leading research grants agency, which is now set to be merged with the federal Department of Health, along with Cancer Australia.

But since 2012, the unfinished trial has been unfunded. Last year, just 15 per cent of applications for $420 million worth of NHMRC project grants was successful, the lowest success rate in 15 years. NHMRC chief executive Warwick Anderson admitted high-quality projects missed out and called for philanthropists to bridge the gap.

Obermair is highly critical of the piecemeal funding system he says could render the $2 million LACE trial's data "of very limited use" if further data is not gathered from the 720 patients until 2017. Key findings so far include that there are 30 per cent fewer surgical complications with laparoscopic hysterectomies than open procedures, recovery is shorter (two weeks compared with six), and about $3700 is saved per case.

About 12 per cent of the 30,000 hysterectomies performed in Australia (for cancer and other reasons) in 2012 were laparoscopic, up from zero in 2000. Obermair says the completion of the study with all relevant data would strongly illustrate the need to train more gynaecologists and nurses in laparoscopic surgery, which in turn would save women time in hospitals and save governments and private hospitals money. "You are having such good data but still not getting funded; what would your conclusion be?" asks Obermair. "That the surgical innovation is not convincing enough or that the current funding models are obviously complete bullshit?" Convinced it was the latter, Obermair and fellow researchers decided to strike out in 2012 and form the Queensland-based fundraising group, Cherish Women's Cancer Foundation. It raises funds from corporations and individuals for research on trials such as LACE and another called feMMe, which is investigating the use of the intrauterine device, Mirena, as a means of fighting endometrial cancer in women for whom surgery would be unsafe. Cherish is not unique; the Ovarian Cancer Australia report found 25 per cent of research in its field is funded by not-for-profit organisations. The report sounds a warning, however, about diversification of research and calls for greater collaboration.

Obermair, like many researchers passionate about their area of interest, is not swayed. "I think it is healthy that there are many voices." He says more researchers will be forced to move to set-ups such as Cherish because of the flawed government funding models. "You will find that, increasingly, innovations will come through corporates, people with nothing to do with government. We need to think and act bold."

THE SIGN JUST BEFORE THE BRIDGE OVER

the babbling creek says "Heaven on Earth" and, after a few hellish weeks, the idyll has returned. A smiling Philp stands side-by-side with Maurice on the verandah of their rambling home beyond the bridge as the irrepressible Buddy, the labradoodle, bounds about. It's been six weeks since the hysterectomy to remove her uterine cancer and Philp has the all-clear. No cancer left, and no chemotherapy required.

"Thank god I woke up to it that something was wrong," says Philp.

It wasn't a hassle-free recovery, though. Philp, who rarely takes an aspirin, had a reaction to painkillers prescribed post-surgery that led to her being readmitted to hospital for almost a week. "I haven't had any trouble with the hysterectomy; there's no pain, no nothing, it was a perfect job," she says. "It was the pain medication that knocked me about." She's a little tender emotionally, too, still battling the niggle known to all cancer survivors – will it come back? Vigilance will be her weapon. Philp plans to keep paying attention to her body and will seek a doctor's advice if anything doesn't feel right. She'll also keep tabs on all tests taken – both Philp and Roper are angry that scans showing abnormalities were not looked at by medical professionals when received. It was only after the women asked about their results that issues were picked up and acted on. "You've got to be on top of these things – it's your health," says Philp.

That's the message she's already taking to her girlfriends. Before Philp's operation, one friend told her she had experienced a similar bleed some time ago but had done nothing about it. Philp urged her to see the doctor. She did. Cysts were found, investigated and cleared of being cancerous. Philp is thrilled for her friend but has not finished spreading the word, fired by a survivor's zeal to cut through prudishness and talk frankly about gynaecological issues. "I've got a lot of girlfriends," says the affable Philp, "and we'll all be talking about it." ●

February is Ovarian Cancer Awareness Month. A volleyball event to raise funds for Cherish's research into gynaecological cancers will be held on Sunday, Feb 22 at Sandstorm Beach Club, Nathan, Brisbane. www.battleagainstovariancancer.org

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