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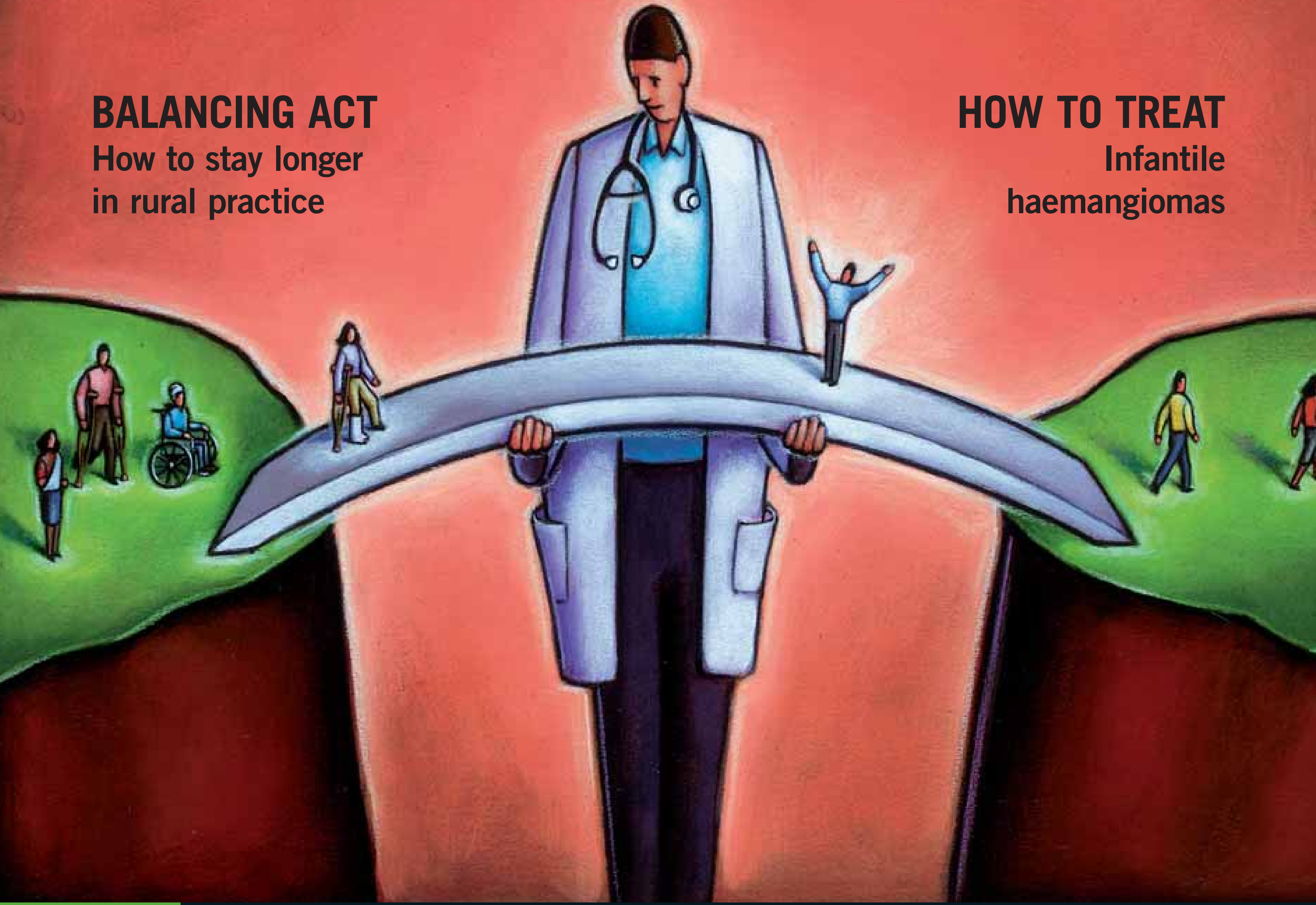
Bridging the gap

in cancer care



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Working to improve cancer care: Border Cancer Collaboration manager Kathryn Josselyn with patient Rebecca Severin, of Balldale, NSW.

Bridging the gap

MAIN PHOTO **SIMON DALLINGER**

Cancer patients from rural areas often face lack of access to care and poorer outcomes. While many problems remain, some key initiatives are helping to close the gaps in cancer care.

STORY **MELISSA SWEET**

So much has changed in the decade since medical oncologist Dr Craig Underhill moved to Albury-Wodonga.

It is not simply that the people of this border region of south-west NSW and north-east Victoria, who previously relied on visiting specialists, now have access to a far greater range of cancer services. These include radiation therapy, three medical oncologists, multidisciplinary care and a clinical trials unit.

Just as importantly, patients' access to care is now determined by their need rather than their postcode or health insurance status, and they are no longer left to find their own way through a confusing maze of different services and providers.

These gains have occurred because a coalition of locals, including doctors, service managers and community representatives, has had the will and the nous to break down the boundaries that once characterised the area – not only the geographic ones but also those between services and providers.

Dr Underhill, who has been closely involved in the Border Cancer Collaboration's evolution, is not alone in seeing it as a model for the development of other regional cancer centres of excellence.

"The penny dropped that by collaborating it was far easier to achieve an improvement in services than any one facility could do on its own," says Dr Underhill, who believes the collaboration provides a model for improving health services generally, not only in the bush.

With countless inquiries and reports documenting the inequities faced by cancer patients outside the major cities – including lack of access to quality services, inadequate travel assistance, and poorer outcomes – there is growing support for the development of regional cancer centres.

Apart from helping cancer patients, they may also have broader benefits, by helping to attract and retain GPs and allied health professionals in regional areas, concluded a 2006 investigation of rural cancer services by the Clinical Oncological Society of Australia.

Critical elements of the Border Cancer Collaboration include the employment of care co-ordinators and agreements for staff from different services to be able to see patients, wherever they live or are being treated.

For example, a social worker employed by a public hospital is able to see patients treated by a private hospital, which in turn freely provides the venue for educational meetings to public hospital staff.

It's a far cry from the days when patients set up postal addresses out of their local area to access services that were otherwise not available to them, despite being only kilometres away.

Manager of the Border Cancer Collaboration, Ms Kathryn Josselyn, says critical factors in the collaboration's success include having clinical champions, a genuine commitment to collaboration, and senior health service executives on the steering committee.

"For the project to work, it needed the buy-in from people who could influence the decision-making," she says.

Basing the collaboration in the "neutral" territory of the Upper Hume Community Health Service has also been important. "It makes all the stakeholders comfortable that the collaboration doesn't have an allegiance to a particular way

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Border Mail

> **“I can very easily with one phone call refer a patient for a number of support services.”**
>
> **DR CRAIG UNDERHILL**

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of doing things,” Ms Josselyn says.

Dr Underhill says the collaboration has also brought dramatic benefits for his working life. “It’s been absolutely fantastic because we now have a number of support staff employed, including care co-ordinators, social workers, counsellors and meeting administrators so that the multidisciplinary meetings run smoothly,” he says.

“I can very easily with one phone call refer a patient for a number of support services. It’s made my job as a medical oncologist a lot, lot better.”

The collaboration arose out of another program whose name has long generated wry smiles, the Victorian Breast Services Enhancement Program, which ran from 1999 to 2004, and showed that co-ordination of care could work across state, public and private, and acute and community health boundaries.

Between 2003 and 2006, these principles were expanded into a pilot project for co-ordinating cancer care more broadly, funded by the Australian, Victorian and NSW governments, which has in turn become the collaboration.

Despite the program’s success – the number of new patients treated locally has increased from 150 to 750 annually – the uncertainty of ongoing funding is frustrating for those involved.

Ms Josselyn, whose position is funded only until June, is focused on securing funds for another year.

Dr Underhill adds: “Our number one priority is to try and sustain the collaboration.”

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Cancer doesn’t only exact a heavier toll on patients from the bush, it also often means an extra burden for their doctors, according to Professor Craig Veitch, formerly professor of rural health at James Cook University in Townsville.

Professor Veitch, now chair in community-based health care at the University of Sydney, has been involved in research examining the cancer experiences of patients and doctors in regional, rural and remote northern Queensland.

The results, not yet published, suggest that while the depth of the relationship between rural patients and their GPs can be a boon for patients, it can also make palliative care a draining, upsetting experience for GPs.

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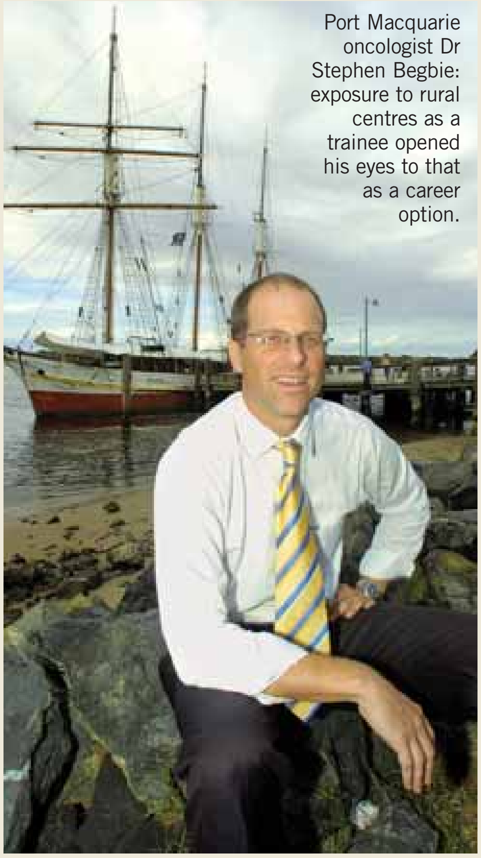

Port Macquarie oncologist Dr Stephen Begbie: exposure to rural centres as a trainee opened his eyes to that as a career option.

Nigel McNeil

Champion of regional services

When Dr Stephen Begbie completed oncology training at the ripe old age of 29, he made what many considered an unusual career choice.

He left Sydney for Port Macquarie on NSW’s mid-north coast. He’d been a regular visitor there during his training, as part of a fly in-fly out service to various regional centres, and had enjoyed the experience.

Eleven years later, Dr Begbie has no regrets about taking the road less travelled. In that time he’s helped build a thriving regional cancer centre, and become an effective advocate for rural cancer services.

Along the way, he’s developed a rewarding connection with his local community in a way that he can’t imagine would have happened if he’d stayed in Sydney.

“I’ve been able to become much more a part of the community and to interact politically with all levels of government because you know directly who’s accountable for things and you can make things happen,” he says. “If you do good work, it flows over into your social and your community life.”

Services at Port Macquarie have expanded significantly since Dr Begbie’s arrival, and now include radiotherapy facilities, two radiation oncologists, a haematologist, cancer surgeons, breast nurses, cancer care co-ordinators and cancer research nurses, many working under the auspices of the new North Coast Cancer Institute.

“It’s all about critical mass,” Dr Begbie says. “Once you start getting some competent, motivated clinical champions into a place, they can then attract other people.”

However, Dr Begbie says many places are not so fortunate and that much more should be done to develop regional cancer centres.

“There are parts of NSW that take it for granted that you’ve got to have a cardiologist in a regional centre to deal with vascular disease and yet some of those centres feel it’s acceptable to manage cancer with people travelling to Sydney or having a fly in-fly out service,” he says. “It’s just wrong.”

His own experience suggests the benefits of basing advanced training in rural areas, and he hopes Port Macquarie will get its first advanced trainee soon.

“That’s why I’m here,” he says. “It was that exposure to rural centres as a trainee that opened my eyes to that as an option. If trainees never get a chance to work anywhere other than big metropolitan hospitals, I don’t think it’s going to occur to them that they could work elsewhere.”

Dr Begbie couldn’t imagine returning to city practice.

“You’d need a crowbar to get me out now,” he says.

> **“Large hospitals often forget there are GPs out there who could look after these patients.”**
>
> **DR ROBERT WHITEHEAD**

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“This study, along with other evidence, suggests that rural and remote GPs play a greater role in caring for cancer patients and are faced with greater challenges to providing optimal care,” Professor Veitch says.

He adds that city-based services and practitioners often do not understand the issues facing rural patients and their doctors.

Many rural patients are reluctant to travel away for treatment and may, for example, prefer to have a mastectomy rather than breast-conserving surgery if this reduces their time away from home.

“Sometimes the urban clinician sees a non-compliant patient rather than a patient being realistic,” Professor Veitch says. “They don’t understand the patients’ priorities, but the rural guys do.”

The research also highlights the need for metropolitan services and clinicians to do a better job of reporting back to rural doctors. “There is room for improvement of the feedback they’re getting,” Professor Veitch says.

At Swan Hill in Victoria, the RDA’s state president, Dr Mike Moynihan, believes some metropolitan services could reduce the travel burden on patients by being more proactive about sharing care with rural doctors.

He says some oncologists ask patients to return an “absurd” number of times for follow-up that could often be done locally.

“Every oncology service should have a condition of their funding that they develop their peripheral chemotherapy procedures and they minimise to the greatest extent the amount of travel that the patient has to do,” Dr Moynihan says.

“There have to be shared-care arrangements so that local practitioners are involved, using local GP and local palliative care services, so that at a recognised time the patient is released to have a comfortable death and that oncology is not given unnecessarily, as it sometimes is.”

Dr Moynihan says regional cancer centres must also be prepared to develop and use local services: “They’ve got to be funded and be prepared to travel out and do the necessary supervision and surveillance.”

Dr Robert Whitehead, the president of RDA WA, who works in Karratha and Port Hedland, agrees that city-based oncologists sometimes hang on to patients too tightly.

He has known patients to travel 1600km to Perth for a 10-minute appointment with a registrar that could have been handled locally.

“A lot of GPs could do the follow-up management,” he says. “Large hospitals often forget there are GPs out there who could look after these patients, with high levels of skill.”

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Over the past 18 months, Adelaide oncologist Associate Professor Bogda Koczwara has gained some personal understanding of the extra burden that long-distance travel puts on country patients.

Every three months, Dr Koczwara has made the 880km round trip to Mt Gambier

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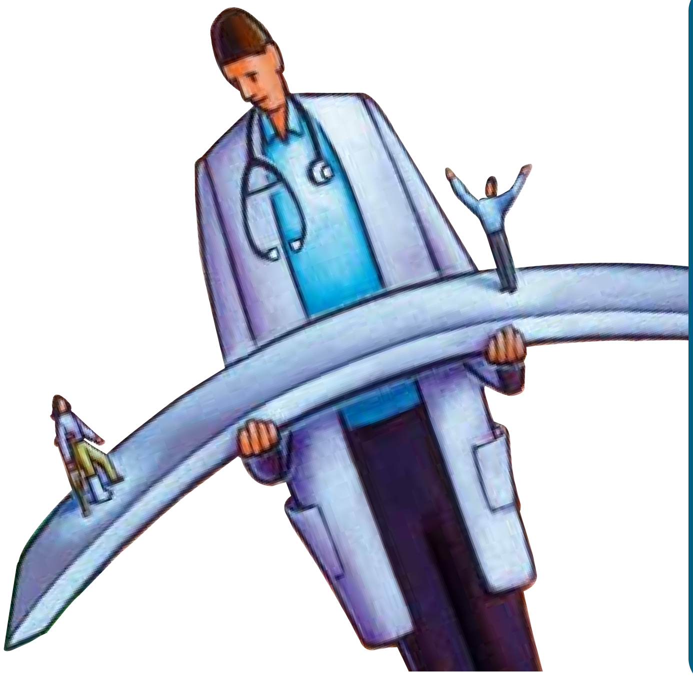

Snapshot: Cancer care in country areas

- **21% of regional hospitals administering chemotherapy had a resident medical oncology service; 41% had access to a visiting service, with access ranging from weekly to as little as once in six months. Another 38% had neither a resident nor visiting medical oncology service but were administering chemotherapy.**
- **58% reported that a medical oncologist wrote most orders. Of concern was the high number of nurses in all states giving chemotherapy without appropriate qualifications.**
- **22% of these hospitals had a dedicated palliative care doctor and 59% had dedicated palliative care nurses.**
- **7% of these hospitals had access to a radiation unit and 3% had surgical oncologists.**
- **43% of these hospitals held multidisciplinary clinics, 39% had dedicated oncology counselling services, and 65% indicated travel support was a problem for rural patients.**

Source: *Mapping Rural and Regional Oncology Services in Australia*, COSA 2006. Report based on survey of oncologists, chemotherapy nurses and other staff in 157 regional hospitals administering chemotherapy

NT GP Dr Hugh Heggie: "Some people will run away in the middle of a treatment or before surgery."

Distance means cancer hits even harder

When Dr Hugh Heggie starts talking about his patients at the Gunbalanya Community Health Centre at Oenpelli in west Arnhem Land, one thing becomes immediately and painfully clear.

The trauma of a cancer diagnosis, bad enough in the best of circumstances, is magnified terribly in remote communities. It inevitably means a long, arduous journey into a foreign world far from home and kin.

The NT's lack of radiotherapy services adds a further burden for patients who have to travel thousands of kilometres interstate.

One of Dr Heggie's patients, an Aboriginal man with a young family, recently had to spend several months living in a hostel in Adelaide while having radiotherapy without the support of a familiar face. It was his first trip outside the NT.

He is not the only such patient Dr Heggie has seen develop serious depression. Others choose to go without treatment. "Some people will run away in the middle of a treatment or before surgery and will come back here with a drip in their arm," he adds.

When patients do return home after treatment, there are often not the facilities or staff to support them. Dr Heggie recalls one such patient who had to be sent back to Darwin, to die without any family around her.

He is frustrated that metropolitan services often do not understand the reality of remote communities, and also by the inadequate level of transport and support services available to his patients.

A high price is paid for such impediments to care. While Indigenous patients with lung cancer in the NT are more likely to be diagnosed with localised disease than non-Indigenous people, they are more likely to die from it. Similarly, Indigenous women are less likely to get breast cancer than non-Indigenous women, but are more likely to die from it[1].

Dr Sophie Couzos, a public health officer with the National Aboriginal Community Controlled Health Organisation, says such problems reflect a systemic failure to engage Aboriginal people in designing and developing programs.

She cites cervical cancer screening as an example of how mainstream programs don't cater for Aboriginal people. While cervical cancer mortality is five times higher in Aboriginal women, national screening programs do not record Aboriginality and have no system to monitor their screening coverage.

Funding agreements with states do not require reporting of their coverage while the Practice Incentive Program's cervical screening initiative locked out many Aboriginal health services. Aboriginal women also missed out because Aboriginal health workers do not attract rebates for taking Pap smears.

"The first mistake made by policy makers is that programs are designed without consideration of the specific demographics, and geographical and social needs of Indigenous Australians," Dr Couzos says.

Meanwhile, it seems that NT patients will continue having to travel to Brisbane or Adelaide for radiotherapy for some time yet. After years of promises and delays, plans to build a radiotherapy service in Darwin have been put on hold – again.

Ms Helen Smith, chief executive officer of the NT Cancer Council, says the impact on territorians is devastating.

"Other people with radiotherapy available locally can often stay at work," she says. "Here they're away for 6-8 weeks and unable to work. A lot of people have lost their homes through having to go through cancer treatment."

The lack of a multidisciplinary service also makes it more difficult to attract staff and adds to isolation and burden on cancer professionals. "It means it's extremely difficult to get other staff to come up and work here," Ms Smith says.

One casualty of the endless delays to the service is oncologist Dr Sid Selva-Nayagam, who left Darwin in 2005 exhausted after several years of working there. One reason he left was yet another delay in the promised radiotherapy service. "I saw myself not having any light at the end of the tunnel," he says.

Dr Selva, now head of medical oncology at the Royal Adelaide Hospital, continues to work in the territory and visits Alice Springs and Darwin regularly.

Along with colleagues at Cancer Council Australia, he plans to maintain pressure on federal and NT governments to fulfil their promises to build a radiotherapy service in Darwin.

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1. Heathcote, KE and Armstrong BK, Disparities in cancer outcomes in regional and rural Australia, *Cancer Forum*, Vol 31 No 2, July 2007.

Philip Martin

Oncologist Dr Bogda Koczwara travels to Mt Gambier to conduct chemotherapy clinics, but is keen to help develop local services.

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to conduct a chemotherapy clinic. It is always a long and exhausting trip, but she is committed to expanding the reach of her hospital's services, and plans to double her visits this year.

Part of her goal is to help develop and support local services to provide treatment and follow-up care for chemotherapy patients.

"We're also trying to assist people out there to solve their own problems," she says. "Any solutions will have to come from the ground up because different country towns have different problems, different challenges."

Dr Koczwara does not believe it sensible to expect every GP to be involved in providing chemotherapy, as most would not have the caseload to maintain the level of knowledge and skills required. She would like to see national standards establishing a minimum level of expertise that GPs should have in order to administer chemotherapy.

She says one option is for GPs in a particular area to nominate one colleague to upskill in oncology so they can be assured of sufficient patient volume to maintain skills.

"There is a need for some practical experience of what cancer treatment is all about and that can only be achieved with some degree of specialisation of providers," she says. "That also means not every small rural town will be able to provide chemotherapy services."

Dr Koczwara believes metropolitan centres have a responsibility to address the needs of rural patients and doctors. "I just feel if you have a person driving five hours to see me for 10 minutes and then have half-an-hour chemotherapy and then driving five hours back, that's not right," she says.

From a personal point of view, Dr Koczwara has also enjoyed developing new networks with country clinicians: "At the end of the day, the fun lies in people working together." ●

NEXT MONTH

Mentoring schemes to improve rural cancer care.

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