

**COMMITTEES**  
**Community Affairs References Committee**  
**Report**  
**Speech**

Senator COOK (Western Australia) (9.40 a.m.)—On behalf of the Chair of the Community Affairs References Committee, Senator Marshall, I present the report of the Community Affairs References Committee entitled *The cancer journey: informing choice*, together with the *Hansard* record of proceedings and submissions received by the committee.

Senator COOK—I move: That the Senate take note of the report.

I seek leave to incorporate Senator Marshall's tabling statement in *Hansard*.

The statement read as follows—

This report, entitled *The Cancer Journey: Informing Choice*, is the result of an inquiry established in February 2005 by Senator Peter Cook into services and treatment options for persons with cancer.

The Committee received over 100 submissions from a range of groups and individuals. The Committee especially thanks the cancer patients and their families who provided submissions and gave very moving testimonies of their personal cancer journeys. The Committee has given voice to these people in the report and hopes that it has done justice to their stories.

This is a unanimous report. It is the Committee's hope that the recommendations will be a guide for government and non-government institutions to improve cancer treatment and services in Australia for all cancer patients regardless of where they live.

Australia can feel justifiably proud of its internationally recognised achievements in the areas of decreased mortality and increased survival for people with cancer. However, despite our achievements and advances in treatment, there are inequalities in the system and not all Australians have access to best practice cancer care. This is true even in some outer metropolitan areas but particularly for rural and Indigenous Australians.

We want to assist all cancer patients to receive best practice care. Cancer is perhaps unique in that it usually requires a whole range of different services to treat it. For example, patients may need to see not only surgeons but also radiographers, oncologists, pathologists and other allied services.

One of the key messages from cancer patients was that their care had been fragmented and disorganised. The Committee heard from witnesses that multidisciplinary care is best practice and provides the cancer patient with a team approach which agrees on a precise diagnosis and a treatment plan and includes a designated care coordinator. Patients experiencing

multidisciplinary care report greater satisfaction with services, less personal distress and improved outcomes.

To improve coordination of care along the care continuum, the Committee recommended that multidisciplinary care be widely promoted through a range of measures including: multidisciplinary cancer centre demonstration projects, enhancing current Medicare Benefit Schedule arrangements to support participation in multidisciplinary meetings and including multidisciplinary care as part of any system of accreditation of cancer services.

Care coordinators play a vital role to reduce fragmentation of care and improve the provision of information. The Committee recommended that all State and Territory governments that have not yet done so, establish designated care coordinator positions to help cancer patients navigate their way through treatment and provide support and access to appropriate information. The Committee recognised the success of the breast cancer nurse model and recommended State and Territories undertake recruitment drives for skilled health professionals such as retired nurses to help fill these positions.

Another key message from cancer patients was the lack of information from the very start of their cancer journey. Along with the shock of the diagnosis, there are a myriad of questions to be answered, the health system to navigate, choices to be made regarding specialists and treatments, and unfamiliar medical terms to learn.

To make more information available to the cancer patient, their families, care coordinators and health professionals, the Committee recommended that Cancer Australia provide access to authoritative, evidence-based information on services, treatment options, government and non-government assistance and links to appropriate support groups.

To provide more information to physicians and patients at the time of diagnosis and to assist making decisions regarding treatment, it is important to link referral pathways to services which are accredited and physicians who have appropriate credentials. The Committee has recommended that Cancer Australia together with the Clinical Oncological Society of Australia and the Cancer Council of Australia develop and introduce accreditation and credentialing systems.

Cancer patients also stressed to the Committee that life goes on regardless of cancer and sometimes the emotional and practical issues they face can be just as challenging as the physical ones. Many stressed the lack of support available and the Committee has recommended that psychosocial care be given equal priority with other aspects of care and be fully integrated with both diagnosis and treatment, including the referral to appropriate support services where necessary.

To address a major concern for regional cancer patients, the Committee has called on State and Territories to adopt and implement a consistent approach

to travel and accommodation benefits which should be indexed or reviewed annually.

To improve the survival rates for Indigenous Australians, we have recommended that Cancer Australia, in consultation with Aboriginal and Torres Strait Islander people and the States and Territories, auspice work to improve access to cancer screening, diagnosis and treatment for Indigenous people that is culturally appropriate.

Cancer patients are increasingly better informed and many want to be active participants in their treatment plans. Complementary therapies was another area highlighted by patients where there is a significant need for greater information. They referred to the negative attitude taken by many medical professionals at attempts by patients to help themselves and investigate complementary therapies.

The Committee heard that the reasons behind the growth in complementary therapies include: greater individual attention from practitioners, holistic values, dissatisfaction with medical outcomes, a desire for improved health, increased access to health information as well as a growth in research based evidence supporting their effectiveness.

There is substantial research literature and growing understanding by patients that some of these therapies can enhance quality of life such as meditation, acupuncture, massage therapy, support groups and relaxation. There is also emerging evidence that some therapies can not only enhance but may contribute to life extension.

In the USA and Europe, the benefits of complementary therapies have been acknowledged and are being actively introduced into the conventional health sector as part of integrative medicine. Integrative medicine combines the best of both worlds, the scientific aspects of conventional medicine with the scientific aspects of complementary medicine.

To support informed choice and attitudinal change in Australia, the Committee has recommended steps to provide greater access to information on complementary therapies, increase knowledge of their potential benefits and increase Australian complementary therapy research.

With increasing numbers of people, including cancer patients, accessing complementary therapies, the Committee has recommended that Cancer Australia access information available internationally on different complementary therapies and alternative products in order to provide authoritative, evidence-based, up-to-date information.

To develop complementary therapy research in Australia the Committee has called on the NHMRC to provide a dedicated funding stream, assist complementary therapists applying for research funding and appoint representatives with a background on complementary therapy to be involved in the assessment of research proposals.

The Committee considers that complementary therapy organisations need to speak with a more influential and unified voice and has recommended that the complementary therapy organisations form a national body to enable its members to discuss issues such as regulation, research, collaboration and cancer initiatives at the Commonwealth, State and Territory levels.

The increasing numbers of people being diagnosed with cancer and living longer with cancer will place pressure on the national health budget and present challenges to the delivery of optimal cancer care services in Australia. We hope this report will contribute to the development of a national, evidence-driven, consumer-focussed approach to cancer care, involving greater coordination of the cancer patient's journey and greater provision of support.

I commend the report to the Senate and I look forward to a positive response from the government.

Finally, I would like to place on record my thanks to all members of the Committee for their empathy and cooperation throughout the hearings and through the compilation of the report and recommendations in the short timeframe available. I also thank the staff of the Community Affairs secretariat who were ably assisted in this inquiry by Lyn Beverley, Ian Kemp and Clive Deverall.

Senator COOK—The Chairman of the Community Affairs References Committee, Senator Gavin Marshall, and the committee have asked me to table this report. I thank them sincerely for the opportunity to do so. I recognise in the gallery members of the committee secretariat. The committee secretariat served us well. This report had a tough deadline and a tight scheduling of hearings. At all times we were conscious of the importance of the subject—cancer—and the need to do a thorough job. I believe we achieved that. Without the help of Mr Elton Humphery and his staff , especially Ms Lyn Beverley and Mr Ian Kemp, it would not have been possible. In particular, I am grateful to my own staff member Mr Clive Deverall for the help he provided. I believe we all owe a debt of gratitude to them.

When I moved the terms of reference for this inquiry in the Senate, I had just come through a traumatic and frustrating period in my life. I had been diagnosed with secondary melanomas and undergone extensive surgery, only to be given a dismal prognosis. Fortunately for me, a lot of good friends came to my aid and helped me, together with outstanding doctors at the Sydney Melanoma Clinic, later at Sir Charles Gairdner Hospital and many others, to develop a strategy to improve the odds.

When I was diagnosed I knew nothing about the disease. Initially it was a frightening and frustrating experience. With little or no knowledge I had to make life-critical decisions in an urgent time frame. Faced with that immense task it is very easy to despair and give up. What I needed was a rational evaluation of all the options—information on diet, exercise, emotional wellbeing and guidance on what was snake oil and what held promise among the alternative treatments. Most of all I needed advice on the various

conventional therapies available. Eventually I found my way through to a treatment strategy that has given me confidence. In all that I have learnt, I have learnt that there is no such thing as a silver bullet here—no single, one solution—and that the answer, if there is one, lies in integrating a number of treatments, or sequencing them in a way to make sure that one treatment does not negate or block another. The other insight I gained is that, as a patient, I had to take responsibility for my own healing.

As I said, I was fortunate to have good friends who referred me to the leading researchers and clinics in all the capital cities of Australia and overseas. Indeed, it was because of these referrals that I came across a congressional inquiry into cancer treatments conducted in Washington some 15 years ago. A book published about it gave me the confidence to assess all of the options, both conventional and complementary, before making a choice on an integrated regime. That American inquiry is now some 15 years old. We have the chance in Australia to replicate and update that very worthwhile work. In fact, we have, I believe, a duty to do it. Cancer patients should not be left to the luck of the draw or to serendipity in order to have their disease treated in the most effective way.

In moving for this inquiry I recognised that the options I eventually chose may not be appropriate to everyone facing cancer. But I believed that the Senate could help others navigate their way through the maze to find the treatment regime which best suited them. An inquiry could survey the field, consider the options, and point to possible solutions; importantly, it could do this by standing in the shoes of cancer patients and hopefully make sense of the system on their behalf.

Too many individuals and families in Australia suffer from cancer or experience its effects at first hand. On current statistics, one in three Australians will have to deal with cancer before the age of 75, and cancer has now, unfortunately, supplanted heart disease as the biggest single killer of Australians. Some families cope well, survive their treatment and carry on with their lives. But there are far more who do not cope, do not survive, and become grim statistics—the technical classification is ‘cancer mortality’. And there are those who achieve remission but live the rest of their lives struggling with the disease.

Our report looks at the experience of cancer patients who have survived what many call their ‘cancer journey’—from the impact at the time of diagnosis through sometimes lengthy cycles of treatment. Others gain full remission or cure, or the knowledge that their cancer cannot be cured and they cope with maintenance therapy until they die—often of something else. One thing we do know is that more people in Australia are getting cancer, in all its forms, and that the incidence is going to increase as our population ages. I hope that our report, which quotes all the statistics, will help people who are currently being treated and significantly improve the outlook for those who are diagnosed in the future.

Australia has a good record, by any international comparison, in terms of its cancer treatment results or 'survival', as it is technically described, but we believe it has the opportunity to do better. However, all the statistics of incidence and survival mask the real, everyday problems that cancer patients face on their individual journeys. All the statistics can never describe the psychological trauma at the time of diagnosis; the financial impact on families as they lose income; the nausea, vomiting and fatigue that so many patients experience as side effects; and the burden that has to be carried by their carers.

During the inquiry we heard details of how patients adjusted their lives and tried, together with their carers, to cope with the progression of their disease and its treatment. It was very evident to all of us on the committee that cancer treatment services in Australia could and should be improved. The system by which patients are managed after their diagnosis and how they are referred is not a scientific or medical issue; it is a health management issue. We received powerful evidence during the inquiry that the present system of referral can be erratic and poorly managed. It often works against the best interests of the patient. The best illustration of how it should be done is from the breast cancer treatment sector, which, since the early 1990s, has been overhauled and brought into line with the modern approach of multidisciplinary care.

Multidisciplinary care is identified by the committee as vital to improving the treatment of cancer in Australia. Multidisciplinary care is teamwork where the different medical disciplines or experts, assisted by allied health professionals, are involved in the treatment program. This includes the psycho-social support of the patient. Multidisciplinary care has been well demonstrated nationally and internationally. It allows GPs to refer their patients to the best-qualified and best-equipped centres which specialise in the treatment of specific cancers. Components of multidisciplinary care, all of which are described in the report, support the patient and their carer throughout the cancer journey.

Included as part of integrated multidisciplinary care is a care coordinator, who guides the patient through their cancer journey. The care coordinator can be a nurse or other trained health or allied health professional who works in the multidisciplinary team and plays a major part in organising the patient's treatment program. Keeping the patient informed and discussing the options available, as well as supporting the patient emotionally, is part of the role of the care coordinator. The National Breast Cancer Centre has already demonstrated the effectiveness of breast care nurses in the multidisciplinary approach to the treatment of breast cancer. It has been established that a care coordinator is not only of great comfort to a patient and their carers but also helps to ensure the most efficient use of professional time.

Part of the pedigree for multidisciplinary care is a national accreditation system that rates the clinic or hospital and a credentialling process that assesses and rates the clinicians who work there. The committee was unanimous that multidisciplinary care must be available for the treatment of all cancers. The systematic introduction of multidisciplinary care in Australia will

also improve treatment services in rural and remote regions of our country, including culturally appropriate services for Indigenous Australians. It is also important that, when cancer patients are treated, we know how they were treated and the outcome of the treatment is measured and recorded. This is an important part of data collection and multidisciplinary care. Data collected should also include information on the patient's quality of life.

Another method of improving treatment standards, in addition to multidisciplinary care, is clinical trials—which also feature positively in the report. Clinical trials help to introduce new treatment techniques, including new drugs, into the Australian treatment protocols which keep Australia up to date internationally. Dramatic improvements have been achieved as a result of clinical trials, especially for treatment of cancer in children.

Several recommendations in the report relate to complementary therapies, or CTs. Complementary therapies are used by over 60 per cent of cancer patients being treated in Australia, yet they are provided, in most cases, outside the Australian health system with few medical rebates. Australians spend upwards of \$1 billion per annum on these forms of treatment.

From evidence presented to the inquiry, it was clear that there is a great divide between conventional medicine and complementary therapy including alternative medicine. Collaboration appears to be virtually non-existent. So we have this strange situation in this country where there are thousands of cancer patients being treated in our hospitals and at the same time a majority of these same patients are using complementary therapies and alternative products without any exchange of information between the two systems. Some witnesses at our inquiry spoke about how in their case their specialists derided their inquiries about specific complementary therapies, or of the ignorance of many doctors about them. There is a void when it comes to the public having access to authoritative, accurate and up-to-date information.

In contrast, the committee heard evidence from overseas witnesses, who included representatives from the famous centre in New York, the Memorial Sloan-Kettering Cancer Centre; the Macmillan Cancer Relief centre in the United Kingdom; Mount Vernon Cancer Centre in London; and the Lance Armstrong Foundation. All the representatives told the committee about their use and endorsement of complementary therapies including herbal medicine and acupuncture, which were described as 'an integrative part of mainstream cancer treatment'.

Integrative medicine is now a standard course of study in most American university medical schools. Australian witnesses representing this sector emphasised how nutritional medicine and techniques such as massage, meditation, sequential muscle relaxation and aromatherapy helped cancer patients having conventional treatment cope better with the side effects of their treatment as well as improving their outcomes. Complementary therapies also help patients who are in remission after successful conventional treatment to maintain good health.

It is the committee's view that Australia is, in comparison with Europe and the USA, behind in the use of complementary therapies. It is clear from the evidence provided that respected scientific journals have published positive results relating to the use of complementary therapies. It also appears that Australian patients are already voting with their chequebooks by their widespread use of complementary therapies. Consequently the committee recommended that the government should publish authoritative, up-to-date information and, in addition, that complementary therapies should be incorporated within multidisciplinary cancer care.

Professor Jane Maher, an overseas expert witness from the Mount Vernon Cancer Centre, recommended that Australia needed to find champions from the conventional medical sector who, like her, would be prepared to foster the use of complementary therapies and alternative medicines in their clinics as well as to encourage more research. The committee recommended that the NHMRC convene an expert working group to identify research needs which must involve representatives from the complementary therapy sector.

I believe this has been an extremely useful inquiry conducted by this Senate committee. Yesterday I delivered my valedictory speech, but now that this is an addendum to what I have done in my 22 years in this chamber I must say this may well be the most important inquiry I have sat on. I would like to thank the chairman of the committee, Senator Gavin Marshall; the deputy chair, Senator Sue Knowles; and the other members of the committee for the work they have put into what I regard as being a vital and important inquiry.

I hope these findings not only reflect the evidence, as I am sure they do, but also receive a sympathetic and understanding ear in government as we try and work our way through improving on the already first-class treatment that this country provides to cancer patients. There are some other steps we can take, and this report recommends them. I think it does so sensibly, and I commend it to the chamber.