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 heath 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.

Senator LEES (South Australia) (9.56 a.m.)—I would like to begin by paying tribute to Senator Cook for his courage and determination at a time when he could be excused for moving on and not putting such energy and effort into something when he is facing a very personal challenge. I would also like to pay tribute to the committee, and this will be for the last time. The community affairs committee is a fabulous committee. I pay tribute to Elton and his team.

For me, this inquiry was quite a moving experience. I think the essence of it was about empowering people who find that they have cancer. One of the big gaps in Australia is the lack of access to alternatives—to complementary therapies—or even finding out about what the alternatives are. As we looked overseas and had overseas evidence by phone linkage we saw that, particularly in the US and also in Europe, they are so much further ahead than we are. We also looked at the breast cancer model in Australia. We saw there the breast cancer nurse and the contact that is made with the woman within the first few days—someone else who has had the experience gets in touch. There is a process then of explaining alternatives, and we are not talking about going on a diet instead of chemotherapy; we are talking about the other things that can be done to help the cancer sufferer and their family through what is a very daunting experience. This is about action. This is about looking at what we do now and better coordinating the excellent services that are available in our hospitals with what people want and, indeed, as Senator Cook has said, what people are paying for out of their own pockets, because the holistic approach is simply missing in Australia.

For me, one of the specific issues we need to deal with urgently is that of adolescents. There is a gap between excellent childhood cancer services and adult services, which tend to be focused cancer by cancer. As I said, the breast cancer model is the one that we should be moving across into all the various sorts of cancers. But somehow the teenagers seem to be slipping through. They do not want to go into cancer wards in the big hospitals. A lot of the adult services are quite daunting for them. So I make an appeal to the government on this to look at firstly making sure that this battle between what is conventional and what is complementary stops, that doctors are supported through the process of understanding that if you empower someone with a chronic illness—if they actually feel better—they will get better. It is very much a part of the process, and this is not going to cost a lot of money.

I only have three minutes to speak on this, and in my last couple of seconds I want to stress that we are not talking about huge input from the budget. We are talking about reorganising what we have got, focusing it on the individual and understanding that anyone with a chronic illness needs to have firstly a real understanding of what they are facing but then some real alternatives and to feel in control of themselves.

Senator KNOWLES (Western Australia) (9.59 a.m.)—This cancer inquiry has been particularly significant for all affected by cancer, both today and tomorrow. I congratulate Senator Cook on taking the initiative to initiate this inquiry. It was a very significant inquiry and it was, in many cases, a very alarming inquiry. The things that have been revealed to this inquiry are certainly food for thought for governments all around Australia and also for medical practitioners. It is very disturbing to see that there is so little communication between various levels of the medical profession where they could aid cancer patients right from the moment of diagnosis all the way through their journey.

Senator Cook well and truly needs to be congratulated for, as Senator Lees said, taking on an inquiry with quite an arduous hearing schedule when clearly it would have been very easy for him to sit at home with his slippers on—so congratulations, Senator Cook. I also will take this opportunity, Senator Cook, to wish you well in your future journey and also for your retirement. I do not want to use much time; in fact, I would like to allocate what time I have left over, when I have concluded my comments, to my colleague Senator

Humphries. As everyone knows, Senator Humphries is the future; I am about to be the past. So I think it is important that Senator Humphries has considerably more time.

I would like to make special mention of Senator Marshall's chairmanship of this inquiry. I think his chairmanship has been absolutely superb. There were a lot of people who were very emotional and very affected by the evidence that they were giving. Thank you, Senator Marshall, for your care, patience and tolerance and the compassion that you showed in your chairmanship. I also, again, would like to thank our wonderful secretariat for the work they have done on this. But I would also like to have the indulgence for a moment of the Senate because I did forget to thank two very significant groups of people in my valedictory speech. One is Hansard: bless your souls, you have managed to get down all the words over 21 years and make sense of them at times. I would also like to thank the library. Both have been wonderful resources over the time. But, as I said, I wish to leave my extra time to Senator Humphries. Congratulations again to Senator Cook and the committee on an excellent report that I hope will see great benefits extended to those who are diagnosed today and deal with it tomorrow.

Senator HUMPHRIES (Australian Capital Territory) (10.02 a.m.)—I was privileged to be part of this fascinating inquiry. I feel that a real contribution has been made to public policy in Australia by virtue of that inquiry having been conducted. Like other members, I commend Senator Cook for the opportunity he created, by virtue of his own experience, to throw the spotlight of the Senate onto this important issue. I think it has produced some value in public policy terms.

As senators have already heard, this problem is a significant problem for an increasing number of Australians. Between 1991 and 2001 there was a 36 per cent increase in the diagnoses of cancer in this country—a frightening statistic. In recent years, it has led to the calculation that half a million potential years of life are lost each year to Australians by virtue of this insidious set of diseases. It is important to note that, although there are certainly improved survival rates for a number of cancers, in fact for the majority of cancers, across Australia in recent years because of improved technology and medicines, the fact remains that all too many Australians each year are finding that diagnosis suddenly placed in front of them. Steps need to be taken to ensure that they are better supported through the process of the cancer experience, the cancer journey.

It is true to say that overall the quality of cancer services in this country is quite good. We have survival rates which are quite high by world standards, and it is important for us not to lose sight of that. Indeed, what this report focuses on is not so much recommending massive new amounts of money to be spent on cancer research or cancer services per se—although, of course, more money would be welcome and would go a long way—but rather looking at ways in which we can improve the delivery of service to Australians by looking at the range of services available in Australia, the information available to Australians who are diagnosed with cancer, particularly the way in which we integrate conventional cancer services with what are variously called complementary therapies and other things for people who find themselves in that position.

An important recommendation from this report is the one that suggests that, with so many information pathways available to Australians affected by cancer, it is extremely important that we begin to channel and tailor packages appropriate to people who are diagnosed with cancer. There is a huge amount of information for people in these circumstances. In fact, there is much information which is probably unhelpful or inaccurate. There is much very useful information provided by clinical outlets, government and semi-government agencies, research bodies and so forth. But, for those freshly diagnosed with cancer, we found evidence that there were too often confusing portals into that information and a lack of a clear set of principles and explanations of clinical pathways available to them. The opportunity created by Cancer Australia's formation to bring this all together is very significant. I think it is most important that this report be taken up by that new body to establish a very clear set of principles for how information is provided to those newly diagnosed.

I want to touch on the issue of complementary therapies. My view during the course of this inquiry about those therapies swung around quite dramatically. I was sceptical about the value of such therapies but have come to the view that they are extremely important for the emotional and spiritual wellbeing of cancer patients. The fact that so many cancer patients in this country turn to them, often sidestepping clinical advice available to them from their GP or specialist, is evidence of the important place that they occupy in the cancer scene by offering hope to people who otherwise might be told by conventional medicine that they have little or no hope.

It is important that we provide a pathway for people who are diagnosed with cancer to access accurate information about complementary medicines. I particularly commend to the Senate the recommendations that provide for the NHMRC to establish a funding stream dedicated to research into complementary medicines, and not because I think it is likely to bring a large number of alternative therapies in from the cold and somehow make them acceptable to mainstream medicine overnight. That may happen over time but it is not likely to happen anytime soon. But it is important for people to know where they stand with those medicines, to know what implications they have in connection with conventional medicine. Many complementary therapies are beneficial, as I have said. In an emotional and spiritual sense they support patients with a diagnosis of cancer. They give them a sense of being empowered, as Senator Lees said, in the circumstances of their condition. But some therapies have the potential to be harmful to a conventional medicine regime. We can overcome that problem if we focus on the interface between the two areas.

Another important recommendation to support that position is that there should be a peak body of some sort, a forum or committee of complementary therapies and providers in this country, so that they are able to deal on more equal terms with the conventional medical hierarchy. We all know that there is something of an art form to writing a good application, and probably no more so than when it comes to seeking large numbers of dollars for research. But very often we have heard that some of those therapies are not in a position to put together suitable and acceptable funding applications, and we need to give them a pathway to ensure that they do not slip outside the mainstream merely because they do not conform to those conventions. I remind the Senate that therapies like acupuncture, for example, were long regarded as quackery but now occupy a very respectable place within conventional medical procedures. Other alternatives deserve to be considered as the evidence comes forward that they are in fact efficacious.

I also believe it is important that we focus on the recommendations about a multidisciplinary approach towards cancer. It is clear that patients do not have a single, one-dimensional set of needs. They are not focused just on the physical presence of a cancer in some particular part of their body. There are a range of problems—psychosocial problems, for example—which absolutely must be addressed as part of a comprehensive approach towards the treatment of a person with cancer. With a greater focus in conventional medical education on how those sorts of multidisciplinary approaches could be achieved, as well as some reorganisation of funding mechanisms to ensure that, I believe we will give much more hope and much more satisfactory experiences to people diagnosed with cancer.

There is also a recommendation in the report that we should encourage doctors to focus on communication techniques. That is obviously achieved partly through medical education as well. It has been disturbing throughout this inquiry that we have heard of so many cases of poor bedside manner used by doctors who come to offer services to their patients. That very clearly is a matter for improvement. I seek leave to continue my remarks.

Senator MOORE (Queensland) (6.24 p.m.)—I was privileged to work on this particular committee, where we had the enormous privilege of listening to the stories of the most amazing group of people, all of whom had some familiarity with what they termed, and which now has become common parlance, ‘the cancer journey’. Through this process we talked with people who indicated that they were working through personal treatments, people who were providing various forms of treatment and—I think, in some ways, most poignantly—the family members and friends of those who identified with having cancer and were trying to work out their role in this journey, in many ways giving us such sensitive information from which we can benefit. I hope people will take the opportunity when they can to have a look at the report of the Community Affairs References Committee. It is called *The cancer journey: informing choice*.

Through this inquiry we were able to look at the way that the treatments surrounding cancer in this country have moved forward over the last 10 years. Certainly, previous Senate inquiries and also House of Reps inquiries had looked specifically at the issue of breast cancer. There was quite groundbreaking work provided by previous committees that led in no small way to changing how treatment was offered to women across this country. One of the clear things to come out of this committee's inquiry, though, is that the work done through the breast cancer movement has benefited other people who are suffering from—who have other forms of cancer. I corrected myself when I started to say 'suffer from', because this is a term that the people with whom we spoke totally reject and one they do not wish to be used. However, all of us seem to fall into usage which we should have learned not to use.

I hope to talk again on these issues at different times during my career in this place, but this evening I want to talk particularly about alternative methodologies. We were privileged in the inquiry process to have submissions from a number of organisations which were looking really centrally at the issue of providing alternative help for people who were travelling on the cancer journey. This evening I want to talk about one that I have been fortunate enough to visit in my home state of Queensland. It is called Bloomhill, and it is located in the extraordinarily beautiful area of the Sunshine Coast, just north of Brisbane.

Bloomhill is an inclusive model of treatment. It operates with the whole team of people involved in the treatment options. There are support mechanisms for people who have been identified as having cancer. The process is linked by people sharing a common goal of having someone be as well as they possibly can. The idea is that everybody has a role to play, but it is focused on the individual choice of the person who has been identified as having cancer. The idea is a community based, complementary care organisation. I know that is a mouthful, but it sums up the philosophy of the Bloomhill centre.

This centre was founded in 1997 by Margaret Gargan, who is a nurse by profession and worked for many years on the oncology wards at the Prince Charles Hospital in Brisbane. After diagnosis, Margaret went from being someone working with people with cancer to being someone who identified as having cancer and was on her own journey. She experienced service models from both sides and brought that knowledge and sensitivity to setting up the Bloomhill model. In 2002 Bloomhill worked at and set up a partnership with the local Blue Care palliative care team. The enormous contribution of the various palliative care teams across the country was documented in the process of this inquiry, and the role of community nursing, actually working with people in their own homes, cannot be overstressed. They are people to whom we should be deeply grateful.

The partnership that has been established at Bloomhill is one where the people at the centre can have access to the kind of professional care that is offered through the hospital system and through the community system, but Bloomhill also looks at the wider needs of people and offers alternative therapies. Not too long ago people tended to laugh at alternative therapies but now, through experience, people understand that these can help. After all, the key issue is wellness. It may not, and in this particular disease often does not, result in cure, but it does create wellness and strength of spirit which is so valuable.

The Bloomhill centre can only operate, as most of these community organisations do, on the basis of a very strong group of volunteers. The whole idea is that volunteers with skills come together to share information and be part of the process. In the period from 1997 until now, there has been such growth and need that there is now a management committee, 10 full-time staff, eight part-time staff and over 250 volunteers who work together to make sure that everybody involved is as well as they possibly can be.

The permanent site, since 1999, is the most extraordinarily beautiful place—10 acres of beautiful rainforest with room to develop respite facilities, chapels and further facilities for extra therapies such as massage, counselling, music therapy and a whole range of different and alternative methods. These are not exclusive of medical treatment but complementary to it, so that people involved feel nurtured, valued and are given the key choice for themselves as to which path they will take down the journey.

Margaret is an extremely passionate woman. She has worked outside the location at the Sunshine Coast and is working with other communities to try and set up similar organisations. I know that they are working together now to try and set up a similar place in the Blue Mountains—another extraordinarily beautiful place. It has been proven that your environment does have an immediate impact on your sense of wellbeing.

Another model of care which also includes a range of complementary systems to make the person and their family members feel better and part of the whole process is the Brown's clinic in Perth. One of the key areas of this model and the difference with the Brown's clinic is that the actual place where these therapies are offered is situated at the hospital. They have a desperate need for more space, but there is something about having this particular centre, which focuses on the wellbeing of people using complementary medicine, co-located with the medical processes at the hospital that I think gives it a special validity.

One of the things to come out of the cancer inquiry is that there was a feeling that the professional medical areas do not give sufficient weight or value to the range of complementary medicines and therapies. There are people with various skills available in our community who are focused on making people as well as they can be. What we do not need, and what no patient or family involved in this process needs, is a sense of competition or any disrespect between the various methods of treatment. What was stressed consistently throughout the evidence received by the committee was that there needed to be a whole-of-patient care and a team approach, because no one system works.

The message that came from the people at the Brown’s clinic and from Bloomhill was that these systems can work. Again, there is no promise or guarantee that people will be cured. During the cancer journey through which people are travelling there will be the consideration that people care, that their views will be protected and valued and that there are ways that this process can work better than it has in the past. The way forward has been led by the enormous amount of work done across this community and also overseas in the area of breast cancer. Throughout the cancer inquiry, the committee learnt lessons from the expenditure, the funding and the research that had been done on the issue of breast cancer. Other areas have also learnt from that.

Each of the words in the title of the report—*The cancer journey: informing choice*—are important. It is a journey. It is one that so many people are now travelling, and the statistics are quite horrific in terms of the number of people who are facing this process. The key area is with the last two words ‘informing choice’. We can learn and we must learn. I seek leave to continue my remarks later.