CHAPTER 6

FUTURE DIRECTIONS FOR CANCER CARE IN AUSTRALIA

6.1 This concluding chapter summarises the major issues examined by the Inquiry as discussed in the report and reviews the actions that have been proposed to improve access to and advance best practice cancer care in Australia. The primary focus of this chapter will be on the cancer journey as it progresses through a number of stages; though there are also issues raised which apply at some or all stages of the journey, such as the need for information and support, workforce shortages, data shortfalls and access to best practice care for regional and Indigenous Australians. This chapter should be read in conjunction with the summary of recommendations.

6.2 The Committee heard that the Commonwealth, Cancer Institute NSW, Victorian Department of Human Services and the Department of Health WA are undertaking initiatives which will continue our success in providing cancer treatment in Australia. While it is apparent that institutions, organisations, practitioners, support groups and consumer advocates are doing their best to provide and promote services which realise the best outcomes for the cancer patient, there are still issues needing to be resolved.

6.3 Though acknowledging Australia's treatment record and the goodwill from all involved to improve the cancer patient's journey, the Committee was concerned at the current gap between what is known to be best practice and what is the reality for many cancer patients as told to the Committee.

6.4 The needs of cancer patients for improved information to make informed choices about conventional treatment and complementary therapies and for better access to coordinated care and psychosocial support have been well documented. Not only are these needs well known but there is evidence available to show that better outcomes accrue when these needs are addressed. The question therefore remains as to why cancer care in Australia is still described as a 'lottery' for the many people who take that journey?

6.5 As described in many reports and by witnesses, the Committee considers that Australia is at a crossroads in cancer care and the direction in which to proceed has general agreement. Indeed, many cancer patients are voting with their feet by making their own enquiries in order to find health practitioners and institutions which provide them with the care that is most appropriate to their needs. The direction is clear and it just seems to be a matter of time before the momentum of evidence and change, together with consumer advocacy, carries us there.

6.6 While Australia is doing well in cancer control across the continuum, improvements could be made through the systematic implementation of best practice treatments for people with cancer. The evidence from overseas witnesses from the

USA and UK, indicated that Australia is lagging behind current best practice especially in areas such as multidisciplinary care and integrative medicine. The Committee sought advice from these witnesses, who are all leaders in their fields, on how Australia can learn from their experience to expedite the natural evolution and overcome the barriers to best practice more quickly. As discussed through the report, this information has been combined with recommendations from Australian witnesses and findings from other reports, to provide the following plan to guide improvements to the provision and delivery of care during all stages of the cancer patient's journey. The plan needs to be read in conjunction with the Committee's summary of recommendations.

Diagnosis and referral

Referral guidelines

6.7 From the very start of the cancer journey, witnesses raised concerns that referrals were largely ad hoc. The Committee accepted that the development of referral guidelines would provide GPs with the information on who best to refer a patient to and would reassure patients that they are accessing the best possible care. The Committee considers that it is vital to ensure patients are referred in a timely manner to high quality treatment services. The Committee noted that work is underway in a number of States to develop referral pathways and recommended that Cancer Australia in conjunction with the States and Territories develop appropriate referral pathways for the management of all cancers.

Empowering cancer patients through provision of information

> An informed and empowered health consumer is critical to good outcome of care.[1]

6.8 The Committee heard that people want to be more involved in their health care and be able to make informed decisions, and that practitioners must respect the fact that people want to be involved. Witnesses told the Committee that they were concerned about the lack of information available for both the general practitioner and the cancer patient at the diagnosis and referral stage. Many patients want to be more involved in choosing their specialist and want information to enable them to engage in an informed dialogue with their GP about who would be best suited to treat them and what their treatment options are. Supporting this view, Professor Currow stated that:

> As I reflect on the cancer journey, you have raised the important issue of how do people win the lottery. At a whole-of system level, we have a couple of options: one is to change the way we deliver health care; the other, in which I believe we can invest substantially, is to have better informed patients. That is to have accessible information specific to each cancer available to people so that they can ensure that the care they are getting is genuinely interdisciplinary…is timely and is credible. We need to

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[1] *Committee Hansard* 19.4.05, p.7 (Professor Currow).

> complement any change to the health system with ensuring that health consumers themselves are adequately informed – not only the person with cancer because the effect does not finish there, but the people around them: their family and friends.[2]

6.9 This call for information has led to the publication of a directory for breast cancer treatment and services in NSW which is very well regarded. The Committee recommended Cancer Australia assist with the coordination of a directory of cancer treatment services in each State and Territory.

6.10 Witnesses told the Committee that from the outset many of them had had little exposure to the health system before they or their relative was diagnosed and they needed assistance to navigate their way through their cancer journey. The Committee considers that in conjunction with more information being made available through care co-ordinators, a common entry point for information for people with cancer was required which would include the development of a website and resource pack which consolidates and provides people with information about various cancers, treatments, support groups and advocacy groups. The Committee considers that the establishment of Cancer Australia provides an opportunity to have an authoritative body that can facilitate access to this kind of information so it is easily available and visible. The Committee therefore recommended that Cancer Australia provide access to authoritative, nationally consistent evidence based information on services, treatment options, government assistance and links to appropriate support groups which can be made available in different forms.

The need for support

6.11 Witnesses emphasised that they needed support right from the time of diagnosis. Evidence has shown that emotional distress is very common in cancer patients and that effective psychosocial support programs are associated with an enhanced quality of life and longer survival. The Committee heard that if a patient feels supported through their cancer journey they comment less negatively on every other aspect of their life and care. The Committee agreed that more options to provide psychosocial support should be pursued and this is further discussed in the section on psychosocial care below.

Improving delivery of services and treatment options

Development of multidisciplinary care

6.12 All witnesses acknowledged that a multidisciplinary approach to cancer care is best practice. There is evidence to show better patient outcomes in terms of survival and emotional well being. Despite this, evidence to the Committee indicated that it is not being widely practiced in Australia. This is due to a range of factors including the way in which services are organised and resourced in different parts of Australia. The

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[2] *Committee Hansard* 19.4.05, p.6 (Professor Currow).

Committee recognised that a range of approaches and models to multidisciplinary care are required for different parts of Australia.

6.13 The Committee noted the 1994 House of Representatives Community Affairs Committee Report on the Management and Treatment of Breast Cancer which found that the management and treatment process for women with breast cancer was fragmented and uncoordinated and recommended multidisciplinary care as best practice for women with breast cancer. In 1995 the National Breast Cancer Centre was established and has been a driving force in improving outcomes for women with breast cancer, advancing multidisciplinary care and producing clinical practice guidelines. It is argued that what was true for breast cancer in 1994, could be seen as true about other cancers in 2005 and inspires the question of why it is taking so long to apply the advances of the breast cancer model to the management of other cancers.

Measures to increase the practice of multidisciplinary care in Australia

6.14 The treatment of breast cancer provides the health system and health providers with a working model of multidisciplinary care which can be adapted for other cancers. The Committee commends the work undertaken on the *National Multidisciplinary Care Demonstration Project* which obtained information applicable to other cancers and made recommendations on the implementation of MDC, and the *Sustainability of Multidisciplinary Cancer Care Study*. There are, however, a number of systemic issues needing to be addressed to progress the practice of multidisciplinary care in Australia including those discussed below.

Multidisciplinary care needs to be better supported by the health system

6.15 Witnesses told the Committee that a multidisciplinary approach is not well supported by the health system and that practitioners have to contend with inflexible funding models. The Committee heard that the current structure of the Medical Benefits Schedule provides minimal financial incentive for clinicians to be part of a multidisciplinary approach. This is even more pronounced in the private system where some clinicians providing treatment to private patients are not funded to participate in MDC meetings. The Committee considers multidisciplinary care must be adequately and explicitly resourced by those funding health services and recommended:

- adherence to clinical guidelines be included in the accreditation process; and
- the enhancement of current MBS arrangements for relevant multidisciplinary care team members.

Accreditation of cancer services and credentialing of practitioners

6.16 It was strongly argued that two systemic changes are required if Australia's cancer treatment services are to continue to improve and meet the increasing demand of the rising incidence of cancer in the Australian community. These are accreditation of cancer services and credentialing of the health professionals who work within them. It is accepted that these systems will take time to introduce which makes it more important that their development is afforded a high priority. The Committee considers that the accreditation of cancer services and credentialing of practitioners is a fundamental priority to ensure that multidisciplinary care is incorporated as a key component of best practice care.

6.17 Work has already commenced on the development of an accreditation framework and the Committee recommended that work should commence on the development of a credentialing process as soon as possible. The Committee also recommended that the practice of multidisciplinary care be included as a criterion for assessment in an accreditation process. The Committee notes that the support of the medical Colleges is fundamental to progress both these issues and they were disappointed by the lack of input from the professional Colleges to the inquiry.

A multidisciplinary team must include non medical health providers

6.18 The issue of including non medical providers in a multidisciplinary team goes to the heart of recognising that a diagnosis of cancer provides the patient with not only physical challenges but practical and emotional issues as well. The Committee accepts that a multidisciplinary team should include not only providers of conventional medical treatment but also health professionals providing psychosocial support and services. The composition of this team would vary according to the medical and social needs of the patient at any one time.

6.19 The Committee also recognises that there are health practitioners who are able to assist cancer patients to better cope with the side effects of conventional treatment, and who can provide an improved quality of life and increase patient well being.

National adoption of clinical guidelines

6.20 Over recent years, Australia has produced a suite of clinical guidelines to support medical professionals, health practitioners and patients on the cancer journey. There is evidence to show that they are effective in improving the quality of clinical practice and the outcomes of care. The Committee considers these to be an important, evidence based resource, endorsed by the National Health and Medical Research Council and that their use should be encouraged nationally using accreditation as a vehicle. The Committee has recommended that the development of an accreditation process should include the use of clinical guidelines and encourages the professional Colleges to promote their use. Translating guidelines into clinical practice and services in both the public and private sectors was agreed by the Committee to be critically important.

Conclusion

6.21 Australia's cancer treatment record is good but services could be considerably enhanced. The introduction of well structured and well funded multidisciplinary care is of vital importance to achieving good outcomes for cancer patients in Australia. The Committee recognises that given the diversity of health care services operating throughout Australia and combined with its diverse geographical spread, it is not appropriate to encourage a fixed approach to multidisciplinary care and has recommended a flexible approach.

Improving care co-ordination

6.22 Witnesses reported experiencing fragmented care during what was often a very complex journey. Evidence demonstrated that a care coordinator has a very valuable role to play in ensuring continuity of care to deliver the full benefits of the multidisciplinary model. The Committee noted that breast care nurses provide a successful model from which to develop care coordinator positions but acknowledged that the person fulfilling the role could vary according to the location of the cancer patient and the availability of services and staff.

Improving access to psychosocial care

> There tends to be a void in the area of meeting psychosocial needs with the physical/tasks often being easier to address by healthcare providers.[3]

6.23 Cancer affects every aspect of a person's life. It affects the patient, family, friends and their physical, mental, emotional and spiritual life. Surveys have found that over 50 per cent of cancer patients feel that the practical and emotional consequences of dealing with cancer were harder than the medical issues. The Committee noted that there is a need to shift mindsets and understand that more and more individuals are going to be living with cancer for longer. There is a need to treat the individual as a whole and not just the disease.

6.24 The Committee also heard that psychosocial support is as much part of multidisciplinary care as surgery, radiotherapy or chemotherapy. Some patients will require more assistance than others, but the Committee agreed that people should be able to access support to assist them cope with issues when they need to and not only when they are in crisis. The Committee recognised that psychosocial support should be given equal priority with other aspects of care and be fully integrated with both diagnosis and treatment. As part of developing multidisciplinary care it is essential that immediate steps are taken to ensure that State and Territory health services address providing psychosocial support for cancer patients, taking into account the NHMRC approved *Clinical practice guidelines for the psychosocial care of adults with cancer*. The Committee considered that the recent changes to Medicare that allow five allied health consultations, including psychological counselling within a registered care plan, need to be promoted and evaluated.

The need for information during the cancer journey

> The most commonly mentioned unmet need is for information. The top seven of the unmet needs from a list of about 30 or so in the questionnaire, were for information and about 20 percent of people had unmet information

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[3] *Submission* 28, p.3 (ACCNS).

> needs. I think a very big message from that is that there is still a lot of work to be done in providing cancer patients with the information that they need.[4]

6.25 As noted earlier, cancer patients told the Committee that one of their biggest challenges was finding and accessing appropriate, authoritative information. In addition to the need for information to make an informed choice about their treatment and care at the commencement of their journey, cancer patients also need information further along the cancer journey about support groups, complementary therapies and other treatment options, and government assistance. The Committee considered that as a part of their role, the care coordinator should be a vital source of information for cancer patients during their cancer journey. The Committee also considered that communication skills training for health professionals was an issue that needed to be addressed at the undergraduate and postgraduate levels and through the Colleges.

The needs of regional and Indigenous Australians

6.26 Access to best practice treatment for regional and Indigenous Australians is challenging. There is little information about how to provide appropriate cancer care for Aboriginal and Torres Strait Islander people. The Committee heard many suggestions on how to provide better services, such as outreach services, developing links with centres of expertise and better access to tele and video conferencing, which they supported. The Committee understands that for logistical and other reasons not all services will be available locally for regional and Indigenous Australians. A major concern raised with the Committee was the disparity in the State and Territory travel assistance schemes. The Committee was advised of and supported the findings of other reviews that there needs to be a standardisation across jurisdictions. For Indigenous Australians the Committee noted the need for culturally appropriate care and recommended Cancer Australia, in consultation with Indigenous people, auspice work to improve access to cancer screening, diagnosis and treatment.

Complementary therapies

6.27 Evidence presented to the Committee showed that a high rate of cancer patients and Australians generally access complementary therapies, though many of them do not inform their medical practitioner as they expect scepticism and little support from them. The Committee heard many stories of this great divide between conventional and complementary medicine and therapies.

> ...the thing that sticks in my mind is the difficulty in finding help, support and wishing like crazy that the doctors and the alternative medicines could see each others values instead of being against each other. I am sure it has a lot to do with fear and lack of knowledge but for the patient it causes even more stress and anguish.[5]

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[4] *Committee Hansard* 18.4.05, p17 (Professor Hill).

[5] *Submission* 76, p.1 (Ms Sally Chambers).

6.28 Clinicians are rightly wary of therapies and products making claims to cure cancer, but medical professionals in Australia seem to be particularly wary of even evidence based complementary therapies which have been embraced overseas. Overseas witnesses told the Committee that about 90 per cent of cancer treatment centres in the USA and UK offer some form of complementary therapies, even if it is on a small scale. Numerous witnesses argued that this situation disadvantages the many cancer patients being treated in Australia.

6.29 The Committee heard from institutions such as the Peter MacCallum Cancer Centre and the Brownes Cancer Centre where complementary therapies are offered. The programs offered by these centres seem to be the exception rather than the rule and even in those settings, the offering of complementary therapies does not constitute a fully integrated service.

6.30 The Committee agrees that complementary therapies must be evidence based and adhere to the same rules as conventional medical treatments. As noted by Professor Zalcberg from the Peter MacCallum Cancer Centre:

> The important thing for people looking after patients with cancer to remember is that they are our mothers, our sisters and our wives. Like everybody else, there is nothing we do not want to give to people that we think works, but we certainly do not want people to go off and have treatments that we think are a waste of time and their money and, in fact, sometimes denies them the actual treatment that does work. So there is not any a priori reason why we do not want to move forward here, but the rules have to apply to everybody for the public's sake.[6]

6.31 However, the Committee acknowledges that there is a case for therapies which intrinsically enhance quality of life, such as meditation and massage, to be more readily accepted.

6.32 The Committee considered that a first step to greater acceptance of complementary therapies in Australia should be the clarification of the terms used to ensure that health practitioners speak the same language. The Committee suggested that complementary medicines and therapies be defined as those which are used in conjunction with conventional treatments to assist with, for example, the alleviation of side-effects. Alternative medicines and therapies are those which would be used instead of conventional treatments or whose affects are as yet unproven.

The need for more information on complementary therapies

6.33 The Committee heard that cancer patients want access to authoritative information on complementary therapies so they can discuss possible benefits with their medical practitioners and make informed decisions about their use. Given the large numbers of Australians using complementary therapies, the Committee

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[6] *Committee Hansard* 18.4.05, p.41 (Professor Zalcberg).

considers that government has a duty of care to provide such authoritative information on an ongoing basis and suggested Cancer Australia as the vehicle.

6.34 The ready availability of information internationally presents an immediate opportunity for Australia to provide patients and carers with authoritative information to help them make informed decisions about the utilisation of complementary and alternative therapies and products. This would go some way towards addressing government's duty of care and responsibilities in this sector.

6.35 The Committee noted the intense interest in the inquiry from organisations representing complementary therapies. It considers that the formation of an umbrella organisation which would be able to represent the sector to government and discuss such issues as standards and regulation is a necessary step towards greater visibility and acceptance of complementary therapies.

6.36 The Committee was concerned that, in Australia, the utilisation and wide acceptance of complementary therapies in order to achieve a better quality of life, relief from the side-effects of conventional treatments and possibly prolonged survival is demonstrably behind the situation in the USA, UK and some European countries. The Committee considers that a critical factor is the lack of authoritative information for medical professionals and cancer patients. As emphasised by witnesses, cancer patients need to use every possible resource to get the best results and it would appear that Australia's conventional treatment sector is reluctant to adopt all that is best for patients from the range of complementary therapies that are available.

Towards Integrative Medicine

6.37 The Committee heard evidence about overseas hospitals such as the Memorial Sloan-Kettering Cancer Center that are using integrative medicine which combines the best evidence based treatments from conventional medicine with the best evidence based therapies from complementary practice to treat not only the disease but the whole person. The Committee supports the following suggestions from witnesses to advance the acceptance of complementary therapies in Australia:

- Therapies should be introduced progressively to facilitate acceptance;
- Developing a shared language is important to facilitate communication between conventional and complementary therapists;
- There is a need to engage local champions with a solid orthodox background who are willing to be actively supportive;
- Australia should make greater use of and adapt information from overseas;
- Complementary services should be located near or next to conventional treatment centres; and
- Education, training and information for conventional medical practitioners has an important role to break down barriers.

The need for more investment in research into complementary therapies

6.38 Witnesses told the Committee that the vast majority of research on complementary therapies has been conducted overseas, especially in the USA with significant funding made available from government. To address the research shortfall in Australia the Committee recommended a dedicated funding stream for research into complementary therapies. The Committee also considers that there is an opportunity for Australia to access and utilise the research conducted overseas as a first step to providing greater information to consumers.

6.39 The Committee also heard about the difficulties experienced by researchers in the sector to obtain funding from the NHMRC. This was acknowledged by the NHMRC which suggested providing mentoring and advice from experienced NHMRC recipients to improve the quality of applications. The Committee agreed with this strategy and recommended that representatives who have a background in complementary therapy be involved in the assessment of research applications received by the NHMRC. The Committee agreed with the recommendation of the Expert Committee on Complementary Medicines in the Health System to establish a working group to identify research needs. The Committee further recommended that this group establish a mentoring program and develop a strategy to coordinate and prioritise research into complementary research in Australia.

Palliative care

6.40 The increasing numbers of people with cancer and who are living longer with cancer means that long term support and palliative care is an area which will require continuing attention. Witnesses noted that as this need continues to grow, planning for associated resources needs to be undertaken. The Committee recognised that the provision of good palliative care affects not only the cancer patient but the carer as well.

Conclusion

6.41 This report provides information on current practices and policies in the area of cancer care in Australia. Firstly, taking a broad perspective, the Committee heard that with the increasing numbers of cancer patients, there is a need to ensure the most efficient and effective use of scarce resources. As described by one witness:

> I get very frustrated by the fact that we could co-ordinate our few resources and our relatively few experts in this country into a more co-ordinated approach to developing and delivering information, and developing and delivering care. I think there is a lot of waste in the current situation.[7]

6.42 The Committee noted that there are many organisations in the cancer sector, some of them sustained by government funds, which appear to be either doing the

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[7] *Committee Hansard* 19.4.05, p.36 (Dr Zorbas).

same thing or competing with each other. It is recognised that this is partly caused by the different types of cancers, especially in the non government sector. However, in the best interests of efficiency and better use of funds, it is important that some re-organisation takes place and this is discussed in chapter 1.

6.43 Looking at cancer treatment and services, it is evident to the Committee that while many improvements in the area of cancer treatment have been made, resulting in better survival outcomes and more people living with cancer for longer, there are areas of cancer treatment services which can be significantly improved.

6.44 From the evidence received by the Committee it is clear that many cancer patients still face fragmented and uncoordinated care along their cancer journey. Many witnesses spoke of their distress when referred from specialist to specialist and left to navigate their own way through the health system. This is particularly an issue for cancer patients living in rural and regional areas who have problems accessing specialist services and also face higher travel costs. This problem is compounded for Indigenous Australians who not only face the difficulties of regional and rural Australians but also cultural and linguistic barriers. Improving access to multidisciplinary care and greater co-ordination of care was discussed in chapter 2.

6.45 The Committee also found that there is a great unmet need for psychosocial support for cancer patients. For those who have cancer the impact is multifaceted. There are not only physical challenges but also emotional and practical issues to be dealt with. It is therefore imperative that cancer patients receive optimal psychosocial support as they need it. Improving access to psychosocial support is discussed in chapter 2.

6.46 From evidence received by the Committee it is clear that Australia is behind best practice in the USA and UK, where integrative medicine is practiced which combines the best of evidence based conventional treatment and the best of evidence based complementary therapies. Evidence also shows that many Australians, and many with cancer, are using complementary therapies but do not discuss this with their medical practitioners. Witnesses spoke of their desire for authoritative information on complementary therapies and the Committee considers that government has a duty of care to provide this using Cancer Australia as the vehicle.

6.47 The Committee considers that more information is needed not only for cancer patients but also medical practitioners and that research conducted overseas provides an opportunity to access and adapt the information for Australia. The Committee would also like to see greater organisation of and collaboration in the sector, including the formation of a national body representing complementary therapies that can interact with government and guide development of issues such as regulation. The Committee also acknowledged the need for further research in the sector and recommended a dedicated funding stream, with more collaboration and assistance from the NHMRC.

6.48 The Committee considers it is evident that without the presence of motivated consumer groups much of what has been achieved would either not have happened or still be in a developmental phase. This is well illustrated in the treatment and support of breast cancer patients. It is important that consumers and consumer organisations continue to be empowered in order to help drive change.

6.49 The Committee believes that the recommendations and plan that it has proposed will greatly assist the delivery of services and options for the treatment for persons diagnosed with cancer as they travel the cancer journey. The successful outcome of these proposals will hopefully be a more informed population that leads to an improved quality of life and prolonged survival time for cancer patients.

Senator Gavin Marshall
Chair
June 2005