

Making the law work better for people affected by cancer



Legal Services **BOARD**

Funded through the Legal Services Board Grants Program

1. Introduction: Making the law work better for people with cancer

Outcomes for cancer patients, their experiences of cancer and those of their families and health professionals, are impacted by the law in multiple ways. Any discussion of the impact of law on cancer cannot be divorced from the context in which laws operate, and the importance of cultural and social norms in the generation and implementation of laws that may impact people affected by cancer. There are certain expectations—for example, the expectation of autonomy in decision making at the end of life and for those decisions to be respected, or the expectation that any person can access the treatment they need when they need it—that some would hold to be so fundamental, that they exist beyond traditional legal frameworks. There is a challenge to ensure the law effectively articulates and responds to these expectations for people affected by cancer.

It should also be acknowledged that for people affected by cancer and their families their experience of the law will be similar to that of people with other life-limiting or chronic illnesses, their families and health professionals with the health system.

The project

In 2012, the McCabe Centre for Law and Cancer and Cancer Council Victoria's (CCV) Strategy and Support Division, supported by a major grant from the Legal Services Board of Victoria, began working on a project on legal issues for people affected by cancer.

The project's key focus areas are:

- Access to treatment;
- Employment;
- Discrimination;
- Decision making at the end of life.

The primary focus is on how law and policy in these focus areas impact on the experience of Victorians affected by cancer; however, many of the issues raised in this paper have national relevance, while some of the laws that are the focus of this paper are Commonwealth rather than Victorian laws.

This issues paper introduces the key focus areas, and discusses some of the practical legal issues arising under each focus area:

- Access to treatment: access to support for travel and accommodation
- Employment: equal opportunity legislation and returning to work
- Discrimination: discrimination in insurance, and genetic testing in insurance
- Decision making at the end of life: advanced care planning, substitute decision making and the right to demand treatment.

In selecting the legal issues above we relied on feedback and contributions from the project's steering committee, and other stakeholders. The purpose of this project is to analyse the laws and policies that impact on Victorians affected by cancer, to encourage discussion about the impacts of these laws, and to formulate recommendations for law reform where appropriate.

To facilitate responses, we have included a list of questions at the end of each section of this issues paper to guide your feedback and discussion. We encourage responses from consumers, carers and health professionals from a wide variety of backgrounds and experience, recognising that a broad perspective from all sectors is critical in understanding and reforming laws that affect people with cancer.

This issues paper will be released online for public comment on Monday 11 March, and will be presented at by regional forums, to be held in the first half of 2013.

Cancer in Victoria: A Snapshot

Cancer incidence is increasing

Cancer is a leading cause of disease in Victoria with 78 new diagnoses and 29 deaths from cancer every day (excluding non-melanoma skin cancers).¹ A total of 28,363 Victorians were diagnosed and 10,631 died from cancer in 2011.² One in three Victorian women and one in two Victorian men will be diagnosed with some form of cancer before the age of 75.³ It is estimated that by 2022-2026 the average annual incidence of cancer will reach over 45, 000, an increase of 60% from 2007-2011.⁴ During the same period, deaths from cancer are projected to increase to over 12,000 per year.⁵

Cancer survival rates are increasing

Survival rates for some cancers are increasing, meaning more people are living longer after a cancer diagnosis. Though cancer incidence rates continue to increase (annual % increases of 0.8% for men and 0.6% for women), death rates have declined steadily since 1982 with average falls of 1.5% per year for males and 1.2% for females.⁶ This reflects earlier detection through screening, falling tobacco-related cancer rates for males⁷ and improvements in treatment and outcome.⁸ During the period 1986-2010, five-year survival increased from 47% to 65%.⁹

Needs of people affected by cancer, their families and carers and health professionals

Stakeholders report concerns that cancer patients are not well served by some of the legal structures that impact on their treatment and support, including access to financial support for travel and accommodation, discrimination in the provision of insurance and superannuation, work-related issues, and uncertainties about decision making at the end of life.

Issues such as these can affect experiences and outcomes for people affected by cancer. For example, difficulties in any of these areas can lead to unnecessary uncertainty, stress and barriers for people already under a range of pressures, including people diagnosed with cancer and their families and carers. For many health professionals, there is uncertainty about legal and related financial issues that may affect treatment and support, and legal frameworks and protections regarding treatment decisions, particularly where substitute decision-makers are involved. This uncertainty can lead to a reluctance to raise awareness or discuss legal issues with patients.

¹ Thursfield V. and Farrugia H. *Cancer in Victoria: Statistics and trends 2011* Cancer Council Victoria, Melbourne 2012, 7 and 11.

² Ibid.

³ Thursfield V., Farrugia H. and Giles, G. *Cancer in Victoria: Social Context 2010* Cancer Council Victoria, Melbourne 2011, 1.

⁴ Thursfield and Farrugia, above, n 1.

⁵ Ibid.

⁶ Ibid.

⁷ Lung cancer has one of the poorest survival rates of all cancers (see above, n 1.).

⁸ Thursfield and Farrugia, above, n 1.

⁹ Ibid.

This paper explores the legal and policy issues in four key areas that impact on people affected by cancer, and seeks to promote dialogue and ideas about how to make the law work better. Your feedback is greatly welcomed.

2. Access to treatment

Financial support for transport and accommodation costs

Background

There is a correlation between cancer survival rates and the quality and availability of services. As geographical isolation increases, cancer care is less accessible.¹⁰ For example, the further from a metropolitan centre a person with cancer lives, the more likely they are to die within five years of diagnosis.¹¹ For some cancers, those who live remotely are up to 300% more likely to die within five years of diagnosis.¹²

The complexity of cancer treatment, including the way in which treatment is delivered, the requirement for input from more than one medical specialist, and the need for highly specialised medical equipment, means that people from rural and remote areas will almost always need to travel for some components of their cancer care¹³ and many people require several weeks of daily radiotherapy and/or regular chemotherapy sessions.

The costs of transport and accommodation for treatment represent a significant burden for people affected by cancer living in rural and remote areas, and contribute to the context in which decisions are made about treatment and recovery. People may defer treatment or seek alternative treatment options, due to the financial burden that travel and accommodation can add to the process. Further, those who are worried about the financial burden of treatment may be less prepared to take on important information about their care pathway to ensure they are fully informed, making financial distress a quality of life issue.

Access to support for transport and accommodation costs

In Australia, travel support is available through state- and territory-based patient travel assistance schemes which subsidise part but not all of the costs of travel and accommodation.

In Victoria, the Victorian Patient Travel Assistance Scheme (VPTAS) subsidises the transport and accommodation costs incurred by rural Victorians and if appropriate, their carers, who have no option but to travel a long distance to receive appropriate, approved medical specialist services.¹⁴

To be eligible for assistance, Victorians affected by cancer must meet all of the following criteria:

- be a Victorian resident
- live in a Department of Health designated rural region

¹⁰ Cancer Council Australia 'Closing the loop: bringing patients to the new regional centres' (31 March 2011) <<http://www.cancer.org.au/policy/electionpriorities2010/remotepatienttravel.htm>>

¹¹ Australian Institute of Health and Welfare and Australasian Association of Cancer Registries *Cancer survival in Australia 1992–1997: geographic categories and socioeconomic status* Cancer Series no. 22. Cat. no. CAN 17, Canberra: AIHW, 2003; Jong KE, Vale PJ, Armstrong BK 'Rural inequalities in cancer care and outcome' *Med J Aust* 2005, 182(1), 13-14; Australian Institute of Health and Welfare *Health in rural and remote Australia* Canberra: AIHW, 1998 (AIHW Cat. No. PHE 6).

¹² Jong K.E., Smith D.P., and Yu X.Q., et al 'Remoteness of residence and survival from cancer in New South Wales' *Med J Aust* 2004; 180: 618-622).

¹³ National Health Priority Action Council, *National Service Improvement Framework for Cancer* (2006, Australian Government Department of Health and Ageing) 42; [http://www.health.gov.au/internet/main/publishing.nsf/content/96C9CD63196A62ACCA25714100045165/\\$File/cancall.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/96C9CD63196A62ACCA25714100045165/$File/cancall.pdf)

¹⁴ 'Victorian Patient Transport Assistance Scheme (VPTAS)' (Rural Health; Victorian Department of Health, 1 August 2012) <<http://www.health.vic.gov.au/ruralhealth/vptas/index.htm>>

- be receiving specialist medical treatment from an approved medical specialist service registered with Medicare Australia; and
- need to travel more than 100 kilometres one way or on average 500 kilometres per week for a minimum of five consecutive weeks.

Assistance may also be provided to Victorian residents who are referred to an interstate approved medical specialist service when the service is not available within Victoria or if this is the nearest location. The approved medical specialist must confirm in writing that the required service cannot be provided in Victoria.¹⁵

Problems with the VPTAS

Concerns have been expressed about access and equity issues associated with travel and accommodation support schemes in Australia.¹⁶ People affected by cancer report low awareness about the schemes¹⁷ or difficulties in claiming money for which they are eligible.¹⁸

In addition, the CCV Strategy and Support Division have recognised the following issues associated with the Victorian scheme:

1. Low level of subsidy provided for travel and accommodation.

In Victoria, patients are eligible for a reimbursement of 17 cents per kilometre where a private vehicle is used. Reimbursement amounts in other states and territories range from 12.7 cents (in NSW) to 30 cents per kilometre (Queensland); in South Australia, patients are required to contribute \$30 to the cost of each journey when they take a return journey.

Victorian cancer patients are also eligible for \$35 per night for accommodation. Accommodation subsidies in other states and territories range from \$30 per night in NSW, to \$60 per night in Queensland. In 2007, Cancer Action Victoria¹⁹ stated that the average night of accommodation near any hospital across Australia was \$90 per night. This data, now five years old, reflects that with inflation \$100 per night would now be expected as a standard expense. At current rates, Victorian patients are required to pay \$65 or more (out of pocket) per night for accommodation. The costs associated with travel and accommodation can add significantly to the overall costs for rural and remote patients who are required to travel for treatment, costs which are compounded if patients have reduced income due to treatment or were financially disadvantaged prior to diagnosis.

2. The distance threshold for eligibility, and the requirement that patients see the nearest specialist rather than the most appropriate specialist.

People with cancer who reside within 90km of a treatment centre will often have the same needs as someone who lives more than 100km away from a treatment centre, yet are not entitled to claim for transport and accommodation support.²⁰ For some people, the nearest specialist may

¹⁵ Ibid.

¹⁶ *Optimising Cancer Care in Australia* A consultative report by the Clinical Oncological Society of Australia, Cancer Council Australia and National Cancer Control Initiative (2003)

¹⁷ 'State and territory travel and accommodation subsidy schemes' (Position statement, Cancer Council Australia, November 2004)

¹⁸ Ibid citing L Beeney, et al. "Needs assessment of rural and remote women travelling to the city for breast cancer treatment." *Australian & New Zealand Journal Of Public Health* 22, no. 5 (August 1998): 525-527.

¹⁹ Cancer Action Victoria is a state-based advocacy organisation for Victorians affected by cancer.

²⁰ Above n 17.

be in another state; for others, the choice to obtain a second treatment opinion, or to choose a particular specialist or treatment centre may be limited by eligibility requirements in the VPTAS.

3. Limited awareness of the VPTAS scheme and complexity of the paperwork and application process acts as a disincentive for both patients and doctors to actively engage with the schemes. Further, Victorian clinicians spend valuable clinical time completing lengthy paperwork for the Victorian Department of Health so that patients can receive their VPTAS rebates.
4. Support for patients to attend cancer clinical trials.
Currently, no jurisdiction provides a subsidy for isolated patients to be involved in cancer clinical trials, despite clinical trials presenting significant benefits for participating patients and Victorian government support for clinical trial participation.²¹

International experience

In the UK, travel support for non-primary medical or dental care services²² is available under a national Healthcare Travel Costs Scheme (HTCS), administered by the NHS, which compensates patients in full for the cost of the cheapest mode of travel, regardless of whether they live in a rural or metropolitan area. In order to be eligible for support under the HTCS the patient or their partner needs to be receiving a qualifying benefit or allowance, or be eligible for the NHS Low Income Stream. Referral requirements also apply. Accommodation costs are not covered under the HTCS, but may be claimed as treatment costs from the hospital or provider.

Questions for consideration

1. What improvements could be made to the Victorian Patient Travel Assistance Scheme?
2. What level of transport and accommodation support is reasonable for those who need to travel for medical treatment?
3. What are the implications if Victoria adopted an NHS style scheme; how would this be funded and administered?
4. Should Australia have a national transport and accommodation support framework to ensure consistency and improved administration between states and territories, and eligibility requirements that recognise need as well as geographical isolation?

²¹ Department of Human Services, *Victoria's Cancer Action Plan 2008-2011*, Victorian Government, Melbourne, 2008.

²² Primary care services, for which travel costs cannot be claimed, include check-ups, vaccinations, cervical cancer screening or minor surgery.

3. Employment-related issues, including discrimination

Introduction

While many employers are supportive when an employee is affected by cancer, retaining, returning to, or finding new employment can be difficult for people who have or have had cancer, depending on their circumstances. Undergoing time-consuming treatments, being physically or emotionally unable to work as a result of diagnosis or treatment, and discrimination are among the range of factors that can impact on employment. Experiences vary according to whether people: stay in their current role while undergoing treatment; take leave for treatment and then return to work; quit their job and apply for a new position after treatment; or do not return to work at all.

Discrimination in employment

Discrimination on the basis of a cancer diagnosis or a history of cancer is unlawful under Commonwealth, state and territory disability discrimination laws. Disability has a very broad meaning in the Commonwealth Disability Discrimination Act 1992 (“DDA”) and includes conditions that presently exist, previously existed but no longer exist, or those that may exist in the future (including because of a genetic predisposition to that disability). The DDA also covers discrimination against a person because he or she is an associate of a person with a disability, for example, a family member, partner, friend or carer.

The Victorian Equal Opportunity Act 2010 (“EOA”) prohibits discrimination on the basis of the protected attributes listed in the Act, which include disability (defined similarly to disability in the DDA). The Commonwealth and state and territory anti-discrimination laws operate concurrently, which means that in general, people may be protected under both the relevant Commonwealth legislation and their own state or territory’s legislation.

Both the DDA and the EOA cover direct and indirect discrimination. Direct discrimination encompasses treating a person with a disability less favourably than someone without a disability in the same or similar circumstances, or not making reasonable adjustments for the person, which has the effect of less favourable treatment of them. For example, denying a person a job or a promotion because of their cancer diagnosis would constitute direct discrimination.

Indirect discrimination occurs when people with and without a disability are treated the same, with the effect that a person with a disability is disadvantaged because they are not able to participate or comply with a condition, or when reasonable adjustments are not made to enable them to participate. For example, requiring that employees in a manufacturing role stand all day, when an employee’s cancer makes standing for long periods difficult, may constitute indirect discrimination - unless reasonable adjustments are made.²³

Given that there is limited evidence of people affected by cancer making employment-workplace discrimination-related complaints to human rights commissions or pursuing court action,²⁴ the extent of

²³ These examples of direct and indirect discrimination are borrowed from Wuellner, L. *Cancer, Work and You: Information for employed people affected by cancer*, Cancer Council NSW, Sydney, 2011.

²⁴ The AHRC Complaint Statistics from 2010/2011 show that of the 1097 complaints received about disability discrimination, pursuant to the DDA, just 104 related to discrimination on the grounds of “presence in the body of organisms causing disease (excluding HIV/AIDS)” (16) and “medical condition” (88). It is not clear whether these complaints were related to people affected by cancer. A search of the Australasian Legal Information Institute case law databases also revealed very few cases relating to discrimination or other workplace related complaints on the grounds of cancer.

the problem is unclear. Consultations with stakeholders indicate that it is not uncommon. Some employers may discriminate against a person affected by cancer if they think that they will need to take extended leave or that their illness or side effects from their treatment will impact on their performance. There may be general discomfort around working with someone who has cancer. Anecdotally, there may also be a gender bias in terms of women affected by cancer experiencing more discrimination at work.

This is despite the fact that there are additional specific prohibitions against discrimination in employment in anti-discrimination laws. The DDA states that employers must not discriminate:

- in offering employment and the terms and conditions upon which employment is offered;
- in the terms or conditions afforded to an employee;
- by denying or limiting access to employment benefits, including promotion, transfer or training;
- by dismissing an employee; or
- by subjecting an employee to any other detriment.²⁵

However, it is not unlawful for an employer to discriminate against a person affected by cancer if they are unable to “carry out the inherent requirements of the particular work” even if “reasonable adjustments” were made for them (section 21A(1) DDA).²⁶ It is also not unlawful for employers to discriminate against someone on the grounds of their being affected by cancer, if avoiding the discrimination would impose “unjustifiable hardship” on the employer (section 21B DDA).

A person diagnosed with cancer is under no obligation to disclose their condition to their employer, a prospective employer or anyone else that they work with. The same is true for employees who are caring for someone with cancer. However, a person affected by cancer may find that they are unable to keep their diagnosis private, depending on the impact of the illness and their treatment type. Additionally, it may become necessary to disclose their diagnosis if it will affect their performance or they need to take leave as a result of their condition, as some employers require medical certificates for personal leave (although they need not disclose cancer in particular).²⁷

An employee affected by cancer may also require reasonable adjustments to be made so that they can continue to meet the conditions of their employment, for example, more flexible working arrangements (hours, location) to enable attendance at medical appointments, or their desk to be moved to the ground floor. A person who returns to their position after taking extended leave may find that they are offered reduced hours, responsibilities or pay, if their employers think that they will no longer be capable of performing at their pre-illness level. And yet employers must take reasonable steps to accommodate the effects of the cancer under the DDA and EOA,²⁸ whether a person continues to work during treatment, or returns to work after taking leave for treatment.

²⁵ Similar (although not identical) protections also apply to commission agents, contract workers, and people considered for partnerships (ss16-18). There are exceptions relating to employment for domestic duties in the employer’s home (s 15(3) DDA 1992). Authorities that authorise, qualify or facilitate the practice of a profession are also prohibited from discriminating on the grounds of disability (s 19), as are employment agencies (s 21) and organisations registered pursuant to the Fair Work (Registered Organisations) Act 2009 (for example unions).

²⁶ To determine whether a person would be unable to carry out the inherent requirements of particular work, an employer must consider their training, qualifications and relevant experience, their existing job performance (if they already work for the employer) and any other reasonable factor.

²⁷ Wuellner, L, above n 21.

²⁸ Ibid.

Other employment-related issues

There are other legal issues that may impact on people affected by cancer in the employment context, including:

- **Taking leave**
Employees are entitled to use paid leave entitlements (personal and annual) or ask for unpaid time off if they are unable to attend work due to their illness or treatment. Employers cannot dismiss employees for temporary absences due to illness (section 352 Fair Work Act 2009 (Cth)), as long as a medical certificate is supplied and the employee's absence is less than three months, or less than a total of three months within a 12 month period (whether based on a single illness or separate illnesses).²⁹
- **Financial support if not returning to work**
People affected by cancer may experience significant difficulties accessing financial support if they are unable, or decide not, to return to work after diagnosis or treatment. They may have limited awareness of financial assistance arrangements, or eligibility requirements for income support may make it difficult for people affected by cancer, and their carers, to access. For example, people affected by cancer may not qualify for a disability support pension, as their condition may not last more than two years; equally, they may be ineligible for a sickness allowance if their condition is not temporary.

People affected by cancer who do not return to work may also experience difficulties in obtaining early access to superannuation funds or in accessing disability insurance, income protection and employer-provided retirement benefits.

Legal redress for employment-related complaints

Deciding which anti-discrimination legislation to complain under can be complex and people who think that they have suffered discrimination may need to seek legal information and advice before making a complaint. A person can make a complaint to the Australian Human Rights Commission (“AHRC”) themselves, or through a solicitor, advocate or other representative, although there may be costs involved in this. Under the EOA the complainant can authorise someone to act on their behalf only if they are unable to bring a complaint because of their disability.

Making a complaint under any of the Acts can be energy and time-consuming and involve a lengthy and costly process, which usually begins with a complaint to the relevant human rights commission, and can result in tribunal or court action if the complaints cannot be conciliated. Both the AHRC and the Victorian Equal Opportunity and Human Rights Commission may decline to offer conciliation if the alleged discrimination happened more than 12 months before the complaint was lodged.³⁰

There are further legal protections and remedies for people affected by cancer who experience unfair treatment in relation to employment. If a person has been unfairly dismissed because of issues related to their cancer, then they may be able to make an unfair dismissal application to the Fair Work Commission (“FWC”), which must be lodged within 21 days. People can also complain to FWC in other circumstances, including discrimination or unlawful termination (for example, if they have been dismissed

²⁹ Reg 3.01, Fair Work Regulations 2009.

³⁰ Section 116(a) EOA and section 46PH(1)(b) Australian Human Rights Commission Act 1986.

as a result of discrimination or another unlawful reason, such as taking temporary absence from work due to illness.)³¹

Because of some of the very short timeframes involved and the complex overlapping avenues for complaint, people who feel that they have been discriminated against on the basis of being affected by cancer, may need to seek legal information or advice quickly if they want to make a complaint. This may present a significant barrier for people who are already busy undergoing treatment or dealing with a host of other matters related to their illness. This barrier may be compounded by costs and the length of time that complaints can take to resolve (particularly if court action is involved).

Questions for consideration

Note that there is some overlap in the issues and questions raised in this section and in the following section on discrimination in the provision of insurance and superannuation.

5. Is discrimination in employment a significant issue for people affected by cancer?
6. What measures are needed to reduce discrimination in employment for people affected by cancer? For example, more legal education for people affected by cancer, employers, and health professionals?
7. Are changes required to current discrimination laws and processes to better enable and support people affected by cancer to pursue discrimination complaints? For example, more advocacy support, or longer timeframes within which to lodge complaints?
8. Are existing legal remedies for discrimination sufficient to redress the needs of people affected by cancer?
9. How could the law respond better for people affected by cancer who:
 - a. Continue in their employment
 - b. Take leave and return to work
 - c. Seek new employment after treatment
 - d. Choose not to or are unable to return to work?
10. Do cancer (and other chronic diseases) require a new category of income support for people affected by cancer and their carers?

³¹ The Fair Work Ombudsman can also investigate complaints of unlawful termination.

4. Discrimination in insurance and superannuation

Access to insurance and superannuation for people affected by cancer

Anti-discrimination laws (discussed above in section 3) are intended to ensure that all people are protected from discrimination and have equitable access to services. The Disability Discrimination Act 1992 Cth (“DDA”) makes discrimination unlawful in defined areas of ‘public life’; the provision of financial services, including insurance and superannuation, is included in the definition of public life.

In Australia, Medicare is a form of universal health insurance, under which most Australian residents receive benefits for health care, with private health insurance available where Medicare coverage is not. Private health insurance is community rated, which means that an individual’s risk is equalized in a large pool of insured people.

Travel insurance, life insurance, superannuation and other annuities are risk-rated through the insurance underwriting process. This means that a person’s risk is assessed taking into account any factors that may increase or decrease the probability that a person may claim against their insurance policy.

For people affected by cancer accessing insurance coverage can be problematic, due to their medical history or pre-existing conditions. Access to insurance (particularly life and travel insurance) and superannuation is a significant issue for people who have finished active treatment for cancer and the denial of insurance can severely hamper their ability to participate in areas such as employment, travel and home ownership.

Insurance exemption in the DDA

While disability discrimination (including on the basis of cancer) in insurance and superannuation is unlawful under the DDA, reasonable distinctions in insurance are not discriminatory. Under section 46 of the DDA a provider that refuses to offer a policy of insurance or membership of a superannuation fund or alters the terms of a policy or membership in relation to a person with a disability, must show that the decision to discriminate:

is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; and is reasonable having regard to the matter of the data and other relevant factors; or

in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.

The exemption gives insurers some room to make distinctions between individuals, but at the same time, seeks to prevent discrimination which is not based on relevant grounds; for example, where there is no evidence to support the conclusion that disability increases that individual’s risk.

In a 2004 case, *QBE Travel Insurance v Bassanelli*,³² the Federal Court upheld the protection from discrimination in the DDA. Ms Bassanelli was declined all travel insurance cover on the basis of pre-existing metastatic breast cancer. The Court found that the insurer had not acted reasonably in coming to the decision to decline cover, and further held that a person cannot be discriminated against for having a

³² [2004] FCA 396 (7 April 2004)

pre-existing condition—in this case, cancer—when the insurance sought did not relate to the condition, and where the insurer had not based its decision to discriminate on relevant factors.

Protecting people affected by cancer—adequacy of the law, adequacy of data

It is difficult to measure the overall effectiveness of disability discrimination laws for cancer survivors attempting to access services such as insurance and superannuation. There have been few complaints under anti-discrimination law about discrimination in insurance on the basis of cancer; however, the Productivity Commission has said that ‘[i]t is not easy to measure intangible concepts such as the level of discrimination’; while a Breast Cancer Network of Australia survey of 750 women found about one quarter had had difficulties obtaining travel insurance due to their condition.³³

The law supports the differentiation between someone with cancer and someone without for the purposes of insurance, but stresses that if such a distinction is drawn, then it should be evidenced through statistics, and not anecdote. However, the quality of actuarial information about people who are living with or beyond cancer is said to be limited.³⁴ This information gap is likely to be compounded as more people survive cancer, or live with a cancer diagnosis for longer.

Genetic testing and insurance

The prospect of genetic discrimination raises serious concerns, not least because:

- Very few current genetic tests are actually predictive and guarantee a specific outcome, for example, disease. Most genetic tests can only indicate, at best, increased susceptibility for particular conditions.
- People may be discriminated against purely on the basis of a family member having a heritable genetic condition.

Genetic information encompasses genetic test results and family medical history; and in Australia, both may be used by insurers to assess applications for insurance products. An insurer may not force a person to take a genetic test, but if a genetic test has been undertaken, it should be disclosed as part of any health assessment, and an insurer may request the result if they believe it to be material to an assessment.³⁵ In 2003, the Australian Law Reform Commission conducted an inquiry into the protection of genetic information in Australia.³⁶ The report included results from a 2001 survey which identified 48 cases of alleged discrimination on the ground of genetic information or disorders in life, income protection and trauma insurance.³⁷

The Commission concluded that the use of genetic information in insurance has had the effect of leaving some applicants with the impression that the underwriting decision was not well informed or fair—even if the insurer’s actions were lawful; but also that there is considerable uncertainty about the nature and extent of discrimination in insurance based on genetic information.

³³ Productivity Commission *Review of the Disability Discrimination Act 1992* Productivity Commission Inquiry Report, Report No. 30, 30 April 2004, Melbourne, 65.

³⁴ Elizabeth Hastings, Disability Discrimination Commissioner 1993-97, ‘Understanding Disability Discrimination: Life Investment & Superannuation Association of Australia’ Speech delivered at the Second Annual Summit, Canberra, 23 May 1997)

³⁵ Australian Law Reform Commission and Australian Health Ethics Committee of the National Health and Medical Research Council *Essentially Yours: The Protection of Human Genetic Information in Australia* ALRC 96, 2003.

³⁶ *Ibid.*

³⁷ *Ibid.* [26.20] citing Barlow-Stewart, K. and Keays, D. ‘Genetic Discrimination in Australia’ (2001) 8 *Journal of Law and Medicine* 250, 254–256.

Protection from discrimination on the basis of genetic information is already contemplated in the DDA which prohibits discrimination based on a past, present, possible future or imputed disability. Where a genetic test indicates a higher risk of cancer, insurers may charge a higher premium or change the terms under which they provide cover (in the same way as if insuring someone with a history of cancer), but only if there is sound actuarial and other relevant statistical data to underpin the decision.

As noted above, there is limited actuarial and statistical data for insurers to rely on; in relation to genetic testing in insurance, this paucity of data is compounded by low awareness of the usefulness of genetic tests for insurers and lack of policy guidance about how genetic tests are to be used in underwriting insurance.³⁸

International perspectives

In 2008, the USA enacted the Genetic Non-Discrimination Act (GINA), which prohibits health insurance plans from requesting or requiring that a covered member or family member undergo genetic testing.³⁹ Access to health insurance in the US is mainly sponsored by employers, through group health plans. The GINA prohibits employers from making adverse employment decisions based on a person's genetic information, including family health history, and employers and health insurers are not allowed to request or demand a genetic test under the law. The GINA forbids health insurers from requesting, requiring or purchasing genetic information for underwriting purposes, and they may not disclose held genetic information for underwriting purposes.⁴⁰ Critically, however, protection under the GINA does not extend to life insurance policies.

In the UK, there is a moratorium on the use of genetic testing in insurance. First established in 2001, the *Concordat and Moratorium on Genetics and Insurance* is an agreement between the Association of British Insurers and the UK Department of Health that states that individuals are not obliged to disclose the results of predictive genetic tests when applying for insurance, except if taking out life insurance over £500,000.⁴¹ Above that amount, insurers will only use tests that have been specifically approved by the Government—only 3% of insurance policies are said to be above this amount.⁴² In 2011, the moratorium was extended to 2017.⁴³

The potential impact of the Human Rights and Anti-Discrimination Bill 2012 for people affected by cancer

Australia does not have specific legislation addressing genetic discrimination. However, currently, both the DDA and the Victorian EOA prohibit discrimination on the grounds of a disability or impairment that may exist in the future – including because of a genetic predisposition to a disability or impairment.

There is concern that the Australian Human Rights and Anti-Discrimination Bill 2012 (“the Bill”) will remove the legislative prohibition against discrimination on the basis of genetic predisposition to a condition. Unlike the current DDA, the Bill does not include possible future disability in its definition of

³⁸ Professor Margaret Otłowski, Submission to the Productivity Commission, Review of the Disability Discrimination Act 1992, 4.

³⁹ Snyder, C. ‘Genetic Information and Discrimination: A Policy Analysis’ (2011) 15 (3) *Clinical Journal of Oncology Nursing* 330, 331.

⁴⁰ Ibid.

⁴¹ . HM Government and Association of British Insurers, ‘Concordat and Moratorium on Genetics and Insurance’ <http://www.dh.gov.uk/health/files/2012/06/Concordat-and-Moratorium-on-Genetics-and-Insurance-20111.pdf>.

⁴² Ibid.

⁴³ Association of British Insurers Insurance Genetics Moratorium extended to 2017 (Media release, 5 April 2011) http://www.abi.org.uk/Media/Releases/2011/04/Insurance_Genetics_Moratorium_extended_to_2017.aspx.

disability. If the prohibition against genetic discrimination is not carried through in the new legislation, then people may find themselves discriminated against, in employment, insurance and in other areas, on the basis of what their genetic material appears to reveal about them.

The proposed new definition of disability in the Bill also omits the current protection from discrimination on the grounds of a disability that previously existed but no longer exists. While medical history is included as its own attribute protected from discrimination in Bill, it is only unlawful to discriminate on the grounds of medical history in work or work-related areas. The protections that the DDA currently provides would therefore appear to be significantly watered down in the proposed Bill, to the detriment of people affected by cancer, unless the wider DDA definition of disability is incorporated.

Questions for consideration

11. How significant is the problem of discrimination in insurance and superannuation for people affected by cancer?
12. What measures are needed to reduce discrimination for people affected by cancer? For example, more legal education for people affected by cancer, insurance and superannuation providers, and health professionals?
13. Are changes required to current discrimination laws and processes to better enable and support people affected by cancer to pursue discrimination complaints? For example, more advocacy support, or longer timeframes within which to lodge complaints?
14. Are existing legal remedies for discrimination sufficient to redress the needs of people affected by cancer?
15. Does Australia need specific legislation prohibiting genetic discrimination or would there be sufficient protection if the disability definition in the proposed Human Rights and Anti-Discrimination Bill 2012 incorporated possible future disability?
16. Should the Human Rights and Anti-Discrimination Bill use the DDA definition of disability, or similar, to ensure that people who have had or may have cancer in the future maintain protection from discrimination under the new anti-discrimination scheme?

5. End of life decision-making

Background

In Australia, the legal framework governing decision making at the end of life is impacted by divergent state, territory and federal laws, leading to drastically different outcomes for patients depending on which jurisdiction a patient is in.⁴⁴

For example, the legal framework around substitute decision making, for situations when a patient is unable to make a treatment decision for themselves, differs significantly from state to state. While the legislation in Queensland and Western Australia clearly defines the powers of substitute decision makers to make decisions at the end of life, including the ability to refuse treatment, in NSW substitute decisions makers are bound to ‘promote and maintain health and wellbeing’ in accordance with Guardianship Act 1987(NSW), and while they may ‘consent’ to treatment, they may not necessarily have the ability to refuse treatment for a patient.⁴⁵ Stewart argues that “the most obvious solution to this problem is for legislation to expressly set out the powers of guardians, enduring guardians and persons responsible.”⁴⁶

Advance care planning

Advance care planning is the process of planning for a person’s future health and personal care, to guide care and decisions if a person becomes unable to communicate or to make their own decisions.⁴⁷ The law facilitates advance care planning in two ways:

- By providing the means for substitute decision-making when a person is not competent to make their own healthcare and other decisions; and
- Through advance directives, which are decisions about what medical treatments a patient would like in the future, if they become unable to make their own decisions. While they usually record decisions about refusing life-sustaining treatments, they are not limited to end of life decision-making.⁴⁸

Ideally these processes occur in tandem holistically, through exploration and discussion of values and desired outcomes, between the person affected by cancer, their family and relevant health professionals. As well as being a beneficial process generally, this increases the likelihood that patients’ recorded wishes will be understood and adhered to. However, decisions made in these contexts are not necessarily legally binding in Victoria, where the legal status of advance directives is unclear.⁴⁹

While the Medical Treatment Act 1988 (Vic) (“MTA”) provides a statutory right for a patient or their agent to make a refusal of treatment certificate, this is limited to refusing treatment for a current condition only (sections 5 and 5A). Similar legislation in other Australian jurisdictions provides for advance refusal and *consent* to medical treatment and allows directions about treatment for *future* conditions, and not just a current condition.⁵⁰

⁴⁴ Stewart, C. ‘Law and cancer at the end of life: The problem of nomoigenic harms and the five desiderata of death law’ *Public Health* 125 (2011) 905-918.

⁴⁵ Ibid.

⁴⁶ Ibid.

⁴⁷ <http://health.vic.gov.au/acp>

⁴⁸ Ibid 915.

⁴⁹Victorian Law Reform Commission (2011) Guardianship: Final Report, Chapter 11.

⁵⁰ Ibid.

It is unclear whether an advance care directive would be recognised at common law in Victoria. Such a right has been recognised in NSW⁵¹ and common law rights generally are preserved in section 4 of the MTA, which states that other legal rights are not affected by the Act.

There is further uncertainty about the interaction between substitute decision-makers and advance care directives; in particular whether a substitute decision-maker can legally consent to treatment that is contrary to the wishes expressed in a (common law) advance directive. As there have been no cases on this issue in Victoria it is unclear whether substitute decision-makers are bound by advance directives or whether they must simply take them into account in a best interests analysis.⁵²

In terms of the actual content of advance directives, the Austin Hospital Respecting Patients Choices Program has previously recommended that advance directives focus on desired patient outcomes rather than specific treatments:

It would be more productive for a person to state their desired outcomes in terms of what level of physical and mental function they would consider an acceptable outcome, so that in the event of an actual condition, their agent would be able to discuss treatment options and likely outcomes with the treating team and make decisions accordingly.⁵³

To deal with all of these uncertainties in the scope and application of advance care directives the Victorian Law Reform Commission has recommended law reform in the following terms:

- Permitting competent people to plan for future decision-making in three ways, through:
 - Appointing an enduring personal guardian with no instructions about the exercise of their decision-making powers;
 - Appointing an enduring personal guardian with instructions about how to exercise their decision-making power;
 - Making a stand-alone ‘instructional directive’.
- Replacing ‘refusal of treatment certificates’ with a statutory scheme that provides for binding ‘instructional health care directives’ (in prescribed form) to be made in a broader range of circumstances, including directives about future as well as current conditions, and the provision of advance consent (in addition to advance refusal).
- In line with the Respecting Patient Choices Program advice, people should be encouraged to write advance directives in outcome-based terms, recording their personal values, ethics, religious and cultural beliefs, wishes and life goals, where relevant. People should be encouraged to discuss their instructions, wishes and values with their family and treatment team.
- Instructional directives should be able to provide binding *or* advisory instructions about health matters (and advisory instructions about personal and lifestyle matters, which should be followed where reasonably possible but should not be legally binding).
- An instructional directive should be binding on health providers and substitute decision-makers if it is valid and the direction operates in the circumstances that have arisen. Circumstances in which a direction may not operate relate to advances in medical science, uncertainty in the

⁵¹ *Hunter and New England Area Health Service v A* [2009] NSWSC 761.

⁵² Victorian Law Reform Commission, above n 46.

⁵³ Quoted in above n 46, 217.

directive, and persuasive evidence that the direction is based on incorrect information or assumptions.

- If a health provider, substitute decision-maker or any person with a special interest in the patient's affairs considers that an advance directive is invalid or that a direction does not operate because the person who made it would not have intended it to apply in the circumstances that have arisen, they can apply to VCAT to make a determination about the effect of the directive.⁵⁴

The high variability in form, name and legislative prescription, means that it is difficult for jurisdictions to recognise advance care directives made in another state or territory, which can obviously result in a great deal of distress at an already stressful time.⁵⁵ The National Framework for Advance Care Directives will hopefully go some way to address this concern.⁵⁶ The VLRC recommends in this regard that advance directives made in other states and territories should be recognised in Victoria to the extent that they comply with their own jurisdiction's requirements and that their provisions could have been validly included in an advance directive in Victoria.

Substitute decision-makers

In Victoria, a guardian or person responsible can consent to medical treatment (except in a limited range of cases) on behalf of a patient who is not capable of making their own informed decisions. For those patients who do not have a representative appointed to make decisions for them (either personally or by a Tribunal or guardianship order), their spouse or partner is the 'person responsible' for giving informed consent to treatments on their behalf. If they do not have a spouse or partner, their primary carer has responsibility for their medical treatment, followed by any children, parents, siblings, grandparents, aunts, uncles and nieces and nephews (in descending order of "nearest relatives").

It is arguable whether persons responsible are able to refuse medical treatment for their family member. Section 42H of the Guardianship and Amendment Act 1986 (Vic) ("GAA"), states that in determining whether *or not* to consent to medical treatment the person responsible must act in the patient's best interests (as defined in section 38 of the GAA); in some cases this could require refusal or withdrawal of treatment.

An agent with an enduring power of attorney (medical treatment) or a guardian appointed with medical treatment decision-making powers (under the GAA) can refuse medical treatment pursuant to section 5 of the MTA if it would cause the patient unreasonable distress or they reasonably believe that the patient would consider the treatment unwarranted.

Palliative care, defined as the provision of reasonable medical procedures for the relief of pain, suffering and discomfort or the reasonable provision of food and water, is not covered by the MTA and therefore cannot be refused by substitute decision-makers. However, the Supreme Court of Victoria has ruled that artificial feeding constitutes medical treatment which can be refused under the MTA, and doesn't fall within the definition of palliative care.⁵⁷

⁵⁴ Victorian Law Reform Commission, above n 46.

⁵⁵ The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers Advisory Council (2011) *A National Framework for Advance Care Directives*, p 1.

⁵⁶ The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers Advisory Council (2011) *A National Framework for Advance Care Directives*.

⁵⁷ *Gardner; re BWV* [2003] VSC 173

Arguably, the right to refuse treatment – including feeding - needs to be more clearly defined in Victoria and Australia, particularly in respect of patients who are not competent to make decisions for themselves. A lack of clarity around the right to limit or refuse treatment in end of life situations can result in patients being given aggressive therapies and denied palliative care until they die.⁵⁸

Is there a right to demand treatment?

While treatment that health professionals deem to be futile cannot be demanded by a competent patient and is not in the best interests of an incompetent patient (and therefore cannot be demanded by a substitute decision-maker),⁵⁹ health professionals report that patients, their family members or medical colleagues requesting such treatments is one of the most common disputes that arises in end of life treatment and palliative care. As one intensive care specialist recently stated:

One of the worst phone calls an intensivist can receive from a colleague goes something like this, “I’ve had a chat to the relatives and they say they want everything done, can you help?” This puts people like me in a difficult position ... there’s the difficult situation of having to explain for the first time that we believe the patient is at the end of her life and any active further management would be futile.⁶⁰

In the recent case of *Slaveski v Austin Health*⁶¹, the Supreme Court of Victoria stated that:

the court’s power was to protect the right of incompetent patients to receive treatment but not ‘extraordinary, excessively burdensome, intrusive or futile treatment, sustenance and support.’ The judge said that futile treatment was at first instance a medical matter, but that the court’s role was to review such an assessment when there was doubt or serious dispute.⁶²

Similar decisions have been reached in the other Australian jurisdictions.⁶³

⁵⁸ Stewart, above n 42.

⁵⁹ Ibid 914.

⁶⁰ Hillman, K ‘Reflections on dying from an intensive care physician’ 16 November 2012 *The Conversation*

⁶¹ [2010] VSC 493

⁶² Stewart, above n 42, 910.

⁶³ Ibid.

Questions for consideration

17. What are the key issues for people affected by cancer in relation to the Victorian Law Reform Commission's recommendations on reforms to Guardianship laws?
18. Does the right to refuse treatment – including feeding – need to be clarified, particularly in respect of substitute decision-makers?
19. Are there limitations to the refusal of treatment certificate process in practice?
20. Do health professionals require further education about legal issues in end-of-life decision-making?
21. How can people affected by cancer, their families and health professionals be better informed about rights and responsibilities at end-of-life?
22. Is there sufficient clarity in practice around whether there is a legal right to demand treatment that health professionals deem futile?
23. Should there be a right for people affected by cancer to demand treatment that their health professionals consider futile? If so, should substitute decision-makers have a right to demand such treatment?
24. Are there other issues that need addressing in terms of end-of-life decision making (for example, advance directives in respect of non-health related decisions, or protection for health providers for non-compliance with advance directives)?

The McCabe Centre for Law and Cancer is a joint initiative of Cancer Council Victoria (CCV) and the Union for International Cancer Control. Its mission is to contribute to the effective use of the law for cancer prevention, treatment, supportive care and research.

The McCabe Centre conducts research, policy development, capacity building and advocacy. It employs lawyers, and hosts international interns and fellows, law student interns and pro bono secondees in a multidisciplinary environment that includes expertise across cancer control generally, including epidemiology and behavioural science. It brings together lawyers, legal academics and cancer control experts and advocates. It collaborates with other non-governmental organizations, law schools and legal practitioners, and works, as appropriate, with governments and intergovernmental organizations.

Cancer Council Victoria's Strategy and Support Division includes the Cancer Information and Support Service (CISS) which provides support and evidence-based information to those affected by cancer, their families and friends; and the Clinical Network office, which supports the work of our Clinical Network (formerly the Victorian Cooperative Oncology Group or VCOG). Established in 1976, the Clinical Network consists of a state-wide representative committee, an executive committee and 16 cancer-site or task-specific advisory sub-committees, involving over 650 specialists. It is the peak multi-specialty representative oncology forum in Victoria, and its aim is to advise the Cancer Council on all clinical aspects of cancer and in particular, on research, prevention, screening, diagnosis, treatment, palliative medicine and professional education.

Making the law work better for people affected by cancer: project steering committee

The role of the steering committee is to assist and advise on the direction of the project and to provide advice and input to project staff where necessary.

The members appointed to the steering committee are:

Lauren Adamson, Senior Rights Legal Clinic, Public Interest Law Clearing House

David Hill, Cancer Council Victoria

Michael Jefford, Peter MacCallum Cancer Centre and Cancer Council Victoria

Carolyn Lethborg, Social Work Department, St Vincent's Hospital

Louise Milne-Roch, Victorian Mental Illness Awareness Council

Paul Mitchell, Austin Health Cancer Services

Peter Noble, Loddon Campaspe Community Legal Centre

Jennifer Philip, Centre for Palliative Care, St Vincent's Hospital

Loane Skene, Melbourne University Law School

Sandra Slatter, Cancer Action Victoria

Cameron Stewart, Sydney University Law School

We'd like to thank the project steering committee for their valuable contributions to the drafting of this issues paper.

Next Steps

The McCabe Centre aims to consult with people affected by cancer, their carers, health professionals and other key stakeholders on their experiences of, and recommendations with regard to, the issues raised in this paper. Regional consultations with stakeholders will be conducted as part of this process. A final report will be produced later in the year, which will draw upon the feedback provided to make recommendations on how to make the law work better for people affected by cancer.