

Report to Australian Human Rights Commission

for

Willing to Work: National Inquiry into Employment Discrimination against Older Australians and Australians with Disability

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Focus: Age and Disability

The focus of this report is on individuals diagnosed with haematological malignancies (blood cancers) that have a strong desire to return to work but are unable to do so because of a range of disabling factors associated with their diagnosis and treatment. The demographic of individuals diagnosed with haematological cancers is predominantly in the older age group. As Bron and associates ¹ recently report,

Cancer, like chronic diseases, increases exponentially after the age of 50 years. This is the result of a combination of both intrinsic (immune senescence, genetic and epigenetic alterations) and extrinsic events (longer exposure to carcinogens, chronic antigenic stimulation). Although malignant hemopathies (myelodysplasia, leukemia, lymphoma, myeloma, etc.) are a major cause of concern in this age group, other hematologic issues (anemia, cardiovascular problems requiring anticoagulation, etc.) also require specific attention and clear recommendations.' ¹

Thus, the focus on older Australians is an important consideration informing this submission. However, whilst acknowledging the ageing demographic, it is also of paramount importance to highlight that there are a substantial number of young to middle age haematology patients for whom employment has major importance but who are likely to face a range of barriers to work. Recent Queensland research indicated that the working age haematology patients below 50 years of age, although smaller in number, have acute psychosocial and financial problems associated with inability to return to work. ² Thus, this submission has a dual focus on both age and on disability.

From an international perspective, the employment of cancer patients has major economic and productivity implications. In the United States, for example, 40% of cancer survivors are working age. ³ Similarly, in Canada ⁴ in relation to breast cancer alone, each year over 20,000 women are diagnosed, most of whom anticipate a considerable number of years of potential participation in the paid labour market. In Korea ⁵ cancer diagnosis adversely affects employment status and the effects are widespread in almost all gender and age groups. Australian research ⁶ which documents the costs both to the individual and society, indicates that on average households can expect to lose \$47,200 in financial costs after a member of that household is diagnosed with cancer. Access Economics ⁶ estimate that the costs to

Australian society of the loss of wellbeing (healthy life) from cancer are higher, with each incident case of cancer costing almost one million dollars per person over their lifetime. Thus, as Amir and associates⁷ argue, maximising opportunities for cancer patients to return to work is a significant concern not only for individuals and employers but also economically for society.

In Australia, return to work issues for cancer patients have particular importance for regional, rural and remote individuals as both the unemployment and poverty rates outside the capital cities are higher than in the metropolitan area.⁸

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The Importance of Work

The financial impact of diagnosis and treatment for a haematological malignancy on the patient and their family can be severe for those dependent on employment as the basic form of income.² The loss of work has been identified as the key factor contributing to financial hardship for haematology patients and their families, and for those without economic buffers (such as home ownership, savings, superannuation) can contribute to a spiral to poverty.²

Work for cancer patients forms a central basis of self-identity and self-esteem, forms and maintains social relationships, and provides a demonstration of individual's abilities.¹² Research by McKay and associates¹³ demonstrates that for those with cancer, the key motivation for wanting to return to work is to maintain normality and regain identity. Of importance to this submission is the concern that post-treatment cancer patients who are unable to return to work not only face financial distress but also lose part of their identity along with the companionship and satisfaction associated with work.¹⁴ The LFQ-funded research on which this submission is based demonstrates that the inability to return to work post-treatment for patients with a haematological cancer is linked to significant financial hardship and life altering personal loss.

Barriers to work

The treatments for many haematological malignancies can involve aggressive and invasive therapies based on radiation and chemotherapy, including for many allogenic or autologous haematopoietic stem cell transplantation (HSCT) which are associated with long-term physical and psychosocial consequences.^{15,16} It is the disabling effects of the disease itself as well as the side effects, both short and long-term, of the treatments that have the potential to impact on employment activities. To date, there is only a limited amount of research that documents the rates of return to work of haematology patients post-treatment, but the figures that are available demonstrate high rates of non-return. Research by Horsboel and associates¹⁶ indicated that a third of haematology patients on sick leave did not re-enter employment. Gruber and associates'¹⁵ research demonstrated that 30.7% of haematology patients who had a haematopoietic stem cell transplantation did not return to work at all.

The LFQ-funded research indicated there were four categories of barriers to returning to work for haematology patients, including:

1. Cancer Related Fatigue (CRF);
2. Long term side-effects of treatment including lung problems, neuropathy, and Graft-versus Host Disease (GVHD);

3. The health system issue of the need to relocate for specialist services; and,
4. Occupational factors.

A major obstacle: Cancer Related Fatigue (CRF)

CRF, described as a barrier by all age groups, is experienced as a profound sense of tiredness that limits an individual's ability to sustain activity. For many, this tiredness was described as combined with mobility problems, lack of energy and pain. The link between CRF and the inability to return to work is affirmed by the work of Dormann¹⁷ who reports that the persistence of CRF, even after successful primary treatment of the underlying disease, not only impacts on quality of life but can interfere with the individual's ability to work and thus leads to vocational disability. Similarly the work of Lawlor and Donnelly¹⁸ found that fatigue was the most commonly reported barrier to returning to work for cancer survivors.

Long-term Side effects of treatment

Because of immunity problems associated with cytotoxic chemotherapy, some individuals suffered from secondary illness such as influenza or lung infections. Neuropathy, or numbness and tingling in the feet and hands, is a serious long-term side effect of chemotherapy that can interfere with the individual's ability to walk and engage in physical activities. Graft Versus Host Disease (GVHD) is a debilitating condition suffered by transplant patients. GVHD may develop after an allogeneic bone marrow transplantation (that is, transfer of marrow from a matched donor to the patient recipient) in which the transplanted marrow (graft) attacks the patient's (host's) organs.¹⁹ All of these conditions were described as significant barriers to return to work.

Health system obstacle: The demands of relocation

The specialist care for patients with haematological malignancies in Queensland is predominantly located in the major metropolitan treating hospitals. Consequently, patients from regional, rural and remote areas have to relocate to the metropolitan area for specialist care.¹⁹ As there is long-term, routine follow-up of patients with haematological malignancies the demands of relocation can continue after treatment and, for many, can require tests and examination on an ongoing regular basis. The findings indicated that the demands of travelling long hours (or days) in return trips to the metropolitan areas can interfere with work responsibilities. The demands of relocation for follow-up review and ongoing treatment, even if the individual was fit enough to return to work, can be a major obstacle to return to work as it requires that the person take regular and numerous days off to visit the metropolitan treating centre. The extensive absences from work make maintaining a position difficult.

Job Stress: The obstacle associated with occupational demands

For some, the reason for not returning to employment was associated with the specific work which was described as 'too stressful'. For others, the opportunity to return to the previous position would no longer be available as the person is not physically able to complete the work as required. This was especially so in regards to those who had pre-diagnosis been involved in manual labour. Similarly, conditions such as sun-sensitivity from treatment prevented others from returning to their previous positions. Whilst some individuals could

re-train for other employment roles, for others there were no further opportunities for training which presented another obstacle for re-entry. Similarly, Stergiou-Kita and associates' ²⁰ research posits occupational factors as potential barriers to return to work including the type of work, the demands of work, and job flexibility. The work of Van Muijen and associates ²¹ pointed to physically stressful work as a barrier to work re-entry.

Groups of patients with regards employment

Retired

Because of the older demographic associated with haematological malignancies, there are many patients who are of retirement age and for who work was not an issue.

Forced retirement

There was a group of patients who took retirement as an option because they were unable to re-enter employment, but the circumstances were forced and the retirement was before the planned date. Also, there were patients, who although of retirement age, for financial reason wanted to continue working but were forced to cease employment. For those forced into retirement, the financial impact had not been planned for and thus contributed to financial distress.

Successful return to work

There were many who were motivated to return to work and successful in their efforts to re-enter employment. Some individuals had sufficiently recovered physically and were able to return full-time to their previous positions with minimal impact from the disease and treatment. Others embraced full time work even though it was physically demanding or accepted reduced hours of work.

The patients of working age unsuccessful in returning to work

The group of particular concern for this submission were those who were in the working age group, dependent on the income from employment but forced to leave because of the illness and treatment. Some of these patients were in the young age group early in their career. Some were forced to seek new employment because the employment in their previous position is terminated by the employer. For many in this group the loss of the opportunity to work came as a shock and was difficult to accept. For those still motivated to work despite the difficulties, re-entering the workforce was viewed as a major challenge, for example:

- “We’re now a bit older and we’re finding that we’ve got to sort of start at the middle or even lower in the job market.”
- “...it’s just hard to try and find a reasonable job.”

The impact of not being able to return to work

Most importantly, the financial impact of not being able to work was acute, especially for younger individuals, for example,

- “I’m just waiting... to feel a lot better again so I can try and get a job again. What really annoys me is I haven’t got a house for my kids, that’s the part that really hurts. It’s had a major financial impact.”

The loss of opportunity to work was also associated with serious ongoing psychosocial consequences. It was noted that loss of work can impact on a person's sense of confidence and competence, for example,

- “At work I was very confident that I knew what I was doing and I was confident and competent. As soon as you leave work and have no feedback of what you're doing, being worthwhile, [you] start to feel that you're not worthwhile.”

Another major psychosocial impact of the loss of work was the break from meaningful social relationships which can be a stressful experience, for example,

- “Usually when you work that's where all your friends and people come from, you know your outside life, so we have a very limited outside life.”

Individuals described a sense of uselessness associated with lack of work, for example,

- “You feel useless. Yeah it makes you feel unnecessary.”

Willingness to work: Efforts to return to work

As Rasmussen and Elverdam's ¹⁴ research indicates there is a strong 'Willingness to Work' demonstrated by cancer survivors who try to get back to work after treatment and try to re-establish their former structure of everyday working-life that is seen as a normal and healthy existence. Especially for the younger age group or those struggling on the subsistence income of a government pension, the financial imperative to find employment can be driven by a sense of urgency.

In the LFQ funded research, many had to leave work immediately at the point of diagnosis and the start of treatment. Both the disease and the treatments created physical problems that prevented the continuation of work. In some cases, the treating haematologist had advised the patient to leave work. Some initially continued working during treatment but eventually had to leave work. Most in this group managed to cope with several rounds of chemotherapy whilst still at work; however the stress, tiredness, side effects and complications (e.g. pneumonia) of treatment eventually forced them to leave work. Some attempted re-entry to work after some time out, but without success.

There were also many examples of patients who post-treatment were successful in returning to work either in part-time or full-time capacity. As the following discussion will demonstrate, the role of the employer was found to be particularly crucial in facilitating this successful re-entry to the work place for these patients. However, it is important to note that many did not have employer support and as a consequence found it difficult to return to work.

The important role of the employer

The key factor that provided a sense of security in returning to work was the strong links maintained with the workplace facilitated by a previous employer. Even for those who had not yet returned to work, links with a supportive prior employer provided an optimism and

confidence that reduced the stress associated with re-entry into the workforce. For some, the employer's commitment to re-entry was organised prior to treatment with the agreement to keep the position 'open'. Keeping the position open was for some, achieved by taking 'unpaid leave'. However it is important to note that some generous employers found creative ways to ensure that their workers maintained an income during treatment. Although some participants did not have a specific agreement to 'hold open' their job they were able to confidently negotiate a re-entry at a starting time of their choice. In some cases, there was a sense that the strong link with the employer was a starting place to begin negotiations.

There are other studies on cancer patients that similarly indicate the important role of the employer for post-treatment return to work. Qualitative research conducted in the United Kingdom by Amir and associates⁷ demonstrated that a positive relationship with an employer or manager was a major influence in returning to work. Furthermore, Lawlor and associates¹⁸ demonstrated that the key facilitating factor in ensuring a return to work and a continuance of employment for individuals diagnosed with cancer in Northern Ireland, was a supportive employer.

As will now be discussed, the LFQ-funded research indicated that employers used two key strategies in assisting haematology patients to re-enter the workforce.

Re-entry strategy: Flexibility in hours

An important aspect of the support provided by some employers was to facilitate re-entry by providing graduated hours of return that ranged from part-time up to full time hours. Thus, with support from their employers, individuals were able to correspond their work hours with their physical capability. There are many short and long-term side effects of haematology treatments that make the staging of re-entry essential. For some individuals, the end point of such graduated work was not necessarily a full-time position as some individuals remained in a part-time position.

Re-entry strategy: Change of role

Flexibility and creativity also played a role in the solutions offered by employers to assist with the physical demands of re-entering the work force. For example, some employers were flexible in changing the work role so that the person could return to another position within the organisation that was more suited to their present physical capabilities. A typical example of a change in role was from physically demanding work to office work where the individual could sit at a desk, as the following statement by a participant demonstrate:

- “And then I ended up back at work only on light duties... I had everything going wrong by my fourth round of chemo, I was having things going wrong, you know the pins and needles in me feet, the neuropathy, and that got worse and worse and worse and like it took me a long time when I first got back to work I couldn't stand on my feet longer than ten minutes, it use to kill me. And so they give me an office job, I was an (description of previous physical job) before that. But I've never worked (in that position) since this happened and they just put me in the office now.”

Many modern developments in technology such as internet, email and laptops not only provide opportunity for creativity in how the work is completed but also flexibility in where the work is completed. Such technology enables individuals to work from home if this is required.

THE WAY FORWARD: EXPLORING POTENTIAL SOLUTIONS

The following section will explore possible strategies for combating unemployment for haematology patients ‘willing to work’ but unable to because of disabilities created by both disease and treatment. The discussion will start by describing recommendations posited by the haematology patients interviewed.

Patient recommendations for return-to-work supportive care initiatives

The clear message from the research is that haematology patients motivated to return to work but challenged by physical limitations need support and assistance in order to overcome the obstacles to employment. As one participant stated,

- The work issue is really important and significant. The thing I do think there needs to be some attention to that.

A core concern for this group is the fact that, although motivated to return to work, they do not have the knowledge, contacts and support to ensure that this can happen. In general, individuals did not know which services were available to help them with their special needs in relation to return-to-work.

The physical limitations of disease and treatment require some individuals to change directions in employment. Thus, retraining and further study were noted as important aspects of re-direction in employment seeking. Vocational advice and information on training and study options are essential for effective decision-making in regards to employment re-direction. The *first consumer recommendation* was for supportive care workers with a background in vocational counselling to be employed to offer support, advice and information on retraining and study options.

The *second consumer recommendation* was a call for engagement of support workers with knowledge and expertise in employment who could build up a profile of organisations who would be welcoming and supportive of individuals challenged with the impact of disease and treatment for haematological malignancies. The role of such a worker would be to build up a data base of potentially supportive employers. With information from a data base of suitable employers, the supportive care worker’s role would be to establish networks with a range of organisation to facilitate the placement of individuals in position appropriate to their interest, abilities, physical and time limitations. The key resource would be the data base of contacts and the significant professional activity would be the matching of the survivor with the appropriate position.

For some people the re-entry to work has to do with seeking meaningful engagement with life rather than financial reward. For these people, volunteering would be a solution to the void in their life and a potential benefit for organisations engaging with them. The *third recommendation* is for the employment support worker to also build up a data base of organisation that are seeking volunteers or develop networks with organisations that are involved in providing networks and placements for those wanting to volunteer. The role of the worker would be to link the individual with volunteer work or, at least, refer to an organisation that is involved in engaging volunteers in suitable positions.

As discussed previously, lack of employment can create significant psychosocial distress. The *fourth consumer recommendation* was to address such psychosocial distress by the

provision of counselling to support and debrief the individual through the difficulties associated with employment problems.

Recommendation to include a return to work focus in the role of cancer care teams

The patient recommendations posited in the previous paragraphs are supported by the literature. Frazier and associates²² recommend that cancer care teams provide employment-related assistance by screening for job concerns, and that such teams should provide information, formulate a return to work plan, and consult with professionals who have employment-related expertise.

Recommendations with regards to the important role of the employer

An understanding of the important role of the employer posits the question of how best to foster this link.

1. The provision of information on disease and treatment to employers:

As de Boer²³ argues, a significant limitation to progress in this area is that interventions are urgently required but scarcely developed. The findings presented herewith indicate that an important focus for the development of such interventions is the provision of information to employers about the disease and treatment. Similarly, Lawless²⁴ argues that employers need updated factual information on cancer in order to appropriately respond to the changes and potential impact of the disease. The importance of strategies such as providing flexible working hours, opportunities to work from home, or changes to more suitable roles in the organisation are ways that employers can assist haematology patients return to work.

2. The need to provide support and education to foster effective patient/employer communication on return to work issues:

The available literature indicates that ensuring effective communication between the employer and the individual diagnosed with cancer is an important place to start. This was confirmed by Swedish research conducted by Nilsson and associates²⁵ which concluded that post-treatment discussions on return to work between the individual diagnosed with cancer and the employer is important to facilitate successful social support from the employer. However, research by Fraizer and associates²² identified communication with supervisors and applying for employer-sponsored benefits were among the most difficult cancer-related employment tasks. Of relevance to these difficulties, advice and guidance on communication with the employer is a key component of an intervention designed by Bains and associates²⁶ for individuals diagnosed with colorectal cancer. The recommendation from their evaluative research was that such an intervention is best delivered in the early stages of diagnosis and treatment. Tiedtke and associates'²⁷ review of the literature on breast cancer indicated that amongst other factors, employers need to consider increasing and improving communication with individuals diagnosed with cancer and to play a more active and supportive role. In their international review of the literature, Islam and associates²⁸ concluded that employer support is noted as one of the key facilitators in enabling individuals diagnosed with breast cancer to return and continue to work. The authors argue that strengthening such facilitators could increase the percentage of return to work.²⁸

3. *The need for further research:*

Research in this area is in its infancy and there is much work to be done. Thus, there is a need to fund and foster further research in this area.

Recommendation with regards to the development of a return to work 'Patient Stories' DVD

'Patient stories' is a medium based on audiovisual interviews with patients that records their experience on specific topics that can be used by supportive care health staff as a tool for offering psychosocial support to cancer patients.²⁹ Prior research indicated that such 'patient stories' can be a potentially effective and beneficial strategy to communicate support and information to haematology patients.²⁹ Research indicates that the use of a 'patient stories' DVD is perceived positively by haematology patients as a potentially beneficial means of communicating information and support to those who wanted to re-enter employment post-treatment. Such a DVD is considered to have potential benefits that include the communication of reassurance, sharing, hope and inspiration, a sense of normalcy, and knowledge.² These findings thus provide a reassuring affirmation to supportive care health workers that this is a direction worth pursuing. Concern is expressed in the literature that the provision of support to cancer patients to assist them to return to work is insufficient, and, as yet, the means available to promote return to work are limited.⁷ The findings presented herewith indicate that a positive direction to follow is the use of a 'patient stories' DVD as a potentially useful communication tool. As a 'patient stories' DVD on return to work issues can be mailed or posted on the internet, it is a particularly effective supportive care measure for patients living in rural and remote locations.

Recommendation for supportive care for individuals unable to return to work

To date, the focus has predominantly been on assisting cancer patients to return to work. This submission also argues for consideration for supportive care provision for those who want to work but, for a wide range of reasons, are unable to re-enter the work force.

Recent research indicates that a major consideration for haematology patients post-treatment is to regain a sense of normalcy where the focus is on living rather than the illness and treatment.³⁰ There will be major challenges associated with the task of creating a re-defined normalcy for the haematology patients who want to but cannot return to work post-treatment. The findings described in this research indicate that there will not only be financial problems but physical difficulties associated with long-term side effects of treatment, and psychosocial problems linked to the negative impact of loss of work on identity and social relationships. Thus, the supportive care strategies for this group of haematology patients will be very different to those who have realistic options of returning to work. Following is a list of supportive care directions for consideration for assisting those who cannot re-enter employment.

- *Financial counselling and assistance:* The direct practical impact of the inability to return to work is financial distress. It is important that the individual is aware of government support in terms of pensions and allowances. In addition, it is important that the individual has knowledge about financial assistance schemes that are available if needed in a crisis.
- *Support to re-define a sense of normalcy:* Individuals in this situation need to have the reassurance that their inability to return to work is accepted without a sense of blame or failure. Information that other patients are experiencing the same dilemma

can help to normalise the situation. Also, knowledge of and discussion about the barriers to returning to work, such as the sided effects detailed in this paper, can assist a sense of acceptance and normalisation. As with any major loss, the loss of a work future will require a process of grieving and the reformulation of a new perspective on the future. This will be a difficult and sensitive time where the individual will require non-judgmental support and caring informed by a professional understanding of the process of grief.

- *Social contact:* The provision of links with and encouragement to join support groups, interest groups or internet chat groups can go some way to meeting the need for social contact denied by the lack of employment networks. For some, the opportunity to engage in suitable volunteering activities can help to build a new sense of meaning and identity.
- *Family counselling:* The loss of work and the difficulties associated with the disease and side effects of treatment will not only have an impact on the individual but will have ramification for the whole family. Thus, effective initiatives in this area may require a family rather than individual focus.

Recommendation with regards to addressing relocation issues

In recent years there has been an increasing attention to the problems associated with relocation for specialist care for haematology patients from regional, rural and remote areas. Research indicates that there are a number of strategies such as the use of tele-health,³¹ the extension of outreach services of specialists and the increasing decentralisation of clinical care³² that are starting to reduce the amount of travel associated with treatment. The final recommendation is that this direction needs to be fostered in order to increase the possibility that, post-treatment, haematology patients can maintain a local commitment to work. The extensive travel to the metropolitan area not only interferes significantly with work but also contributes significantly to the financial impact of the disease and treatment which can be serious during times of unemployment.

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