

My initial submission to the 'Enquiry into funding for research into CANCERS WITH LOW SURVIVAL RATES' outlines the premature loss of two loved ones to these Cancers, however it does NOT articulate the IMPACT on the Carer & family. Hence I submit this ADENDUM as a way making a CARER IMPACT STATEMENT.

### **BACKGROUND**

- My family has been covered by Private Health Insurance for many decades (40+ years)
- Australian families have been conditioned to think that Private Health Cover is beneficial if a catastrophic health event should occur
- My husband (Bruce Hearn) was diagnosed with **Pancreatic Cancer** in 2012 after months of complex tests, biopsies and investigations
- He died in June 2014

During my late husband's relatively long Pancreatic Cancer Illness (about 30 months duration) he was hospitalized a few times for complex, life-saving surgical procedures including:

- Whipples Procedure
- Complications requiring a lengthy emergency operation to stem massive haemorrhaging
- Infections
- Intensive Care
- Coronary Care (due to incredible stress on an otherwise healthy heart)
- Sudden impact of Type 1 diabetes due to removal of pancreas
- Hip Replacement (due to frailty from cancer)
- This complex Cancer case required the involvement of a multi-disciplinary team of specialists including – Gall Bladder (ERCP) Specialist, The Pancreatic Surgeon, Anaesthetist, Oncologist, Liver Stent Specialist, Endocrinologist, Infection Control, Heart Specialist, Physician, Orthopaedic Surgeon, ICU Specialists.

And Cancer Care primarily at home including:

- Wound dressing
- Personal care – toileting, showering
- Visits from Palliative Care Nurses
- Chemotherapy appointments
- Administration/management of strong pain relieving medications
- Metastatic complications
- Financial stress over cancer medications not on the Pharmaceutical benefits Scheme (PBS)

After 2 years of solid caring and support of Bruce through this complex journey, he was admitted to a Private Hospital for Palliative Care

## PALLIATIVE CARE

When he was eventually admitted to a Private Hospital for Palliative Care, and very unwell and frail - clearly close to “end-of-life” stage, the inadequacies of our health system became patently clear to me. After merely **one week in a private hospital palliative care bed**, I was told by the Oncologist , Bruce would have to move to a public hospital palliative bed, or go home or to a Nursing Home (where I know from prior experience the level of care at Aged Care is not what is required for palliative Care.)

## ADVOCACY

At this stressful time (May 2014), I had to become a strong advocate for my husband’s care needs.

The Oncologist came to my husband’s bedside and proposed that Bruce be moved to another facility. I realized that basically he wanted to ‘handball’ Bruce around the health care network. This could not be in the interests of best practice & best patient care. Bruce was barely conscious but he could hear the doctor putting this pressure on me and tears were rolling down his cheeks – so he was aware of what was going on – disgraceful!

I had to insist he was not to be moved from one palliative bed in one hospital to a palliative bed in another hospital; enduring the ambulance transfer and subsequent disruption that the introduction of new staffing would bring to an already difficult situation.

I had to ask myself WHY. I checked with my private health insurer and they had not interfered or made this demand. My Health fund said “they would only make a courtesy call to the hospital, after 30 days of palliative care, but would provide funding support till death occurred.” My guess is that the Oncologist, as an employee of the hospital, was under pressure to apply hospital policy ie: move patients on to maximize funding, which is probably on a sliding scale.

**This could have only been in the interests of the hospital’s” bottom line” and not in the interests of patient care!**

After a stressful couple of days of me trying to avoid the Oncologist, when I next saw him, he backed down & agreed that Bruce could stay “until the end.” To his credit he had acquiesced and apologised to me and agreed that Bruce could stay in that palliative bed, at that hospital.

Bruce died about 3 weeks later!

I stayed on a camp bed in Bruce’s room to make sure he did not die alone. Patients are encouraged to “die at home” where obviously, I now know, it would not be possible to satisfactorily administer the correct level of intravenous morphine 24/7. It is not about dying at home, but dying in a pain free dignified way, with the support of loving family.

By- the way – even though Bruce was not eating for probably 3 weeks , I was not even offered a meal by the hospital for many weeks, while I supported my dying husband & there was no cafeteria on site where I could even buy a meal. To add insult to injury, a room that was supposed to be a visitor lounge area, near my husband’s room was being used as a store room. Must maximize that “bottom line”!!!

The memory of this experience has left me somewhat embittered & critical of this “business strategy” which is obviously to maximize health insurance funding to hospitals at the expense of patient care. I was told if he (we) didn’t like it (at another facility) then to come back & be re-admitted. I am determined to speak up in the hope that these injustices cease for others who are now (& in the future) enduring such unacceptable treatment from our private palliative care hospitals.

I was aware that other patient’s families were also being put under this pressure to move their loved one out of this hospital to another facility. I did not discuss with them how strong carer/family ADVOCACY is vital in this current climate of ruthless business practices. ADVOCACY helped my husband die peacefully ----eventually. I am just fortunate to have been able to provide this support to my dying husband (as I am retired), but for Carers having to hold down a job and with other family responsibilities, the task would be impossible and they would be’ putty in the hands’ of those who participate in this unacceptable policy.

I appreciate that being privately insured ultimately enabled Bruce to remain in the same Palliative Care Unit, but the private hospital’s policy to attempt to maximize their finances was seriously flawed. In my opinion and experience, the hospital’s policy was manipulative, unethical and adds another dimension of stress to a very challenging event – the impending death of a loved one.

#### **THE FUTURE - CHANGE**

- This experience occurred almost three years ago, and a part of me wants to “move on”, however what occurred during the Palliative Care Stage actually haunts me, so I feel compelled to share it in the hope of change.
- Change to Government Funding into Research of Low Survival Rate Cancers is long overdue
- My hope is that pressure is brought to bear on private hospitals to cease these unacceptable business practices.
- I agree with Pancare’s submission that states “ patients.... Do not have access to information about treating hospitals to facilitate decisions about where to go for treatment to receive optimal care that has been shown to maximize survival. A System of Recognition for Centres of Excellence in pancreatic or other cancers with low survival rates, could be developed.... To improve the quality of health service provision.... Special criteria for recognition could be developed, with the program of recognition aligned to the various state hospital accreditation programs...”

Organizations such as the *Pancare Foundation* and *Cure for Brain Cancer Foundation* do a great job to raise funds, awareness and advocate for specific cancers. The good work of *The John Logan Foundation* which offers financial assistance to some patients experiencing hardship as a result of GI Cancer issues should also be acknowledged. I am grateful for their help to cover the exorbitant cost of life-extending chemotherapy for Bruce a drug which was not on the PBS for Pancreatic Cancer but which is on the PBS for other cancers eg :Breast Cancer – so be careful which cancer you get or it may break you financially! Inequity of Cancer is crazy in Australia. Future Government funding to start to address the many issues highlighted to this enquiry is vital. RESEARCH must be adequately funded by Government to improve survival rates to ensure improved outcomes in the future.

**JUDITH HEARN**