



BALLARAT
HOSPICE
CARE INC.

“The experienced, compassionate, dedicated nurses who visited us at home helped me to know what to do, what to expect, and it meant no disruption to the care routines, especially when he was so sick and his mobility poor. And we were there when the kids came home from school, not stuck waiting for hours in a clinic or doctors surgery.”

Young Bereaved

***Submission
to the Senate Enquiry
on Palliative Care***

**from the focus
of younger carers
of patients
requiring palliative care**

“I wonder how many patients die in a hospital when they would rather die at home just because they don’t know what is available for them.”

“I dropped my husband at the hospital then drove the kids to school and went back to the hospital to meet with the oncologist. It was just before Christmas and the Clinics were overbooked. The staff apologised, but the hospital policy didn’t allow for meals or even a cup of tea, we just had to sit and wait. We waited all day. I had to organise someone to pick the kids up, we didn’t see the oncologist until nearly 7pm. She told us he had cancer and had to be admitted, so I left him there and went home to the kids. It’s stupid, all that long, long day I was just so desperate for a cup of tea and usually I only drink coffee!”

Terminal diagnosis of a younger patient is almost always unexpected and devastatingly life changing for the patient, the partner, immediate and extended families. Young families may not have had previous exposure to serious illness, death or grief, nor formal contact with the medical maze – GP, specialists, hospital, health care and community support services. Many have little experience seeking psycho-social assistance or family income support. The impact of diagnosis, grieving, care, death and bereavement on the social, educational, psychological wellbeing and family life of patient, carer, children and teenagers is bewildering and devastating.

Every carer faces unknown challenges, especially when living in remote locations or with limited access to family support. And family dynamics surrounding a younger palliative patient are complex. Young families living with a loved one with terminal diagnosis have particular challenges maintaining household dynamics while caring for the patient over a period that could be as short as a few days, months or even stretch out to years. Some patients have rapidly escalating needs, others less so, and may not need much assistance for some time. Some cancers, such as brain tumours, involve changes to mental and behavioural state and can quickly affect mobility or capacity, impacting dramatically on family function, resilience and participation in routine activities. It is to be noted though that all unexpected terminal diagnoses result in trauma for the patient and carer and dramatic changes to family dynamics and function.

“I wasn’t eligible for carers payment because I shared the full time care with my sister.”

“Medical aids are so expensive to hire & we had no income and mortgage payments. Hospice provided a wheely-walker and shower chair then arranged funding for a hospital bed so we could set it up in the living room and organise care around meals and the children’s normal family routines.”

“Ballarat Hospice Care provided education for me and support so I could care for my brother. He benefited from my being able to access knowledge of medical issues and how to deal with problems. Where he lived the medical services didn’t work as a team and the GP refused to consult with the palliative doctor.”

Access to counselling, psychological support and crisis intervention is limited in rural areas and usually unavailable in remote areas. Access to these services is costly and time-consuming, involving extensive waiting lists and travel. At the same time the pressures on a young family carer are enormous. It is difficult to make and keep appointments for family members when the person they are caring for requires around-the-clock support at home and rural appointments require booking months in advance. Likewise, it is difficult to maintain attendances for the patient at medical appointments, tests, treatments and services, or to pick up prescriptions, referrals and medications whilst also juggling care of babies, toddlers, school children or teenagers, along with the myriad of other requirements of caring for children in young families, all whilst attempting to maintain the usual function of the household, schooling and employment.

It is in collective experience that community palliative care services offer and provide holistic care – addressing financial entitlements, carer education, medical and nursing issues and psychosocial, spiritual and culturally sensitive care. The unit of care includes patient and family, and each “unit” is considered in the context of its individuality and uniqueness.

In-home support for younger patients requiring palliative care makes sense. It also reduces the burden on acute hospital and institution based health care professionals and services. Assisting terminal patients to die at home, or remain at home for the majority of their palliation eases disruption to the entire family, demands on community resources and provides the maximum possible quality of life for all involved also making sense is the bereavement support component of community palliative care.

“My 51 year old husband was diagnosed with cancer, the week before Christmas, and given 2 months to live.

The hospital said I would have to give up work to care for him.

We provided everything they asked for then

Centrelink sent a letter that said

Rejection of Your Claim.

We cannot pay you

Disability Support

Pension because you did not reply to our letter.

How do I describe to you the devastation caused by that letter, with such lack of compassion and toxic wording, on top of everything else!”

*“My husband was given a prognosis of 2 months
The earliest possible counseling appointment I was able to organize for him was 5 months away – until Hospice intervened.*

Ballarat Hospice Care Inc. commenced a pilot program in 2009 for “Young Bereaved” users of their bereavement program.

Eligibility criteria:

- for aged 55 or under
- with infants, adolescents or young adult children
- not retired, still employed or returned to education
- socially or culturally isolated or compromised because of bereavement status.

Multiple bereavement types participate in the monthly forum.

Participants are invited and screened for suitability by the groups’ facilitators. Longer term participants assist newcomers to integrate by providing role models of survival.

This submission to Senate outlines the challenges faced by these particular carers of their younger husbands, wives and, children or being younger carers of their parents. Their experience is representative of families of all ages countrywide, in either rural or urban centres. Group discussions are informal, and guided by counseling staff. The agenda is flexible, a usual format followed, the rhetoric is allowed to flow and evolve naturally. All participants praise the format and opportunity to verbalise their experiences, to hear how others manage, and to be able to ‘lift off the mask’ speaking openly to others who identify with similar circumstances, and many coping and management strategies are offered and discussed.

The following points are collated from contributions and experiences of members of the Young Bereaved carers group:

“My husband was a fit and active tradie. He got cancer. He hated being in hospital. There was no fresh air, the noise and routines were disturbing, car parking for his family (who traveled from interstate to visit) was hopeless and when he was in a shared ward one of the other cancer patients with dementia kept hovering over his bed and screaming at him. Once we were referred to Hospice they arranged the nurses to visit us at our home at a time that suited us.”

“I am very fortunate that I was able to care for Dad throughout his illness and right through to the end. Ballarat Hospice made that possible for us.”

Hospice organized a volunteer carer when I had important appointments for me or the kids. It gave us peace of mind and no extra financial costs.

The majority of the Ballarat Hospice Young Bereaved participants continue to juggle life challenges since their recent bereavement: including the ongoing care of children or extended family of varying ages, employment commitments (employees and self-employed), financial, social, socio-economic and geographic challenges or have become socially or culturally isolated. Some have access to extended family support, others have no family remaining at all. Each appreciates the opportunity to access bereavement support specific to their age and stage-of-life issues.

Unexpected diagnosis usually involves many immediate and sudden medical expenses and travel commitments, especially for those in rural or remote locations, which may translate to immediate loss of employment income and the need to seek financial support through the social security provider, Centrelink.

The description of experiences of some young families with the Centrelink process is scathing. Cancers can take weeks to diagnose, medical bills mount up, (often requiring up-front contribution) and the family income only lasts as long as sick leave (if any) allows. Modern medical treatments can prolong a terminal illness but individual responses to treatment remain uncertain and unknown. Seeking financial support at the Centrelink office involves standing in queues for long periods, in public, regardless of the person's state of health or needs of children or patient; rarely speaking to the same official when palliative medical circumstances can be so complex to explain; and the requirement to provide medical and insurance documents that are simply unattainable in a short time frame. Alongside the psycho-social stress and pressures of a terminal diagnosis.

“Our house was in the middle of an extensive renovation when my husband was diagnosed with cancer. After he died Centrelink told me I had to return to work or my son would lose his Youth Allowance. Hospice social workers helped me to organise a bereavement extension to give me time to sort out the house.”

“I came home from the funeral and there was a letter from Centrelink. It said “IMPORTANT INFORMATION: you have 0 working credits.” I didn’t understand what that meant. I had provided care around the clock for my husband and the kids, then organized the funeral. And that wasn’t working? I was tired to the bone. It made me feel that all my care over so many months was considered completely worthless, a big fat zero.”

Some people do not qualify for Centrelink assistance because they share care or are unable to provide requested documents even though their carer role can involve extensive time away from employment. The letters claimed by Centrelink as ‘generated by computers’ can be insensitive, inappropriately worded or even offensive to some recipients in crisis.

Patient, carer and consumer surveys indicate overwhelming satisfaction with the services provided by Ballarat Hospice Care Inc. The majority of consumers express gratitude that association with Ballarat Hospice Care Inc gave the patient and carer the opportunity and ability to choose to stay at home as long as possible, even until death; along with the ‘umbrella support’ of immediately accessible assistance especially when hospitals or health practitioners required clarification, GP appointments or medications were unattainable, psycho-social access or for help with complex applications for funding and financial support.

Ballarat Hospice Care Young Bereaved would like to make the following recommendations for palliative services to younger people:

- Recognition that there is significant impact on younger people with families once diagnosed with a life threatening illness
- Continued and increased funding for palliative care services recognising that holistic palliative care includes the patient, the carer and the family
- Continued and increased funding for psychosocial and counselling services as part of community palliative care
- Emergency Funding Packages for families given palliative diagnosis who suddenly lose income

“After the cancer specialist told us there was no hope we were able to travel away to visit family for his last ever Christmas.

His parents were too frail to travel to us and they live in a very remote area but we knew that if there was a medical emergency we had the phone number for Ballarat Hospice and no matter where we were as much medical support on the end of the line as we needed.”

- Changes to Centrelink funding to recognize that terminal and palliative diagnoses impacts immediately on family income and dramatically on family function and that supporting documentation is often not procurable, sometimes unobtainable, and that there are many conflicting demands on carer time.
- Access to bulk billing during testing and investigations for diagnoses
- Continued and increased funding for access to outside of business hours palliative services to meet the needs of families
- Funding for carer education, support and respite
- Access to emergency community organisations while waiting for processing of pension applications
- Access to around the clock in-home palliative support which causes the least disruption to young families and is required regardless of business hours or public holidays.

Prepared by Amanda Larcombe
for Young Bereaved, Ballarat Hospice Care Inc.

Reference:



Australian Government



2 January 2009

Rejection of your claim for Disability Support Pension

- We cannot pay you Disability Support Pension because we have not received a reply to the letter/s we sent you.

Contact information

If you have any questions about this letter please ring:



13 2717 OR
13 1202 for Multilingual Services

Monday – Friday 8.00 am – 5.00 pm
(Please quote reference number **204 518 688X**)



Your local Centrelink Office:
Corio Shopping Centre
Cnr Bacchus Marsh & Purnell
Corio VIC 3214



Office Hours:
Monday to Friday 8.00am to 5.00pm