

To whom It may concern,

My name is Melanie Rolfe, and I write to you in regards to palliative care services for adolescents and young adults (AYAs) in Queensland.

My primary training is in psychology, and I am currently engaged in postgraduate studies in adolescent health and welfare. I have previously been employed with the Starlight Children's Foundation, providing diversional therapy to seriously ill and hospitalised children and adolescents. I am currently working for CanTeen as a Member Liaison Officer, serving the psychosocial needs of young people living with cancer.

CanTeen provides a mix of psychosocial, psychoeducational, and recreational activities to people aged 12 to 24 who have cancer themselves, a sibling or a parent with cancer, or who have lost a parent or sibling to cancer. Whilst this submission is aimed at meeting the needs of this age group, I would also like to acknowledge the vast under-resourcing of palliative care services for children younger than this age range in Queensland.

Through my work with CanTeen I have become aware of *Queensland Kids*, and their work towards a respite centre for families with a terminally ill child, *Hummingbird House*. It is my hope that the suggestions outlined in this submission be taken in to account with the knowledge that *Queensland Kids* already have a vast wealth of resources in terms of the knowledge and dedication of staff and families who are willing to speak about their needs in supporting a terminally ill child. It seems logical that some suggestions outlined in this submission could most efficiently be implemented through government support of *Hummingbird House*, for the best outcomes of all terminally ill children and adolescents in Queensland.

Kind Regards,


Melanie Rolfe


The needs of Terminally Ill Adolescents & Young Adults (AYAs) and their Families

Adolescence is a unique period of physical, emotional, social and psychological development. Various developmental theories outline this period as one of increased independence from parents and increased influence of peers, the starting point of career and romantic relationships, and a time when 'fitting in' is paramount. A terminal diagnosis during this stage has ramifications across the board; parents become full time carers at a point when the AYA's peers are enjoying more independence than ever. The physical environment of a hospital setting and the constraints of illness prohibit much social contact with their friends, including opportunities for romantic relationships. The terminally ill AYA will have a reduced, if not completely negated, prospect for career development. Add to this the vast difference between the situation a terminally ill AYA finds themselves in, and that of those around them, and the terminally ill AYA can feel completely isolated from their peers and family.

Around the world, many terminally ill AYAs are receiving stellar palliative care. The UK has 44 children's hospices who offer respite and end of life care for young people up to between 18 and 25 years of age. As you are no doubt aware, Queensland does not have any children's hospices. Presently the options for families with a terminally ill child under 18 are that the child pass away in hospital or at home. Over 18s can utilize adult hospice services where staff have predominantly adult and older adult training and experience. Places in such facilities are also hard to come by and can still be very isolating for the adolescent who is away from their peers and normal interactions with younger siblings may be stifled.

With the present lay out of oncology services within Qld Health, adolescents can be treated in an adult setting from as young as 15; I have heard many AYA oncology patients talk about the isolation that comes not just from having no one around who is in a similar age range, but from being around people who have lived their lives and are ready to die. Being a terminally ill AYA in this setting would mean facing death with others who are at a hugely different stage of life. Conversely, AYA oncology patients can be treated in a pediatric hospital up to 18 and occasionally even beyond. This brings with it similar isolation in being unable to relate to peers, and both settings fail to provide adequate environment for proper bonding with friends and family, at a stage of life when peer support is increasingly important. Ideally, adolescents would be treated in a unique adolescent ward (as is the case in the Royal Children's Hospital, Melbourne- but that is a topic for a separate inquiry) and palliative care would be a flow on from that.

At present the other option for terminally ill AYAs is for them to die at home. In some cases this is not an option, due to rural home locations or specifics of treatment. For those that it is an option for, it means a huge commitment to care (usually from the parents), frequently around the clock. This brings with it intense pressure on the carer to learn and commit to the medical management of symptoms, as well as the financial strain of a parent being unable to work, and the sleep deprivation that generally accompanies this kind of care. There is also the emotional strain on the family of having the young person pass away at

home and the ongoing reminders of this time being built in to the family's future and connection with that house.

Jenny Hynson, from the RCH Melbourne, speaks about families' reflections on an 'ideal death' for their child. The common themes were:

- Minimal suffering
- The patient was able to 'live as fully as possible for as long as possible'
- Opportunities for friends and family to spend time with the patient in the lead up to the death- both in the months before and the time immediately surrounding the death
- That the patient died peacefully and with family around them
- That the family were able to spend time with the patient after their death
- That the family receive support through the bereavement
- That the family can find meaning from the patient's life and death

The families stated that in order to achieve this, they needed:

- Clinical expertise
- Knowledge about the illness and treatment
- Emotional, psychological, and spiritual support
- Practical assistance
- Hope
- Privacy, comfort, rest, and nourishment
- Trust in the service providers
- Compassionate care

Through *Queensland Kids* I was fortunate enough to sit in on a forum where parents spoke about their experiences with palliative services for their children. Some of the issues they highlighted were:

- Difficulties for siblings, as the hospital is not set up for them to interact with the ill child
- Parent exhaustion from sleep deprivation
- Marital difficulties because of stress
- The secondary loss of services and relationships with service providers post-bereavement
- Lack of knowledge of ways to prepare for the bereavement
- Lack of knowledge around services and funding available
- Difficulties of Centrelink paperwork
- Lack of respite

Some of these parents were not introduced to the idea of palliative care until the day their child passed away. They had no support through the hospital to prepare their family psychologically for the loss of their child and no follow up after. This needs to be addressed.

The benefits of support through this very difficult time go beyond compassion; for the patient, early referral to palliative care services can actually prolong life(Temel et. Al, 2010).

The care of a terminally ill AYA patient is likely to effect- at the very least- their immediate family. Due to the age of an AYA, this could mean that siblings are affected at the point of life when they're likely to be undergoing education and starting employment, and parents are needing to leave work indefinitely to care for their families. The cost of their experience goes beyond the lost income and this effect on the economy, to the increased mental health resources that may be required by all members of the family, if they were to not have access to appropriate supports through their grief journey. Investment in support services at this point can reap economic rewards for the community as well as psychological and emotional rewards for the individual.

The model that has been adopted in many children's hospices throughout the world addresses a great deal of these concerns. *Bear Cottage*, attached to the Royal Children's Hospital in Melbourne, is a wonderful local example of this. It is my first suggestion that the Queensland government implements or financially supports the implementation of a children and adolescent hospice and palliative care facility.

The hospice, following best practice as is outlined in research (see Zwerdling et.al, 2000, for discussion of *StarShine*, a pediatric hospice in the US) and following the lead of established facilities here in Australia, such as *Bear Cottage*, would provide holistic care of the patient through management of physical, spiritual and psychological pain, as well as providing opportunities for socialization with other patients, friends and family. The opportunity for these families to meet each other will in itself have the therapeutic effect of allowing them to build connections with others in similar situations to themselves, and showing them that they are not alone in their journey, a powerful tool at the core of CanTeen's peer support model. Following models which have proven successful overseas, families will also have opportunities to share their experiences with others in their situation through patient, sibling, and parent- specific group therapy, and learn coping strategies through complimentary and expressive therapies. *Bear Cottage* also has facilities to allow families opportunities to create keepsakes of their children, such as photographers and fingerprint jewellery makers, and a beautifully decorated cool room, to allow the family to spend time with their child posthumously. Even having relevantly trained staff present who can suggest other ways of remembering their child- though it may seem like a small thing- is hugely beneficial to the grieving process. Having a centralized palliative care service for children and AYAs would also allow for specialist knowledge to be most efficiently disseminated to those who need it. This would include medical and psychological expertise, as well as workers who could help families navigate other services such as Centrelink and disability services to minimize familial costs and stress through this period.

The hospice could also be the base for community pediatric and AYA palliative care workers, who provide care in the home for those choosing this option. Having these workers linked with the hospice provides continuity of care, as families often utilize a combination of home and hospice care where that is an option. The hospice would also be the base of ongoing support for families post-bereavement, and offer psycho-social services to patients, siblings and parents throughout the palliation and bereavement. The continuation of services is important to avoid families being re-traumatized by the loss not only of their child, but of the service providers who have been there for them throughout their journey.

A review of the point of referral to palliative care services is also fundamental to the functionality of a pediatric and AYA hospice. At present, where there is nowhere in particular to refer young patients to, the stage at which a patient is deemed terminal may not have many practical ramifications (though the psychological effects of a less than desirable period of time to prepare for bereavement can be huge), and may therefore be being overlooked. Palliative care services can in fact be integrated with disease focused care, and is not just for the end stages of life. It's important to stress to families that transitioning to palliative care does not mean that they are giving up hope, and research has shown that early referral to palliative care services decreases depression and symptoms in the patient, as well as increasing their quality of life and can mean that they live up to a couple of months longer (Temel et. Al, 2010). Training in the medical and nursing fields typically fails to prepare practitioners for these decisions and conversations, a fact that as a government you are in an excellent position to change, through requirements of registration boards or employment within Queensland Health.

In summary;

- Adolescents and Young Adults with a terminal diagnosis are in a unique position due to their developmental stage requirements and their ability to comprehend the future they will miss. They require specific medical, psychological and social supports to ensure they get as much out of their years as possible.
- Queensland is completely lacking in hospice and respite care for both pediatric and AYA patients.
- The following would improve services for terminally ill young Queenslanders and their families:
 - The provision of a respite and hospice centre, which would house young people and their families for respite visits and end of life care, as well as provide psycho-educational, psycho-social, and spiritual supports specific to the age and needs of the patient and their family
 - The provision of staff to help families navigate the various services they are eligible for, such as Centrelink payments and disability support services
 - Ongoing support post-bereavement for both parents and siblings of the patient
 - Community-based palliative care workers to support young patients in the home
 - Training of medical professionals about the advantages of early referral to palliative care and in the tactful delivery of these conversations

The delivery of these suggestions does not require scientific or medical breakthrough; the resources are already at hand, and the question of how to distribute them is primarily a political one. Young families of Queensland need a place to help them through what will likely be the most difficult time of their lives, in order to ensure they are able to continue on to again lead fulfilling lives. The longer we leave improvements in the area of AYA palliative care, the more families will miss the boat for quality end-of-life care and optimal wellbeing post-bereavement. This is not an area that can afford to be put on hold.

References

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