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Sub# 10



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July 30, 2012

Mr Peter Dowling, MP  
Chair  
Health and Community Services Committee  
Parliament House  
BRISBANE QLD 4000

Dear Mr Dowling,

**Inquiry into Palliative care and Home and Community Care Services in Queensland**

Thank you for the opportunity to submit Youngcare's response to the Inquiry into Palliative Care services in Queensland.

Please find attached our submission in regard to this issue.

Yours sincerely,

**Anna Cox**  
**Acting Chief Executive Officer**

## **SUBMISSION**

### **Inquiry into palliative care services and home and community care services in Queensland**

#### **Introduction:**

Youngcare believes that all young people deserve young lives.

More than 7,500 young Australians (under the age of 65) with 24/7 care needs are living in aged care simply because there are few alternatives (*The Senate Community Affairs Reference Committee 2005*).

There are also more than 700,000 young Australians being cared for at home with family or friends as their carers.

They are people who have high and complex support needs and are suffering illnesses and conditions you have heard of – and accidents that can happen every day. All it takes is an accident – a brain injury, an unexpected stroke, or a diagnosis of MS or Huntington's.

As young people with high care needs deserve to live young, dignified and relevant lives, they also deserve to die with the same choices as those without a disability.

Youngcare believes that the policy positions stated below are relevant for young people with high care needs in life and at the end of life.

**1. Young people with high care needs should have choice**

A young person with high care needs does not have the same choices as those who don't have high care needs. Greater supports and options are needed to offer choice, both during life and at the end of life.

**2. That aged care as the only choice, is not appropriate**

In most cases, specific end of life care needs of a young person will not be met in aged care as they differ greatly from the needs of an elderly person.

**3. That there should be housing choice for people with high care needs**

Currently, there are limited accommodation options for people with high care needs. Youngcare supports greater resources targeted to provide appropriate housing options and services that reflect a flexibility to meet the needs for people with high care needs and their families.

**4. That there should be relevant and appropriate care models**

Youngcare believes that young people deserve to live young, dignified and relevant lives; regardless of their care needs. We believe young people deserve to have the same choices at the end of their lives.

**5. That the Federal and State Governments must address the issue through policy change**

Youngcare believes there is an urgent requirement to address the gap in the Australian healthcare sector which has been put into the "too hard" basket for far too long.

As such, we welcome the Federal Government's support for the implementation of the National Disability Insurance Scheme.

**6. Youngcare supports the implementation of the National Disability Insurance Scheme**

Youngcare supports the introduction of the National Disability Insurance Scheme, however this needs to be supported both federally and by each state to ensure there is adequate planning, funding and robust provisions that do not disadvantage any recipients and provide genuine improvements to current services.

**7. That young Australians with 24/7 care needs should have access to relevant information**

Youngcare believes people with high care needs, their families and carers and those who provide support services need relevant information and advice to enable them to make decisions and choices that are relevant to their needs.

Many young people with high care needs will require palliative care; Youngcare believes in age appropriate care at all stages of life. It is imperative that all people at the end stages of their life have choice. We advocate for people to live well, but it is essential that people are able to also die well.

- a. As a condition progresses, all efforts should be made to avoid exacerbations, maintain functions and support specific advance plans for the individual and their family.
- b. When a person's condition becomes frail, carers need to be supported in their role to maintain function, skin integrity, mobility and continue with advance planning.
- c. As a person is actively dying, comfort and dignity is essential for the person and their carer. Support is needed to support the person and the family to affect closure.

Often the end of life process occurs in pain, without loved ones and not in the environment of choosing. There is a lack of choice, control and dignity with scarcely enough support for loved ones and carers.

As in life, Australians should expect to have self-determination and control of their environment and condition management at their end of life; to be an active participant over when, where, how and with whom. The person, loved ones and carers are supported before, during and after.

It is evident that you don't have to be old to need palliative care. Dying well is a key objective of the Youngcare/Griffith University model-of-care which aims for comfort, dignity, care giver support and planning ahead.

Dying well incorporates the person's needs and wishes to provide appropriate care when a person needs it, where a person wants it and with whom they share their end of life.

On behalf of Youngcare Ltd



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