



The Prince & Princess
of Wales Hospice

a pool of tears: a young person's lived experience through COVID

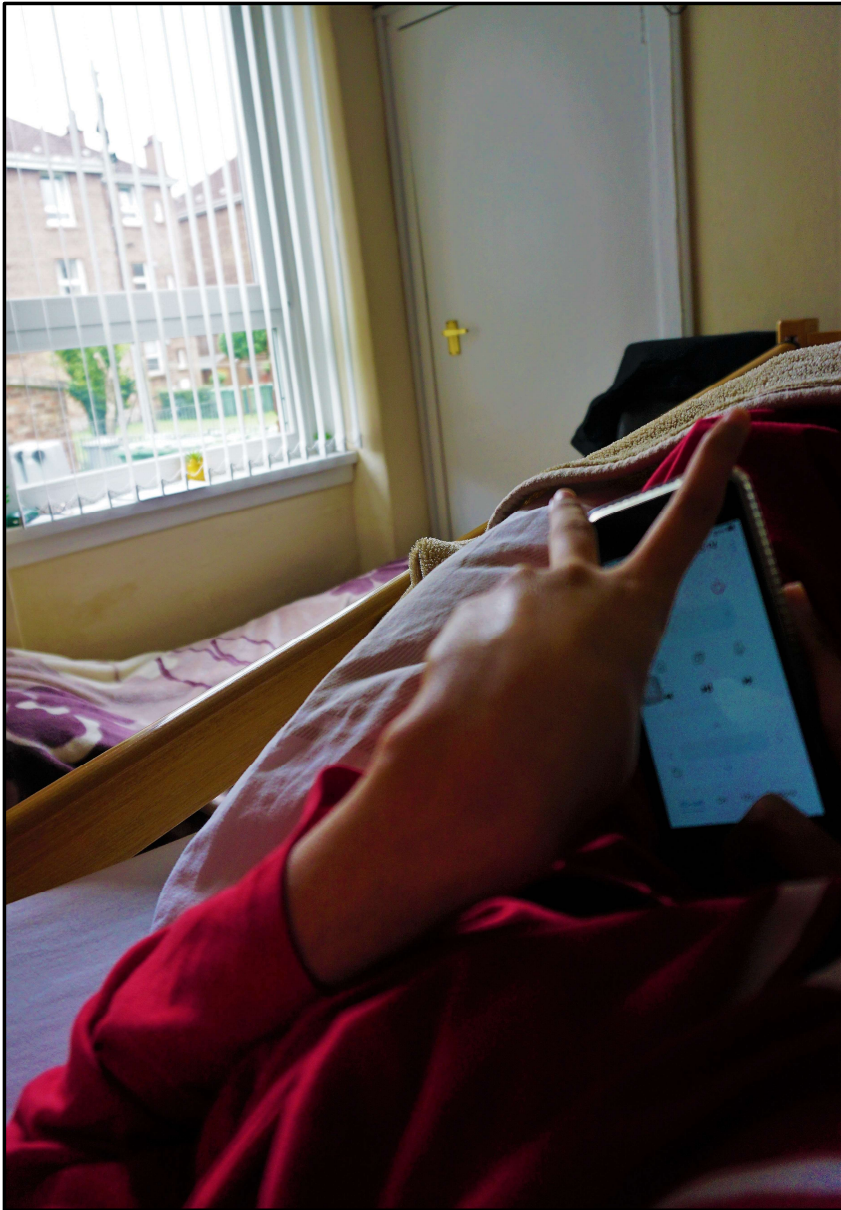
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Young Adult Service, The Prince and Princess of Wales Hospice

A young adult with a life-limiting condition, fearing their untimely death: their physical ability not allowing them to wipe away their own tears. Dependent on others for all cares, confined to bed due to pain and anxiety, they shielded in their bedroom during the COVID pandemic, isolated: a young life with a block of flats view - day in, day out - simple life aspirations unattainable.

Photo 1: bed with a view

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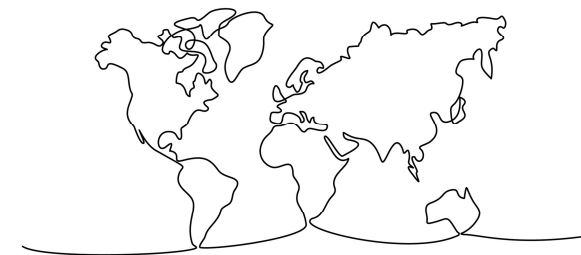
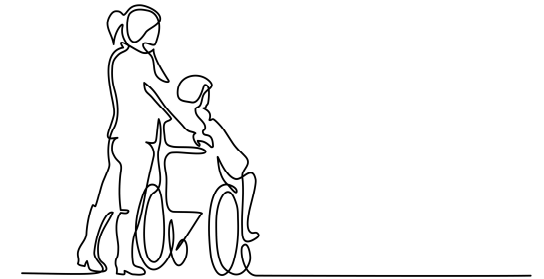




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background

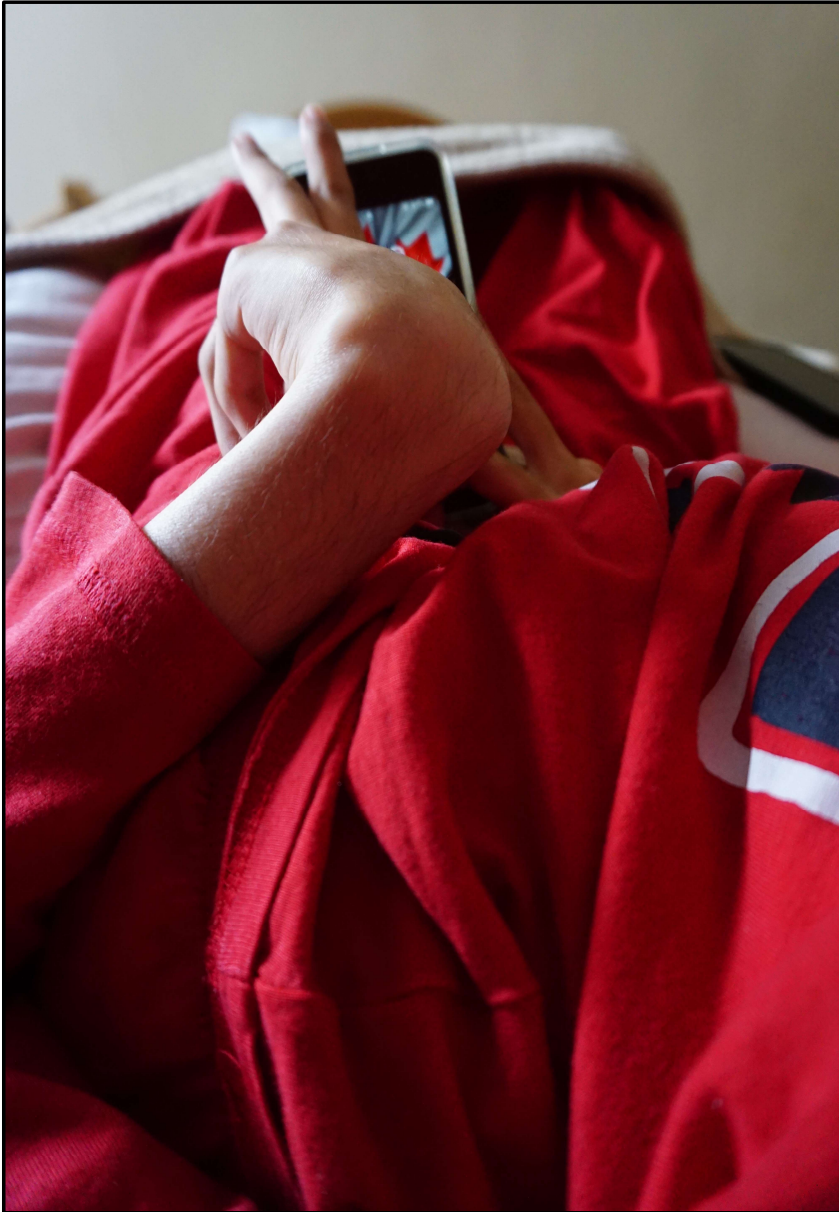
- 20-year-old with duchenne muscular dystrophy
- Neuromuscular scoliosis – no surgical intervention possible
- NIV overnight
- PEG fed – but partial to a cheese and tomato toastie!
- Anxiety, low self-esteem, poor body image
- Mixed “total” pain: physical (positional, neuropathic) and psychosocial
- Lives with mum and siblings
- No package of care despite best efforts to secure one
- Once dreamt of being a pilot, but their body failed them
- Aspirations to attend college thwarted
- Has travelled the 7 continents via YouTube



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- Referred to Family Support Services
- Time to talk offered. Coping mechanisms explored. Support given.
- High levels of anxiety and depression.
- Disappointment in lack of care.
- Angry at not feeling listened to.
- Frustrated with health and social care professionals.
- Set up to fail - aspirations unattainable with barrier after barrier put in place.
- Worried about mum's worsening own health, struggling under burden of care.
- Sister a young carer, missing school to provide cares.

Photo 2: his world

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recommendations

- “Walk in their shoes”: **understand the lived experience of young adults** – see the person first and not their disability.
- Encourage and **enable young adults to have their voices heard** and to share their stories.
- “I’m the captain of my ship”: **recognise their need for control** in their lives.
- **Accept and explore their “challenging” teenage behaviour** as being normal, coming from their rite of passage into adulthood.
- Recognise that a **“one size fits all” care package does not meet the needs of young adults**. Financial resources are needed to create individualised person-centred packages of care.