THE ART OF BEING WITH: PATIENT AND FAMILY CENTRED CARE IN AN ADOLESCENT AND YOUNG ADULT HOSPICE

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KEYWORDS

Dementia, Art Therapy, Inclusion, Patient Centred Care, Family Centred Care, Trauma Responsive Care, Palliative Care

EXECUTIVE SUMMARY

This case study highlights an innovative, person and family centred approach to caring for a 27 year old with younger onset dementia at the Adolescent and Young Adult Hospice. Facing rapidly changing cognitive and emotional needs, the team implemented flexible, multidisciplinary care with a focus on art therapy. This approach improved engagement, reduced distress, highlighted nonspeaking communication, while supporting family connections. Central to success was a collaborative team model and a willingness to adapt care in real time. The model is low cost and easily transferable, offering valuable insights for services supporting young people with complex, life limiting conditions.

INTRODUCTION

Young adults living with life limiting conditions such as younger onset dementia represent a uniquely underserved population within palliative care. Their needs often sit at the intersection of paediatric and adult services, creating gaps in age appropriate, meaningful care. Cognitive decline, loss of identity, and reduced ability to communicate can significantly impact quality of life, particularly for individuals who are nonspeaking and rely on others to interpret behavioural cues. Despite this, traditional models of care frequently prioritise physical needs over personhood, agency and relationship.

This case study explores an innovative, person and family centred approach to care for a 27 year old man with advanced younger onset dementia in a hospice setting. It highlights how flexible, sensory based, and nonspeaking therapeutic interventions, underpinned by strong multidisciplinary collaboration can support agency, relationship and personhood to enhance quality of life. The role of Art Therapy allowed both the young person and his family opportunities for meaningful connection, an outlet for processing their experience and a chance to reflect on legacy. By reorienting care toward experience, creativity, and responsiveness, this approach challenges conventional paradigms and demonstrates that meaningful engagement remains both possible and essential, even in the context of profound cognitive and functional decline.

YEAR CASE STUDY WAS IMPLEMENTED

2026

CASE STUDY DETAIL

A 27 year old male with younger onset dementia was admitted to the Adolescent and Young Adult Hospice for ongoing respite and supportive care. Younger onset dementia presents unique and complex challenges, including rapid and unpredictable cognitive decline, fluctuating communication abilities, behavioural changes, and profound psychosocial impacts. Traditional aged care dementia models are often inappropriate for younger individuals, who have different developmental, emotional, and identity needs. This created a need for a flexible, person centred approach that could adapt to daily changes in cognition, mood, and functional ability.

A highly individualised, multidisciplinary approach was developed, centred on flexibility, creativity, and responsiveness to daily changes in the patient's condition. This required close collaboration between nursing and medical staff, allied health, care workers, and the patient's family. Emphasis was placed on creating a calm, familiar environment and maintaining a predictable routine, while remaining flexible to the patient's tolerance and engagement levels.

Furthermore, recognising that traditional verbal therapies were not aligned with the patient's functional abilities, the team prioritised sensory based and nonspeaking therapeutic modalities. Art therapy became a cornerstone of care, adapted to meet his cognitive level and physical ability on any given day.

The art therapy sessions were individualised through the art therapist seeking session subject and direction from the family; creating opportunities for agency, creative self expression and exploration of identity. Using family feedback and combined with therapist experience, materials and subjects were anchored to specific sensorimotor and cognitive memories held by the patient and his family to further enhance regulation and connection.

In addition to art therapy, the patient was engaged in other sensory and movement based activities such as music therapy, gentle massage and exercise, time with the therapy dogs and time in nature. Familiar visuals, sounds, and scents were used to provide nonspeaking cues of emotional safety and offer reassurance.

Implementation relied on strong communication systems, including daily handovers and documentation of subtle changes in behaviour, preferences, and responses to therapy. Staff were supported through ongoing education, pre briefing and reflective practice to build confidence in delivering a flexible, non traditional care.

Of particular importance was transparent and open communication with family, who were strong patient advocates; with the patient's care plan constantly adapted to reflect their knowledge and priorities. This approach provided a whole of family experience and recognise the importance of their relationships in both informing and improving patient care.

Outcomes of this approach were consistently assessed and used to inform ongoing care. Due to the patient's communication being primarily nonspeaking, experiences were measured using behavioural observation and family and staff feedback. Through this, several positive outcomes were noted:

Improved Engagement: The patient would consistently return to rooms and seek out materials he felt connected with such as oil pastels and colouring in, even when agitated.
Reduced Distress: Episodes of agitation and frustration decreased, attributed to the flexible, low demand nature of art based interventions
Enhanced Communication and Connection: Art therapy provided an alternative means of expression, allowing for the patient an experience of agency and providing them with a sense of dignity and identity.
Family Satisfaction: Family reported feeling more connected and reassured by the personalised, dignified approach to care, noting the patient appeared more relaxed and "present".
Staff Confidence: staff members reported increased confidence in managing complex, fluctuating needs through collaborative practice.

This model is highly scalable and transferable to other hospice, palliative care, and community settings. Key components, such as art therapy, flexible scheduling, and multidisciplinary collaboration can be adapted to suit varying resource levels. Importantly, the approach does not rely on high cost interventions but rather on a shift in mindset towards flexibility, creativity, and person centred care.

A key lesson is the importance of shifting the focus from task oriented care to experience oriented care. Nonspeaking therapies provide a valuable resource in enhancing patient voice and care, contributing to increased emotional wellbeing and overall experience not only for the patient but also the family.

Critical success factors included strong team communication, flexibility in care delivery, and genuine engagement with the patient as an individual. Family involvement was essential in understanding the patient's identity and preferences. Additionally, staff confidence in adapting activities in real time contributed to more meaningful interactions.

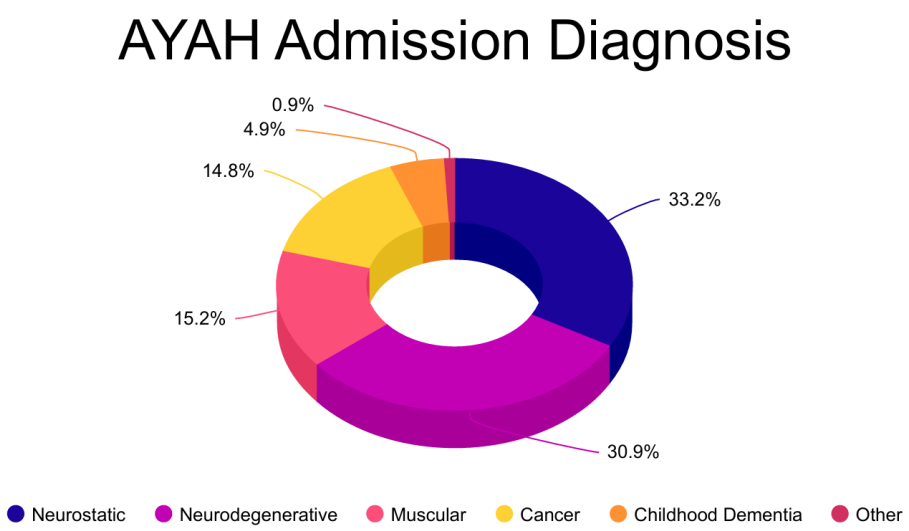

Figure 1: AYAH Admission Diagnosis

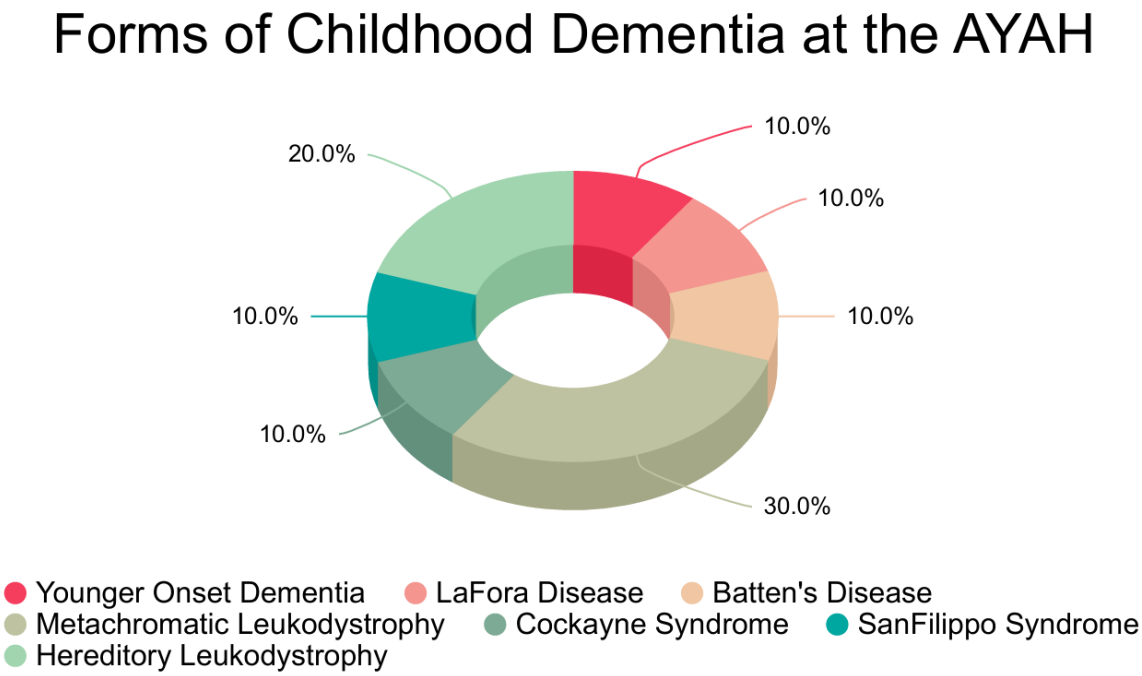

Figure 2: Forms of Childhood Dementia presenting at the AYAH



Figure 3: Example of patient's artwork prior to diagnosis



Figure 4: Example 2 of patient artwork prior to diagnosis

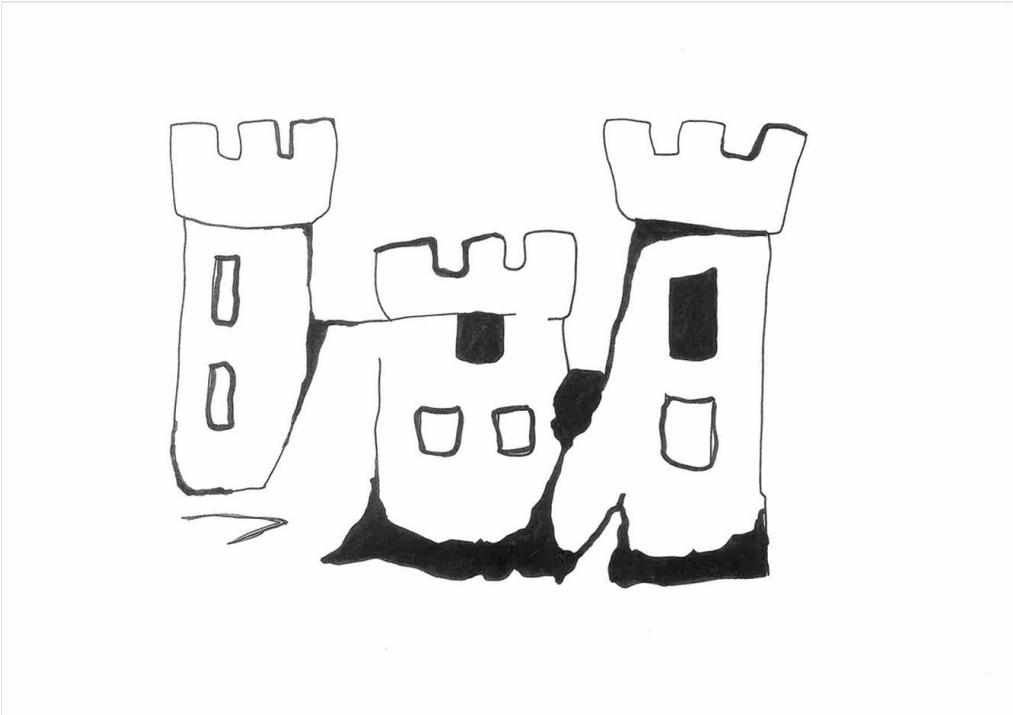

Figure 5: Colouring in page created of patient tattoo to act as transitional object



Figure 6: Colouring in page created of patient tattoo, completed by family and friends of patient