Grampians Regional
Palliative Care Team

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A CASE STUDY SUPPORTING A PATIENT WITH DISABILITY TO DIE WELL IN THEIR ‘HOME’

This case study highlights the effectiveness and collaboration of teamwork in overcoming barriers to support a person with Down Syndrome to die comfortably at her home within a disability house.

Annie’s Story….

Annie, a 56 year old lady with Down Syndrome suffered recurrent, uncontrolled epileptic seizures leading to multiple hospital admissions for aspiration pneumonia and hypoxia. She also had autism, cognitive impairment and dysphagia, was blind and non-verbal.

Whilst living in fully supported accommodation most of her life, she had loving, supportive family and carers who knew and cared for her and her family exceptionally well.

Background

Annie was having multiple presentations/admissions to hospital, every 10-15 days, for increasing seizure activity lasting 2 to 5 minutes or longer, with associated hypoxia and aspiration pneumonia. Myoclonic jerking episodes occurred up to 200 times daily from mild twitching to leg kicking.

A referral for end of life care was received by the consulting palliative care team after one of these episodes. Annie however had made a recovery, smiling and eating breakfast with her support worker assisting. She had survived previous episodes where death seemed likely but rallied after a course of intravenous antibiotics. Despite making another recovery, Annie’s health was deteriorating and a family meeting to discuss treatment options was arranged.

Family Meeting

Aim of the family meeting was to prevent further hospital admissions and keep Annie at home with a good seizure management plan which could subsequently result in her being more sleepy but suffer less epileptic episodes.

Her family were distrustful of the hospital system having seen her recover from previous dying episodes, they wanted comfort without denying treatment if beneficial. A distressing experience of a relative’s death had also left them with little faith in the palliative care process. They were fearful that by giving medication that could increase her sedation, she would not be able to eat and it would be starving her.

Whilst the family meeting was attended by the multidisciplinary team, it was the trusting relationship and good communication skills that the care facility supervisor had with the family that enabled them to feel reassured that it would be the best outcome for her.

Discharge Planning

Annie was not imminently dying and was to be discharged home with a good plan in place for comfort care, better seizure control and effective symptom management plans. Keeping Annie at home for end of life care presented a major problem as the staff could not give injectable medications.

Barriers

Disability carers are not medically trained, have strict protocols and scope of practice not allowing them to give injectable medications. They administered buccal midazolam for seizures, calling an ambulance if prolonged for greater than five minutes.

NDIS budget would not cover private nursing for end of life care (EOLC).

There were no formal Goals of Care or Advance Care Plan in place.

Prolonged seizure activity often led to hypoxia requiring oxygen therapy.

Talking through some of these barriers, the palliative care team and the supervisor were able to overcome many of the barriers that existed.

The Discharge Plan

A referral to the community palliative care team for symptom management/emotional support and advance care planning was completed.

A seizure management plan using clonazepam drops was agreed and a symptom action plan with clear instructions was written for the staff to follow. The hospital pharmacist provided education to the supervisor on administering clonazepam drops so that she felt comfortable and could then train the staff.

The treating team were to contact the GP to update and engage with the discharge plan.

The medical team prescribed oxygen for the community palliative team who would provide education and a concentrator.

A copy of the hospital discharge plan and current goals of care were given to the disability house supervisor. The goals of care form created the foundation for the end of life conversations that she had with the family for Annie to remain at home with no further transfers to hospital.

The supervisor contacted the State Trustees and confirmed that money could be released to pay for private nursing to administer subcutaneous medications when required for end of life care.

Both the regional and community palliative care teams provided increased support and education to the carers around all aspects of the care that Annie would currently require and then for end of life care including signs, symptoms and how to care for an actively dying patient.

Annie already had a hospital style bed and any equipment identified was supplied by the community team.

Annie would automatically be a Coroners Case as part of the standard practice within disability care homes.

Discharge Home with Rapid Decline

Annie was discharged home with the supervisor ensuring that she had all discharge paperwork, scripts, medications, symptom action plans, drug charts and contact details. The community team were linked in to visit and support as necessary.

Annie enjoyed the weekend at home but on the Monday staff saw a demise in her condition. She was no longer eating or drinking, was sleeping more and they felt that her condition had rapidly deteriorated.

Our focus had changed from comfort care to end of life care more rapidly than expected.

Despite Annie having funds available through the State Trustees for private nursing, there was no nursing agency available who could offer 24 hour care. This presented a major problem if Annie developed distressing symptoms, no-one was available to administer the required medication.

After some discussion with the Supervisor and the Area Manager, it was decided to keep Annie at home for as long as her symptoms could be well managed. If not, hospital would be the place of care.

A syringe driver was commenced with clonazepam and Buscopan to manage seizure activity, myoclonic jerking, terminal agitation and potential secretions. Pain had not been an issue for Annie and she had no comorbidities that would indicate that it should become problematic.

The staff could administer prn clonazepam oral drops for potential jerking/seizure activity not controlled with the syringe driver. Oxygen was available for comfort measures but was not required.

The supervisor spoke to the staff and everyone wanted to care for Annie at home, whilst acknowledging that this would be challenging for them, having never looked after a dying resident before.

She was cared for in her own room, the staff knew all her likes/dislikes, music played and she was never alone. The supervisor was able to gently guide the family through this process and they were at her bedside.

Conclusion - A Good Death

Annie was not in a clinical environment in the last hours of her life. She died peacefully in her own ‘home’, with the love, comfort and respect of her carers and family who knew her well, supported by the community and regional palliative care teams. The amazing teamwork and collaboration to achieve this result for Annie was a very gratifying experience. The staff continued to be supported after Annie’s death as they in turn provided care to the family.

All identifiers have been removed and pseudonyms used to maintain privacy and confidentiality.

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