



## POP UP CASE STUDY

The following case study is one example of a pop-up intervention initiated by the specialist paediatric palliative care team to support a child and their family in the community. The issues and interventions provided were specific and individualised to address the needs of the child, family and local health providers during the course of illness.

Each pop-up intervention provided for a patient and their family will be different. The following factors are often considered when as assessment for a pop-up intervention is needed by the specialist PPC team:

- The age of the child
- The diagnosis
- Family support
- Home location
- Requirements of the local services

Multiple PPC pop up interventions can occur during the trajectory of a child's illness. Pop up can be provided face to face or by using telehealth technology (e.g. videoconference).



NSW Paediatric Palliative  
Care Programme

the  
children's  
hospital at Westmead

The Sydney children's  
Hospitals Network



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Kaleidoscope  
HUNTER CHILDREN'S HEALTH NETWORK

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## **PATIENT INFORMATION**

**Patient:** Emily Smith\*

**Diagnosis:** Peliazeus-Merzbacher (inherited condition of the central nervous system leading to:

- Impaired intellectual functions (e.g. language and memory)
- Delayed motor skills (e.g. coordination and walking)
- Blindness and deafness

**Age:** 7 years

**Sex:** Female

**Cultural background:** Australian

**Home:** Rural NSW (300km from Sydney)

## **FACTORS IDENTIFIED FOR POP UP INTERVENTION (TRIAGE ASSESSMENT)**

- The geographical isolation for local services to support the child's complex care needs
- The child is unable to tolerate the trip to Sydney so it is impossible for her to attend the children's hospital for review
- Complex and increasing symptoms related to Emily's medical condition are requiring specialist PPC advice.
- Emily's immobility (no weight bearing, requiring heavy lifting) has impacted on the parents physical health
- Ongoing psychosocial stress experienced by the family requiring additional support

## **ISSUES IDENTIFIED**

### **1. Equipment needs**

Prior to the initial consult, Emily hadn't had a physical assessment review by a physiotherapist or occupational therapist for a number of years to assess level of function. Emily's mother communicated that many items of her equipment were now inappropriate for her size. Emily's father had developed an inguinal hernia and back pain from lifting Emily and due to her weight, her mother was unable to lift her at all. Manual handling advice was needed.

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## **2. Symptoms**

The parents reported that Emily was experiencing a change to her seizures that involved staring, breath-holding and on occasion's cyanosis. They occurred at least twice a day and lasted 20-30 minutes. These were managed using oxygen and anti-convulsant medications.

Parents also reported that Emily had difficulty regulating her temperature and this could lead to a seizure when she overheated or became distressed. Her bedroom was temperature controlled and Emily disliked leaving her room. The bedroom therefore became the main area in the house where care was provided. Due to her blindness and deafness, her mother spent a lot of her time holding Emily for comfort. This is significant due to intensity of time spent in the bedroom.

## **3. Feeding**

Emily had a history of reflux. She required a gastrostomy tube for feeding and often experienced constipation and discomfort from flatulence.

## **4. General Practitioner (GP) support**

Emily was linked with a local GP however additional specialist PPC intervention was needed to support the GP in caring for Emily. As a result of Emily's increased symptoms related to her illness, it was apparent that end of life care conversations and planning were needed and these had not yet occurred. GPs (and other community care providers) may have limited experience in caring for children in palliative care as the population is relatively small in comparison to adult palliative care. Support by the specialist paediatric palliative care service can help to develop confidence and knowledge for the GP to provide care locally to the child and family.

## **5. Parental stress**

Although Emily's parents reported to be coping very well, the combination of the above factors increased concern for Emily's health which increased their anxiety. A need for psychosocial support for the parents was identified because of her decline in health and the increasing uncertainty about Emily's prognosis. This also contributed to Emily's parent's experiencing anticipatory grief and requiring support around this.

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## **POP UP INTERVENTION**

Due to the progression of Emily's illness and the issues listed above, it was apparent that the current care plan needed to be reviewed and modified by the specialist PPC team. Improved knowledge and education was also needed to support the local health services involved in Emily's care. Therefore in-time training that included responding to the specific changes in Emily's care was provided by the SPPC team. The following pop up interventions were applied to each of the issues.

### **1. Equipment needs**

An assessment was completed via telehealth. Manual handling and positioning issues were discussed by the PPC Occupational Therapist and Physiotherapist regarding both Emily and her carers. The assessment established Emily's level of function and identified her physical needs and the equipment required to assist with mobility, positioning, bathing and other care needs.

Following this initial assessment, the PPC Occupational Therapist and Physiotherapist contacted the local Allied Health team to arrange for a review of the highlighted issues with a view to arranging appropriate equipment.

### **2. Symptoms**

The PPC staff specialist made changes to medications to help manage the increased frequency and severity of seizures. Seizure medication dosages were increased. Midazolam was also introduced to manage prolonged seizures. The GP was involved in discussions regarding medication changes to ensure ongoing management occurred locally. Contact details for the PPC service were made available including after-hours support when needed.

A multidisciplinary discussion was conducted by the PPC team in relation to Emily's temperature regulation and subsequent bedroom confinement. Planned interventions to improve this situation included an adjustment in the Gabapentin dose. The GP would provide ongoing follow up to see if this helped improve Emily's temperature regulation.

### **3. Feeding**

To assess Emily's feeding issues the specialist PPC team contacted the hospital dietitian so an assessment could be completed to review her current feeding regimen. A videoconference was arranged so that the dietitian could discuss current issues with the parents who had also organised the local dietitian to be present at the home during the video consultation.

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#### **4. General Practitioner (GP) support and parental stress**

In the initial face to face pop up the specialist PPC team travelled to Emily's home town and met with the General Practitioner together with the family. This enabled a valuable discussion, supported by the PPC service to address family goals regarding the progression of Emily's disease and changing care needs. The value for the face to face meeting could not be under-estimated in this context as it established a strong relationship for ongoing support (using telehealth) throughout illness. In addition, the discussions helped to build confidence and capacity for the local GP to assist the family in the local management of Emily's complex care needs.

\*The name of the patient in this case study has been changed to protect their identity