

Information to identify expressions of interest:

We are seeking expressions of interest from Providers to provide a 24 hour nursing package of care to support a child with highly complex medical needs at home. This child requires the support of trained nurses due to the clinical judgement required when meeting the child's needs and to manage the intensive and complex medication regime in response to the child's constantly fluctuating condition.

We require the provider to undertake a competency based training programme that will include the ability for nurses to administer intravenous medication via a Portacath; competencies need to be achieved prior to the Nurses being phased in to care for the child.

Alongside this the Provider would need to complete risk assessments, develop comprehensive care plans and undertake full case management of the package. The expectation is that the clinical oversight, care plan development and clinical governance would be managed by an experienced children's nurse.

A summary of the child's needs follows:

- Child is unable to communicate their needs; a process of elimination is therefore required to determine needs.
- Child is doubly incontinent requiring frequent nappy changes, and may require administration of suppositories and enemas to manage constipation.
- Child requires full support with mobility as is unable to mobilise independently.
- Child has complex seizure activity requiring administration of Buccal Midazolam or Rectal Paraldehyde up to three times daily.
Clinical judgement is required to monitor changing seizure pattern and to prioritise the course of actions in relation to administering rescue medication, oxygen and providing suction to minimise risk of aspiration from potential vomiting. Clinical judgement is also required to determine whether seizure activity is reducing in intensity with likely recovery and that rescue medication is not required.
- Child requires administration of medications via gastrostomy and jejunostomy 1-2 hourly and potentially intravenously during the 24 hour period for both pain and infection management.
- Child has Visceral Hyperalgesia and experiences Neuropathic pain for which Symptom management support is being provided by a Childrens Hospice; subsequently medications to manage pain are changing frequently.
- Child has Gut Dysmotility which is a contributing factor to pain, and results in erratic absorption of feeds and medications which needs close observation and reaction, and may result in medications needed to be given via an alternative route
- Child may be prescribed IV antibiotics or other IV medications. Nurses are required to be trained and be competent in administering IV medications via Portacath-
- Close monitoring of the child's condition is required in order to identify deterioration and seek support from the GP, Community Nurse, Hospice or Hospital as appropriate.
- Monitoring for signs and symptoms of deteriorating condition resulting from Renal Tubular Acidosis is required for which regular blood gases are required.
- Child is prescribed a Ketogenic Diet, nurses will be required to make up the child's feed and be responsive to changes in the recipe; they are also required to check recently prescribed

medications are compatible with the Ketogenic diet. Daily checking of blood sugar and ketone levels will be required, and action taken if results are out of range.

- Child may require unblocking of gastrostomy tube as a result of medications causing blockages.
- Child has a fluctuating respiratory pattern, oxygen and suction will need to be administered as required.
- Child experiences Oesophageal reflux, a bile drainage bag is utilised to minimise the occurrence of this however close monitoring is required in order to respond appropriately. Suctioning will be required to avoid aspiration.
- Paediatric life support skills are required.

This child lives at home with their family, older 4 year old sibling and their family dog. It is important to the child and their family that disruptions are kept to a minimum and to have reliability within the team.

It is also important that the nursing staff can be flexible to be able to support the sibling if either parent is attending to the child for whom the package is commissioned, to take part in family activities and to assist with some household chores when required.

It is vital the child is entertained and engaged in play activities to promote physical and cognitive development, and for staff to help with physiotherapy exercises.

The child also has frequent hospital admissions and/or potential symptom management/respite stays at a hospice, during which the package staff may need to accompany the child for consistency.

It is also important to the family to ensure nursing staff do not have allergies to dogs and are non-smokers due to the child's respiratory needs.

The nursing staff must be confident and competent in meeting the child's needs upon appointment. It has been determined that a minimum of three shadow shifts are required in order to get to know the child and to become familiar with care plans, location of equipment and the daily routine.

Due to the child's fluctuating condition; the family's preference is where possible, for full time members of staff to work within the package and for staff to work on consecutive days or nights to promote consistency and continuity of care, and for the stability of both young children in the home. It is essential to have good contingency cover for sickness and absence to ensure continuation of the support at home.