**Multidisciplinary care for Neurology patients with Static Neurodevelopmental Disorders – Proposed guidance**

**Background**

These guidelines are proposed to ensure uniformity of approach by different professionals across the Eastern region towards children with complex needs who are diagnosed with a static neurological disorder.

1. Children with neurological disorders should be considered to have a static process, unless documented as degenerative by a tertiary Paediatric neurologist. Due to improved medical and MDT management, many children with complex neurological conditions survive well beyond childhood and into adulthood. Life expectancy of children with static neurological disorders (SND) therefore should be assumed to be normal adult expectancy (or at least beyond the age of 40), unless a consultant Paediatric neurologist/ neurodisability specialist has documented otherwise.
2. Children with SND may require input from a number of teams. Their care should always be led by a consultant community or neurodisability Paediatrician, with expert advice from specialists as required. The lead Paediatrician **should always** be part of all MDT meetings (including palliative care meetings) and decision-making process for children who are under their care.
3. The palliative care team have specific expertise in symptom control. They work alongside the local team and other specialists to achieve symptom control even while investigations are being carried out.
4. Children with SND can present with an array of symptoms which can change over time despite the static nature of the underlying condition. Some are extremely vulnerable

physically e.g. may have recurrent chest infections etc.

***However, it is unusual for them to have pain or distress in isolation.*** Unusual symptoms should be questioned and investigated with the help of specialist teams for an underlying cause and never treated without this process. This will often require an inpatient assessment and investigations.

1. Symptom control should be done in parallel with investigation. The local named Paediatrician leading the child’s care should be jointly involved in all decisions on symptom control for their patients. A child with unexplained symptoms should not be referred for symptom control in isolation.
2. In line with RCPCH guidance, safeguarding issues should be considered in all unexplained symptoms and unexpected requests for escalation of treatment or care.
3. Management of symptoms which remain unexplained should be undertaken as a joint MDT process led by the named Paediatrician When palliative care is proposed to treat

unexplained signs or symptoms, decisions should be made via an MDT process led by the lead Paediatrician. The MDT should consist of specialist services, palliative care and

safeguarding team when appropriate. All discussions should be documented.

**Pathway for addressing unexplained symptoms in Neurology patients with Static Neurodevelopmental Disorders**

Lead consultant decision regarding further assessment

**Management of unexplained symptoms including institution of palliative care should be undertaken as a joint MDT (specialist services, palliative care ± safeguarding team) process led by the named**

**Paediatrician.**

**Safeguarding issues should be considered in all unexplained symptoms and unexpected requests for escalation of treatment or care.**

**Symptom control through joint working with symptom management team**

**Respiratory**

Recurrent chest infections / apnoeas /

Increased secretions

**Gastroenterology**

Abdominal symptoms / unresolved swallowing or feeding issues / unexplained vomiting / reflux / aspiration / severe constipation /Weight related issues

**Neurology**

Increased seizures / sleepiness / irritability with no clear focus / dystonia /Focal neurology/ Weakness

Referal to appropriate team

Lead consultant refers for further assessment

No further action

Symptoms addressed and resolved

If symptoms persist

Assesment of symptoms

Lead consultant

with MDT support

+/-Pain or distress

Any Acute deterioration in Child's health