

**NETWORK DAY 07/11/2023**

**OBJECTIVES DISCUSSION NOTES**

## **1. Gastrostomy:**

### **Challenges:**

- Hitting window of opportunity
- Who is responsible for referral?
- Huge disparity in dietetic cover+ RISK
- Timing and quality of conversations about PEG
- Dietetic gap: LFU- end up relying on LFU service.
- How commissioners fund services
- Difficult to plan active treatment in physio
- Unsure how much to exert patients.
- No clear pathways for PEG referral, how to identify at need patients, gastro referral pathways,
- RIG vs PEG, which is best.

### **Works well:**

- Referral to LFU and local provision
- Local hospice all brilliant

### **Ideas:**

- AHP training on gastrostomy, confidence to refer on id unable to offer full info.
- Hospice should have funding for dietetic input/staff training
- Training and skills
- Confidence in having conversations.
- Capacity in teams to react quickly
- Make MDT work better, Nutrition nurse, NGs need team support

## **2. Emotional/Psychological support**

### **Challenges and issues:**

- RSCH no funded neuropsych for neuro ward. could SAGE attend?
- Delays of DC, increase anxiety, issues at home once discharged
- Need for counselling early on in diagnosis?
- Community: E Sussex different to Kent
- Not knowing services available
- Missing support for children at hospices, remote support help?

- Referral pathways in place, but no clear which is best
- Capacity and wait times.
- Sometimes online only
- How services are labelled can make it unclear what's on offer, pts may be unaware its for them
- Lack of specialist support for staff
- Getting timely specialist intervention is challenging

**Positive:**

- SAGE service highlighted as good
- MND SPs work well to signpost
- Role of social prescribers- can they be more involved?
- Importance of choice for pts
- Raise profile of SW emotional support
- Importance of relationships- to offer support.

**Ideas:**

- More training for staff
- Emotional support for staff in MDT
- Magnify family issues.
- Link up better with psych services

### **3. Respiratory:**

**Challenges:**

- Travel to LFU
- Late diagnosis delays access to service
- Clinical knowledge
- Withdrawal of NIV and various trigger points
- Coverage off community services
- Out of hours and outreach
- Disparity btwn East & west Sussex

**Working well:**

- LFU are experts
- Short gastrostomy intervention duration, reduces risk
- Not having to travel in E Sussex
- E Sussex service links with MDT
- LFU liaison

**Ideas:**

- weekend service, virtual wards
- localised care with expertise
- MND training more accessible to more HSCPs
- 24 hour service/ hospice MND champions
- Greater parity between E and W Sussex

- Training on simple trouble shooting, signs and symptoms.
- Greater clarity on who to go to for advice
- Shared access to notes/updates
- Greater use of self-Mx plans

## **4. Genetics:**

### **Challenges:**

- Genetic testing: poor prognosis regardless
- Counselling
- Timing- results take too long.
- Consent of family members- who needs to know?
- Reasons for testing
- Family planning
- Infrastructure for a small cohort of pts, eg if a Tx were available in future
- Genetics service in a silo with no local services
- Funding
- Financial impact, health insurance??
- Palliative care team need to be more educated.
- Impact on families
- Limited HCP and pt understanding of the impact of genetics on MND risk- who to refer to –
- Testing number likely to increase with potential treatment options
- Impact on ACP if genetic results awaited
- Delay in results when progressing ++

### **Works well:**

- Gives hope for future to pt and others

### **Ideas:**

- need a clear referral/testing pathway.
- extra clinic time, more appts and flexibility
- availability on clinical trials

