Complex Care – Collaborative Working in Shropshire: Small Changes – Big Differences

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Overview:

- Complex Symptom Management in MND
- Case Example – Identifying the need to make changes
- The middle ground – MND Progression
- Case Examples – A changed approach
- Outcome of changes
- Challenges

Complex Symptom Management in MND:

- Symptom management is complex and often involves:
- NIV
- PEG/RIG
- Cough Assist
- Nebulisers
- Secretion Management – PSU, Complex medication regime, posture
- Respiratory insufficiency
- Pain / Discomfort – joint, muscle, pressure, postural changes, pre-existing
- Psychological impact
- Mobility
- Cognition

Case Example: Identifying the need for change

- Emma: 74yo Lady, lives with husband PD, supportive family but live a distance away
- PBP – speech affected – communication via iPad and writing
- Very innovative and independent
- Secretions became excessive and difficult to manage
- NIV, PEG, Nebulisers, Medication regime, Cough assist, PSU, Postural changes – neck weakness/ head control – impact on comfort and posture maintenance
- Self care – managing own PEG (with clamp), remain in control of own needs
- Care support – self funding – utilising carer who attends to husband, lives remotely

Case Example - Emma

- Managing at home but requiring increasingly complex interventions
- Wishes to be at home for end of life
- LPA – son and daughters
- CHC Checklist completed
- Hospice admission for secretion management – medications and care support
- Inpatient – Fast track paperwork completed and sent to CHC
- Date identified for DST Meeting but due to subsequent fast track date cancelled and care support sought for QDS for discharge
- No care agency availability – Emma continued to fund husband's carer and top up with family/ friends

Case Example: Emma

- Large parts of the day/weekend/nights – no support available – increased burden on family and existing carer
- Needed increased carer support / live in carer
- Family offered to 'top up' – tried to source agencies
- CHC told them QDS daily and 2 nights a week was maximum due to fast track
- Emma's needs becoming increasingly unpredictable
- Contact with CHC to try to review and get a better tailored package (more attractive to agencies)
- CHC Nurse Manager visited and reviewed – agreed needed more support than QDS and 2 nights/week – completed DST and funding agreed for care 'blocks' and agency sought and found
- Emma died 2 weeks later

The Middle Ground

- MND – changes are ongoing and can often be unpredictable
- Prognostication is difficult
- Rapid progression
- Symptom management – increasing needs
- That place between Checklist and Fast Track!
- Require individualised care and flexibility
- Ongoing review and ‘tweaking’

Moving Forward:

- As a result of Emma's and her family's experience:
- Identify a person who is changing quickly but requires above and beyond the QDS and 2 nights/week care support
- Complete CHC Checklist – email nurse manager/CHC to alert
- Send Checklist via secure email
- Suitable next available date identified informally between CHC assessor, SW, MND CS and patient/family approached
- DST completed giving greater depth to assessment– CHC assessor rings potential care agencies for availability – care agreed between CHC, Agency and patient
- Result – more tailored care support and faster access/assessment

Case Example: John

- John – 79yo man
- Lived with wife – diagnosed MND July – rapid progression 4 months later – NIV – difficulty tolerating, PEG declined, deteriorating posture and mobility
- Care needs increasing complexity – Checklist completed
- Emailed to CHC with explanation re: fast progression and need for tailored package
- Patient admitted to hospice for symptom management
- Fast track not completed as CHC assessor agreed to complete DST during admission
- Care support sourced and patient discharged with tailored care package

Case Example: Gary

- Gary: 64yo man – lives with wife (working),children live nearby but work /families
- Rapid onset and progression – lower limbs, mobility deteriorating – wheelchair dependent / hoisting within 3 months
- Respiratory involvement – NIV, PEG declined – swallow intact but changed over a couple of weeks
- Weekly deterioration – social care providing care agency support
- Identified to CHC as needing complex management – checklist completed and mutual date for DST meeting agreed
- In depth DST assessment completed and care support sought

Difficulties:

- Care agency availability – remote / rural
- Care agency availability – nationwide problem generally
- Blocks of care – more attractive – can sometimes feel overwhelming for patient and family
- Training for care staff – enough trained staff – covering sick leave/holidays etc

Outcomes:

- Timely access to complex care assessment and support
- Tailored care support – meeting the needs and changing needs of patients ongoing
- Better informed care agency staff
- Patient and family members more confidence in needs being met
- Admitted patients – altered the way we refer to CHC – Fast track vs Checklist
- Improved relationship with CHC assessors and MND MDT