A Co-ordinated Approach to CF Care

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Team Context

- CF Care is complex + requires expertise from many different disciplines
- Aim of care is to promote optimum health alongside a good quality of life
- Specialist centres worldwide + organisations such as CF Trust promote a multi-disciplinary team (MDT) approach as the gold standard
- To be effective this MDT expert care must be co-ordinated

Family Context

* CF team must work in partnership with families, each other + local services
* Every child or young person is an individual at the centre of that care
* Parents play a pivotal role between their child + CF team
* Parents deliver the care on a day to day basis, the CF team must remember + respect this

Co-ordinated Care is essential for Families

- At diagnosis parents experience bereavement for loss of 'normal child'+ feelings of isolation + guilt
- Expected to perform complex + time consuming medical tasks on a day after day basis
- Expected to be vigilant in monitoring + assessing child's condition + knowing when to alert CF team
- Live with "chronic sorrow" + adapt to changing adversity (Gravelle 1997)
- Co-ordinated care is essential to enable families to continue to cope + meet the needs of their children

Essentials of Co-ordinated Care

- Effective communication

- Cohesive team work

- Provision of contact point for families which is: easily accessible, approachable, responsive + reliable

- Consistency in advice given – RBH CF Guidelines

Communication

- Persistent liaison between CF team members themselves - local services + with family
- Documentation - written + electronic
- Meeting together verbal exchange – handover + updating re-individual children
- Clinical Nurse Specialists provide frontline contact for families Mon – Fri via telephone = a bridge between hospital + home
- Specialist Registrars (SpR) provide 24 hour on call service

Communication Example Weekly MDT Meetings

Out-patient MDT meeting

* Consultants
* Specialist Registrars
* Clinical Nurse Specialists
  Hospital + Home Care
* Physiotherapists
* Dieticians
* Psychologists

Inpatient MDT meeting

* Team as at OP MDT

  +
* Senior Ward Nurse
* Play Therapist
* Hospital School teacher
* Family Liaison Officer
* Social Worker

Example cont.

Outpatient MDT Meeting

- Home Care CNS present all children visited at home or school previous week
- Doctors present all children seen in clinics previous week
- SpR presents pertinent information relating to children attending clinics forthcoming week

Inpatient MDT Meeting

- SpR / SHO give clinical presentation of all IPs in preparation of walk round ward round
- Children + parents often confide in staff providing practical care
- Forums enable all members of team to contribute relevant information

Team Strengths

- Mutual respect between all disciplines within team + for local services
- Input from all disciplines + individuals is encouraged + valued
- Open honest team culture in which practitioners feel able to ask questions to further knowledge, to offer treatment suggestions + also challenge treatment decisions
- Team that works well together + communicates well within itself is more effective in providing a comprehensive + co-ordinated service to families

Co-ordination of Care = Role of Clinical Nurse Specialist

- First point of contact via telephone service for families caring for children at home.
- Provide continuity, know children + families well - are able to make time to listen to their concerns
- Co-ordinate care of inpatients + at clinics
- Co-ordinate investigations, follow up results + direct to appropriate team member for discussion + action
- Liaise with + act as a resource for local services
- Visit children at home – assess, educate, support, advocate
- Act as 'safety net' e.g. check attending OPAs

Co-ordinated Care Taken into School

- Visit school with parent to educate staff re-CF enabling staff to feel confident in care required + be sensitive to needs but not treat child as an ‘invalid’ ensuring child enjoys school day as close to that of peers as possible
- Advise re-enzymes, cough, physical activity, toilet needs, curriculum issues – sometimes physio at school
- Train staff to perform care to enable child to go on residential school trips. If child wishes talk to classmates about CF

Co-ordinated Care in Transition

- Preparation for transition is long term process for children + families starting at diagnosis
- Prior to transition young people attend at least two transition clinics these are paediatric clinics also attended by the adult MDT
- Transition documentation is collated by CNS + includes contribution from young person themselves
- This information is presented to adult team prior to the clinic
- Adult home care nurse is introduced to young person at joint home visit

Conclusion

* Complex needs require complex care best provided by a team of experts from different disciplines but to be effective in it's delivery that care from individual experts must be co-ordinated

* The CF team has a duty of care to ensure that care is seamless, allows parents to be parents, children to be children + not only adds years to life but life to those years

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