A Co-ordinated Approach to CF Care

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PBS, RBH 2011
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
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

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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

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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

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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

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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
• 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

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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

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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

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Co-ordinated Care in Transition

- Preparation for transition is a long-term process for children and 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 and includes contributions from the young person themselves.

- This information is presented to the adult team prior to the clinic.

- Adult home care nurse is introduced to the young person at a joint home visit.

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Complex needs require complex care best provided by a team of experts from different disciplines but to be effective in its 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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