

Palliative Care in the UK

- brief overview.

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Aim of Talk

- To briefly explore palliative care services within the UK.
- To look at how those services interact with CF services.
- Home care – palliative care.

Palliative Care in the UK

- Variety of settings – hospital, hospices, community.
- All services work closely together.
- Palliative care is not just provided by palliative specialist service.
- Hospital services may go into hospices & community.

Palliative Care in the UK

- Not just used when death is immanent.
- Palliative care teams are experts in many different areas of medical care.
- Resource for other services.

Palliative Care in Paediatrics

- Open to every child, regardless of underlying medical condition
- Can accept children aged 0 – 18years.
- Most children referred will not be expected to live into adult life
- Palliative care team may advise on non terminal care too .

Palliative care and Home care

- These are not the same thing
- Any child can receive home care for variety of reasons.
- Palliative care is for those who are felt to have a limited life expectancy
- Palliative care does not give different level of care - just a different type of care.

Palliative Care in CF

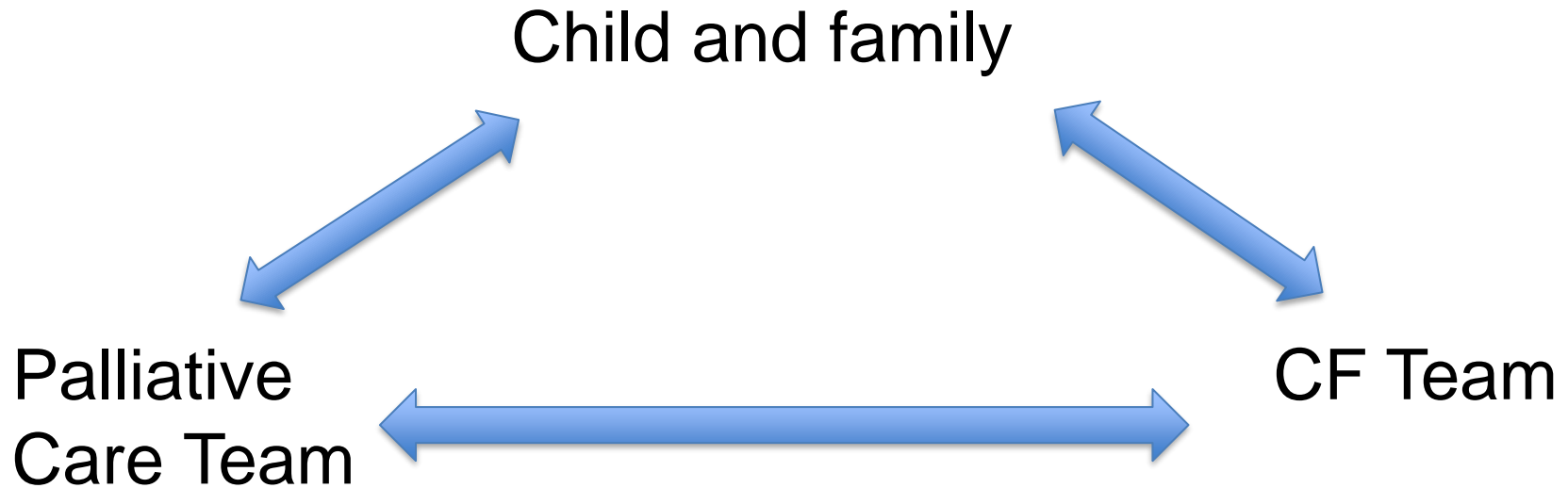
- Increasing life expectancy
- Less likely to require palliative care in childhood.
- Expert involvement in symptom management.
- Will still be involved with sick patients

CF and Palliative Care.

- CF team will usually make the referral , after discussions with the family.
- Important family understand why the Palliative care team is being involved.
- Early referral is best.
- Two teams work together.

CF and Palliative Care

Communication is vital



CF and Palliative Care

- CF team remains as main team.
- CF related equipment
- Specialist Palliative equipment
- Medication – either team

Ventilation in Palliative CF

- All types of ventilation are rare in CF children
- NIV can be used for physio and night time support.
- Care supervised by LTV services
- Equipment comes from LTV service.
- Invasive ventilation

IVs and Ports

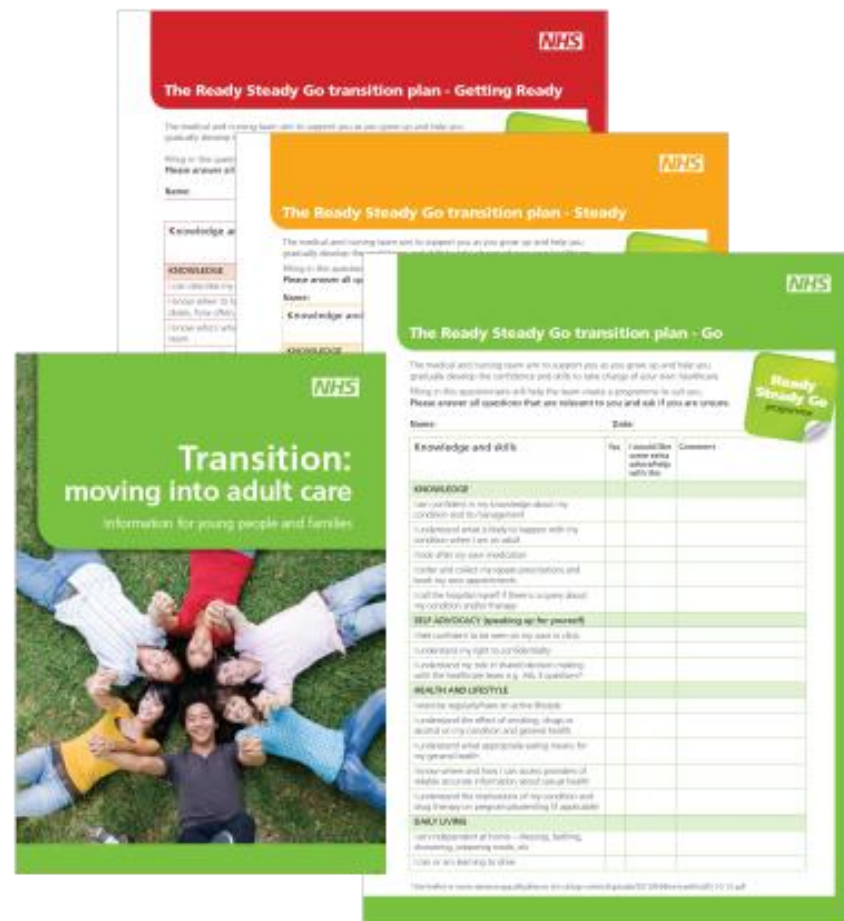
- Management remains the same.
- If at home – community nursing service.
- IVs generally continue.
- If stopped “are you giving up”
- Port management.

Transition

- Whole talk on its own!
- **Ready Steady Go:** Transition Programme

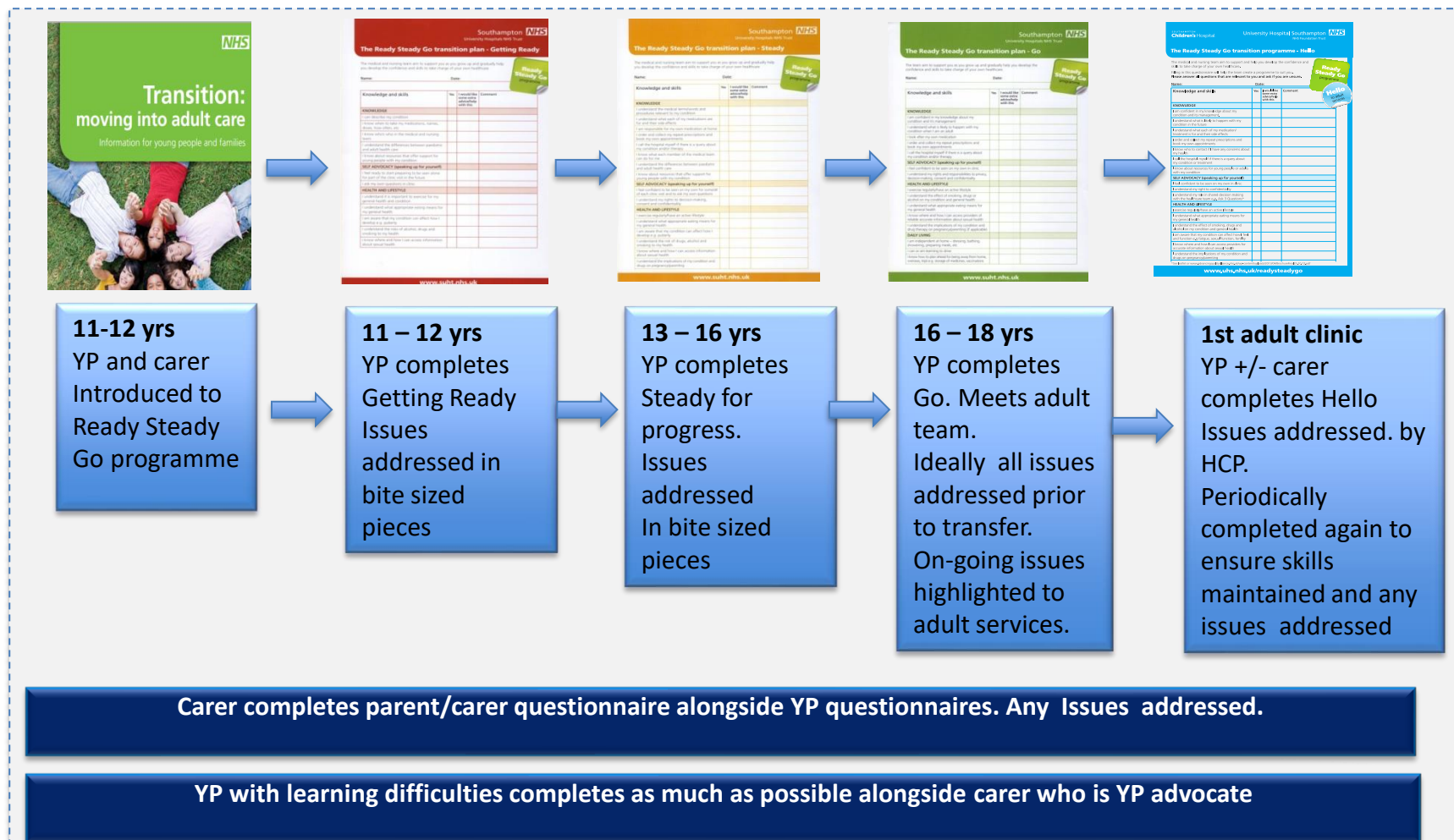
Ready Steady Go: Transition Programme

- Knowledge
- Self advocacy
- Health + lifestyle
- Education/future
- Psychosocial issues
- Transition



Ready Steady Go: Moving through the programme

Ready Steady Go: Each Young person (YP) progresses at their own pace



Transition

- Use of Transition programme.
- Terminal patients likely to stay within service but consider adult team involvement.
- Importance of patient preference.

Summary

- Any child can have access to Palliative care, if clinically required
- Palliative care is rare for CF children.
- Palliative care can take place in the home but is not the same as routine home care.
- Palliative care teams are an amazing resource and can support all aspects of care – at any time.

Thank you for listening

Any questions

