Advance Care Planning

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Why talk about dying?

- Deaths are rare in paediatric services in UK
  - ≤19 years: 8 (49% of total population) (1,464 UK childhood deaths related to chronic disease)
  - ≥20 years: 140 (total pop:10,461)
- Median age at death: 31 years
- Predicted median UK survival: 47 years
- Mortality mostly respiratory related
- Unpredictable disease progression
- Balancing hope of transplant with reality of death
- Active and palliative care, even during terminal stages

UK CF Registry (2016), Lowton 2009, Mitchell et al 2000

Where are we today?

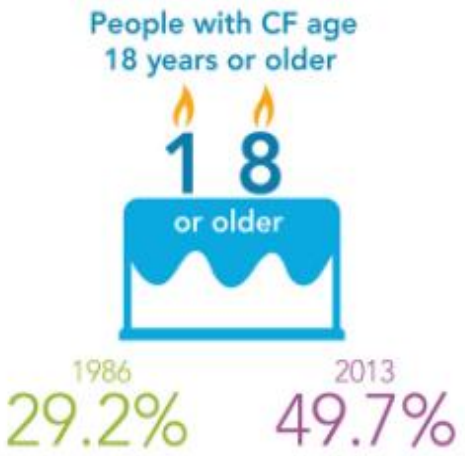
- Remains life limiting
- Few childhood deaths – chronic disease of childhood?
- *'At birth, I was not expected to live much past my teens'*
- *'living with'* not *'dying of'*
- For family, death is a shock

'How have I cheated death?'

Very few people with cystic fibrosis reach the age of 40. Tim Wotton is 39

'Every day has been a battle to stay alive and defy the odds,' says Tim Wotton, pictured here with his wife Katie and son Felix. Photograph: Frantzesco Kangaris

For most people turning 40 is a shock, but for me it will be a revelation. I have cystic fibrosis (CF), and reaching this age was always unlikely. Life expectancy is currently set at 38 years for CF sufferers - though for a long time it was fixed at 30. Reaching my 30s often seemed unachievable, while 40 felt impossible. Not many people with CF in the UK make it this far. It always feels inspirational when someone hits this milestone.



Guardian 2011
CF Foundation 2013 (USA)

Talking about dying

- Most people with CF know they are dying
- Often dealt with own mortality issues
- Grown up with knowledge of prognosis
- Unrealistic expectations? (transplant, gene therapy, new drugs)
- Pick up information from family, staff, internet, media etc
- Patients need to talk about what is happening to them, control

Talking about dying

- Physicians don't talk about what dying is like, uncomfortable talking about death
- Only 28% of CF clinicians ask about end of life wishes
- Patients can talk about death, dying and bereavement with minimal stress and find it helpful
- Adults with CF informally speak to family about wishes in advance
- Patients want to discuss end of life with the MDT member they feel closest to, irrespective of profession

Sawicki et al 2008, Mc Skimming et al 1999, Emanual et al 2004, Curtis et al 2004, Braithwaite et al 2011

Talking about dying

- Lack of training in basic palliative care skills, even in experienced CF clinicians (particularly in paediatrics)
- Many CF team members feel inadequately prepared
- More education requested – CF specific
- Advanced care planning late in the disease process when patients are too ill to participate

Goggin & Cohen 2016, Linnemann et al 2016, Dellon et al 2016, Madge & Sands 2016

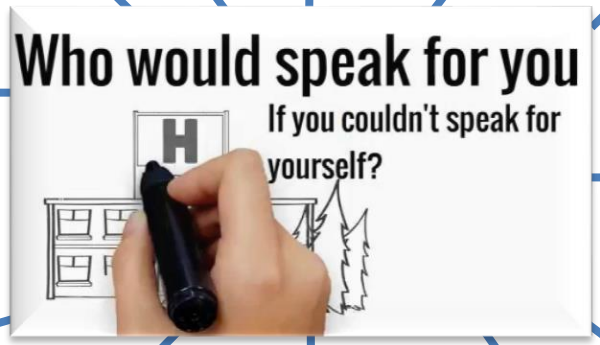
Talking about dying

- Multidisciplinary approach essential
- Symptom control - integration with palliative / symptom care teams
- Psychological / spiritual support
- Encouraging open communication
- Liaising with community services e.g. Hospices
- Supporting patients & their relatives
- Identify and document to avoid repetition or forgetting

Sands et al 2011, Bourke et al 2009

Advance care planning

- Advance care planning
  - voluntary process of discussion about future care
  - between an individual and their care providers - irrespective of discipline
- Recommended that with the individual's agreement the discussion is:
  - documented
  - regularly reviewed
  - communicated to key persons involved in their care



Power of attorney

Transplant

Things that make you comfortable

Preferred place of death

Who is important to you?

What would you want your family and friends to know
(Next of kin)

DNAR/ceilings of treatment (ITU/ECMO)

Will
Financial affairs

Spiritual/religious

Funeral plan
Organ donation

How would you like the team to talk about death/afterlife

Preparing children/memory boxes

Sawicki et al 2008, Steinhauser et al 2001

Advance care planning - RBH

- Partnership with CF Trust
- An open meeting was held with the CF-MDT and hospital PCT
- Several areas of concern were highlighted including:
  - lack of end of life education
  - no formally recognised ACP
  - poor support and a perceived lack of understanding between the team and the PCT about role definition and expectations
- Routinely discuss ACP but informal and not consistently being documented
- Centred on medical management, including ‘Do not attempt cardio-pulmonary resuscitation’ (DNACR), ceilings of treatment and lung transplant status

ACP

- Review of literature, including web based documents already in use by other hospitals, hospices and disease specialties
- Draft document reviewed by the CF-MDT, PCT and Royal Marsden Hospital
- Revision following comments and suggestions
- Reviewed by patients, families and bereaved relatives - comments were reviewed and document revised
- Sent to 7 large UK CF Centres (adult) and 3 UK CF special interest groups, (physiotherapists, psychosocial, clinical nurse specialists)
- Once finalised it was used with a number of patients with a short satisfaction questionnaire to gain further feedback

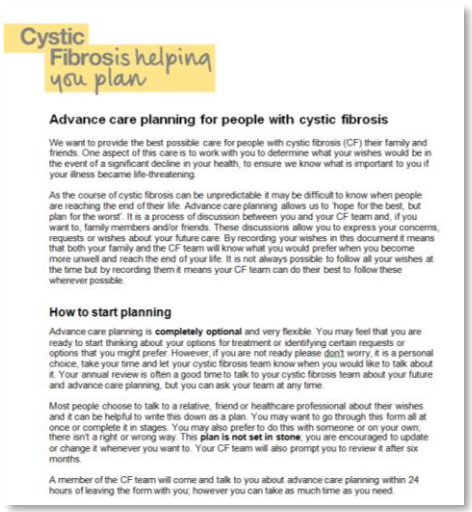
Content

- Next of kin and important people (names of people not to share information with)
- Specific plans for loved ones (memory boxes etc)
- Supporting children, how much involvement, help?
- Psychological support – anywhere
- Transplant
- Resuscitation, ECMO, ceilings of care
- Religion / spiritual beliefs
- Preferred place of death
- Concerns around symptom control
- Any other concerns, specific goals
- Funeral arrangements
- Financial affairs – account numbers, passwords, loans etc
- LPA
- Will
- Documentation and information – on your own electronic records (obvious tab, paper copy, ACP shared, social media etc)
- Organ donation

ACP

- The ACP was introduced in October 2016
- Suitability and appropriateness of each patient is discussed at CF-MDT meetings
- The addition of an identifying tab in EPR allows the ACP to be uploaded and accessible to all members of staff
- Patients are given a personal printed copy and are invited to review or change their document whenever they wish
- Timing

www.cysticfibrosis.org.uk/the-work-we-do/clinical-care/supporting-clinicians/resources-for-clinicians


Cystic Fibrosis helping you plan

Advance care planning for people with cystic fibrosis

We want to provide the best possible care for people with cystic fibrosis (CF) their family and friends. One aspect of this care is to work with you to determine what your wishes would be in the event of a significant decline in your health, to ensure we know what is important to you if your illness became life-threatening.

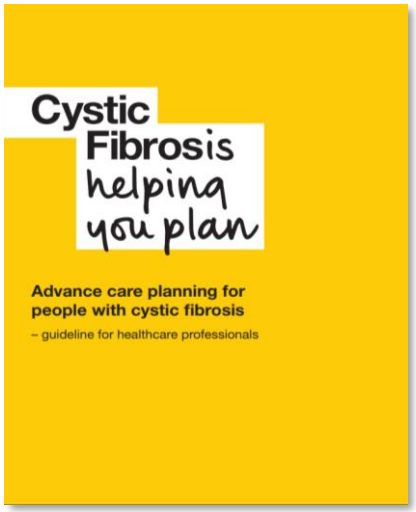
As the course of cystic fibrosis can be unpredictable it may be difficult to know when people are reaching the end of their life. Advance care planning allows us to 'hope for the best, but plan for the worst'. It is a process of discussion between you and your CF team and, if you want to, family members and/or friends. These discussions allow you to express your concerns, requests or wishes about your future care. By recording your wishes in this document it means that both your family and the CF team will know what you would prefer when you become more unwell and reach the end of your life. It is not always possible to follow all your wishes at the time but by recording them it means your CF team can do their best to follow these wherever possible.

How to start planning

Advance care planning is **completely optional** and very flexible. You may feel that you are ready to start thinking about your options for treatment or identifying certain requests or options that you might prefer. However, if you are not ready please don't worry, it is a personal choice, take your time and let your cystic fibrosis team know when you would like to talk about it. Your annual review is often a good time to talk to your cystic fibrosis team about your future and advance care planning, but you can ask your team at any time.

Most people choose to talk to a relative, friend or healthcare professional about their wishes and it can be helpful to write this down as a plan. You may want to go through this form all at once or complete it in stages. You may also prefer to do this with someone or on your own; there isn't a right or wrong way. This **plan is not set in stone**, you are encouraged to update or change it whenever you want to. Your CF team will also prompt you to review it after six months.

A member of the CF team will come and talk to you about advance care planning within 24 hours of leaving the form with you; however you can take as much time as you need.



Triggers to start ACP

- Discussions with the MDT around prognosis, transplant or transplant referral
- Unpredictable disease (history of severe exacerbations, haemoptysis or pneumothorax)
- Some may be keen to start ACP earlier, especially those with children or those who are planning a family
- Readiness to talk

Introduction of ACP

- Patients admitted to the adult CF ward (October 2016-April 18)
  - FEV_1<40%
  - Transplant listed/referred or with another end stage complication
  - Completed with a member of the CF-MDT who had an established relationship with the patient
- Offered ACP during an admission: n=33 (19 female)
  - Median age: 37 years (IQR 30-47)
  - Median FEV_1 % predicted: 28% (IQR 20-33).
  - Transplant listed: n=10, referred/being assessed: n=11, not eligible/declined: n=12
  - Documented ACP: n=26 (79%), partially completed: n=4, declined: n= 2 (n=1 completed own ACP)
- Satisfaction survey completed: n=19 (95%)

Satisfaction Survey n=19

- Pleased to have been approached: n=17 (89%)
  - not sure: n= 2 (11%)
- ACP offered at the right time: n= 15 (79%),
  - not sure: n= 2 (10.5%)
  - should have been done earlier: n= 2 (10.5%)
- Important it was completed with a member of the team they had an established relationship with: n= 17 (89%).
- Member of the CF-MDT who is best placed to complete ACP:
  - physiotherapists (95%), nurse specialists (84%)

Comments

'I found it enlightening and comprehensive'

'Necessary - do it while there is no rush'

'Daunting but necessary'

'The way it is set out is not so morbid, it's direct but not so harsh you can't answer '

'I found it helpful as it made me think about things that I wouldn't have otherwise thought about writing down'

'I think it is important that it is a member of the team that you can trust and easily talk to'

'I think the form should be introduced to all patients with CF no matter how well or ill, as it would have your wishes in place if you were to suddenly become unwell'

'It should always be done by someone who the patient is comfortable talking to and I think it's a very good idea and so do my family'

'The form is a really good idea and think it covered everything'

EoL course

- Joint grant with CF Trust
- Online – hosted on the online CF Course platform
- Accessible via CF Trust website (extra module for CF course)
- Free
- 10 multi-professional speakers
- Disease trajectory, end of life care, introduction to palliative care, transplantation, symptom control, advance care planning
- Experiences of a partner (lecture) and patients – animations and short interviews

Questions for the group

- Are you aware of CF specific training addressing end of life?
- If yes what is your experience of this?
- Do you feel confident in having EoL conversations?
- Do you support colleagues with EoL Conversations?

DNAR

- What are your experiences of DNAR Conversations?
- Do you support this practice? - give reasons for Y/N answers

Advanced care planning

- What are your experiences of ACP?
- CF specific/generic?
- What elements do you address? (wills, funeral planning etc)
- If this is practiced, how often is it reviewed?

For all groups

- What support training would you like to support Advanced care planning and EoL care?

With thanks to the CF team at the Royal Brompton Hospital and the CF Trust