



What NICE NG61 says about ACPs, and how we got there

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Introduction

- Thematic analysis maps of the systematic reviews on:
 - ACPs
 - Communication
 - Information sharing
- Quotes from the focus group of YP that relate to care planning
- The first of the six quality standards released as a draft to stakeholders related to ACPs (final version due 12th Sept 2017)

Quality statements

[Statement 1](#) Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Providing Information Review Question

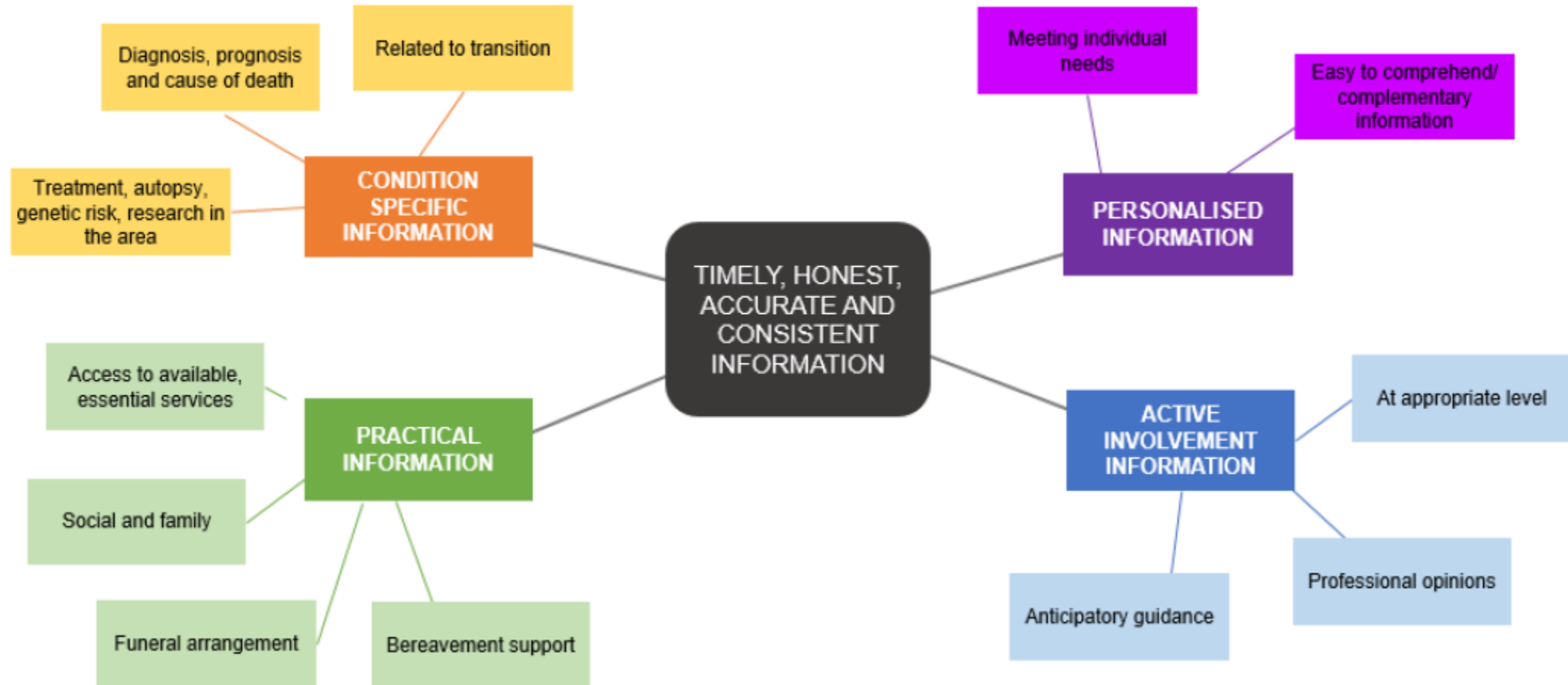
Review question:

What information and information type (written or verbal) is perceived as helpful and supportive by children and young people (if appropriate), and their family or carer before and after an infant, child or young person dies including managing practical arrangements, and care of the body?



Providing Information Themes

Figure 4: Theme map – barriers and facilitators for effective information provision



Providing Information Recs

- **Provide information about child's condition and its management:**
 - Specific to the child's individual circumstances
 - Clearly explained and understandable
 - Consistent
 - Up to date
 - Offered verbally and in writing (where appropriate)
- **Be aware that child & family may be anxious about receiving information**
- Provide information about the family's role in advance care planning, membership of their MDT, all care options available and any resources available to support them
- **Ask the child & family HOW they would like information to be shared:**
 - Topics that they do and don't want to address
 - How much the family feel the child ought to know
 - Review these issues regularly

Communication Review Questions

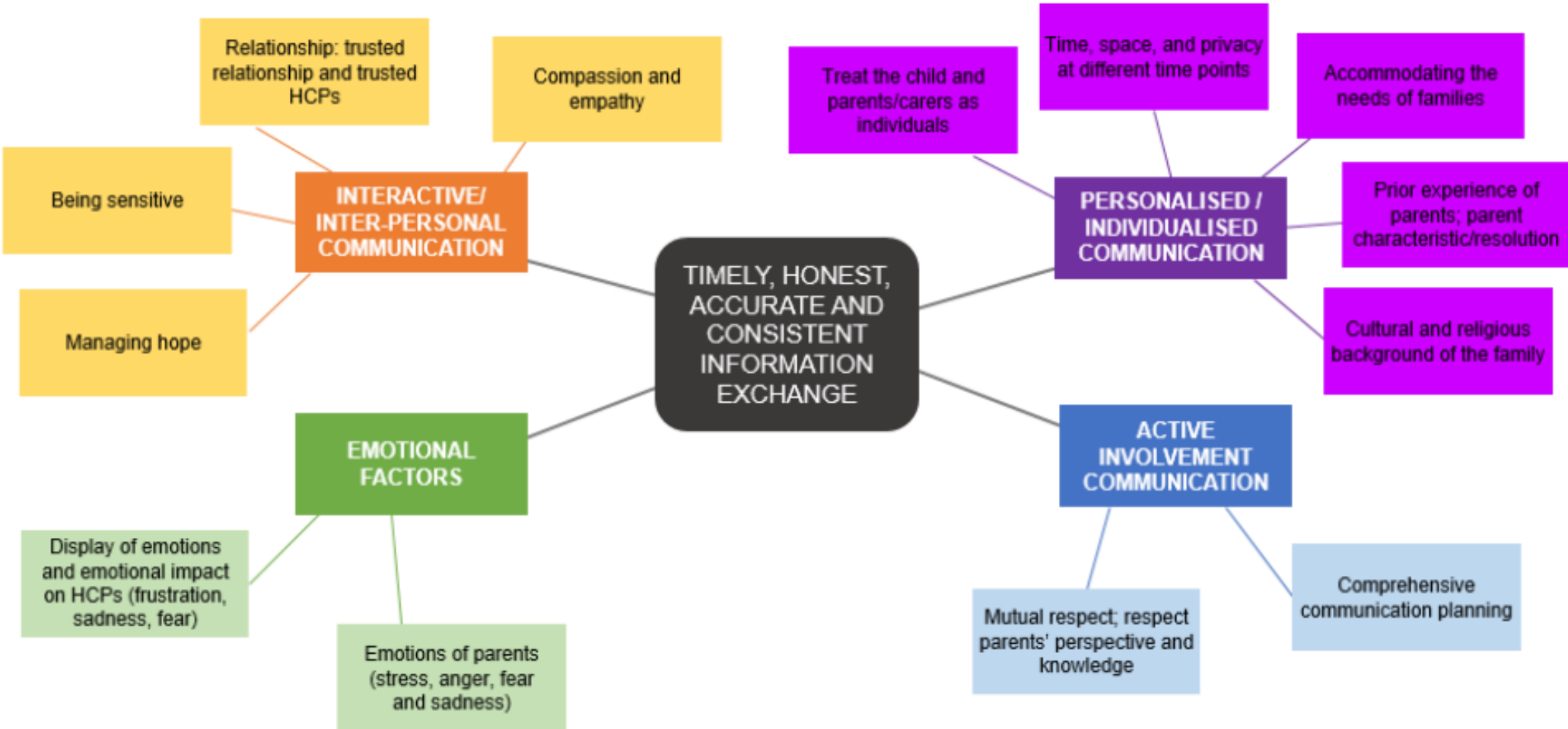
Review question:

What are the barriers and facilitators to effective communication between the child or young person, the family or carer and the healthcare professionals about the life limiting condition and likelihood of imminent death?



Communication Themes

Figure 5: Theme map



Communication Recs

- Allow enough time and opportunities for communication
- **Think about how to provide age / level of understanding appropriate information:**
 - One-to-one discussion
 - Play, art and music activities
 - Written materials and pictures
 - Digital media
- **Take in to account:**
 - Personal and family situation
 - Religious views
 - Special needs such as communication aids or interpreters
- Ask if there are other people important to them who they would like to be involved (friends / boyfriend / girlfriend / grandparents)
- **When choosing who should lead on communication, take in to account:**
 - Their expertise to discuss the topics involved
 - Their availability if frequent discussions are needed
 - The views of the Child or young person & their family
- **Acknowledge the importance of talking about dying and also that families may have difficulty asking directly whether their child is dying.**

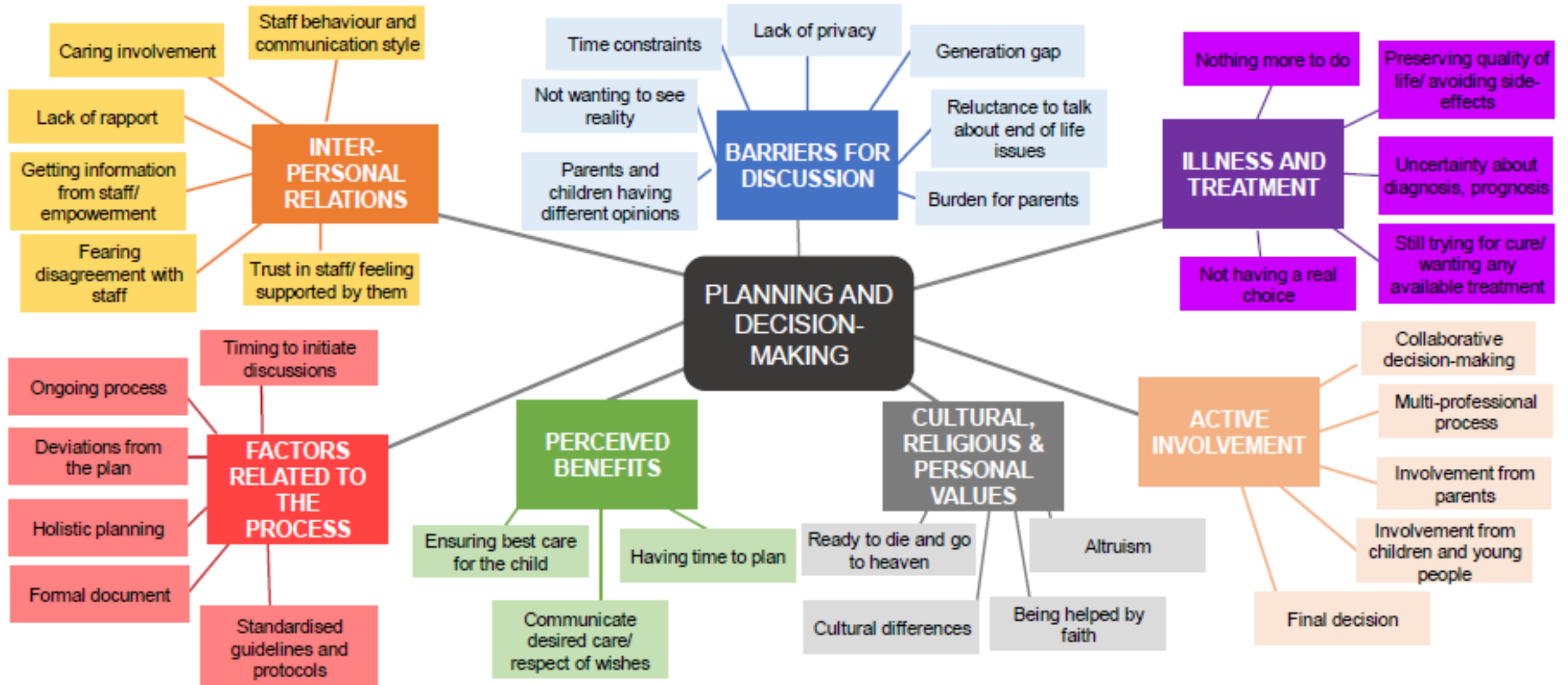
Advance Care Planning Review Question

Review question	What are the barriers and facilitators to the child or young person, the family or carer of the infant, child or young person and the multidisciplinary team in being involved in decision making to inform the development, assessment and reviews of personalised, parallel and advanced care planning (including if appropriate decisions about continuing or stopping life-sustaining treatment and attempting cardiopulmonary resuscitation)?
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Advance Care Planning Themes

Figure 6: At the centre of the map is the overarching theme, which was mentioned as part of most of the other themes and subthemes, and is relevant for Advance Care Planning



Advance Care Plans Recs

- **Recognise that children and their parents have a central role**
 - Discuss how they would like to be involved
 - Explain that they do not have to make decisions alone
 - Take in to account values & beliefs
- The ACP should use parallel planning to acknowledge uncertainty and be regularly reviewed
- **Begin discussing ACP during pregnancy if there is an antenatal diagnosis of a LLC**
- Ensure that the ACP is widely shared
- **Attempt resuscitation unless there is a DNAR in place (no assumptions)**
- Discuss prognosis include anticipated benefits & possible harms of all treatments.

ACP Key 'data set' Recs

- Demographic Information
- **Up to date contact information (Parents / Carers / HCPs)**
- Statement about parental responsibility
- **Summary of life limiting condition**
- Agreed approach to communication (frequency / interpreter / etc)
- **Outline of CYP's ambitions and wishes (may include education plans)**
- Record of significant discussions to date
- **Agreed treatment plans and objectives**
- Record of discussions about
 - Preferred place of care / death
 - Organ and tissue donation
 - Management of life threatening events (Fits, infection, etc)
 - Resuscitation plans
 - Specific wishes about funerals / care of the body after death
- **Distribution list for the ACP**

The Process

- There is a section for each topic in the Guidance called ‘Linking Evidence to Recommendation’, as well as an introduction to each section
- The page references in the full guidance for ACP section are:

6.1	Advance Care Planning.....	139
6.1.1	Review question.....	139
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TfSLs Focus Group

End of life care for infants, children and young people with life-limiting conditions: planning and management

Appendix L: Together for Short Lives Report: Exploring Palliative Care Needs and Provision for Children and Young People with Life-Limiting and Life-Threatening Conditions: a Consultation with Young People

NICE guideline NG61

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TfSLs Focus Group

- 14 young people with LLC aged 12-18 (7 male, 7 female)
- Conditions included SMA, cancer, CF, as well as other rare degenerative diseases
- Interviewed in hospice or at home – focus groups and individual interviews (Bristol, York, London)
- All had capacity to consent
- Predefined themes were developed with the NICE Guideline development committee

Over-arching themes

- **Seeing us as an individual**
 - Most were keen to be involved in care planning – but preference varied
 - Providing timely, personalised information
- **Recognising individual needs and preferences**
 - Participants needs for information varied and changed over time
 - Involvement in planning conversations to the extend desired (only!)
- **Quality of care**
 - Continuity of relationships – particular concerns around transition
 - Feeling heard – not having to repeat oneself / have the same conversation twice
 - Desire to have access to a ‘specialist’ with specific knowledge of their condition
- **Emotional well being**
 - ‘Talking to others’ usually seen as helpful but some expressed and unmet need for this
- **Living as a young person**
 - Access to own technological devices with which to communicate
 - Own peers identified as a useful source of information

Quotes – Seeking information

“I listen to other people with [my condition] ... I have a number of friends with [my condition], I've got three in [my area], so I talk to them quite a lot, because they're all older than me so they have the experience.” (y3, age 14)

“It's very useful having friends with the same condition because you can then swap notes...Me and [friend] are always like talking to each other about different experiences that we've had and, yeah, it's very useful.” (y10, age 17)

“He [my dad] does make them find the answer. They can't get away with not having the answer because they're supposed to be the professionals ... I'm still learning to be an advocate for myself so I don't really know what I'd do.” (y3, age 14)

“I think the doctor should do it first and bring it to you and see if you're happy with it all.” (y14, age 12)

Quotes - Controlling information

“If the doctor isn’t giving you all the information, the doctor’s not being honest. I think that they should give you all the information.” (y3, age 14)

“I don’t need information referring to my disability all the time ... I’m involved with the updates but halfway through I blank out and play games on the computer.” (y3, age 14)

“I wouldn’t always recommend it because sometimes it does give you like big over exaggerated information and that sometimes may cause panic.” (y5, age 17)

(with reference to searching on-line)



NICE Pathway

Information from the guidance can also be accessed by a Pathway on the NICE website:

