ADVANCED CARE PLANNING
PICKING UP CUES FROM PARENTS

MODULE: PAEDIATRIC END OF LIFE

TARGET: ALL NURSES AND DOCTORS

BACKGROUND:

Advances in medical care have led to there being an increasing number of children living with life limiting or life threatening conditions. Currently the majority of these children end up dying in hospital which may not be their preferred choice. The importance of family choice in making prospective end of life plans has been recognised nationally. NHS South England has now produced an advanced care plan (ACP) for children. This ‘purple form’ is only as good as the communication skills of the professionals facilitating the ACP discussions. These discussions should take place at a time and pace appropriate to each family. However, most families feel unable to initiate advanced dare planning discussions and therefore it is important that professionals learn to pick up on any cues parents give as well as in some circumstances initiating the conversation themselves.

RELEVANT AREAS OF THE CURRICULUM

<table>
<thead>
<tr>
<th>ST 6–8 General Paediatric Curriculum</th>
<th>Standard 27: effective skills in conveying and discussing difficult information, including death, bereavement, with young people and their families</th>
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<td>Practise with compassion and respect for children, young people and their families and act as a role model to others</td>
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<td>ST General competencies</td>
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<td>Relationships with Patients</td>
<td>To be able to convey and share effectively difficult or bad news, including end of life issues, with children, young people, parents or cares and help them to understand any choices they have or decisions to be made about ongoing management</td>
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INFORMATION FOR FACULTY

LEARNING OBJECTIVES

- Demonstrate an ability to pick up cues from parents with worries around end of life management
- Demonstrate an ability to recognise blocking behaviours and minimise them
- Demonstrate an ability to listen to and facilitate timely discussions around ACP
- Apply the communication skills learnt to other clinical situations

SCENE SETTING

Location: In a side room on the ward
Expected duration of session: 30 mins

EQUIPMENT AND CONSUMABLES

2 chairs
1 box of tissues

PERSONNEL-IN-SCENARIO

Mother (Julie)
Doctor  (Dr Jay)
Narrator / Facilitator

Can use doll and cannula equipment as props

PARTICIPANT BRIEFING

You are going to take part in an interactive demonstration or goldfish bowl technique. You will observe a scenario be played out in front of you. At a certain point we will stop the scenario and you will be asked to comment on what you have seen. You will then be asked for your input as to how the professionals in the scenario may move things on. You will be asked to make suggestions as to the actual phrases they should use. We will then try out some of your suggestions.
In-Scenario Personnel Briefing

This scenario can run prior to the “Initiating discussions with parents” scenario or on its own

| Narrator/Facilitator | I would like to introduce you to Tina who is 4 years old and a current inpatient. She is an only child and lives with her mother Julie and father Steven. She was born with a severe progressive neurodevelopmental disorder and developed epilepsy at the age of four months. She needs care around the clock as she is non mobile, has gastrostomy feeds and regular fits. She has had numerous hospital admissions for seizures and chest infections and this winter has been particularly bad.

Over the last few weeks she has deteriorated significantly. Her fits have also got much worse and despite changes in medication she is now fitting 4-5 times a day. She no longer smiles and is often drowsy and poorly responsive and is also requiring up to two litres of oxygen at home. She has been having support from the community nurses. She has just been admitted back onto the ward, 3 days after going home with a high fever and difficulty breathing.

Dr Jay has been asked to cannulate Tina for her antibiotics. She is very difficult to cannulate and both she and her mother are getting more distressed with each attempt. I would now like to introduce you to the characters |

| Julie | I am Tina’s mother. I was a teacher but I had to give that up to look after Tina. She is my only child and means the world to me. I am really worried about how ill she is looking at the moment and I am also shattered because of all the time I have been spending in the hospital over the last few months. I don’t want Tina to suffer. |

| Dr Jay | I am a paediatric trainee and I have been on duty a few times when Tina has been admitted. I dread having to cannulate her as it is always tricky. |
Scripted Scenario

<table>
<thead>
<tr>
<th>Narrator</th>
<th>Finally Tina is cannulated in a tiny vein.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor Jay</td>
<td>There we can give the antibiotics now. I am sorry the cannulation was so difficult and distressing.</td>
</tr>
<tr>
<td>Julie</td>
<td>Thanks. I know Tina is often tricky to cannulate but this time it felt somehow different. It seemed just too cruel to have to put her through all that.</td>
</tr>
<tr>
<td>Doctor Jay</td>
<td>I know but at least it’s done now. I’ll just go and get the nurse so she can have the antibiotics right away.</td>
</tr>
<tr>
<td>Narrator</td>
<td>We are going to pause the scene there and discuss what</td>
</tr>
<tr>
<td></td>
<td>What do people feel about that conversation?</td>
</tr>
<tr>
<td></td>
<td>What did Dr Jay do well?</td>
</tr>
<tr>
<td></td>
<td>What do you feel about what Julie said?</td>
</tr>
<tr>
<td></td>
<td>How did Dr Jay respond? What could he have done differently?</td>
</tr>
</tbody>
</table>

Discussion about “Blocking behaviours” and how we unconsciously often revert to discussing physical and practical things as we are more comfortable doing that than discussing emotional issues. Also how naturally we want to get out of difficult situations where we may feel we could have done better (e.g. got the cannula in first time)

After the discussion the scene is taken back to where Julie opens up and run again using suggestions from participants about how Dr Jay might take things further.

Possible subjects to include are

- Why is this time different?
- What does Julie feel about how Tina has been over the last few weeks
- What options does Julie have in terms of Tina’s care
- Has Julie thought about plans for Tina’s future care
- May introduce the idea of an advanced care plan
- Has Julie discussed her feelings with her husband Steven
- How can Julie be supported to be able to open up with Steven
- How to end the conversation with a plan for follow up and permission to share what has been discussed

ADDITIONAL INFORMATION

Background information for the characters
Julie is starting to accept that Tina is probably coming towards the end of her life. She doesn’t want her to suffer any more. She hated having to watch her having cannulas inserted. She wants Tina to be able to die peacefully at home if possible but is scared that she will panic as the time comes particularly if she has major fits. She hasn’t talked about this with Steven as there never seems to be the right time and she is worried that he will want Tina to stay in hospital.
CONDUCT OF SCENARIO

INTRODUCTION

Introduce story and characters

SCRIPTED PART

Run scripted scenario
Participants observe

EXPECTED ACTIONS:
Group to notice blocking behaviours and suggest a more open question or reflection

IMPROVISATION

Julie doesn’t want Tina to suffer any more and wants to be able to get her home of possible.

EXPECTED ACTIONS:
Try to gently elicit Julie’s concerns
Listen then ask Julie for suggestions as what she would like to happen
Encourage her to discuss her feelings with Steven
Explain alternative treatment options

LOW DIFFICULTY

When given an open question Julie is very honest about wishes and worries

NORMAL DIFFICULTY

Julie is upset and needs to be helped to find the words to explain her worries. The doctor needs to use the words dies / dying first as Julie won’t

HIGH DIFFICULTY

Julie gets very distressed and starts crying

RESOLUTION:
Permission needs to be gained to share what has been discussed and Julie needs to be left with a clear plan

OTHER INFORMATION

Be aware of the palliative care option for status epilepticus is a subcutaneous infusion of midazolam or phenobarbitone.
DEBRIEFING

POINTS FOR FURTHER DISCUSSION

- What are cues and what different types of cues do parents give
- What things do we do as professionals that inhibit communication
- What can we do to facilitate communication
- How do you deal with both emotional and physical or practical issues
- What do you do if someone becomes very upset
- What do you do if you feel out of your depth in a conversation
- The importance of sharing information with permission
- How to end conversations

DEBRIEFING RESOURCES

Communication Tips Handout for participants


This gives a copy of the South of England Children’s Advanced Care Plan (ACP) as well as the policy and at the end of the policy is a copy of the parent and young person’s leaflet about ACP.

http://www.endolifecareforadults.nhs.uk/publications/finding-the-words

An adult based work book written by a group of people with life-limiting conditions, and those who have experienced the death of a loved person to help professionals in finding the right words to use end of life discussions. It has some useful ideas also relevant to paediatrics.

http://www.gp-training.net/training/communication_skills/calgary/

Illustrates the Cambridge Calgary model of the medical consultation. Revises basic communication skills.
ADVANCED CARE PLANNING – PICKING UP CUES FROM PARENTS - HANDOUT

INFORMATION FOR PARTICIPANTS

KEY POINTS

• Actively look for cues from parents with worries around end of life management
• Recognise your own natural blocking behaviours and try to minimise them
• Give parents time and space to talk and listen to what they have to say
• Don’t worry if you can solve everything
• Don’t make assumptions always ask

RELEVANCE TO THE CURRICULUM

ST 6-8 General Paediatric Curriculum
General competencies - Relationships with Patients

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FURTHER RESOURCES

See Communication Tips Handout


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Communication Tips Handout

Behaviours that inhibit communication

1. Blocking
Moves the person away from saying how they are feeling and can be done in a number of ways
  - Physical: How is your breathing? Do you have much pain?
  - Closed: Did you tell anyone?
  - Multiple: How are you, is the pain better?
  - Leading: You’ll feel better in a minute won’t you?
  - Defending: I’m sure the doctor didn’t mean to upset you
  - Minimising: It won’t be as bad as you think
  - Jollying along: Come on you have to stay positive

2. Switching focus
This is when some of the content is picked up on but the focus is changed
  - Time: So how do you feel now?
  - Topic: Tell me about your pain
  - Person: And how did your wife feel?

3. Distancing strategies
Here timing matters. The first three are appropriate at some point in a conversation but if done too soon can limit full disclosure.
  - Premature advice: You need to
  - Premature reassurance: You’ll feel better after you’ve seen the doctor
  - Passing the buck: I’ll arrange for you to see....
  - Normalising: Most people feel like you do, it’s only natural
  - Using jargon

Picking up Cues
Cues are things that people say or do that hint there may be more to be explored
Verbal cues may include
  - A mention of psychological symptoms: I am worried
  - Describing physiological symptoms of poor emotional states: Poor sleep / loss of libido
  - Suggesting vague undefined emotions: It feels odd / weird
  - Hinting of hidden concerns: It was difficult
  - Neutral mention of stressful life events: I lost my job / My mum died
  - Repetition: I don’t know how I feel
  - Communication of a life-threatening diagnosis: He told me I had cancer

Non-verbal cues can be crying, sighing, frowning or a look of despair

Exploring cues
Some techniques which can help are
  - Listening and SILENCE
  - Reflection: Repeating the patients words back to them
  - Clarification: What do you mean by that?
  - Empathy: It sounds as if it has been hard for you?

  I see that this is making you very upset
  - Encouragement: Is there something else?
  - Summary: So to recap....
  - Challenge: You said you have no worries but are feeling anxious?

Remember empathy is not understanding from the professional’s point of view DO NOT USE I know how you feel or I understand how you feel.
PARTICIPANT REFLECTION

What have you learned from this experience? (Please try and list 3 things)

How will your practice now change?

What other actions will you now take to meet any identified learning needs?
PAEDIATRICS > Scenario 2

PARTICIPANT FEEDBACK

Date of training session:.................................................................................................................................

Profession and grade:............................................................................................................................................

What role(s) did you play in the scenario? (Please tick)

Primary/Initial Participant

Secondary Participant (e.g. ‘Call for Help’ responder)

Other health care professional (e.g. nurse/ODP)

Other role (please specify):
..........................................................................................................................................................

Observer

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found this scenario useful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand more about the scenario subject</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have more confidence to deal with this scenario</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>The material covered was relevant to me</td>
<td></td>
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How could this scenario be improved for future participants? This is especially important if you have ticked anything in the disagree/strongly disagree box.
FACULTY DEBRIEF – TO BE COMPLETED BY FACULTY TEAM

What went particularly well during this scenario?

What did not go well, or as well as planned?

Why didn’t it go well?

How could the scenario be improved for future participants?