NHS
Health Education Thames Valley

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

ST 6-8 General Paediatric Curriculum General competencies **Relationships with Patients**	**Standard 27: effective skills in conveying and discussing difficult information, including death, bereavement, with young people and their families** Practise with compassion and respect for children, young people and their families and act as a role model to others **Standard 28: effective skills in giving information and advice to young people and their families in common and complex cases** 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

Editor: Dr Andrew Darby Smith
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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

Can use doll and cannula equipment as props

PERSONNEL-IN-SCENARIO

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

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.

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FACULTY BRIEFING

'VOICE OF THE MANIKIN' BRIEFING

No speaking manikin required. Doll can be used as a prop as the cannulation is happening.

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

Each character is given a sticker with his / her name on it and introduces themselves

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

Narrator	Finally Tina is cannulated in a tiny vein.
Doctor Jay	There we can give the antibiotics now. I am sorry the cannulation was so difficult and distressing.
Julie	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.
Doctor Jay	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.
Narrator	We are going to pause the scene there and discuss what **What do people feel about that conversation?** **What did Dr Jay do well?** **What do you feel about what Julie said?** **How did Dr Jay respond? What could he have done differently?**

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.

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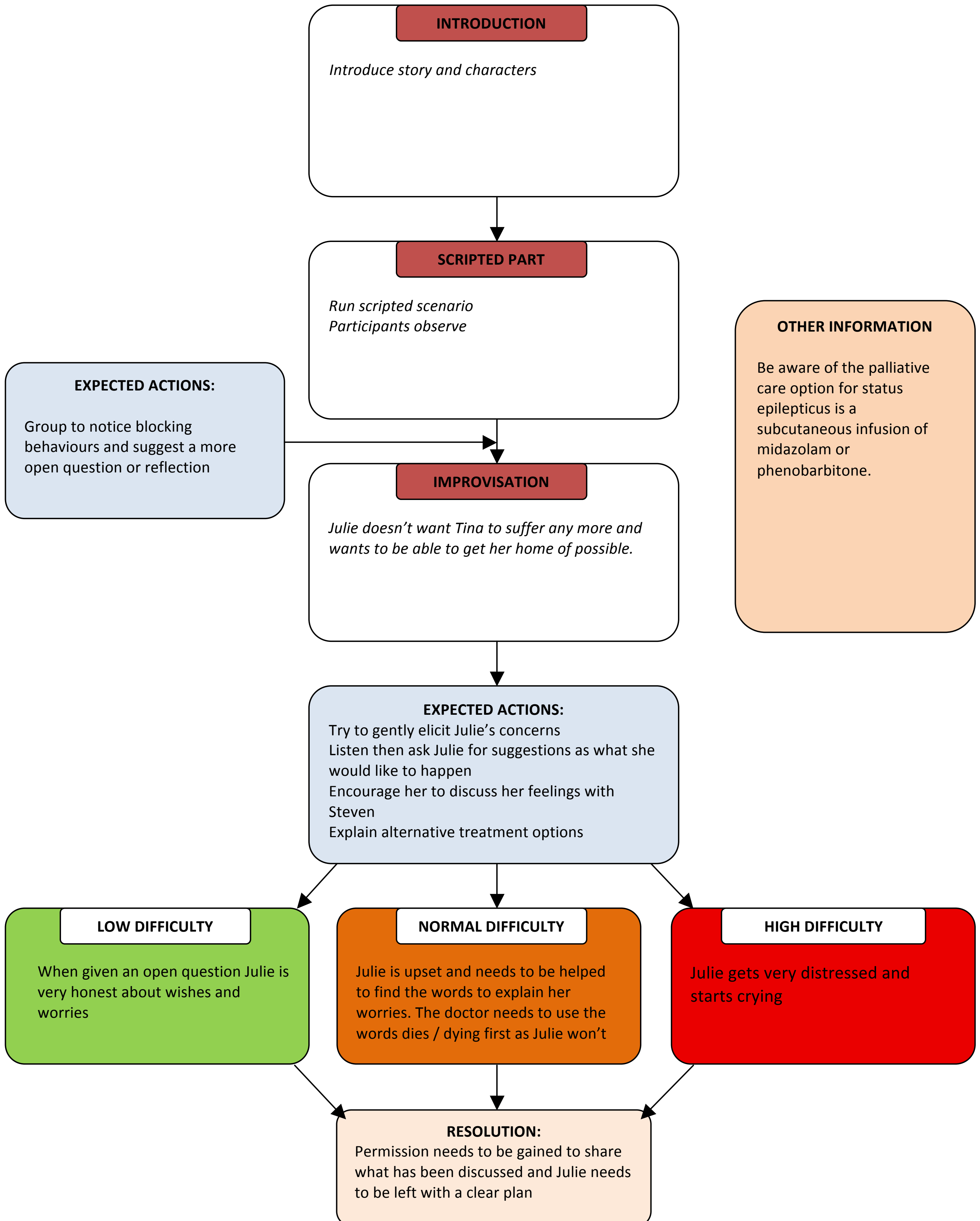
CONDUCT OF SCENARIO



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

http://www.southofengland.nhs.uk/what-we-do/end-of-life-care/central-area-documents/

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.endoflifecareforadults.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.

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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

Standard 27: effective skills in conveying and discussing difficult information, including death, bereavement, with young people and their families

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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.

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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?

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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	

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
I found this scenario useful					
I understand more about the scenario subject					
I have more confidence to deal with this scenario					
The material covered was relevant to me					

How could this scenario be improved for future participants? This is especially important if you have ticked anything in the disagree/strongly disagree box.

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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?

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