

ADVANCED CARE PLANNING INITIATING DISCUSSIONS WITH PARENTS

MODULE: PAEDIATRIC END OF LIFE

TARGET: ALL DOCTORS AND NURSES

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 care 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

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

LEARNING OBJECTIVES

- Demonstrate an ability to open and facilitate conversations around ACP
- Demonstrate awareness as to when families may or may not be ready to discuss ACP and respond appropriately.
- Apply the communication skills learnt to other clinical situations

SCENE SETTING

Location: Quiet room on a ward
 Expected duration of session: 30 mins

EQUIPMENT AND CONSUMABLES

4 chairs
 1 box of tissues

PERSONNEL-IN-SCENARIO

Mother (Julie)
 Father (Steven)
 Doctor (Dr Jones)
 Nurse (Kim) non-speaking
 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.

FACULTY BRIEFING

'VOICE OF THE MANIKIN' BRIEFING

No manikin required

IN-SCENARIO PERSONNEL BRIEFING

Narrator / Facilitator	<p>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 over the last few weeks she has deteriorated significantly.</p> <p>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. She is very difficult to cannulate and each attempt caused her and her mother more distress. Finally she is cannulated in a tiny vein and antibiotics are given.</p> <p>On the ward round Dr Jones asks Julie if it might be possible to arrange to have a chat with both herself and her husband in order to discuss Tina's care. The meeting is arranged for 2pm and Julie is happy for Nurse Kim to also be present at the meeting</p> <p>Since it is midday and the ward round has finished, what can Nurse Kim and Dr Jones do prior to the meeting at 2pm? (5 mins discussion in the group)</p> <p>Two o'clock has arrived so I would now like to introduce you to everyone at the meeting...</p>
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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 and would really like her fits to be better controlled.
Steven	I'm Tina's father. I am an engineer and I have to work all over the country. It's really hard being away a lot of the time and I feel guilty that I am not around enough for Julie and Tina. I hate hospitals they make me feel so helpless. I just want Tina to have the best possible care and just want to protect her and Julie from everything.
Nurse Kim	I usually work as a community nurse but today I am doing a bank shift on the ward. I have nursed Tina on a number of occasions and know her mother quite well. I am upset because I feel that all the attempts at cannulation are just causing Tina more distress than good and I know that the present cannula won't last long. I can also see that Tina is rapidly deteriorating and there is no plan in place as to what should happen. I really don't think that resuscitation would be in her best interests.
Dr Jones	I am frustrated because Tina's regular consultant is away on holiday this week and I have only met the family briefly once before. I feel that time is not on your side as Tina seems to be deteriorating rather rapidly and you happen to be consultant of the week. I worry that in view of her condition and general deterioration that resuscitation would be traumatic and futile but do not know what the parent's views are. I am nervous about the meeting as I don't want to say the wrong thing and upset the parents.
Narrator	The meeting commences
Dr Jones	Good Afternoon please take a seat. My name is Dr Jones and I am the consultant currently in charge of Tina's care. I met Julie earlier today and I know you both know Kim our senior nurse Thank you Steven for managing to come to this meeting. Now I saw Tina on the ward round today but in order to get a better picture I would be really grateful if you could both tell me how you feel Tina has been over the last couple of weeks.

Julie	Well it's been really difficult she just seems to be getting worse and nothing is really helping.
Dr Jones	What do you mean by getting worse? Can you describe that to me?
Julie	She keeps having more fits and not being able to breathe. She is responding to us less and less.
Steven	(Jumps in) Yes and typically her own consultant Dr Graham is away at present.
Dr Jones	That must be really hard for you.
Steven	It is everything feels really out of control. I am not sure what we are going to do?
Dr Jones	Do you know what you want to do?
	Julie and Steven look at each other Julie starts to cry Kim hands her a tissue and Steven puts his arms around his wife.
Steven	I don't know, I just want her to get better and come home with us. I don't want her to spend any more time in hospital.
Dr Jones	What about you Julie, are you able to say what you want for Tina?
Julie	*sighs* I don't know, of course I want Tina out of hospital but it is just so hard to cope with things as they are at home at the moment.
Dr Jones	I see it sounds as if you are both very keen to get Tina out of hospital as soon as possible but that we may need to get you some more help and support in order for that to happen. Is that correct?
	nod
Narrator	We are going to pause the scene there and discuss what What do people feel about that conversation? What good communication techniques were illustrated? What have you seen in the scenario that you think you could use more of in your own practice?

After that discussion the scene is progressed using suggestions from participants about how the doctor might take things further.

Possible subjects to include are

- How to discuss what they would like to happen if Tina doesn't get better
- How to introduce palliative care
- How to deal with parents who have different opinions regarding care
- How to end the conversation

ADDITIONAL INFORMATION

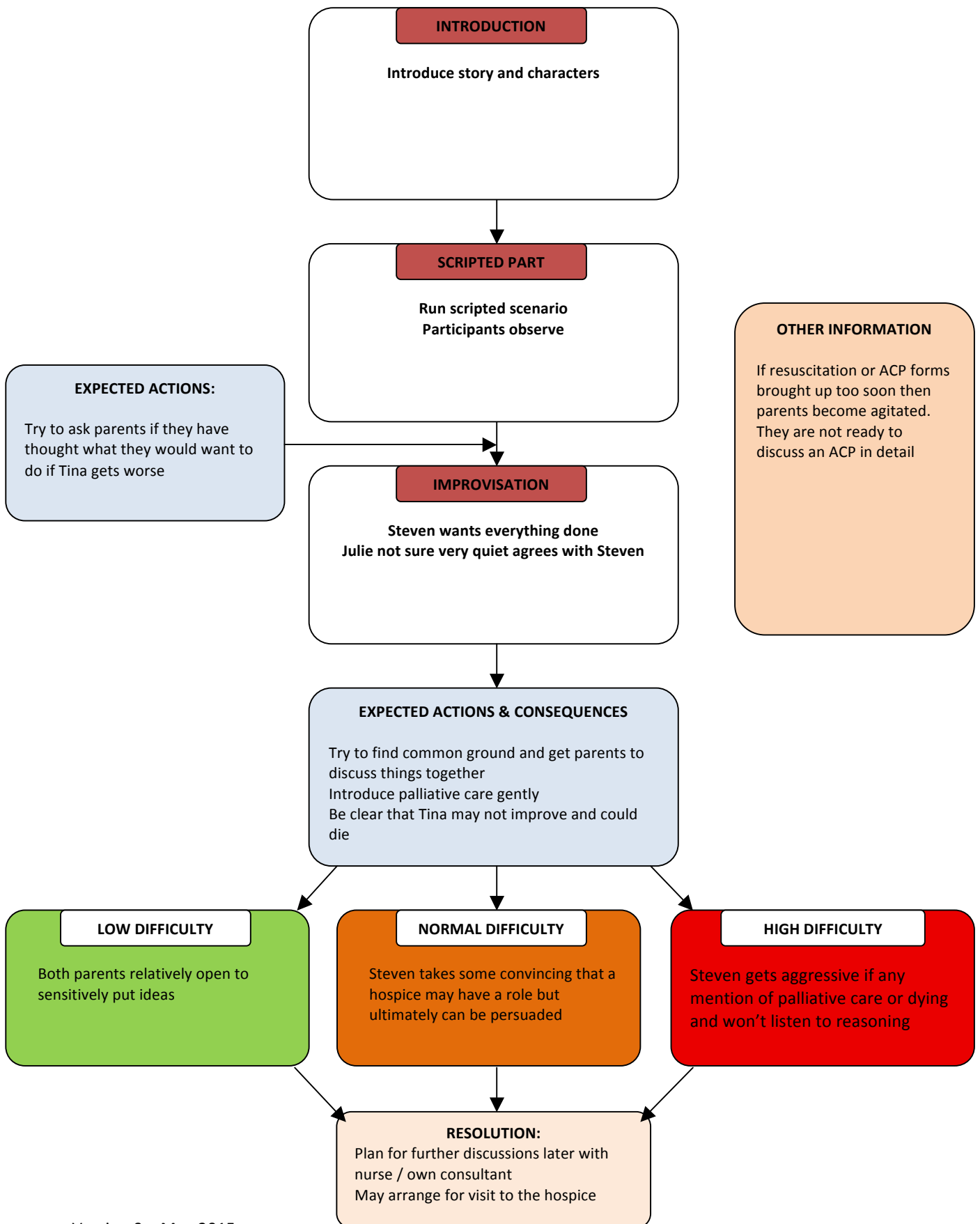
Background Notes for the characters

Julie is feeling relieved that Steven is finally around to make decisions and take charge. She is not sure what she wants at the moment so is happy to let him take the lead. She knows she doesn't want Tina to suffer but she isn't ready to accept that she is nearing the end of life. She is scared that by talking about Tina dying, it will become real. She therefore generally doesn't say much or agrees with Steven.

Steven wants to protect his family and make sure that they get the best possible treatment. He wants everything to be done for Tina although he has never experienced intensive care and does not really know what ventilation entails. Nevertheless he feels that by accepting that the doctors won't do something for Tina, he is giving up on her and failing Tina. He can't do that.

When suggested Julie and Steven are happy to go and visit the hospice and palliative care nurses to be involved. They are also happy to think about things at home and would definitely prefer to discuss plans with their own consultant.

CONDUCT OF SCENARIO



DEBRIEFING

POINTS FOR FURTHER DISCUSSION

What Dr Jones and Nurse Kim could do prior to the meeting

Set up the room – chairs / notice on door / tissues

Arrange for play therapist to look after Tina

Nurse could chat to mother to try to find out where mum is and what she is feeling

Doctor to read through notes find out about disease / prognosis and also about Tina.

Contact her neurologist to confirm prognosis

Make sure that they are clear on possible treatment options both intensive and palliative

Find out the local support and care options and perhaps contact palliative care team for advice or to assist.

Have a discussion together nurse and doctor

Perhaps get an example of the ACP What if ... parent information leaflet or print out an example of an ACP

Positive communication techniques illustrated in initial conversation

Good introduction

Importance of using both parent's names

Body Language

Clarifying comments

'What do you mean by getting worse? Can you describe that to me?'

Empathy

'That must be really hard for you.'

Picks up cue

'Do you know what you want to do?'

Silence

Negotiation

'What about you Julie, are you able to say what you want for Tina?'

Summarising

'I see it sounds as if you are both very keen to get Tina out of hospital as soon as possible but that we may need to get you some more help and support in order for that to happen. Is that correct?'

Other points to discuss

- How to sensitively introduce the concept of palliative care
- How to deal with conflict between parents
- How to deal with anger
- When to introduce the idea of a written Advanced Care Plan
- How to end the conversation

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.

ADVANCED CARE PLANNING – INITIATING DISCUSSIONS WITH PARENTS - HANDOUT

INFORMATION FOR PARTICIPANTS

KEY POINTS

- Preparation before planned conversations is the key
- Do not make assumptions always ask
- Find out what the parents feel and want first
- Do not push parents who don't want to talk about things just sow seeds
- Ensure follow up and a clear plan

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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To be able to convey and share effectively difficult or bad news, including end of life issues, with children, young people, parents or carers and help them to understand any choices they have or decisions to be made about ongoing management

FURTHER RESOURCES

See Communication Tips Handout

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Communication Tips Handout

Advanced Care Planning discussions - 10 top tips

1. Check you are the right person to have the conversation and that the right people have been contacted and are present
2. Check you know all prognostic details and treatment options as well as the palliative care alternatives
3. Planning is a process of conversations not just a one off or a form filling exercise. Can use a staged approach e.g. letting them know the form exists, giving them a leaflet, giving them a blank form etc
4. It should take place when the family is ready and progress at a pace appropriate to them. Make sure you leave enough time to do that.
5. Think about why you are doing each intervention and to what end. Make sure anything you write is practical e.g. Cannot bag indefinitely so it needs to be time limited
6. Do not make assumptions so ask about what they want to know. Ask about tissue donation +/- post-mortem if appropriate. Make sure you know all the facts before doing so by contacting the appropriate people
7. Encourage families to involve the child if appropriate as their wishes are paramount. Give them support to do this but do not force them.
8. Encourage families to think of siblings and give support with talking to them
9. Make sure the information is shared appropriately with permission from the family
10. Make sure you follow up with a family after completing the document to ensure they are still in agreement with it

Finally if you ever see a completed Advanced Care Plan in a patient's medical notes please go through it as if you were a very junior medical professional alone in the middle of the night – could you follow it? If not alert the appropriate person to get it altered.

Dealing with conflict

- Be brave set down the ground rules about listening to both parties and not interrupting
- If necessary interrupt and halt an escalating argument
- Use names and be firm
- Acknowledge differences and then try to bring them back to common ground where they agree
- Try to get them to resolve their differences themselves

Dealing with anger

- Acknowledge the anger You seem to be very angry
- Understand the cause Can you help me understand what is making you so angry?
- Listen
- Focus on feelings
- Use empathic statements
- Apologise if appropriate and offer some way of improving the situation
- Do not become defensive
- Try to negotiate a mutually acceptable solution

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?

PARTICIPANT FEEDBACK

Date of training session:.....

Profession and grade:.....

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

Primary/Initial Participant	<input type="checkbox"/>
Secondary Participant (e.g. 'Call for Help' responder)	<input type="checkbox"/>
Other health care professional (e.g. nurse/ODP)	<input type="checkbox"/>
Other role (please specify):	<input type="checkbox"/>
Observer	<input type="checkbox"/>

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
I found this scenario useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand more about the scenario subject	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have more confidence to deal with this scenario	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The material covered was relevant to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?