Cases for Difficult Conversations Workshop

9th May 2019

# Case 1

After many weeks during which her parents felt she was developing too slowly, Danielle is diagnosed with Lobstein’s disease at the age of six months. The natural history of Lobstein’s disease is progressive neurological deterioration to the point where a child is no longer aware of her surroundings and ending in death before the age of 18 months, usually as the result of respiratory failure.

As Danielle approaches one year of age, you are introduced to her family by the general paediatric team who ask you to take forward advance care planning.

**Questions:**

* Is this an appropriate request ?
* If not, why not ?
* How, in practice, do you take it forward ?

*RH comments: ACP should usually be led by the team most familiar to the family. This is an appropriate request, however, because the general team has not developed a close relationship with the family and the likelihood is that palliative care will be key team caring for this child for the rest of her life. It is reasonable for palliative care to take the lead in ACP when the role of other teams is subsidiary. The same would not be true if this were a child who was already well known to the neurology team for example.*

*There are lots of right ways to take this forward. Main thing is that there should be no hurry, and that the family is given plenty of time to think about the issues over several visits that are spread a fair time apart. Important role for specialist PC nurse (less threatening than doc in early discussions) but also important that doc is involved in process in timely way once family is comfortable. Importance of setting out principles of benefit and harm from the outset.*

After a few meetings with the family, you introduce the ideas of harm and benefit and the idea that some interventions might do more harm than good. The family seems to understand the issues. You leave them with a copy of the PAC-Plan to look at and invite them to come back to you with any questions they might have. A few weeks later you ask if they have completed the form. They reply that they have not yet done so and need more time.

**Question:**

* What are the possible reasons the family feels they need more time ?

*RH comments: Of course there could be an almost infinite number of reasons, including simple practical ones like not finding enough time (or not finding enough time for both parents together). The key ones for people to identify are that parents might be finding it hard to bring themselves to think about it, or that they might have discussed it between themselves and found they disagree.*

Some weeks later, the nurse on your team tells you that she has now completed the PAC-Plan with Danielle’s family at home. It advises that when Danielle deteriorates she should have comfort measures only. You agree that sounds reasonable and arrange to see the family at home. When you meet the family again, however, they explain that they still want to think about it more and are not quite ready to return the document to you. Over the next few months, you visit the family several times. Each time, they explain that although they are quite happy with what they have written, they have not signed it. You are becoming increasingly worried, because Danielle’s health is continuing to deteriorate and it is beginning to look as though she is approaching the end of her life.

**Questions:**

* Why do you think Danielle’s parents are reluctant to let you have the PAC-Plan, even though they have completed it ?
* What would happen if Danielle were to die before her parents have signed the PAC-Plan ?
* What is your response ?

*RH comments: The main thing here is to recognise that signing the PAC-Plan has a significant emotional burden for many families. For some, that burden is so great that they are not able to sign PAC- plan, even if they are ‘happy’ with its content. The important thing for clinicians to remember in that situation is that it is the discussions, and not the signature, that represents the purpose of the PAC-Plan process. It is not the end of the world if Danielle dies without the PAC-Plan having been signed. The signature is helpful but it is not legally necessary.*

*It would be wrong to insist on a signature if that would damage the family’s own coping mechanisms. One solution would be to circulate the PAC-Plan without a signature (it would still need parents’ permission to disseminate). Another would be to summarise the relevant points in a letter, email or phone call to the relevant people.*

# Case 2

You are a paediatrician. During one on-call night you are contacted by the locum paediatric intensive care (PICU) consultant. He tells you that a 13-year old girl under your care has developed yet another severe chest infection (her fourth in the last six months). The PICU consultant has been asked to review her on the ward to consider escalation of ventilatory support. The PICU consultant already knows the child, who has severe cerebral palsy. She has had a slowly increasing number of admission to PICU over the years and is not expected to live for more than several months or, at most, a small number of years.

**Questions:**

* Do you think PICU is the best way forward for this patient ?
* What are the reasons for your answer ?

*RH comments: the key thing here is that there isn’t really enough information yet to make the decision one way or another. The frequency of chest infections and the estimates of her prognosis makes it reasonable to ask the question as to whether PICU would be of benefit, but on its own it doesn’t provide the answer because at least two things are missing; an idea of the quality she herself considers her life to have and an idea of how her parents understand the situation. A PAC-Plan should, of course, ideally provide both of those.*

You advise the PICU consultant to access the patient’s electronic notes to read the PAC-Plan. In the PAC-Plan, her parents have expressed that they do not want escalation of care beyond face-mask oxygen and suction. On that basis, he explains, he is not planning to review the child on the ward because the decision not to escalate has already been taken.

**Questions:**

* Given that the PAC-Plan asks for no esclation, is it reasonable to ask the PICU consultant to reiew the child ?
* Is there anything else that might be relevant ?
* What is your response?

*RH comments: the key thing here is that having a PAC-Plan does not automatically rule out escalation, even if that is what parents have said they want. That’s true first of all because parents can change their minds and secondly because the child’s own interests at the time an intervention is considered override any preference her parents might have experessed in the past.*

*It is never acceptable for a doctor to refuse to assess a patient when asked to do so (assuming the assessment is within his field of expertise). In this case the decision to escalate or not required more information than the PAC-Plan alone could offer, and the PICU consultant was being asked, on the basis of his expertise, to provide that additional data.*

# Case 3

Jack is a child of normal intelligence but with severe restriction on his physical movement as a result of cerebral damage at birth. There was a generous legal settlement running into several millions of pounds, and Jack’s routine care is provided by a private healthcare company. Although the condition is not progressive and there have been no episodes of seizure or chest infection, or indeed any other serious illness, Jack’s parents have always struggled to come to terms with having a disabled child and her mother in particular has had episodes of depression which she has attributed to that cause.

**Questions:**

* Why might Jack’s parents find it difficult to ‘come to terms’ with having a disabled child ?

*RH comments: In the first question I am anticipating that many participants will feel that Jack’s parents should by now have adjusted to being parents of a disabled child. The point here is to remind ourselves how relentlessly difficult it is to care for a child with physical disability. The remarkable thing is the extent to which most families thrive and find caring for their child a positive experience – it should not surprise us that some families don’t.*

At six years old, Jack needs to have a spinal operation to correct scoliosis. One of the services Jack’s healthcare company offers is end of life care planning, and in preparation for Jack’s operation they have generated what they call a ‘Wants and Wishes’ document explaining that Jack’s parents would prefer that in the event of cardiorespiratory arrest no resuscitation of any kind should be carried out. They have asked that the Wants and Wishes document be laminated and kept in Jack’s medical notes. His paediatrician, who at this point expects Jack to survive well into adulthood, asks you to start formal PAC-Planning discussions with parents.

**Questions:**

* What is the status of the Wants and Wishes document compared with the PAC-Plan ?
* Do you agree with Jack’s parents, and what are your reasons ?
* Is the fact that Jack’s intelligence is normal relevant ?
* Is there anything else that might be relevant ?

*RH comments: I am anticipating that many participants will feel that Jack’s normal IQ automatically means he should have full resuscitation, either because they equate normal intelligence with full personal value, or because they link it with a good quality of life. I’d like to encourage them to think about IQ as just one factor among many that has an impact on the sort of action that will benefit or harm a patient. It’s also relevant because, if he can express them, Jack himself might have preferences in the matter.*

*The key thing here is that the family might have something to gain from Jack’s death, especially if his mother blames his disability for her own depression or if the financial settlement would pass to them if Jack were to die. They are not necessarily considering Jack’s own interests.*

*The fact that they asked for the Wants and Wishes document to be laminated suggests how important it is to them but in fact it has no authority beyond what any note written in the notes by a doctor might have. One key thing for people to realise is that that is largely true of the PAC-Plan as well – it is not a legal document. But a PAC-Plan signed by parents and consultant is more likely to be read, and acted on, by people needing to make decisions.*

# Case 4

At the age of two Jonathan suffered catastrophic brain damage as a result of non-accidental injury on the part of his father. His mother, who has learning difficulties, was not a party to the injury.

Now ten, Jonathan is in full time care, with parental responsibility being shared between his mother and social services. His father is no longer on the scene. Jonathan has had many years of repeated hospital admission for seizures and chest infections which have needed increasingly long episodes of invasive ventilation. Knowing that, the community paediatric consultant caring for Jonathan feels he is reaching the end of his life and asks you to take forward PAC-Planning. When you meet Jonathan’s mother, she expresses clearly that she wants ‘everything done’ for Jonathan and ticks all the boxes including cardiopulmonary resuscitation and invasive ventilation.

**Questions:**

* Do you feel Jonathan’s mother is right to want ‘everything’ to be done for her son ?
* What are your reasons ?
* Is there anything else that might be relevant ?

*RH Comments: I’m anticipating that there will be different views about this and it’s more important that participants set out the justification for the position that they take than that they should agree. Hopefully some will approach it as a balance of burden and benefit, while others will consider his mother’s authority to make the decision and/or have a preference in the matter.*

*Participants should pick up on the fact that Jonathan’s mother has learning difficulties, and address whether that is relevant – even whether it means her views can be set aside on the grounds that she lacks capacity. The key message here is that the PAC-Plan is not about giving legal permission – it is about engaging the right people in the discussion. His mother’s views are not binding, but irrespective of whether or not she has capacity her views are relevant and important.*

You are contacted by social services, who tell you that they disagree with Jonathan’s mother and that, in their view, in the event of an acute deterioration there should be no attempt at invasive ventilation.

**Questions:**

* How do you go about dealing with the situation ?
* You discover that social services has ‘overriding’ parental responsibility. How, if at all, does that change your approach ?

*RH comments: A reminder that the PAC-Plan is not a legally binding document and that, the key thing is that, irrespective of the legal situation, the PAC-Plan should be an opportunity for both points of view to be explored. There needs to be a joint meeting with all ‘stakeholders’ present.*

*The question of overriding parental responsibility is interesting. It makes no difference to the legal authority of the PAC-Plan (it has none) although it does mean social services can give permission for data to be shared. But the reason for giving overriding responsibility to social services might be relevant because it might uncover something that suggests Jonathan’s mother is not able to balance harms and benefits appropriately, in which case her opinion about his interest is more likely to be wrong. The key thing here is that his mother’s opinions are not invalid just because she does not have PR.*