

Planning dementia care through case conferencing

Transcript

Elsbeth Correy: Using case conferences to manage conflict (long)

A facilitated case conference can be useful when you've got different ideas in a family or between family and staff about a particular care issue.

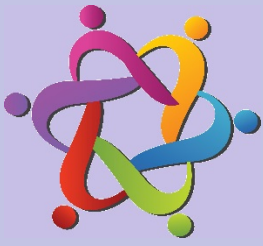
So in the setting of advanced dementia, the main type of things that I find that there are disagreements around are nutrition / hydration; whether someone should be hospitalised when they become unwell; whether you treat infections or not; and the other issue is around symptom management, how you can get adequate symptom management say for something like pain vs the side effects and adverse effects that you may get from some of the medications.

What you really want to do is make sure you are prepared beforehand, that you are all coming in prepared, particularly when you are anticipating there's going to be some conflict within the situation.

The planning includes

- making sure the family can attend, that you give them enough warning
- that you've given them the pre-family conference questionnaire so that they can think beforehand about the issues that you've already said are going to be discussed in the meeting
- that you can actually also ask your care team if they've got any information that they'd like to have brought forward at the meeting and that you've decided very deliberately who you'd like to have at that meeting so that's one part of the preparation
- The other part is making sure when you actually start the family meeting, that you've got a clear agenda and that you are going to be sticking to that agenda within the meeting
- You also make sure from the information that you've got from the family, that any medical information that you have, any results, anything like that, you've already got that available so that you are not caught off guard.

After that, the next thing is to be aware that in situations where there's conflict, you are likely have high emotions and that really can be an issue, reflect on that and put it in check, think about other people within your care team who are going to be attending the conference and get them to check their emotional responses as well and be aware that



Planning dementia care through case conferencing

you may be meeting some quite hostile responses perhaps or emotive responses of the family members and to think to yourself how you are going to handle those.

Once you've done that, then you can get to listening to the family members so we use what we call '**active listening**' which is making sure that you are listening to understand and that you can reflect back to each person what they're saying. So you give them an adequate and balanced amount of time to say their piece. If there are members who are not contributing, you may reflect back what another family member has said and say "what do you feel about this?" So you do make sure that each person has had the opportunity to say something and also to be heard to reflect back that you've understood what they're needing to have said at that time. Another thing in making sure that they're feeling heard is the documentation that they know what they've said is being documented.

Acknowledging the emotional side of the responses too, when you are listening to someone is really important because as we've said, talking about some of these things - which is for the person who you are caring for, is moving towards a matter life or death, that they really are emotive, and I always check in with the family to say "I understand that you are the advocate", but you all need to make sure that the best care possible, can happen in this situation.

So when you have a family meeting, you're wanting to come up with a plan. The plan may not always be an agreement at that stage, but we talk about it and negotiate a plan. You are wanting to do 'shared decision making' where it is very obvious that you've listened to and are seeking to incorporate the information that you have been given from the family. The other really important thing though is to have **accurate information about the medical issue** at hand so the decision is to include what is appropriate medically. That may include what you've heard back from the hospital, it may include getting some resources on things like tube feeding to give the family information. So you put all that altogether and on the basis of that, you would work out a plan going forward: There may be the need for a meeting again; it may be we have decided "this" at the moment.

A time when I've seen this type of issue is when we had someone come back to the aged care facility. A lovely Italian lady with an Italian family Anna had advanced dementia where she had been bedbound for some years, was nonverbal, had had problems with swallowing for long time and she came back to the facility after some time in hospital when she had a choking episode. In the discharge summary it actually said "unable to have goals of care discussions with family because they did not want to discuss any limitation of treatment and they wanted that discussed again when she came back"



Planning dementia care through case conferencing

So there are the issues around not even wanting to talk about 'not for resuscitation'; wanting to still look at the idea of tube feeding for their mother and still wanting her to go to hospital.

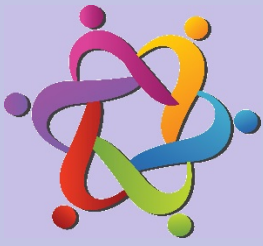
So I've sort of worked out a word 'stay CALM', 'be CALM' that we can use to help us remember the different steps going through this.

The 'C' in calm is **come prepared**. So in the situation with Anna, we would ask the family to do the questionnaire and also for the team members to do that as well. We would make sure that we would have the information on tube feeding, on CPR and on what is the appropriate way to introduce that and talk with that with the family of someone who has advanced dementia; that we'd have up to date assessment of Anna's dementia, where it was in the trajectory of dementia and decline. We would come with that information. The beginning of the meeting we would let them know and go through again what the meeting was for.

A in CALM is for being **Alert to emotions**. Then when we're talking about the emotions, we would be checking ourselves, checking them, I mean tube feeding isn't something that I would recommend but I have to realise that for this family, they may have a different approach. So putting all those things into line and perhaps talking with my other team members and saying "what do you feel about what we are discussing now?"

Coming under that is **L for listening**, then you would be doing the **active listening**. So in this family's case, this Italian family, we would be exploring not only what they've brought up in the preconference questionnaire, we would also be saying "from a cultural, from a personal and from a religious point of view, how does that influence how you're feeling about these decisions?" and when I talk to this family about that, beautiful information came out. I find out that for the husband, his life is his wife and always has been. It was devastating for them when she had to go into care because she had really bad behavioural problems, but for the last few years she has been comfortable and bedbound and quite calm and he very much enjoys going and spending so much time with her every day and he really does feel that she has quality of life. She enjoys being with him, he enjoys being with her.

From the point of view of the quality life being that the doctors and the hospital said "she has no quality of life" he disagreed with that. So we agree that for him, there is richness in the ongoing relationship and in the personhood of that situation. We then hear from the family that their father's parent's died on the same day when his mum died, his dad died of heartbreak the same day and the family all think the same thing is going to happen with them.



Planning dementia care through case conferencing

You've got a lot of layers of emotion that are under this issue of going to hospital and this issue of keeping on being fed. You've got one son who's got on the internet now and had a look at tube feeding and he realises now that it's not the right thing for his mum but the others still feel that their mum's being denied appropriate treatment.

M in CALM is for make a plan. So you go through and you hear those emotions, you go through and hear what's important for them and how important their relationship is and then on the basis of that, you go to **make a plan** and you would give the appropriate information on tube feeding, you give the appropriate information on CPR not being appropriate in that situation and you would let them go through that 'the best care in this situation would be supporting her within the facility' and when they feel that you are on their page rather than the other way around, they may well be able to come around to a plan that would incorporate some less active treatment in that situation.

This is a transcript of Elspeth Correy: Using case conferences to manage conflict (long) video. To view the video visit www.caresearch.com.au/DementiaCare