Transcript Topic 1

Multidisciplinary care

Betty's story

Betty's story
1 min 31 sec

Betty: I'm seventy-nine years old and about two years ago my doctor told me that my kidneys were not working properly. He sent me to a renal specialist and he told me I had stage 3 chronic kidney disease. Now I have diabetes and high blood pressure, but I had no idea that my kidneys were not working, so I'm on a special diet and taking tablets. And Alan, Alan's been so good, making most of the meals. My daughter Cheryl has been popping in from time to time, keep an eye on me, and check up on me and she brings our lovely grandsons, and they certainly cheer me up. The team at the clinic have been very supportive; they've told me that overtime this kidney function will only worsen and I do understand that I'm not going to get better. Actually, I'm worried about what's happening at the moment. I'm tired all the time, my legs are swollen, I feel sick, I can't eat. I think I'll have to talk to Leanne and make a decision about what is going to happen when I'm sicker.

The team meeting
4 min 31 sec

Gillian (Nephrologist): Well Thanks for coming everyone and Chris is online.

Chris (Clinical Psychologist): Hi all

Leanne (Nurse practitioner): Hi Chris

Gillian (Nephrologist): Let's start with Betty Harrison. Now I saw Betty and Alan last week and things have really deteriorated. Leanne would you like to start?

Leanne (Nurse practitioner): Yeh, Thanks, I am concerned about Betty, her kidney disease has progressed to stage four. So I would like to discuss her symptoms management and end-of-life care for Betty.

So she's seventy-nine years of age, she's a diabetic type two, she has ischemic heart disease, and had a myocardial infarction about two years ago and has peripheral vascular disease. When we saw her in clinic last week and she had quite a few symptoms including lethargy, oedematous legs, some slight shortness of breath. She was hypertensive and has also been experiencing some nausea in the mornings.

So let's start with a review of our plan with Betty's management of her co-morbidities and some of these symptoms.

Tony (Pharmacist): Last week we noticed quite a difference in Betty. She raised some concerns about the number of medications she's on; she's starting to get a little bit muddled. So I did a medication review, looked at all her medications, sent her home with a list of them all. I need to flag though that we're going to need to start withdrawing her medications in the not too distant future and obviously we'll have to do this very carefully given all her co-morbidities.

Gillian: So let's review her medications at each team meeting okay? We'll address those polypharmacy issues as they come up.

Tony: That sounds good, but for the new symptoms we've started her on a diuretic and just adjusted the dose of her ACE inhibitor as well.

Leanne: Yeh and we've decided to start her on an erythropoietin-stimulating agent. So hopefully this will give her a boost just to help to make her feel a little bit more energetic and less symptomatic with the tiredness.

Tony: So I think we've pretty much got her on the right medications at the moment. I'll see her again in a week or so, and she knows if there are any problems to contact us. Hey Jane!

Leanne: I'd also like to look at some non-pharmacological measures as well and I'll write those into her care plan. So Jane let's talk later about some strategies to help manage Betty's activities and her rest.

Are there any more comments/ questions about her symptoms?

Team: No

Leanne: Alright well I'd like to talk about Alan and Betty's emotional wellbeing. Gillian, how was your meeting with them?

Gillian: Well I spoke to them both last week, and talked to them about end-of-life care and what Betty does and doesn't want. She asked me about dialysis and in particular wanted to know if it might improve her quality of life. So, I spoke to them about her co-morbidities and explained to her that for her dialysis might not extend either quality or the length of her life.

Pamela (Social worker): It's a lot for Betty to take in. How did she respond to that?

Gillian: It was a lot for her to take in and she was quite overwhelmed by the change in her condition.

I reassured both of them that there's no rush to make any decisions and that our team will be there to support them through the entire process. She seemed certain by the end of session that she wants conservative management with supportive palliative care at end of life. I'm not concerned about her decision-making capacity and I'm fairly confident she's not clinically depressed. But I did refer her to Chris for a psychology review because it gave her a chance to talk about it all. So Chris would you like to fill us in please?

Chris: Hi all, I was able to see them yesterday and Betty was quite settled and as you say she isn't clinically depressed. She does have a good understanding of her situation, we talked about symptom management and her options around palliative care. Betty was quite clear, she doesn't want dialysis and she would like to die at home.

Pamela: Hi Chris, it's Pam here. Sounds like you've had a good session with Betty.

Pamela: In light of these end-of-life discussions it would be good to see Betty for some advanced care planning, and to explore what's really important to her. And to have it all documented, if that's what she wants. I'm seeing her later this week, and I'm happy to raise it with her. Is everyone okay with that?

Team: Yes

Chris: That sounds good. I'm also happy to see them again, although can I just flag with everyone, I will be on holidays for a few days now. But I'll forward details on who's covering for me.

Ongoing information and communication
3 min 36 sec

Chris: I'm concerned about the burden of Alan caring for Betty at home. He is very supportive, but he is also quite frail.

Leanne: Yeh I agree, Alan is 79 he has his own medical problems to worry about. Jane, do you have any thoughts on that?

Jane (Occupational therapist): What's Betty's home situation like?

Leanne: She lives in a two bedroom unit on the ground floor, there are lot of neighbours who support them.

Pamela: Alan and Betty's daughter Cheryl, she lives locally, she's very supportive. She drops in all the time with her two little boys.

Jane: Are there any community services going in?

Pamela: No, not at the moment. I have offered to arrange for help with the cleaning and the shopping and I've also explained respite care options, you know to help give Alan a break but they're pretty keen to cope on their own.

Jane: Yeh and that's pretty understandable isn't it? What about Cheryl, you said she lives locally.

How involved is she?

Pamela: She's a single mum, she's got two young kids and she works three days a week, so she's a very busy woman. But I'm meeting her at the house later in the week, so I can see how she's going and let you know.

Jane: That'll be great. I'm really keen to do an OT function and an ADL assessment in the home, and could we maybe do that as a joint visit with the community palliative care, and that way I can give them some advice about how to deal with lethargy. Has Betty been referred to the community palliative care?

Leanne: Yeh, I referred Betty a few weeks ago, and Sue, one of the nurses has been in to see them, and meet them in preparation for when the disease progresses. But we've discussed that and agreed that at this stage we don't really required a lot of input from them, I'm just going to keep Sue up to date with our meetings. But you can organise to meet with her back at the house if you want to.

Jane: Okay, well I'll give Sue a call and make it a time when Alan and Cheryl can be there as well. And then that way I can show them both some strategies to help them deal with caregiving tasks and make it a little bit easier for them.

Leanne: Um Anna, How is Betty doing from a nutritional point of view?

Anna (Renal dietician): Oh she's been managing her diet really well ever since she's been diagnosed. So I've spoken to her about the different food types, about the relevance of protein and potassium in her diet and she seems to be taking all that on board. Um the only thing is her serum phosphate levels, they are a bit higher than they used to be and that's a bit of a concern for me.

Leanne: Well I'll organise to get her bloods checked regularly, and I'll keep you updated with the results. I mean we may need to put her on a phosphate binder if her phosphates rise too much and she becomes symptomatic.

Anna: Yeh Betty did ask me what will happen once her kidney function gets worse. So I've given her as much information as possible, including the food types that she will have to stop eating and drinking. She seems to be okay with that, I've also given her resources on how to deal with the nausea, the headache, the itchiness, and the tiredness. Oh I've also given Alan and Cheryl some new recipes, so hopefully that will take their mind off things for a little bit.

Gillian: That's good Anna, it sounds like you've covered everything. Well given the change to Betty's situation and our plan to coordinate care to support a home death, let's review Betty again next week and share our assessments. There's a lot going on for them in the next few weeks so please contact Leanne or I if any of you have any concerns.

Leanne: Are there any more comments or questions?

Team: No

Leanne: Okay, well I'll give Betty's GP a call tomorrow and just update him on what we discussed today in our team meeting. He's been really involved in Betty's care and wants to be kept in the loop. So just to prioritise then from today's meeting, the important things about Betty's symptoms are her oedematous legs, her shortness of breath, her lethargy, hypertension (fades out).

Betty’s disease progresses
1 min 29 sec

Betty: Things have been awful really, the tablets help but not very much, it’s… it’s always there. And as for the retched itching, it never stops. I’ve just had enough of these tablets and I can’t… can’t even swallow them, I choke every time. I know I’m going to die. I just want to be home with my family, I want to be able to have a laugh with them, I…I want to see my gorgeous grandsons before I die, I know I will never ever see them grow up.

The clinic has been so… so good to me and they’ve listened to what I’ve said, and try to find every way possible to ease my pain. I couldn’t have done this without them. Everything’s in order, and all my affairs have been sorted.

I… I do worry about Alan, I don’t know how he’s going to cope when I die. But I know Cheryl and the boys will look after him.

The team implements an end-of-life care plan
2 min 4 sec

Leanne: Okay, it's been several months now since we discussed end-of-life care with Betty and Alan.

Betty is now in stage 5 of her kidney disease. Her GFR is 6 and her creatinine is 438. So we've discussed openly with Betty and Alan since the diagnosis and both Betty and Alan are aware that Betty will die soon, so our main goal now is to support Betty at home with her symptoms management and support Alan and Cheryl with this as well.

Chris: So how's Betty doing?

Leanne: Hmm not so well, she has severe pruritus, which is driving her crazy, she's got nausea she's very weak and lethargic. So she's actually having a lot of trouble swallowing her tablets, the palliative care team will have to start a syringe driver soon for the pain I think. Umm so they've actually asked if they could collaborate on her medication management. Uh so I'm going to organise a meeting with the palliative care team and Betty's GP in the next couple of days, so that we can review her care plan and her medication management

Tony: I can provide some input around the subcutaneous medication if necessary.

Leanne: Okay great, Thanks Tony

Pamela: I'd like to refer Alan and Cheryl to the bereavement support program, run by the palliative care team.

Anna: I'll also like to check to see if they need any additional nutritional support perhaps at this point.

Leanne: Okay thanks

Chris: Can I also just take this time to remind everyone that Craig our staff counsellor is always available. He could come and have a chat with us as a group or individually if anyone wants.

Leanne: Yeh thanks Chris. Actually last time I spoke with Betty and Alan they asked me to pass on their sincere thanks to the team for the ongoing support over the last two years. And I think they've both progressed really well and hopefully we've managed to meet our goal, which is for Betty to die at home with some dignity and some comfort.

Alan’s perspective
2 min 48 sec

I can’t help but worry about looking after Betty at home. Not that I told her that. I didn’t want to worry her. The team has been great, always keen to help us no matter what the problem; I could not have done without them. Betty’s renal team have seen her regularly and the community palliative team sees us now at home. Everything seemed so well planned and coordinated. I still feel on top of things but, with all these people surrounding us and so willing to help. The team arranged for some volunteers to be with Betty when I go out. I don’t go much, walk down to our favourite spot, talk with Cheryl and the boys sometimes. I know Betty’s had enough now, she’s ready to die. She’s suffered nausea, she’s suffered these terrible itchings; the palliative nurses have some idea of how to manage these things so we’re going to try them. I worry about what will happen when all this is over. Will I fall in a heap? When all the team has gone. Those wonderful grandsons, they’ll see me through. We had a great life together…