

Handout: Care planning - what to do if things don't go according to plan

Scenario

You are a nurse at a busy primary care practice in a regional town. One of the GPs has asked you to see Tania, a 23-year-old single woman who you knew as a patient when she was a child. Tania has epilepsy which was initially quite difficult to control, but in her late teenage years her neurologist prescribed a medicine that worked really well. As a result, Tania was able to move to Wellington and study at university.

However, Tania was recently prescribed a new medicine for her epilepsy which is not working very well and Tania has had to give up her Master's study and part-time job and move home with her parents. The GP saw Tania recently and blood tests show she has high blood pressure. The GP reminds you that Tania's father is on dialysis as a result of renal disease from high blood pressure.

The GP told you she suggested Tania come to see you to talk about a care plan for her epilepsy and high blood pressure. She said Tania was keen to do that as she remembered you from when she was a teenager. The GP commented that Tania was very quiet during the appointment but as she hadn't been Tania's GP previously, she didn't know if that was usual. The GP did a PHQ9 screening check with Tania and it didn't show she was depressed or suicidal.

You prepare for your 30-minute appointment with Tania. You look at her records and see that Tania is up to date with her cervical screening and has had a flu shot this year.

Tania was previously on sodium valproate which had her epilepsy well controlled. You know that sodium valproate can have significant side effects and women taking it have to take great care not to get pregnant as sodium valproate can cause a range of birth defects. Tania has recently been prescribed a new anti-convulsant medicine which you are not that familiar with.

This new medicine is not controlling her epilepsy well and so Tania is unable to work, study or drive and this is why she has had to move home to be with her parents. You know Tania's parents from various shared community events. You know they belong to the local church and are also heavily involved in Rotary. Tania has brothers who are older than her and live overseas.

You think about what might be important to Tania – getting control over her epilepsy and getting her independence back – but you realise that could take some time.

Appointment with Tania

You go into the waiting room to greet Tania and see her mother is there as well. Tania comes into your room and you greet her and say that the doctor has asked you to talk to her and work out a plan for managing her epilepsy and high blood pressure. You ask Tania what she wants to get out of the appointment.

Tania has her head down and you suddenly realise that she is crying – tears are running down her face. You get Tania some tissues, sit next to her and put your hand on her arm. You ask Tania if she wants you to go and get her mother and she shakes her head and looks up with a panicked look on her face. You say to Tania that you are going out to get some water and then you will sit with her until she is ready to talk if that is what she wants to do.

You go out and get some water and ask a colleague to arrange for someone else to cover your next appointment which is a four-year old's immunisation.

A few minutes after you return, Tania stops sobbing and has a drink of water. It is clear that she is still very upset and you are very aware it wouldn't take much for her to start crying again.

Tania tells you that she wanted to come and see you because she needed to talk to someone and you had been kind to her when she was a teenager. She said you needed to guarantee that what she told you would be confidential and no one else could ever know about it. It is really important to her that no one else knows. You say to Tania that part of your job is about keeping patient information confidential but from a safety point of view you need to keep some notes.

Tania starts to cry again and you say to her *"Look I am not sure what you are going to tell me so let's have a talk and at the end you can tell me what you want me to put in your records."* Tania nods slowly and then tells you her story.

When she was at university she had a relationship for about a year with a guy who she really liked. Because she was on sodium valproate and was aware of the possibility of birth defects, she went to Family Planning and got advice about 'double contraception, and was very careful to follow it. Her boyfriend got a good opportunity to do some work overseas and as she was only part-way through her Masters, they agreed they would end their relationship. He went back to his hometown and just before he left to go overseas, he came and stayed with her and they slept together. Unfortunately, the condom Tania's boyfriend was using split and Tania was so worried she went to a pharmacist the next day and got the morning after pill. A few weeks later Tania realised she was pregnant and that the baby could have birth defects. She went to Student Health rather than her own GP and asked for a termination and had a termination six weeks later. Everywhere Tania went she asked them not to record what they were talking about, but Tania is still concerned there will be records somewhere.

After the termination Tania rang her neurologist and said she wanted to go off sodium valproate. The neurologist insisted on seeing her and tried to persuade Tania to keep taking sodium valproate as it was so effective in managing her seizures, but Tania kept saying she was getting really bad side effects. She admits this wasn't really the reason but she didn't want to tell her neurologist about the pregnancy. In the end the neurologist agreed to put Tania on a different medicine. Since then, her seizures have been poorly controlled having a big impact on her life - having to leave her job and her study, and move back in with her parents.

You tell Tania that she has been through so much and that it sounds awful. Tania says she feels so cross with herself for not being careful and also sad that she has lost her independence and her job and study – all the things she really enjoyed and which made her feel good about herself, even though she had epilepsy. She says that having the termination was awful too.

You ask Tania if she had any support going through all this and she said no, she was too scared to tell anyone. You ask her if her parents know. She looks panicked again and says no, they are religious, they think having a termination is a sin and would ask her to leave home if they knew.

You thank Tania for telling you her story and say you want to help her sort out what she needs. You ask her what is the most important thing to deal with. Tania looks at you and says it is all overwhelming. You ask if it is okay if you talk about something you noticed when Tania was talking. Tania nods and you say that Tania talked about being really sad about so many things – losing her

independence, her study, her job, her control over her epilepsy, driving and her termination. Tania nods and agrees that she does feel sad all of the time.

You ask Tania if she had any grief counselling when she had her termination. She said she had counselling in order to get the termination but can't remember getting information about what she could do afterwards.

You ask Tania if she would like to go and see a grief counsellor as the first step in dealing with her sadness. You say she doesn't have to decide straight away but you know of a good counsellor who visits the practice once a fortnight and you could try and get an appointment for Tania to see her. Tania is relieved and says it is good that the counsellor comes to the practice so she doesn't have to get her mother to drive her somewhere else. Tania asks you to try and get her an appointment with the counsellor as soon as possible.

You ask Tania if she has talked to her parents about being sad, about losing her job and study and so on. Tania says she has been too scared to talk to her parents in case she blurted out that she had had a termination. She says she feels better now she has got it off her chest.

You check the counsellor's bookings for the next month, but she is fully booked. You tell Tania not to worry – the counsellor sometimes has cancellations or will fit people in – and say you will ring the counsellor and see what you can sort out and get back to Tania.

You have been thinking about something else and ask Tania if you can ask some questions. Tania nods. You say *"Given that sodium valproate worked so well for you, why did you decide to stop it? Was it a reaction to the termination or something else?"* Tania thinks for a minute and then says she has thought about this a lot lately and realises in hindsight it was a big reaction to the fact that she knew about the likely side effects but had been so stupid in taking a risk and getting pregnant and then having to have a termination. It was like she was lashing out at herself.

You say to her *"I can really understand why you might have had that reaction in the circumstances. Is it ok if I make another suggestion?"* Tania says yes and you say *"Look this might not be the right time for you, and if it isn't don't worry, we can talk about it later, but maybe you could start to think about going back on sodium valproate."* Tania looks a little taken aback but then nods slowly and says she will think about it as it was the best of all the medicines for her epilepsy. Tania says her neurologist will think she has gone mad if she changes her mind. You tell her that the neurologist might be pleased. Anyway, Tania should think about it – she doesn't need to do it right away, just think about it.

You ask Tania if she would like you to show her something that might help her when she is deciding. She nods, so you print off the decision-making process for her.

Decision-Making

- Step 1. Work out the different options.
- Step 2. Write down the pros (good things about the option) and cons (not so good things about the option).
- Step 3. Score each pro and con from 1 (not important to the person) to 5 (very important to the person)
- Step 4. Add up all the scores for the pros and cons to find which side has the highest score.
- Step 5. Before the person goes ahead with the side with the highest score, ask them if it feels right for them. If they say yes, then they should go with that decision.

Decision:			
Pros	Score	Cons	Score
Total		Total	

You then say to Tania you and she need to agree what goes in her Care Plan and records. Tania looks panicked again and you say to her you suggest putting something in her record that says Tania is slowly coming to terms with her very complex health and social issues. You show Tania what the GP wrote in her records at the end of the last visit. The notes say Tania has had to leave her study and job and return to live with her parents as a result of poorly controlled epilepsy. You point out that you are just adding a bit more to the earlier record.

Tania says that seems ok as long as there is nothing about the termination. This is a small town and the termination is her private business.

You say you understand, thank her and tell her you will let her know about the appointment with the counsellor. You arrange another appointment , give her your card and say she can ring you any time and you will get back to her as soon as possible. You then say goodbye.

You realise that you have not discussed managing her blood pressure with Tania. You make a note in her records to bring it up at her next appointment as the time wasn't right at this appointment.

Tips for managing care planning situations if things don't go according to plan

International and New Zealand research shows that things are more likely to not go according to plan if staff have preconceived ideas about the person's problem and how to address it. In these situations, staff often want to set the goal and 'fix' problems by suggesting solutions such as lifestyle changes or referrals. Research has confirmed that success is much more likely if the person identifies the problem and possible solutions. Here are some tips for you to consider.

Tip	Comment
What is my purpose/what am I trying to achieve here	Initial purpose – develop a care plan with Tania to better manage her epilepsy and high blood pressure. Revised purpose – if appropriate, listen to Tania and try and work out what is important to her and how you can help meet her needs.
Decision-making	Let decisions be guided by the person rather than what you think would be best for the person. If people want to do something different from what you think will work, that is okay. Listen really carefully to understand their reasons for doing something different. Trying to persuade the person to make the change you think is best will only work while the person is with you. Afterwards, they will not be able to recall your reasons for wanting them to make a change.
Patient-centred	If things are not going to plan, you need to find out what is happening for the person that has caused their upset/resistance/lack of engagement and work from there. Often it is not a health issue that it is affecting the person's health.
Cultural competence	How would you have felt as a health professional/health coach listening to Tania's story if you were a religious person? How would you have managed your explicit bias? How would you have placed your personal feelings to one side? At times like this, being aware of your biases is the first step. Recognise the sense of unease or discomfort where your brain wants to stop listening. Stop for a moment and acknowledge what is happening and then decide to move past that discomfort and focus on what the person needs. This is a sign of someone who has high levels of cultural competence.
Ask questions	Use active listening techniques such as nodding and saying <i>"Tell me more"</i> to encourage the person to keep talking.
Listen to understand	Paraphrase to check that you have understood what the person is saying and feeling. <i>"It sounds like you feel really upset about ..."</i> <i>"From what you are saying, this has had a really big impact on you....."</i>
Show empathy	This is linked to listening. Acknowledge what the person has been through and how difficult that has been for them.

	<p><i>"You have been in so many difficult situations."</i></p> <p><i>"It must have been really hard doing all of that by yourself."</i></p>
Be non-judgmental	<p>This is linked to cultural competence and bias. People have their own reasons for doing things. These reasons can be seen as illogical and unreasonable from your perspective.</p> <p>Being non-judgmental means finding out the reasons why the person wants to do something so you can understand their perspective and what they want to do as a result. Remember, you are not questioning whether the reasons are valid for that person. People are very quick to pick up when you don't think they are doing the right thing.</p> <p>The role of people working in health is not to judge but to provide support that meets a person's needs as much as possible. Making judgements can contribute to ongoing inequities in healthcare in New Zealand as people feel they can't have a trusting relationship with you and tell you what is really going on.</p>
Ask permission	<p>Before you make a suggestion, seek the person's permission to share your idea or suggestion. They may not want to hear your ideas but instead just want to know you have listened.</p>
Be comfortable with no action	<p>Sometimes, just telling you their story is enough for the person. Cognitively they may not have the energy to make decisions about changes.</p> <p>Sometimes people are at a stage where they can't make any changes. Acknowledge that and say you will follow up. <i>"It sounds like you have got too much on at the moment. How about I ring you in two weeks and see how you are going?"</i> Or <i>"I understand you don't want to make a change at this time. Is it okay if I check with you from time to time in case you have changed your mind?"</i></p> <p>Follow up in a few days when the person may have had time to think about what they want to do. Be prepared to follow up again if they are still not sure.</p>
Provide thinking frameworks	<p>This is linked to the previous tip and other areas such as action planning, problem-solving and decision-making.</p> <p>Give people a piece of paper with some ideas about how they can order their thoughts before they see you again.</p>
Learn from the situation	<p>Afterwards, think about what you did well and what you could do to improve for next time.</p>
Don't be too hard on yourself	<p>Dealing with situations where things don't go according to plan is tricky and you won't always get it right.</p> <p>Thinking on your feet can be difficult and affected by what else is going on. Follow the supervision process in your practice or have a trusted colleague you can go to for general advice.</p>