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Planning

Te whakamahere tiaki i mua i te wā taumaha
Advance care planning

Communication video transcripts and facilitation notes for
DHB trainers delivering the L1A one-day workshops

Version 4.0 April 2021



HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND

Kupu Taurangi Hauora o Aotearoa

Having an advance care planning conversation video transcripts and notes

The facilitation notes and discussion points are meant as a guide. You may not want to bring every detail into each group’s discussion. Points for discussion will, to some extent, depend on the needs of the group. The facilitative skills named in the notes are for the facilitators, who will understand their meaning. Bear in mind that not all groups will have such an understanding of those specific skills, and discussion may need to be more general, using language that the group understands – e.g., what was said, together with the context and the impact may be sufficient in some circumstances.

1. Bob – well person, primary care

Context

Bob is a 67 year old semi-retired business owner in good health. He has come to his GP practice for a routine ‘well-man’ check-up. The practice nurse knows that his wife has recently died of cancer and is keen to take the opportunity to check in with him, see how he is doing and to explore if this experience has surfaced any thoughts about his own future care preferences.

Bob had been married to his wife Charlotte for 39 years and they have two daughters and more recently three grandchildren. Bob has worked hard to provide for his family over the years and was looking forward to retirement to spend more time with Charlotte and his grandchildren, and to indulge his passions for tramping, hunting and fishing. He is fit and active and finds getting out for a walk or a mountain bike ride a good way to clear his head and order his thoughts.

He is meeting with Jane, one of the practice nurses today after his ‘well man’ check.

| Who | Script | Facilitation comments |
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| Discussion points | Ask the group how they might start the conversation. What strategies or skills might be important at the beginning of the conversation? | |
| | Part One | 01:52 mins |
| Nurse | Bob thanks for popping in to see me today, I know you've been through with Karen having your well man check. And I thought this was probably an opportunity for us to have a bit of a catch-up. Because there's been quite a lot going on for you in the last few months hasn't there? | <i>Valuing Bob's time. Re-connecting. Agenda-setting. Permission/offer to talk about recent happenings</i> |
| Bob | Yeah, yeah, I mean Charlotte and, you know that business, and 2 daughters having to look after her, that sort of thing, and yeah, bit of a hard time. | <i>CUE: daughters having to look after her CUE: bit of a hard time</i> |
| Nurse | It sounds like it's been a really hard time for you. | <i>Empathy</i> |
| Bob | Yeah. | |
| Nurse | How are you feeling about things? | <i>Open question re above</i> |

| Who | Script | Facilitation comments |
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| Bob | Oh not too bad, a few adjustments, you know, yeah (sigh). Daughter's getting back on track after having to put a whole lot of time into her, mmm. | <i>CUE: reference to daughters having spent a lot of time looking after Charlotte</i> |
| Nurse | So there's been an awful lot going on for all of you hasn't there and – I'm guessing it's been a pretty tough road to hoe the last wee while? | <i>Empathy Educated Guess</i> |
| Bob | Yeah. | |
| Nurse | Yeah. | |
| Bob | Yeah, but I'm fortunate that I don't have to go to work every day and I can choose my time and everything else like that. But yeah you can't sort of, you have to restrict some of your activities and I like to get out and about, so yeah. Now I can get back to it I suppose, yeah. | |
| Nurse | Yeah absolutely. You mentioned a little bit about your daughters and things being a bit tough for them? | <i>Responding to CUE about daughters</i> |
| Bob | Yeah well I mean I had to rely on them to sort of provide most of the care. I mean it was 24 hour in the end and so I was sort of a bit in the background because I'm not quite as good at that as they are. But it was pretty hard on them, you know and their families, you know they've got young kids, so yeah. Sort of wondered if I could have done a bit more here and there, yeah. | <i>CUES: Reliant on daughters to care for Charlotte Could he have done more?</i> |
| Nurse | It's hard knowing quite where to sit in some of those situations isn't it? | <i>Empathy</i> |
| Bob | Yeah, yeah, well – | |
| Nurse | Tough. | <i>Empathy</i> |
| Bob | Yeah. | |

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| Discussion points | <ul style="list-style-type: none"> • <i>How was the conversation initiated?</i> <ul style="list-style-type: none"> ○ <i>Let Bob know she knows the reason he came to see Dr and reference to recent death of his wife (so both start on same page)</i> ○ <i>How did the nurse communicate empathy?</i> <ul style="list-style-type: none"> ○ <i>'It sounds like it's been a really tough time for you'</i> ○ <i>What was the impact of this?</i> <ul style="list-style-type: none"> ○ <i>Bob felt heard, that the nurse cares, he engaged in the conversation</i> • <i>What were some of the cues that Bob gave?</i> <ul style="list-style-type: none"> ○ <i>Daughters having to look after Charlotte; bit of a hard time; he was reliant on daughters to care for Charlotte</i> • <i>Were any responded to?</i> <ul style="list-style-type: none"> ○ <i>'You mentioned a little bit about your daughters and things being tough for them'</i> • <i>What is the relevance of the conversation so far regarding advance care planning?</i> <ul style="list-style-type: none"> ○ <i>Recent bereavement, family, setting the scene</i> • <i>Where would you go next in this conversation?</i> <ul style="list-style-type: none"> ○ <i>Allow group to come up with suggestions. Acknowledge all suggestions – there are no right or wrong answers.</i> ○ <i>If needing to prompt, ask 'what are some of the ways we might start to talk about his preferences for the future?' Again, acknowledge all ideas.</i> |
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| | Part Two | 02:49 mins |
| Nurse | Bob I'm wondering today and I'm not sure how it feels for you, and whether it feels like it might be the time to start these conversations ... but often we find people, when they've had the experiences, and the things that have happened like recently for you with Charlotte's death, that sometimes it gets them thinking about the things that they might want for themselves if something was to change and happen with their health in the future. I'm wondering whether that might be something you want to chat to me about today, if there have been things that have been sort of percolating, or happening and thinking about for you around what you might like? | <i>Agenda-setting Negotiation Tentative</i> |
| Bob | Well I'm pretty fit and healthy I, you know I don't have any immediate worries or anything else like that. But I mean my older brother he keeled over on the golf course, you know with a heart attack and, you know they resuscitated him. But (sigh) he had pretty severe brain damage and he only lasted a week and yeah, so, it does make you think when something like that happens to somebody pretty close to you like that, yeah, yeah. | <i>Picked up on the concept straight away CUE: brother's death</i> |
| Nurse | What sort of things did it make you think about in particular? | <i>Exploring thoughts with open directive question</i> |
| Bob | Well, you know I mean if that happened to me, well I certainly wouldn't want to be still alive if I had severe brain damage, I wouldn't see the point in that. If there wasn't any quality of life, if couldn't get out and about, enjoy my friends and, you know the family, and probably more so than ... I mean they're more important than ever now, the grandkids and all that sort of thing. If I couldn't do something, you know actively with them, and help here and there, well (sigh) I don't think there'd be a lot of point in carrying on, yeah. | <i>Described Quality of Life, and what he wouldn't want. CUE: family more important than ever now</i> |
| Nurse | So that sense for you that it's really important to still be part of that, part of your family, being active, and being out and about I heard you mention as well? | <i>Reflection</i> |
| Bob | Yeah, oh yeah, well I'm pretty active outdoors, you know out tramping and, you know the occasional hunting trip, things like that with some of my mates. | <i>Gave more info in response to reflection</i> |
| Nurse | The great Kiwi outdoorsman, absolutely – | <i>Reflection</i> |
| Bob | Yeah, yeah, yeah, yeah, yeah, yeah. | |
| Nurse | I sense maybe if some of those things were more restricted that that would be feeling quite different for you and – | <i>Reflection Clarification</i> |
| Bob | Yeah it would, it certainly would change my outlook on life because it's been part of my life, you know right from when I was a youth. So yeah I'd miss that and it | <i>Gave more info in response to reflection</i> |

| Who | Script | Facilitation comments |
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| | would, you know I don't know what I'd replace it with, you know, yeah, yeah. | |
| Nurse | So that's really helpful for me to know that for you being able to be out and about, to be able to be active, to be able to be still, you know interacting with the outdoors, is a really important thing for you in your life. And if you couldn't do that at this stage you're not quite sure how it would feel going forward, is that, have I captured that right? | <i>Validating what he has shared</i> <i>Internal summary</i> <i>Clarification</i> |
| Bob | Yeah, yeah, yeah, yeah, I mean that would be, you know I would think I'm having a lesser standard of life than what I'd been having previously and yeah it would colour my thinking – | |
| Nurse | Colour your thinking a little bit? | <i>Reflection</i> |
| Bob | Yeah. | |
| Discussion points | <p><i>Did the nurse bring up advance care planning? [Yes]</i></p> <ul style="list-style-type: none"> ○ <i>How did she do that? [I'm wondering ... after experiences ... sometimes it gets them thinking about things they might want for themselves...]</i> <ul style="list-style-type: none"> ▪ <i>She was tentative</i> ▪ <i>She made it relevant to him by linking this conversation to his experience with Charlotte</i> ▪ <i>She asked permission/negotiated proceeding [I'm wondering whether that might be something you want to chat to me about today ...]</i> ○ <i>Was advance care planning named? Does that matter at this stage? [No ... the important thing is that it is relevant to him ... naming it can come later]</i> <p><i>How did she move through the conversation?</i></p> <ul style="list-style-type: none"> ○ <i>Explored CUE- brother's death [What sort of things did it make you think about in particular?]</i> ○ <i>She reflected back to him what he had shared [So that sense for you ... part of your family...]</i> ○ <i>Internal summary and clarification [for you being able to be out and about ... outdoors ... important to you ... have I captured that right?]</i> <p><i>What was the impact of following the cue, reflecting back what he had said, summarising and asking if she had got it right?</i></p> <ul style="list-style-type: none"> ○ <i>He shared more. He gave us information about what quality of life means to him (without being specifically asked).</i> <p><i>So we've learnt a bit about what Quality of Life means to him, and something of what he would not want. How might you move forward?</i></p> <ul style="list-style-type: none"> ○ <i>Allow the group to come up with suggestions.</i> ○ <i>If needing to prompt, suggest:</i> <i>'Would you want to move the conversation towards end of life preferences for example? How might we do that?'</i>[Pick up on when he talked of Charlotte's end of life] ○ <i>Or other open question linked to something he has previously said?</i> | |
| | Part Three | 01:38 mins |
| Nurse | And I know that you sort of mentioned a wee while ago in this conversation about Charlotte and how tough it was with the girls looking after her. If things were to change and meant you needed increased support and | <i>Open question related to what he has shared already.</i> |

| Who | Script | Facilitation comments |
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| | care, and maybe even thinking about sort of as things were coming closer to the end of your life, have you thought about what you might like in that situation? | <i>Exploring End of Life preferences</i> |
| Bob | Mmm, well I certainly wouldn't wanna be kept alive artificially, you know I mean yeah. If I can't have, you know make my own decisions and, you know choose when I wanna go out and things like this. And if I couldn't get out and about (sigh) I wouldn't be too happy about it, yeah. | |
| Nurse | So that's definitely feeling important ... | <i>Acknowledgement</i> |
| Bob | Yeah. | |
| Nurse | What about where you might wanna be in terms of your care? | <i>Exploring further</i> |
| Bob | Well I wouldn't wanna have to be reliant on my daughters again, I think they've done enough, you know caring for the family. And I'd rather go into somewhere like a Hospice or somewhere like that where, you know you've got professionals looking after you. And your family are your family, and your friends can come and see you and yeah, that's a pretty good sort of a place to be from what I've seen with people, friends that I've had in there, yeah. | |
| Nurse | So that sense for you that actually if things did deteriorate with your health and you were needing that increasing care it would be important for you be having your daughters to be your daughters – | <i>Reflection Clarification</i> ↓ |
| Bob | Yeah. | |
| Nurse | And your friends to be your friends – | |
| Bob | Oh yeah. | |
| Nurse | Not the people that are taking care of you? | |
| Bob | Yeah, yeah. | |
| Nurse | That would be okay to be kinda left to the experts? | |
| Bob | Yeah. Yeah, yeah, certainly, yeah. | |
| Nurse | Yeah. Okay. | |
| Discussion points | <p><i>So how did nurse bring up End of Life? [You mentioned ... Charlotte and how tough ... girls looking after her ... If ... you needed increased support and care ... have you thought about what you might like ...]</i></p> <ul style="list-style-type: none"> ○ <i>Open question linked to what he had shared earlier</i> <p><i>What was the effect?</i></p> <ul style="list-style-type: none"> ○ <i>He shared something of what he wouldn't want at the end of his life</i> <p><i>What else have we learned?</i></p> <ul style="list-style-type: none"> ○ <i>He wouldn't want his daughters to have to care for him ... he'd rather be somewhere where family can be family ...</i> <p><i>What did the nurse do to elicit this information?</i></p> <ul style="list-style-type: none"> ○ <i>Acknowledged what he said [so that's ...important]</i> ○ <i>Open question [what about where you might wanna be...]</i> <ul style="list-style-type: none"> ▪ <i>This works because the questions have been linked to what he has shared, and he understands the relevance to him ... the same question might not be so effective, without this 'groundwork'</i> <p><i>Where would you go next?</i></p> <ul style="list-style-type: none"> ○ <i>Allow group to come up with suggestions.</i> | |

| Who | Script | Facilitation comments |
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| | <ul style="list-style-type: none"> ○ <i>If needing to prompt, ask 'what else would you want to try to cover in this conversation?' OR</i> ○ <i>'If you wanted to start to wrap up the conversation, how might we do that?'</i> | |
| | Part Four | 01:25 mins |
| Nurse | That's really important information, thank you so much Bob, a really great chance to start thinking about these things and for me to hear where you're up to with some of this thinking – | <i>Acknowledgement</i> |
| Bob | Yeah. | |
| Nurse | And I wonder if it's something that we might be able to pick up a conversation again in the future a little bit more about this. Because I think given the experience you've been through with Charlotte and the experience with your brother, and the thinking that you've clearly been doing about some of this, it might be the opportunity to create something we call an advance care planning document. Have you heard of that before? | <i>Negotiating further conversation Introduce the words advance care planning and concept of a documented plan Find out knowledge of advance care planning – open question</i> |
| Bob | No, no I haven't, but I, yeah being a businessperson I know that you've gotta plan for things and if you don't they jump on top of you when you least expect it, yeah. | <i>He gets it Agrees important</i> |
| Nurse | Absolutely, and I guess this is a chance to put down some of those things on paper, those things that you've talked about that are important for you, and why they're important for you. So that we've got some guidance in the future about how we might care for you and look after you if something did happen with your health that meant you weren't the person that could tell us those things anymore | <i>Explanation of advance care planning</i> |
| Bob | Yeah, yeah, well that's the problem, if you can't communicate your wishes you're gonna get all sorts of things foisted onto you aren't you, yeah, things you don't want? | <i>Hearing her</i> |
| Nurse | Absolutely and this is a chance for you to say what you do want, what you wouldn't want so that we have a real clear sense of the care that we give you. | <i>Expands explanation</i> |
| Bob | Yeah. | |
| Nurse | Something that you'd be interested in talking a little – bit more about – | <i>Negotiation</i> |
| Bob | Yeah I think so, yeah. | |
| Nurse | Okay well let's set up a time and we can have a bit more of a detailed discussion about that in the future? | <i>Planning</i> |
| Bob | Great. | |
| Nurse | Thank you. | |
| Bob | Okay. | |
| Discussion points | <ul style="list-style-type: none"> ● <i>Does he understand advance care planning? How do we know?</i> <ul style="list-style-type: none"> ○ <i>Yes</i> ○ <i>'I know that you gotta plan for things'</i> ○ <i>'yeah, well that's the problem, if you can't communicate your wishes...'</i> | |

| Who | Script | Facilitation comments |
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| | <ul style="list-style-type: none"> • <i>Would the explanation have been as effective at the beginning of the conversation? Why?/Why not? (Why does it work now?)</i> <ul style="list-style-type: none"> ○ <i>Done the ground work</i> ○ <i>Linked explanation to what he has shared in order to make it <u>relevant</u> to him</i> ○ <i>He has been heard (reflection, empathy => shared more info)</i> • <i>You may like to get the group to list what Bob has shared in terms of preferences (depending on how time is going and needs of group)</i> • <i>Get the group to summarise the communication tools that the nurse used to gather information from Bob about his preferences</i> | |

2. Gladys – post stroke, Residential Aged Care

Context

79 year old lady who was living with her husband, Rex, in a Retirement Village townhouse until 2 months ago when she had a stroke. Following treatment in hospital with several weeks of rehabilitation, she has been admitted to an Aged Residential Care facility where she has been for 3 weeks. She walks with a frame, has some right-sided deficit so requires help with showering and dressing and cutting up her food. This conversation is part of the process of developing Gladys's long-term care plan. The nurse having the conversation today has provided Gladys with the written information and they have had an introductory conversation about Advance Care Planning. Gladys did not want her husband present during this initial conversation.

| Who | Script | Facilitation comments |
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| Discussion points | Ask the group how they might start the conversation. What strategies or skills might be important at the beginning of this conversation? <i>Get ideas from the group. Refer to the list we have made if necessary, and to what worked for the conversation with Bob.</i> | |
| | Part One | 02:02 mins |
| Nurse | Gladys thanks for making the time to come and see me today and to catch up – | <i>Valuing Gladys's time</i> |
| Gladys | It's okay. | |
| Nurse | How are you going? | <i>Open question</i> |
| Gladys | Not bad, not bad. I'm not enjoying it, you know, the hospital people are lovely, you know and they try to entertain you and things. And worrying about my husband Rex because he's on his own, and I do most of the stuff at home. And I don't know whether he'll remember to do anything, you know, and he suffers a lot from arthritis. So I always have to watch out for him when we go out, like you know because he tends not to look where he's going, so he trips up. And if I'm not there I'm worried that he'll have a fall somewhere and break something, and you know I just, you know. And I miss being with him. | <i>CUE: Worried about Rex CUE: Miss being with Rex Minimal prompts from nurse ... ok ... nodding Allow to 'vent'</i> |
| Nurse | You've had some big changes haven't you Gladys in the last few weeks? | <i>Acknowledgement of Gladys's situation</i> |
| Gladys | Yes, yes I have coz, you know I'm used to being busy in the village, I get involved in a lot of things there, you know. I, I do the gift table there and organise getting the money, and delivering the gifts, but who's gonna do it if I'm not there? Because nobody else seems to want to do anything like that, you know and I dunno – | <i>CUE: Missing identity of being a member of the village? Not feeling useful anymore?</i> |
| Nurse | Gladys it's been a huge change for you hasn't it – | <i>Empathy</i> |
| Gladys | Yes | |
| Nurse | Since you had that stroke, now you've ended up needing more care and so that's why you're here | <i>Acknowledgement of current situation and past life</i> |

| Who | Script | Facilitation comments |
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| | with us. And it sounds like you've been very active and busy in your life – | |
| Gladys | Yeah. | |
| Nurse | And that's, you're not able to do those things anymore – | <i>Reflection</i> |
| Gladys | This is right, I mean I make my own birthday cards and Christmas cards, and now I can't do that – | <i>CUE: Feeling useless?</i> |
| Nurse | You can't do anything – | <i>Reflection</i> |
| Gladys | Coz I'm right-handed, you know I don't know who's gonna do the cooking when I, you know I am going to get back home aren't I? | <i>CUE: getting back home</i> |
| Discussion points | <ul style="list-style-type: none"> • <i>How was the conversation initiated?</i> <ul style="list-style-type: none"> ○ <i>Thanking Gladys for her time – valuing her</i> ○ <i>Open question “how are you going?”</i> <ul style="list-style-type: none"> ▪ <i>Need to find out if she is in a space to be able to have this conversation</i> ▪ <i>What she says may be a starting point for discussion</i> • <i>What cues did she give us?</i> <ul style="list-style-type: none"> ○ <i>Worried about and missing Rex</i> ○ <i>Missing her identity as a member of the village? [used to being busy and involved in the village]</i> ○ <i>Feeling useless? [used to do the gift table]; [I make my own ... cards ... now I can't...]</i> • <i>What does it sound like is happening for Gladys?</i> <ul style="list-style-type: none"> ○ <i>Grieving for her past life</i> • <i>How did Carla respond?</i> <ul style="list-style-type: none"> ○ <i>Acknowledgement [you've had some big changes..]</i> ○ <i>Reflection [you're not able to do those things any more...]</i> ○ <i>Summary of current situation [since you had that stroke ... needing more care ... been active and busy...]</i> • <i>How would you respond to Gladys's last question?</i> <ul style="list-style-type: none"> ○ <i>Allow group to come up with suggestions and then say “let's see how Carla responds”.</i> | |
| | Part Two | 01:04 mins |
| Nurse | Gladys you know we need to see how things go, it sounds like being at home with Rex is something that's really important to you – | <i>Honesty; tentative Acknowledgement of importance of being at home</i> |
| Gladys | Ooh yes I can't, I can't even begin to imagine not being there with him, you know, and I worry about him being on his own all the time, he'll be so lonely. I might not get back home again, I just – | <i>Affirms importance CUE: worried about Rex (2nd time) CUE: thought about not getting back home</i> |
| Nurse | You've obviously thought about that? | <i>Exploring thoughts of not getting back home</i> |
| Gladys | I have a lot. | |
| Nurse | What if you couldn't get back home. | <i>Prompting disclosure about that</i> |

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| Gladys | Exactly. I worry that, you know I know he could get meals delivered, what's he gonna do all day on his own? I mean we do everything together always. | <i>CUE: Worried about Rex (3rd time)</i> <i>CUE: being together (2nd time)</i> |
| Nurse | Do you know maybe that's something that we can follow up with him – | <i>Negotiate following up Rex's needs (attempting to 'park' Rex)</i> |
| Gladys | Oh that would be good. | |
| Nurse | Yeah. And make sure that his needs are taken care of as well – | <i>As above</i> |
| Gladys | Yes. Yeah that would be lovely. | |
| Nurse | So leave that with me and I'll let you know how we've got on and what's happening – | <i>As above</i> |
| Gladys | Oh that would be great, yeah I would appreciate that. | |
| Nurse | Alright we can do that, that's not a problem. | <i>Reassurance</i> |
| Discussion points | <ul style="list-style-type: none"> • <i>How did Carla respond to 'I am going to get back home aren't I??'</i> <ul style="list-style-type: none"> ○ <i>Tentative [see how you go...]</i> ○ <i>Honest [not just saying what she wants to hear]</i> ○ <i>Acknowledgement that being at home is important to her</i> • <i>What was the impact?</i> <ul style="list-style-type: none"> ○ <i>Gladys expanded on her thoughts around this</i> ○ <i>More cues – worried about Rex (2nd time); not getting back home</i> • <i>How did Carla use what Gladys said to explore the possibility of not getting back home?</i> <ul style="list-style-type: none"> ○ <i>'You've obviously thought about that?'</i> ○ <i>'What if you couldn't get back home'</i> • <i>How did Carla try to move the conversation on?</i> <ul style="list-style-type: none"> ○ <i>Acknowledge the importance of Rex's wellbeing</i> ○ <i>Offer a solution – attempt to 'park' Gladys's worries about Rex</i> • <i>Where would you go next?</i> <ul style="list-style-type: none"> ○ <i>Allow the group to come up with ideas and acknowledge them.</i> ○ <i>If needing to prompt, ask, 'what kind of things would you want to discuss with Gladys, in terms of the future?'</i> ○ <i>'Let's see what Carla does'</i> | |
| | Part Three | 01:03 mins |
| Nurse | So Gladys just going back to thinking about what's important to you, what you're saying to me is if you could get back on your feet – | <i>Steering the conversation</i> <i>Acknowledgement of what's important</i> |
| Gladys | Oh yes. | |
| Nurse | And get back home that would be your ideal – | <i>Acknowledgement</i> |
| Gladys | Yeah, ooh yes definitely and get back to a normal life again. Am I gonna be able to do things that I used to do, or am I going to be unable to? See at the moment I can't shower or dress myself properly, I can't expect my husband Rex to do it can I? | <i>More scattered thoughts</i> <i>CUE: wants to get back to a normal life again – unrealistic?</i> |

| Who | Script | Facilitation comments |
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| Nurse | No, so I guess that's – why you're with us so we can help you with those things – | <i>Acknowledgement of reality</i> |
| Gladys | Yeah. | |
| Nurse | So getting back on your feet is important to you – | |
| Gladys | Oh yes, yeah. | |
| Nurse | But Gladys have you thought, I know you don't want to consider this scenario – | <i>Warning shot of difficult question, linked with what's been said</i> |
| Gladys | Right. | |
| Nurse | But what about if things didn't quite get back to how you'd like? | <i>Exploring thoughts and feelings if home not possible – attempting to re-align Gladys's reality</i> |
| Gladys | I don't wanna think about it actually, I've never had any real problems and this has really thrown me. The thought of having another stroke scares the hell out of me. | <i>CUE: Thrown me CUE: scared of another stroke</i> |
| Discussion points | <ul style="list-style-type: none"> • <i>What did Carla do to keep the conversation on track?</i> <ul style="list-style-type: none"> ○ <i>Acknowledgement of what's important</i> ○ <i>Acknowledgement of the reality – gentle, tentative</i> ○ <i>Explored 'if home not possible' – thoughts and feelings</i> • <i>How was the question of not getting back home opened up?</i> • <i>When Gladys says, 'I don't want to think about it' would you take that at face value and move away from that topic? Why?/Why not?</i> <ul style="list-style-type: none"> ○ <i>She has previously says she is worried about not getting back home</i> ○ <i>It sounds like it's a possibility she may not – so should we offer the opportunity to talk about it?</i> • <i>How would you respond to Gladys's last statement?</i> <ul style="list-style-type: none"> ○ <i>Allow the group to come up with ideas</i> ○ <i>'Let's see where Carla goes next'</i> | |
| | Part Four | 01:15 mins |
| Nurse | I wonder whether it would be really helpful for all of us to start thinking about those things that would be important to you and to Rex if your health did change? Because one of the things that you've said is that stroke happened out of the blue – | <i>Tentative negotiation to discuss if health did change (linked with previous statement)</i> |
| Gladys | Yes it did. | |
| Nurse | You were well and you're worried about what happens if it happened again – | <i>Reflection Acknowledgement of worry</i> |
| Gladys | Yes. | |
| Nurse | If you had another stroke – part of taking away, or at least easing some of that worry – is about making some plans around those things. | <i>Relate worry of another stroke with concept of advance care planning</i> |
| Gladys | Oh what sort of plans can I make? | <i>Engagement – asking about it</i> |
| Nurse | Well thinking about how you would want us to respond if you were very unwell, if something | <i>Explanation</i> |

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| | happened. How you'd want to be cared for if you couldn't speak to us and tell us | |
| Gladys | Oh if you, I don't want, if I had another stroke and I got worse and couldn't talk or anything, I just wouldn't wanna be here. Because I think Rex would, it would upset him even more and I couldn't bear the thought of him just watching me like that, that would be horrible. It would be like looking at a vegetable, I don't wanna be like that; I couldn't cope with that. | <i>CUE: What she would want if he had another stroke</i> <i>CUE: worried about Rex seeing her even more sick</i> <i>CUE: Vegetable</i> |
| Discussion points | <ul style="list-style-type: none"> • <i>How did Carla start to explore getting more unwell?</i> <ul style="list-style-type: none"> ○ <i>Link to Gladys's worry about another stroke</i> ○ <i>Introduced the idea of making plans for if that happened (linking fear of another stroke with advance care planning)</i> • <i>What was Gladys's response to this suggestion of making plans?</i> <ul style="list-style-type: none"> ○ <i>She asked what sort of plans – she is engaged</i> ○ <i>When she heard the explanation, she started talking about what would be important to her – she sees the relevance for her</i> • <i>What information did we get from her?</i> <ul style="list-style-type: none"> ○ <i>Being able to talk is important to her</i> ○ <i>Worried about Rex seeing her very sick</i> ○ <i>She wouldn't want to be a 'vegetable'</i> • <i>How would you respond to that last set of statements?</i> <ul style="list-style-type: none"> ○ <i>Allow the group to come up with suggestions</i> ○ <i>If needing to prompt, ask 'what do we think she means by being a vegetable? Do we need to check this out?'</i> | |
| | Part Five | 01:29 mins |
| Nurse | You wouldn't want to be a vegetable? | <i>Explore what she means by repeating her words back to her</i> |
| Gladys | No. | |
| Nurse | Is that what you're saying? | |
| Gladys | No. I couldn't bear the thought, I would want somebody to pull the plug, the thought of just lying there not being able to do anything, or being with Rex, or, I just. I mean what would there be for me? I mean if I'm going to like just lying there day in and day out what is the point? | |
| Nurse | Okay so am I right ... help me to understand what you mean by that. So if you were not able to do anything for yourself? | <i>Clarification of meaning of vegetable using reflection with a questioning tone</i> |
| Gladys | Exactly. | |
| Nurse | And not able to interact with people? | |
| Gladys | Yeah I couldn't cope with that and as I say I'd want either to have another stroke and that's it, finished, you know. I don't want anybody to try and resuscitate me, or try and do anything because I | <i>CUE: Resuscitation</i> <i>CUE: Rex couldn't cope [with her being a 'vegetable']</i> |

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| | couldn't cope with that, and I don't think Rex could, it wouldn't be fair. | |
| Nurse | Alright so if you were ever in that situation then what you're saying to me is that you wouldn't want us to try and pull you out of that so that you – could exist. | <i>Reflection Clarification of what she means by above statement</i> |
| Gladys | No, no, no, no. I mean what sort of a life would I have and what life would Rex have? It would be worse than if I went suddenly, that would be it, you know. I mean oh I can't even begin to think about that. | <i>Affirmation</i> |
| Nurse | Do you know that's really helpful for us to know that, because everyone likes different things. | <i>Validating disclosure</i> |
| Discussion points | <ul style="list-style-type: none"> • <i>What did we learn in this section?</i> <ul style="list-style-type: none"> ○ <i>She doesn't want to be left in a situation where she is 'just lying in a bed', unable to do anything for herself</i> ○ <i>She doesn't want Rex to have to see her like that</i> ○ <i>She would rather die suddenly</i> • <i>What did Carla do to enable this disclosure?</i> <ul style="list-style-type: none"> ○ <i>Explore and clarify her meaning of being a vegetable</i> ○ <i>Reflection ['so if you were ever in that situation ...']</i> ○ <i>Validate disclosure ['really helpful for us to know that ...']</i> • <i>What is needed now? How might you facilitate that?</i> <ul style="list-style-type: none"> ○ <i>Allow group to come up with ideas</i> ○ <i>If needing to prompt, ask, 'what is one of the things we can do if someone has shared quite a bit of information with us?'</i> | |
| | Part Six | 01:45 mins |
| Nurse | Can I just summarise what I've heard from you – about what's important, coz I wonder whether we might, if you're agreeable, if I can write some of these things down – | <i>Summary Tentative negotiation of documenting</i> |
| Gladys | Yeah sure. | |
| Nurse | So that we're all on the same page – coz you shared some valuable information – | <i>Validating importance of disclosure</i> |
| Gladys | Yeah, no, that would be good. | |
| Nurse | So the things that are important to you are, you're worried about Rex – | <i>Summary...</i> |
| Gladys | Oh yes. | |
| Nurse | And, and he's the most important person in your life? | |
| Gladys | He is, he is, I mean I don't have any other family you see – | |
| Nurse | You really want to be together, yeah, you really, if you possibly could you'd want to get back on your feet and back into your cottage? | |
| Gladys | Yeah, yeah. Yes I do, I do. | |
| Nurse | And you want to get back into what you were doing in the village with – the crafts table | |

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| Gladys | Yeah I do. because I love socialising with, we've made a lot of friends in the village, you know. And I organise street parties so that we can all coz, you know neighbours, we're all busy. And so I try to organise a street party every now and again so that we can all sit down together for a change. | <i>Expands on the things that are important</i> |
| Nurse | So being part of that village is – really important to you? | <i>Acknowledgement</i> |
| Gladys | Yes exactly. It's wonderful there, you know. | |
| Nurse | And what else you've shared with me is if you had another stroke – or something equally as serious and you were not expected to recover – then you wouldn't want to be here? | <i>More summary</i> |
| Gladys | No I don't want anybody to make an effort to try and bring me back because I can't see me, if I had another stroke, or anything like that, I'd be worse than I am now. And I just couldn't cope with that. | <i>Calmer?</i> |
| Nurse | Okay. And what you couldn't cope with is the, not being able to do anything for yourself – | <i>Summary continued</i> |
| Gladys | Exactly. | |
| Nurse | And not being able to interact with people? | |
| | Exactly, you know and I don't want Rex having to do things for me because I don't think he'd be able to. | |
| Discussion points | <ul style="list-style-type: none"> • <i>Discuss the impact of the summary</i> <ul style="list-style-type: none"> ○ <i>Clarification of wishes and what's important to her</i> ○ <i>More information (and probably more to follow...)</i> ○ <i>The summary was in several parts, because Gladys was clarifying and adding information as we went</i> • <i>Gladys appeared a little calmer during the summary – any thoughts about why?</i> <ul style="list-style-type: none"> ○ <i>She felt heard:</i> ○ <i>Acknowledgement</i> ○ <i>Picking up of cues and questions linked to the cues</i> ○ <i>Acknowledgement of the importance of Rex</i> | |