John, Mary and Cheryl Example Conversations

First conversation:

Good morning Mr Y, good morning Mrs Y is it OK if I sit here where I can see you both?

"Yes please sit down"

Thank you. Mr and Mrs Y do you prefer to be addressed as Mr and Mrs Y or would you like me to use your Christian names?

"You can call us John and Mary dear, not so formal".

Thank you John and Mary. So as I said when I came in I'm Cheryl and I'm the social worker who is going to be supporting you with the concerns you raised when you contacted Adult Social Care. I just want to check first of all that you still want us to discuss these together today?

"Yes, I usually need a bit of time to think things through and Mary always supports me in meetings and helps me say the things I want to say if I am struggling. She will answer if I can't find the words – she knows me inside out don't you love?"

OK I will remember that and give you time. You should have been sent some information last week but would it be helpful if I explained first a bit about what today is about and the sort of things we will be discussing?

"Yes, please explain a bit, we got sent some information but I'd rather hear it from you we've both been a bit anxious about what to expect. Give me plenty of time to think though, my brain doesn't work as quickly as used to."

If either of you need me to slow down or repeat anything then please just say. We can take as much time as you need to cover what is most important. And, hopefully, I can help you feel less anxious. What in particular was worrying you?

"Just having a stranger coming in and asking questions about our life. Being interviewed about personal stuff".

I can appreciate that and I know we have just met so if there is anything you don't feel comfortable talking about at any point let me know. We will keep things informal, a conversation rather than an interview – how does that suit you both?

"That would be good, I can't cope with lots of questions but I know we need some help so we have to do it."

Well if you get tired at all and need a break please say. If you don't mind, I will make notes as we go along so we know have an accurate picture of things – is that OK?

"Yes, that's fine and I will let you know if I need more time"

So basically today I want to sit down and talk to you about the different aspects of your life so we can get a picture of your needs, the impact they are having on different areas of your lives and where you want to get to in terms of managing that impact – your outcomes if you like. Then we can look at what support might be available to help you achieve your outcomes.

We will cover the things that are important to you both and get both your perspectives – normally that includes how you are managing at home, how you manage getting out and about, any support networks you have.

Also, when you contacted us, John you mentioned you have a diagnosis of Huntingdon's Disease so we can cover how this might be affecting you. We will also talk about the impact of things on you too Mary as you said this was one of the main reasons for contacting us. How does that sound?

"That sounds fine – it's what we thought you would want to know about".

Great, so to start off can you tell me a bit about your lives together first of all?

"Mary and I have been married for 49 years. We have three children – Robert, Annie and Jo. Robert and Annie have two girls each and Jo has two boys and a girl. We see them a lot as they all live nearby – I love spending time with them all especially my grandchildren………

Your family seem to be really important to you John – is that right?

"Yes, they are so important, Mary is the most important though, I'd don't know what I'd do without her. She helps me with everything."

I can see how important she is by the way you look at her John - married for 49 years. Have you any plans for you golden wedding?

"Yes the children are organising a party for us – just family though as I don't go out much, if I do go Mary has to go with me because my mobility is so poor".

When you do go out what is that for normally?

"It's normally for shopping or appointments – doctor's, hospital and so on."

How often do you go out other than for appointment – shopping or meeting friends for example?

"We go shopping three times a week together. Other than that I don't really go out, but we always spent a lot of time together and never went out much. I do think my having Huntingdon's stops Mary from meeting up with her sister and friends. She stays with me all the time because she doesn't want to leave me with anyone else. I was a carpenter by trade and I still like to work in my shed, I make bird tables and other things from wood and give them to a charity shop to sell. Mary even comes to the shed with me, she doesn't stay all the time but she pops back and forwards a lot to see that I am OK."

So you seem to be saying that you feel you get out and about enough and see plenty of people John but you feel Mary maybe isn't– is that correct?

"Yes, I do as much as I want to do and get out enough. I go shopping and see my family that's all I want."

Can I ask how you feel about that Mary?

"I like to look after John, he is my husband and I want to keep looking after him for as long as possible. It does get tiring though and I know he worries about me. So do the children they've suggested we get some kind of alarm so he can buzz for help if he gets into difficulty, then I can leave him in peace in the shed and get on with my jobs."

OK, so can you describe a typical day for me? Or if there isn't a typical day can you describe what a good day would look like compared to a bad day?

"Mary you will have to answer now please I'm tired". "OK John, I will. Well there isn't really a typical day, each day is different depending on how the Huntingdon's is affecting John."

[Mary describes a good / bad day – covering eating/drinking, personal care, mobility, social contact, activities, safety – practitioner uses prompt questions as necessary to verify information and ensure completeness]

So that seems to cover the impact on how you function day to day John, but how does all of this affect you emotionally?

"I don't like to have help, or to be a burden on Mary. I can get very low and tearful or sometimes frustrated and angry."

And what do you do when you feel like this?

"Mary normally manages to cheer me up reminding me about the good things in life. I love to spend time with my grandchildren, I told you that didn't I? I like to make them laugh, that always cheers me up."

And how does it affect you Mary?

"I do get tired like I said and I can feel low when I get tired. But I don't want to leave him with someone else I didn't trust, it wouldn't feel right."

Is anyone else affected?

"Yes, it impacts on the children, especially Robert as he does all the paperwork and finance stuff now John can't".

How does the fact that you need help with that make you feel John?

"He gets frustrated and also feel a bit hopeless, if that makes sense. He feels he isn't contributing anymore. The Huntingdon's has stopped him."

We haven't talked specifically about the Huntingdon's Disease. I've read some background information about it and we have the report that you agreed we could request from John's consultant, but is there anything else you want to tell me about how it affects you?

"We've covered most of the impact on John I think, generally it is the fluctuation that causes problems for us. His mobility, mood and memory change from day to day and that makes it really difficult to plan ahead. It limits everything."

When you contacted us you told us that your condition has changed and your needs have increased can you explain a bit about what has been happening?

"John was diagnosed in 2009, his grandfather had it so we knew what to expect. At first we managed fine but as time has passed the symptoms have increased and a few months ago we reached the point where I had to do everything for John some days, and most things on the other days. We both knew we needed to do something – just in case, you know?"

Yes, I think I understand. In case for some reason you are unable to care for John, to have a contingency plan? Is that what you meant?

"Yes, and to get enough help so that I can keep caring for him. Although I don't really want help – does that sound silly?"

No, it doesn't sound silly at all Mary. It sounds like you both want to make sure you can stay together and support each other as much as possible – I can see you mean the world to each other and just want to keep going but maybe need a little support to do that. Have I picked that up right?

"Yes, that's right. We want to keep going but realise we might need some help to do that. But the kind of help that doesn't take over what I do completely – and if it's people coming in only someone I can trust 100%".

What are the good aspects of your life that you don't want to change?

"John wants to be able to keep spending time with the family. Entertaining the grandchildren. He enjoys working on the bird tables and so on in the shed. It's good for him to have something to do that he enjoys and that does good for others too."

"I want to keep doing as much as possible for John, but he worries about me such a lot, I want him to stop worrying but still be supported as much as possible by me".

What, if anything, do you want to change? (wellbeing, support network, environment)

"I know John wants me to take a break now and again, have a holiday with my sister. But I'm not sure I could bear to leave him with anyone else. I'd not trust them 100%."

You've both mentioned trust as the main barrier to getting help that would let Mary have a break. What do you think might overcome that barrier? Who might you trust?

"I don't know I've not really thought about it. I suppose I would trust family. Or it would have to be someone we knew well, that John and I felt comfortable with in terms of helping him get washed, personal stuff like that and helping him safely."

What might it feel like if we were able to find someone who you could trust?

"Well it would feel OK I think, I don't know, at least it might stop John worrying. We'd need to talk about it and maybe we'd have to meet the person so we could decide."

So thinking about what you've told me can you tell me about the things that are most important to you, and why?

"We are the most important thing in each other's lives. Then family are most important after that."

What else do you think it is important for us to be aware of?

"I'm not sure I think we have told you just about everything."

When I was listening to you I wondered if you had thought about setting up Power of Attorney, you mentioned Robert does a lot of the paper work and finances for you now. Is that something you have considered or might do in future?

"Yes, we have considered that, Robert is going to apply for it – John wants to keep doing bits but realistically Robert will need to do it all soon."

We have covered a lot so far - do you want to have a break before we cover the next steps?

“Yes please, I’ll make a cuppa for us all”.

That would be lovely thank you.

Lovely tea – thank you Mary. OK thinking about what we have talked about so far what might your desired outcomes be? *[Cheryl explains that by outcomes she mean what end-results he wants to achieve, what he would see as being the impact of any changes he has said he wants and the things he wants to keep the same.]*

“Can you give me an example of what you mean so I can explain to John?”

Yes, of course. John has said he worries about you being tired and you have said you want him to stop worrying so the outcome for John would be he is less worried about you because you are less tired. Once we have worked out what the outcomes are we can look at how John might achieve them and whether he will need any support to do it.

“That makes sense now thank you – that would definitely be one outcome. We’d also want to make sure that if I am ill or go away he is well looked after, safe and gets his meals, showers and so on.”

Right, so that’s two outcomes. You also said that each other and then family were the most important things for John and for you. What would the outcome be in relation to those?

“Well I suppose being able to stay together with me doing as much caring as I can”

OK, I’ve got that one down. And in terms of family?

“Spending as much time with family as possible.”

And in terms of keeping active and making the bird tables?

“Yes, can you put that down that’s important to John. He needs to keep active and feel useful”.

So if we put ‘being as active as possible and continuing to make bird tables for charity’ is that OK?

“Yes that’s fine”.

Any others?

“No I don’t think so. Those are the critical things. We have plenty of equipment, rails and so on so we don’t need stuff like that. It’s just really the caring side of things and being able to keep doing things and seeing people.”

What are your thoughts on how would you like to go about achieving these?

[Mary, John and Cheryl have a discussion about each outcome and how might be achieved, what support networks already there e.g. family and what options there are for contingency / respite / break for Mary].

I think I have all the information we need now so if you are happy I will just go over the outcomes we have agreed and what needs to happen next.

My actions are: *[Mary, John and Cheryl have a discussion about actions such as]*

- Write up conversation
- Eligibility determination
- Provide copies to John and Mary
- Financial assessment
- Provision of information on carer support / respite
- Set up next contact
- Support planning

Your actions are: *[Mary, John and Cheryl have a discussion about actions such as]*

- Review information on carer support / respite – consider options around informal support or use of paid support

Further conversation – planned review at six months

Hello John, hello Mary. It's nice to see you both again. Is it OK if I sit here today?

"Yes that's fine. You sit there."

Thank you. It's a few months since I was last here and I know we have spoken on the phone briefly about how you are getting on but we need to do a proper review, see how everything is going or if anything has changed. Is that OK with you both?

"Yes"

Good, I've brought a copy of your last assessment and your support plan along as a reminder and for us to refer to if need be. Would you like to have a look over it before we get going?

"No dear, I think were fine. We can look at it if we need to can't we?"

Of course you can. And as always let me know if you need me to slow down or repeat anything. And just say if you get ready for a break.

"I will".

So how have things been going?

"Well things have been going OK. We've had some ups and downs, haven't we John but were managing mainly".

How about you tell me about the ups first then we can talk about the downs?

"Well we had our party for our Golden wedding. That was a great day. All the family came round and the grandchildren. We had a barbeque in the garden. I was feeling quite well that day and so we all really enjoyed it – Mary got a break because the children were around to help."

That's lovely. I'm so pleased you had a good day. What else has been going on?

"I've had to have an operation on my knee. I was in hospital overnight then on crutches for two weeks. It really limited what I could do for John."

Ah when I was reading through your information before I came out I noticed you had accessed some of your contingency direct payment. Was that when you used it?

"Yes it was."

I know you were a bit reticent to have help from an agency or using respite so how did you manage John's care while you recovered?

"When I was in hospital overnight Robert came and stayed with John. I was only in for one night but Robert stayed for two or three, all the children chipped in to help out. We did use some of the direct payment to pay for a carer to come in too though to help with getting John up, washed and dressed."

How did you both feel about that?

"It was fine for us both really. We got someone from a couple of agencies to come out and we talked to them before deciding who to go with. John really liked the carers that came, Susie and Angela." "Yes, they were very kind and good at what they did, I made them both a bird table." "Because I was there when the carers came so I could see how they were with John and it helped me feel a bit more confident in having them in when I'm not there."

So how would you feel now about having a break Mary?

"I'd feel better about it. I think I would feel comfortable they would look after him properly while I go out for the day. And maybe Robert or one of the others could stay over at night if I went away. I wouldn't want John go into a home even for a couple of days."

You were very worried about Mary before John, how do you feel now?

"I still worry about her but I think she got more of a rest when she had her knee done. It wasn't nice to have the operation and the pain, but she was forced not do things so she had a good rest. I think she would be able to go away for a break now and not worry so much about me so that's better."

Well that's really positive way to look at things John. I'm pleased that you both feel that it's an improvement.

I was having a look back over our past conversations before I came and when I first visited you we talked about how you felt your health was deteriorating and because of that your needs were increasing. We haven't discussed that for a while - how are things in that respect?

"My health is still deteriorating am I am having more bad days than I did but I feel better for having thought about the support we need and having a plan in place for care if I need it."

How are you finding the other support you have in place now?

"I'm still seeing lots of the family, that is working well still. They pop in regularly." "Oh and having the falls alarm gives us a bit of peace of mind too. John takes it into the shed with him." "Yes I take it into the shed, Mary can leave me to potter on with my woodworking without checking up on me all the time".

Ah, so you're still managing to get to the shed then, that's good. How are you managing with the other day to day activities?

"OK, like John said he has more bad days than good days now so he needs a bit more help more often. But having the contingency plan, and knowing that we can get carers who we can trust helps. At least I know there is back up if needed. After you had been we talked to the children and they come and do bits and pieces for us more often."

I've got the of the outcomes you identified here and a record of how where you felt you were in relation to achieving them. Where do you feel you are in relation to these now?

[John, Mary and Cheryl have a discussion about John's desired outcomes and where he feels things have improved, stayed the same or deteriorated]