

**File:** DemYouth-3-group 2 activity 1.wav

**Duration:** 0:28:36

**Date:** 01/02/2016

**Typist:** 677

START AUDIO

Roison: John always makes such nice things.

Facilitator: It's not nice things really, it's just nice paper that covers a whole load of things.

Roison: It's better than mine, I just use paper.

Anna: Did you want juice?

Roison: No, I'm fine thank you.

Sam: Thank you, is it half/half?

Anna: Yes.

Sam: Very good.

Facilitator: So do you want to just pass these round the group and then just talk through them a little bit? Flick through them, read some of them and read what's on the back. Speak among yourselves. Sam and Nadia, you're more than welcome to just pretend, once again, that you haven't done this before or you can just ask questions in relation to them.

Nadia: I remember there was quite an extensive debate last time.

Facilitator: There was an extensive debate.

Roison: Were we involved in creating these as well?

Leanne: Yes, was it that first one?

Anna: Yes, it was a while ago so it would probably feel a-

Facilitator: It was a long time ago. So this is a way to get back up to speed, I guess, on the things that we were taking about last time.

Roison: So these are the main things that people said they would like in the future.

Sam: I can't remember what I put.

Roison: I'm trying to find your... Let's have a look at some of the-

Suran: So maybe if there's any that surprise you or interest you?

Facilitator: The idea of this activity, to let the ball out of the bag here, is you've got to choose three to take forward to the next activity. So what you think the three most important agenda points are, or manifesto points, I keep changing the way of talking about these things.

Suran: Is there anything that links in to what we were talking about from experiences?

Anna: I suppose the themes are kind of like frustration, understanding, kindness, support. I think there's an interesting point about the person and the illness, listening to it I thought that that was quite a nice-

Roison: [Definitely special one, those words 0:02:05].

[Silence 0:02:05-0:02:20]

Is there anything that's standing out?

[Silence 0:02:21-0:02:35]

Sam: So we have to pick three that we think are more relevant?

Roison: Yes, is there anything that stands out to you that would be very, very important?

Sam: I'm not going to say because I'm going to say my idea.

Roison: Well why don't you say your own idea?

Sam: I'm going to be very biased but...

Roison: Why don't you say your idea and just start us off and then we can...

Anna: Then we'll say, "No Sam, that's terrible." What do you think?

Sam: I'm going to see if one of you pick it.

Anna: Okay, right.

Sam: I'm going to go and get some pizza.

[Silence 0:03:19-0:03:31]

Anna: Some of them kind of link together don't they, like, 'We need to consider young people's opinions' and 'We need to stop

leaving younger people out and get them more involved.' I feel like those two are like friends.

Roison: Then there are some about information as well really aren't there? There is quite a lot of stuff about information.

So think about what we talked about here and the things that were important to everybody in the room from their experience. What did we say it was? Stopping frustration... Is there anything that we could use here to help people understand a little bit more about dementia so that they wouldn't get frustrated? Do you think that would help?

[Silence 0:04:25-0:04:37]

Anna: I suppose perhaps the attitude thing there, 'We need advice on the best attitude', might link to frustration because it's [on about 0:04:44] people had that tension of what their natural reaction was and actually going, "Wait a minute..."

Roison: So the quote says, 'This is also about how you interact with them but it's to do with the attitude that you have when talking to people to show them or kind of educate people on what a good or the best attitude is to have towards someone with dementia so that the person who has dementia doesn't feel like they're different, so they feel like it's a normal conversation.'

Okay?

Suran: So are there any others that maybe link together?

Roison: Go on Sam, tell us your one.

Sam: Okay, it's that one.

Roison: Okay, personalised guides.

Sam: It actually fits with that one I think.

Roison: How does it fit with that one? This was, 'We need personalised guides that are easily to hand to find out more about what to do.' What's that related to?

Sam: Information on how to react or how to ask questions to stimulate a conversation with someone or a family member with dementia. That was my idea.

Roison: So to stimulate conversation?

Sam: Yes, but it would be for all different ages.

Roison: Shall I read the thing on the back?

Sam: Perhaps, I can't remember what I said. It's going to be so embarrassing.

Roison: 'When I was thrown in the deep end there was no information for me. I'm not proposing anything electronic but a pocket guide for various ages. They wouldn't need to carry it round with them, perhaps they could put it in their grandma's biscuit tin or whatever. Incorporated in the pocket guide would be a hotline number in case you needed more information about something that wasn't in the pocket guide.'

So it's all about information really here isn't it?

Anna: So that probably links with this one that's, you know, 'We need ways to communicate information that isn't just text and helps people to try...' That probably links to that one.

Because obviously hearing what everyone else said was the one thing that you felt that you heard everyone saying over and over, or did it all sound quite personal and different?

Suran: A lot of people mentioned how it can be quite frustrating.

Anna: Are there any that you think... Like you were asking us before, are there any that you think that would maybe directly help with frustration?

[Silence 0:07:15-0:07:32]

Actually those two link together don't they, better information, information that's young person friendly...

Roison: General awareness of what dementia is... This actually, 'Was of connecting with information that young people engage with and not paint a negative picture', that sounds like this one.

Anna: So basically if we can get these into three easy groups then we don't have to pick.

Sam: That's true.

Anna: We can just give them their own new heading.

Roison: So what's this one, Suran?

Suran: 'We need ways of being with people with dementia when we can't physically be there.'

Roison: That's interesting. So that sounds a bit like-

Anna: Particularly for you because you were at uni weren't you? That kind of explains itself on its own.

Roison: 'We need ways to communicate with and between others that are affected.' So this one said, 'Not just focusing on communication with the person with the dementia but also



communicating with the other people who are affected. So having strategies to communicate with them better so that they can better approach dementia within the whole space around them.'

So if you were feeling frustrated... You mentioned whenever you were talking about your grandma, were you saying that you didn't really feel involved in the family conversation about it?

Sam: No, just that everyone was really frustrated.

Roison: Everyone was really frustrated.

Sam: It got to a point where no one went to visit her or anything, apart from my grandad.

Anna: It's a lot of pressure on him isn't it?

Sam: Yes.

Roison: So did they have anyone to talk to about it or did they just talk among themselves about it? Did that help?

Sam: What do you mean?

Roison: I suppose if you are somebody who's experiencing a loved one who has dementia would it help to have other people who...?  
That's a very leading question.

Sam: I think he handled it very well actually, my grandad.

Roison: Did he have anybody to talk to about it?

Sam: No.

Roison: Do you think that would've help?

Sam: Probably not.

Roison: Why?

Sam: Because it's still his mum isn't it and he could talk to her about 40 years, or however long they'd been alive.

Suran: So he that much knowledge of stuff she did still remember?

Sam: Yes, so he could talk all day to her really.

Roison: Yes, okay, I got it.

Anna: So I suppose thinking about young people, if there's something about how, sometimes, we're more distance from our grandparents anyway, so then if you have something that distances you further, like a condition like dementia, you're already at arm's length. Then maybe that one about if you can't physically be there does become more... It might link into things like that.

So what you were saying about personalised guides, maybe part of that is when you see them but part of it is also how they're able to interact, whether it's in person, on the phone or with letters, or actually through information that they're able to still engage with. I don't know what is best. It might be specific to the individual.

Sam: Or it might be how bad the progression of the dementia is and what state they're already in.

Roison: We seem to have a lot of chat about communicating with people with dementia actually. It's about actually starting up a conversation. There's quite a few here about communication as well isn't there?

This is kind of like communication.

Sam: I think that's about a robot.

Roison: Do you? 'It'd be good if there was someone there all the time who just knew what was going on. So we thought about

something like a robot companion or a robot that could just be with a resident who could almost read their minds and understand what was going on with them. They interact with the robot and you interact with the robot.'

That's one crazy idea. (Laughter)

Suran: Expensive idea as well.

Roison: Well, have you heard of the PARO robots, the robotic seals?

Anna: Only because it was in...

Roison: 'Master of None'? I've read about them before.

Anna: Good knowledge of sitcoms though.

Roison: I think it was in Japan and they gave them to residents in an old person's home to keep them company. The seal acts a little bit like a puppy I suppose.

Anna: Like, "Hmh" when it wants attention.

Roison: So they kind of have this relationship with this seal I suppose just to combat the loneliness.

Anna: Just an animated teddy bear basically isn't it?

Sam: Does it work?

Roison: Yes, I think so. I read a paper that talks about it. I've definitely read something about it and then I saw it on that show. Have you seen, I think it's called 'Robot and Frank'? That's a very good movie anyway. That's about a robot and an older person as well. They do crimes together though.

Anna: Maybe not such a constructive example.

Roison: No.

Anna: But I suppose if there are things about feeling isolated or feeling like it's hard to communicate, are there things that we find in our lives which overcome that and then maybe we could adapt that across?

I like for me personally that I can text people until I'm blue in the face but I'm a massive extrovert, so I have to really see people and I have to talk to them, even if I just go for a walk just up the high street then I'm happier. Some people hate being around people but I like people. If I've spent too long on my own I get tired.

I suppose it's things like that about not just seeing the person as having dementia but actually what was that person before they started to lose themselves within the condition. I guess even in their confusion they're still going to be themselves.

Roison: You only really know that through talking to them I suppose.

There's the whole thing about grandparents I suppose as well. I certainly when I was very much younger your granny's always your granny really, your grandad's always your grandad. Then as you grow a little bit older, it's like with your parents, you begin to realise that you parents are actually people with pasts and who have had life experiences. It's the same with your grandparents.

Especially if you're quite a bit younger and your grandparent gets dementia maybe you haven't had that much of a chance to build an adult relationship with them.

Okay, let's start cutting some out. What do you definitely think should not go on our manifesto? We need three. What do you think's just like...?

Anna: If there are ones that seem together can we choose the one that maybe catches most of it?

Roison: Yes. So let's think about the first one here, what do you think that these all relate to?

Anna: I wonder if even... Not that you want to make them alike too much, but the last one links to the other one, sort of, doesn't it? You can still keep a bit of a gap there; I don't want to be bossy.

Roison: What do you think the top row's about?

Suran: Getting more information.

Roison: Yes, it seems to be doesn't it? So that seems like it's been quite a big theme of the discussion from the first workshop then, and it's something that we've talked about today as well.

Suran: Was there much information available for you?

Sam: Nothing.

Roison: Would you've liked to have known a bit more?

Sam: Probably.

Roison: A couple of different people said the things that they would tell their younger selves would be to give some more information to their family members and to tell them not to be frustrated. But you can only really tell somebody to not be frustrated if you can tell them why.

Okay, so which ones...

Anna: More information was that first one.

Roison: Yes, do you think we need better general awareness for young people or for everybody?

Sam: I think the general awareness is plentiful already isn't it with the advertisements and what not.

I don't want that to be my decision though.

Roison: What do you think?

Anna: So within school, if we were to ask everybody within Cardinal Hulme, "What's your definition of dementia?" do you think most people would have an answer or most people wouldn't have an answer?

Suran: I think they'd have an answer but it would just be, "Something that old people get when they get confused" or something, they wouldn't actually know what it is but that would be their definition.

Anna: So it maybe that the general awareness in society's okay but if you were to take each particular age group in that, say school age, it might be one of those... I guess if you're in your senior years, so 50 plus, that's a really long time away from when you're in your teens but...

Roison: Okay, so that maybe links into this one then?



Anna: Yes.

Roison: Is that our first choice?

Anna: Why don't we leave at one there because that one probably covers that one.

Sam: Yes.

Roison: We have to pick three though.

Anna: Well we can whittle them down. So we take that one out.

Sam: But do we not need more information for everyone including young people.

Anna: So we can do that as like a caveat. But you'd hope that if it was relevant to young people then it would be easy to read.

Sam: That's true.

Anna: But then some people might think it's patronising.

Sam: Yes.

Anna: So what else have we got going on here? I'll move them all up so they're not-

Sam: We should have our first choice, this one?

Anna: Yes.

Sam: Shall we put that somewhere else, here?

Anna: You decide.

Roison: Okay, and then these are kind of linked-

Anna: We can always reserve the right to change it if we get five and then we decide to whittle them down again.

Roison: These are linked to young people as well, the second row down.

Anna: But this is more about, like it says, interacting. So it's less about just information and it's more about their involvement I suppose.

Facilitator: How are you guys doing?

Roison: Okay.

Facilitator: Do you need a push? You've got five minutes, there you go.  
\_\_\_\_[0:19:37] I said five minutes about three minutes ago to those guys, so two minutes.

Anna: Oh wow, okay.

Roison: Okay. So I suppose we could think as well about reasons that people might do this, so why is it important to have interaction with somebody with dementia for young people?

Suran: At the end of the day they're still people and they're still their family, or whatever relation...

Sam: 'We need more interaction between the young and people with dementia', why?

Roison: Because they're still their family and they're still the person.

Sam: But what if the young person doesn't have any family with dementia?

Roison: I actually think that this might help to increase your information and your knowledge about dementia.

Sam: I do as well.

Roison: A lot of people's knowledge about dementia is around their experiences with it as well, especially some of the very specific symptoms that you might not learn about. So you can learn about the fact that they lose their memory and often they retain their memories from a long time ago and they lose a lot of the shorter term memories, but what about things like the odd behaviours and sometimes people can be violent and things like that?

Sam: I actually think that one covers all three of those.

Roison: Okay, so maybe we don't need this one? Excellent.

Anna: I would make a case for at least considering that one if it isn't covered in something else because I think sometimes what you do comes out of how you feel. So if you're confused, angry or frustrated then you're more likely to be... But if you're actually thinking, "This is still the person I love but they've got a condition that means it's hard to see them straight away."

Roison: So how do you think that you could do that?

Anna: Tricky.

Roison: I suppose, again, if you give people information that's all well and good but we talked about putting the information into practice I suppose and then that's where this comes in.

Anna: I suppose even if some of the stuff we've maybe covered in here, like ways to communicate, because if you know how to see the person then maybe that helps you. So like it's my best friends I probably have the least patience with because they should know better because they've known me for longer. It's the same as someone being my grandparent or whatever, they should be... But actually going, "They're my grandparent, but..."

I don't know, maybe come back to that one. Maybe look at the others because these were, kind of, clustered together weren't they?

Roison: We did talk about communication quite a lot actually. I actually think that the communication side of things moves on a little bit from giving people information to what you then do with it. Have you ever learnt something at school and then you've had to go and do it? Did you ever do first aid or anything?

Sam: Yes.

Suran: I haven't done it at school but I do St John's Ambulance cadets.

Roison: Have you ever had to do first aid on somebody?

Suran: Yes.

Roison: It's kind of like you learn about it but when you do it it's very, very different.

Anna: That's true.

Roison: Okay. So I think we've definitely highlighted the communication as one, so which one do we-

Anna: So which one-

Roison: Oh sorry Suran, you can't really see them there. I've mastered the art of reading upside down at workshops.

So we had, 'We need to communicate with and between others that are affected' and we talked about that a little bit earlier about having a link with someone else who's going through the same thing as you.

'We need ways of connecting information that young people would engage with.'

Suran: We've got information for young people in the other one.

Anna: Maybe get-

Sam: Shall we bin that one?

Roison: Yes, okay.

Suran: Might just have to get a bit ruthless now.

Roison: This one is, 'We need personalised guides that are easy to hand to find out about what to do.'

Suran: I feel like we can't not have that one can we Sam?

Sam: We can bin it if you want.

Suran: No, leave that one. It's different because that's not just about communicating is it, that's about how to isn't it?

Sam: It kind of links with this one and the first one doesn't it? So perhaps we've already covered it.

Roison: I mean I suppose there is some discussion to be had around the ways that we present information to people. Yes, it's all

well and good making it younger person friendly, but is it a course that you do at school, is it some workshops that you do, is it a website, do you have a mobile phone app or do you have something specific that you're taking with you, like a guide.

Anna: But I wonder if you just did it at school and if you didn't have an emotional connection to it would you even connect with it? I don't know, I just wonder. I don't know.

Sam: It could plant the seed though couldn't it, in case you ever come across it.

Anna: That's true. To make sure it's more present and more talked about.

Sam: Yes.

Anna: Yes. I don't know if it still is but I know, when I was at school at least, that people would use the expression demented to be critical. I don't know if that still gets used.

Roison: Medically we use it to say somebody is confused.

Anna: But in terms if someone was being a bit daft at school then people would say that.



Roison: We used to use it for angry, “She’s demented” like, “She went crazy.”

Anna: But it’s that thing isn’t it, I suppose, of people saying, “What do you mean when you say that?” I reckon that half the people who say that wouldn’t know that that linked to an actual condition.

Roison: Okay, we’ve got a couple of minutes so let’s be ruthless, we’ve only got one. So, ‘We need ways of being with people with dementia when we can’t physically be there.’ Do you think...?

Sam: I think those two are similar then aren’t they?

Anna: Which one would you say is more...

Roison: Important?

Sam: This one.

Roison: What do you think?

Suran: Yes.

Roison: Okay, bin.

Anna: Do you want to put it over with our chosen ones?

Roison: Is this the one, 'We need ways to communicate with and between others'? Yes, because that covers both communication with people with dementia and also with your family.

Anna: Excellent, that's one.

Sam: I think mine should go as well because I think that one's a better idea.

Anna: Oh Sam, you've sacrificed yourself. But I suppose in any conversation we have the goodness of that suggestion will still be in our chat won't it?

Roison: I actually think that there's more to the back of this than there is to the front because you kind of talk about... I like the idea of a personalised guide. We've got one left, quick.

Anna: I think we're all just too kind, we don't want to cut anything off.

Facilitator: Too kind? Don't worry.

Anna: We're getting there.

Roison: Okay, 'Advice on the best attitude to have or ways to communicate'?

Sam: It could link in with that one again though couldn't it, the guide thing that we just binned.

Facilitator: This should be easy for Sam because he's done this all before.

Sam: I didn't want to put mine influence on it though.

Anna: He's been very diplomatic.

Suran: Very conservative about it.

Roison: So this is about different ways to communicate information.

Sam: Which needs to be personalised doesn't it, or ideally be personalised.

Roison: To the person with dementia or to the person-

Sam: To the sufferer.

Roison: Okay. Which one does that relate to?

Sam: I think [it could go on 0:28:29].

Roison: This one?

Sam: Yes, okay.

Facilitator: There we go. Well done.

END AUDIO

[www.uktranscription.com](http://www.uktranscription.com)