**G08**

**Speaker key**

## UCLRA01

## UCLRA02

## G08BCF45

## G08ICF46

## G08BCM47

## G08BCM43

## G08BAF44

00:00:16

## UCLRA01:

Okay, thank you, everybody, for coming today, and for taking part in our research. So, as you know, we are researchers from the University College London, and with the, the idea of the topic we’re researching, it’s finding out how people from the black African and Caribbean community deal with memory problems, when they get old, so we’d like your point of view, your experience of… feel free to share anything you like, there’s no right or wrong answers, so it’s up to you, what you’d like to say. The session’s going to be recorded, but any information that you’re going to share here, will be confidential. However, we are going to ask you to introduce yourself first. This is simply because, when myself and UCLRA02 are going to type the information, we’d like to be able to associate each comment, with the right person. So, I’ll start by myself, I’m UCLRA01, and as I said, I’m from University College London. Would you like to…? Oh, do you want to start?

## UCLRA02:

We will go this way. Okay. I’m UCLRA02, from the University College London.

***G08BCF45:***

I’m G08BCF45, from Brighton.

00:01:35

***G08ICF46:***

I’m G08ICF46, from Brighton.

***G08BCM47:***

G08BCM47, from Brighton.

***G08BCM43:***

Ooh, we’re getting like that?

***G08BCM47:***

Yes.

***G08BCM43:***

I’m CuthG08BCM43, MBE, from Brighton.

[Laughter]

***UCLRA01:***

Thank you very much. G08BAF44.

00:01:53

***G08BAF44:***

I’m simply G08BAF44. From Brighton. I work here.

***UCLRA02:***

Thank you.

***UCLRA01:***

Thank you. So, to start the conversation, I’m going to set the scene with, just an example. I’d like you to think about a lady called Mrs. Abraham, she’s seventy years old, her family members have noticed that she’s more forgetful lately. She cannot remember conversations with people, and forgets appointments, with the doctor. She often misplaces important items, also, like her keys, and her glasses. She is physically healthy, however. But, she is concerned, about her own memory. Now, as I said, she is healthy, she is not a real person, obviously, this is somebody we just made up. But, there are quite a few people who have that kind of problem, of forgetfulness, healthy, yet forgetting important items, important appointments, appointments with the doctor. Now, if you knew somebody like Mrs. Abrahams, do you think that she should be getting help for her memory problems?

00:03:05

***G08BCF45:***

Yes, I think she should. Simply because, as you said, if it can be observed and noticed early, then yes.

***UCLRA01:***

Okay, thank you.

***G08BCF45:***

I know your question is simply, should she, but what you find, invariably, is that people don’t admit to things like that.

***UCLRA01:***

Okay, thank you.

***G08BCM47:***

Do we necessarily have to go in the order which we sit, or can we contribute at any stage?

***UCLRA01:***

No, please just feel free to take the floor anytime you’d like.

***G08BCM47:***

I would also agree that, the lady should have help. Although she’s healthy, the fact that she’s forgetting things, like a lot of us do, she needs to seek help, because you can never tell how serious her problem is, or how serious it could become, in the near future. So, certainly, I would support her seeking help.

00:04:14

***UCLRA01:***

Thank you.

***G08ICF46:***

She’s seventy plus?

***UCLRA01:***

70, yes.

***G08ICF46:***

Well, at seventy plus, we ought to be, yes.

[Overtalking]

00:04:26

***G08ICF46:***

We don’t want to admit that we forgetful, but you [unclear], and you find what you’ve forgotten, back again. You find the key, something will trigger you off [unclear], you go back in the direction, that you were meant to.

[Overtalking]

00:04:48

***G08ICF46:***

If she is living, by herself, she might well, not think that anything’s happening to her. If she’s with somebody, a husband, or a wife, or a daughter, it’s not forgetful, it’s… we all forget. But the bit about forgetting your doctor’s appointment, I think that’s vital that you should have been there.

***UCLRA01:***

Okay. Thank you.

***G08ICF46:***

But, on the other hand, you’ve got the doctor involved, she’s forgotten his appointment. It all now comes in to step in, to say well, this lady’s forgotten to come to see me, should I be doing something about her memory? And, move her in the direction, in the right way? She might not think she needs to go in any… she’s just a little bit, memory loss, it could be anything, it could be first thing in the morning, we all forget everything until we have a cup of coffee. I do. I can’t surface without one [Laughs].

***UCLRA01:***

You made a very interesting point, is that everyone forgets. So, you seem to say that, you’re not sure whether she should be going to the doctor. So, my next question will be, why would she go to the doctor for just forgetfulness, or, at which point, should she think, okay, I should go into the doctor, or maybe, or no, I’ll just laugh it off, and say oh, I forgot my keys, and just carry on with life. What would make that leap, that would make somebody go to, decide to actually go and take an appointment, sit at the doctor, and explain, that I forgot my key.

00:06:30

***G08BCM43:***

Am I dealing with that lady, or is that lady a part of my family, because I might have a different opinion, if it was part of my family. I think it would be different, than if it was somebody that, my neighbour, or two doors down, that I don’t see or hear about. And, we have friends, who are in similar situations, with their parents losing their memory. I think they’re very lucky, I shouldn’t say lucky. They have a caring family, who they can stay with, and care for them. But, it’s a lot of pressure on those individual family, at the present day, if they’re working, and have children, and have to look after elderly, elderly mum [?]. And then, there’s a pressure from the friends, who think you’re doing goody-goody to that person, who’s looking after her mum, and maybe she wants to go on holiday, and so she put her in a halfway house, and then you get the pressure from their friends, oh, you put your mother in a home. So, there’s pressure from the community, to care for their family. Normally that, I think, maybe the family is pressurised by their friends, to care for them, put extra care for them...

00:07:54

***G08BCF45:***

But G08BCM43, you are looking at it, when it has already developed, it has gone beyond just simple forgetfulness. Simple forgetfulness, and the question would be, had I done something at that point, or is there something I could have done, at that point, which maybe, would delay, the time, when it gets to the point where I need the help of my immediate family. And I think that’s what your question was about, should she, at that point, be seeking help, because now you go to the, you could go to the doctor, and the doctor might say, suggest some things that you can do, which could delay that day, when you need that help, need to be put in the halfway house, as you said, or need to be put in a home, simply because they can’t cope with you.

***G08BCM47:***

I think there is some difficulty in determining, at what stage, does one seek help, because I think that, over the years, there are times, when I have forgotten things, things that I need to do, like, a lot of other people. But, am I at that stage where, I feel concerned, that I should get help? It depends on how frequently, the forgetfulness takes place. And how many other things, which are attached to that, which we regard as, oh well, there’s a loss of memory, in this respect, so the question is, at what point, can, do you seek help? Because, we’re not quite sure, whether it’s just a phase that we’re going through, and then…?

***G08BCM43:***

Are we stable again [?]?

***G08BCM47:***

Yes. It wouldn’t happen, in the near future. So, it’s dependent, if it frequently happens, then, you get a bit concerned.

***G08BCM43:***

[Unclear] how do you see, do you go to the doctor, to say that oh, the problem starts from that situation, I don’t think I’d go to the doctor, and say doctor, I can’t remember anything. I think, I would forget what I go to the doctors for.

00:10:15

[Laughter]

***G08BCM43:***

So, putting yourself in that situation is very, very difficult. It’s suffering with that sort of thing, I never experienced this, in the Caribbean, in Jamaica, but we’re more family orientated, and I wouldn’t even think that we would have known it happened with us, the memory, you’d think they’re mad, or… so, it’s how you judge them, don’t you? Mental health, you think they’re mad, so you lock them up, and put them in a prison, or… that was the attitude. Don’t forget, I was born in the 40’s, I’m talking about absolute attitudes here. Now, I’m losing my memory.

00:10:57

[Overtalking]

***G08BAF44:***

Yes, I was going to say, and it’s interesting, because you said, at which point, would someone go to the doctor? And I think that is it, isn’t it, because you’re then thinking, oh, I must be really bad, the attitude would be, oh, I really need to go and see the doctor, so it must be really bad. And yet, you will discuss your memory loss, with friends, with colleagues, oh my memory, I keep forgetting. You laugh about it, because I remember, we were talking about this, in the [unclear], and you used to come in, and laugh, and say, oh, you know, this and that. And we’d talk about it, like that. But, at that point, it’s not serious, of course, but when you get to a point where one is nearly housebound, because every time you go out, you lose your way, then I think, that’s when people will consider it to be serious enough, to go to the doctor. But before that, which is a shame really, people think, oh, let’s talk about it, and laugh, oh, my memory’s going, because of old age, I’m seventy after all, and at that point, there doesn’t seem to be a need to go to the doctor. But, you can talk to friends.

***G08ICF46:***

But we’re all saying go to the doctor, but you try and get an appointment, with a GP, and it’s like, going to Mars. And half the time, if you go to the doctor, saying, oh doctor, I think my marbles are going. I’m sure he’ll turn round and say, just take these few pills dear, and go home. And it might be paracetamol, or some placebo of some sort. But, GPs have got tough life, at the moment, you try and get an appointment, and to sit down, and say, well, there’s something not quite right, up here. I don’t think many of them are going to take any notice of you, straightaway.

00:12:41

***G08BCF45:***

I think the point at which the individual was likely to seek help, I mean, you’ve got your relatives, you’ve got your friends around you, they could be observing you. They’re the people, because you personally, might not even realise, that you’re talking, you’re telling them the same thing, a million times. Because you’ve forgotten you told them, before that time. But, the friends, the relatives, who were so close to you. They are the people, who should be, should observe you. I hope that mine, would observe me, when I, I mean, I might be already, going there, but, you never know. But, they will feel able to come to me, and say, well you know, I think you, things are happening, I’ve observed you for the last year, or something like that. And they notice, this, that, perhaps, they ought to approach, and I think that’s how it should be. And not wait until you start losing your way, when you go out, and you don’t know which bus to take, or that. It’s…

00:13:48

***G08BAF44:***

But, what I noticed also, from some members of my family, it comes with sort of behaviour change, in the individual, and when you do bring the subject up, and say, you know, really, you need to go to the doctor, something is not quite right. Oh, my gosh, how dare you, accuse me of losing my memory. They get really defensive, and I think sometimes, it’s really difficult, to assist the individuals, because they, they are your parents, after all, and, or you elders, in your family, and you respect them, and it’s very difficult, to actually convince them, sometimes.

***G08BCM43:***

It’s more difficult for the elderly Caribbean people, in particular, and that’s a fact is, it’s because the majority of them arrived from 1948, onwards, right. So today, they could be the highest population, of the elderly, BME, could be the highest population, today, of the elderly population. There seems to be a norm, maybe just a man and a wife, and maybe one child. There’s no extended family. So, what we all create, is families, is friends, becomes. We create family, that you can call on them, these two, they’re as thick as anything, they call each other twice a day, you know. So, they’ve got additional support, in the community, there, or that. But, there’s no extended family, with the West Indian, there might be… there’s no grandma, there’s no grandma, there’s no uncles, there’s no aunt, because they are immigrants, that came over. And, if you look at the refugee population today, I mean, G08BAF44, you know this, more than I do, because you’re working with the refugees, a lot of them, and they’re on their own. There are no… there might be a man and a wife, and there’s nobody, so there’s no support group, there’s nobody that they can go and report, if they have mental health illness, too. Because, they’re on their own. A lot of the BME, or the black people, seem to be on their own.

00:16:03

[Overtalking]

***G08ICF46:***

There’s a stigma, there.

***G08BAF44:***

It’s a stigma, absolutely.

[Overtalking]

***G08ICF46:***

In the black community, in particular, nobody wants to say that you’re mad. In inverted commas, not that you’re a little bit senile.

***G08BCF45:***

But this is not madness, this is just simply an illness.

[Overtalking]

***G08ICF46:***

Well, we know it’s not madness

***G08BAF44:***

But the stigma, is associated with madness, I agree with you

00:16:26

***G08ICF46:***

Yes, and I remember people back home, that mad is the word you used. That uncle is mad. Where is he? He’s probably locked in a room, we don’t let him out.

***UCLRA01:***

So, on that topic, would you say that, getting a diagnostic of, let’s say dementia, would be different to getting something else, like diabetes, or arthritis, or something like that?

***G08BCM47:***

I should think so, yes, it’s different.

[General agreement]

***G08BCM43:***

I’d probably level it [?] with mental health, is stigma, attached with it, is similar to, for mental health.

***UCLRA01:***

So, you’d be more likely to go and see a doctor, if you think you have diabetes, than if you have a memory problem?

***G08BCM47:***

Absolutely.

00:17:12

[General agreement]

***UCLRA01:***

Why would that be, apart from stigma?

***G08ICF46:***

Purely because it’s a GP you’re going to, rather than somebody that specialises in what you were talking about. And I’m not sure how much GPs will act, that quickly, to get you seen, if you think, you’ve got something wrong, he hasn’t seen you in your surroundings, whether you’re there, you’re there for a few minutes, and you’re perfectly all right. You’re answering all his questions, but he thinks he might have to do something, or he might not have to do something. You’ve got a few minutes with your GP, you can’t sit there for half an hour.

***G08BCM47:***

Well, how would you approach, how would you approach your GP? Would you go on your own, or would you ask a member of the family to accompany you, to give you support, when you approach the doctor, and say, well look, as far as I’m concerned, I seem to be suffering today, from forgetfulness, and I would like to know what can be done, at this stage?

00:18:36

[Overtalking]

***G08ICF46:***

No, I’d go alone

***G08BCF45:***

For me, I suppose I’m lucky in that I have a GP, that I’m quite happy to discuss things with, when I… If I feel, that, or somebody has pointed out to me, oh, you’re getting really forgetful these days, I would go and talk to my GP. I would. Because, it’s… at the moment, the GP I have, is somebody who I feel, he would sit, and he would listen to me, when I go in.

***UCLRA01:***

So you’re happy with your GP. How about everybody else? Would you go and see your GP, or would advise a friend, to go and see a GP, if you notice that they’re having memory issue?

***G08BCM43:***

You’ve got nobody else. There’s no other support you can go to.

00:19:22

***G08BCM47:***

It comes as a point of reference, yes, you have, in order to, to get, if you think that your GP cannot deal with the problem, himself or herself, the GP would have consultants, to whom he can refer. So, if the question is, what is the first step you take? You go and see your GP, with the problem, hoping that the GP will refer you to someone.

***G08BCM43:***

Can I just ask you, to umh

***UCLRA01:***

Sure.

***G08BCM43:***

Is there any support groups, beside the doctor, if you’re suffering with Alzheimer’s [?], that you can go to?

00:19:59

***UCLRA01:***

There are groups, that would support you, but would probably direct you to your GP, which is the first point of contact.

***G08BCM43:***

All right, all right.

***UCLRA01:***

But we do need to know what the population actually, the people in the population, actually do. Because, it’s quite likely that lots of people don’t know where to go, or don’t want to go to the GP.

***G08BCM43:***

I think we’d all go to the doctor, I feel we’d all go to the doctor. I feel that would be the first…

***G08BCM47:***

But what is the position today? Do people who suffer, from such memory loss, do we go to the doctor? Or is it matter dealt with, within the family group, or within the circle of friends and family?

***G08BCM43:***

Yes, it is. Yes, yes.

00:20:47

***UCLRA01:***

That’s a very good question….

***G08BAF44:***

Yes, it’s a good question…

[Overtalking]

***G08ICF46:***

Well, I don’t think, if you’re just forgetting something, you’ll find it in two minutes time, where you’ve put it. That you’ve got…

[Overtalking]

***G08BCM47:***

Was that not serious? The question is, how often the thing happens. Yes, yes. You know, if you for example, you’re using the kitchen, you keep on leaving the fire under the saucepan, and so forth. [Laughs]

***G08ICF46:***

Well, I’ve… We’re not talking names, but I’ve got a very good friend, where, she put the drying up cloth in the microwave, inside the microwave oven. And blew up the microwave. Yes.

00:21:31

***UCLRA02:***

That’s really good points, that all of you are making, and just thinking about, what you’re said, and…

***G08ICF46:***

But no, nothing was wrong with her, she was perfectly all right, in her head.

***UCLRA02:***

No, that’s really interesting. I want to just pick up on a few of those points, really. You were talking about family, and G08BCM43 you mentioned about maybe, pressure from the community, to, for people to care for their own, within family networks, and things like that. And I just wondered about, wondered what you thought, in terms of other people influencing whether you would seek help. Whether that be in the community, or perhaps you have an extended family network, here. Do you think others would influence, whether you’d seek help for memory problems?

***G08BCM43:***

Depend on how you live in the community. We live in a society, where we don’t even talk to our neighbours. We don’t know who our neighbours are. We don’t know who is the person opposite us. So really, the community, really, that we live in, in Brighton, it’s, you couldn’t compare it with the textbook of living in Cara Lane [?], or… you can’t come here, Brighton, no. It’s, none of us live next door to each other. I don’t live next door, or five doors, or 10 doors, against a BME person, so, it’s different, you couldn’t sort it out, in the community. We don’t live in a very loving society. We don’t live in a loving society. We don’t live in a caring society. So, it’s very difficult to get support from the community, itself.

***G08BCM47:***

I think Brighton, is a sort of peculiar place, in so far as, it’s only recently, that we have seen quite a substantial increase in the number of black people. When we came down, in, to Brighton, in 1971, there were very few black faces around, people who lived in Brighton. Because, Brighton has been a very expensive place to…Most of the black faces, you saw then, in the early 70’s, were people who attended universities, and the polytechnics. In fact, when we came, G08BCM43 and G08ICF46 were the only people there, and one or two others, that we knew. As, that we could say, we know these people come from the sort of similar area, from the Caribbean area. But, you’ll have [unclear] found, people coming from other parts of, say, well London, or other parts of England, coming to live in Brighton, because there was not a great deal of employment, for… we didn’t have, we don’t have factories, and so, which attract a lot of immigrant people. So, the support network, at that time, was rather limited. Now, it’s different, you know you have more black faces around, but even so, we still carry on with the way in which the host community treat one another. For example, if you were in the Caribbean, you would know the people who live close to you, you’d be friends, and so forth. Over here, although we live next to people who are very friendly, and we talk to, it’s limited, the sort of communication we have with them, is mainly good morning, or good afternoon. Lovely day, and so forth. But, with regard to developing a friendship, as such, I think, it’s very limited. I mean, I go to the gym, at times, and you don’t find people exchanging views. You go in, and you do your own thing, so to speak, and you still have the reservation. I mean, I remember the experience, my first experience, in Britain, when I came, and introduced to various people, even at university, you introduce to them, today, and tomorrow, those people pass you, as if they’ve never seen you. I mean, that’s the way in which, people behave. And, it’s not that, I mean, it’s not only to black people, talking about the host population, treating the black student or immigrant, but that’s the way, that they treated their own people. So, it’s, so this is [Laughs]

***UCLRA01:***

This is a very interesting topic, actually, because we did talk to a few groups, already, and asked them, dealing with memory problems, is it better to be here, in England, or to be back home, whether it be Guiana, or anywhere in the Caribbean. So, what are your feelings about that? Where would be best, if yourself or someone you knew, had memory problems? Where would be best to deal with it?

00:26:53

***G08ICF46:***

Back home.

***UCLRA01:***

Back home.

[Overtalking]

***G08BCM43:***

Yes, I would say amongst family. You’re here. Oh, sorry.

***UCLRA02:***

No, no, that’s fine.

***G08BCM43:***

You’re here alone, aren’t you. You’re here alone, in England. And, if you’re home, you’ve got your family, plus your neighbour’s support, and if you have money, you get better care, still. But, I think, yes, amongst your own family. I mean, if I was suffering with mental health, and I had the money, I would say, get a family member, from Guiana or Jamaica, well not Jamaica, but…

[Laughter]

00:27:31

***G08BCM47:***

Not Jamaica.

***G08BCM43:***

But, from Guiana, to pay them, to look after me, and I think, if I had the money, that’s the care I would want for myself.

***G08ICF46:***

Whereas here, you’d probably end up in mental health institution, and then you’ve got all that stigma attached to it, and you probably won’t see another member of your family come to see you.

***UCLRA01:***

Could you explain a little bit more about that.

***G08ICF46:***

What?

***UCLRA01:***

You said, here, they’ll send you to a home, wouldn’t they do that, back home? You said they’ll send you to an institution, did I understand it right?

00:28:04

***G08ICF46:***

No, no, not necessarily. We have had, we’ve got places in Guiana, called a mad house.

***G08BCM43:***

Stigma attached to it.

***G08ICF46:***

But, but…

***G08BCF45:***

Go on, explain.

00:28:13

***G08ICF46:***

My grandmother lived to 101, yes, had all her faculties. But I’ve seen members of a family, where my parents have said, oh he’s mad. I don’t want to question, what do you mean by that? But, once they institutionalised, they lived within the family, and the family knew that person’s history, and they quite happily live among the family, they know how to treat him, how to keep an eye on him, make sure he didn’t wander off 20 miles away, got lost, kept clean, and everything else.

[Overtalking]

***G08BAF44:***

So I suppose the difference is, there’s more support, there than here.

***G08ICF46:***

So, the extended family, that you have, that you kept and looked after, my grandma died at home, and she had eleven children. And they took it in turns, to look after her, till the day she died. And I was only a girl of 15, but I can remember, as a big, adult woman, going to see her, how clean and nice she looked. And there was always somebody there, in the family, married or otherwise, that was there, to keep her company, to talk with her. Isolation is such an awful thing. Not, that could send you mad. No fault of your own. Well, that is what I think, anyway.

00:29:43

***G08BCF45:***

I agree with what G08ICF46’s saying about isolation, but if we are looking at it, from the point of view of treatment, if there is some treatment, or something that can delay the inevitable, then I think, here, you’re more likely to get something done. At home, they will take very good care of you, as G08ICF46 has explained, you’ll be wanting for nothing, but you’re not getting any treatment, for the condition, it’s just a case of people looking after you, and making sure that you are kept safe, whereas here, if there is any medication, or anything like that, most likely, you will get it here, and not there.

***G08ICF46:***

And then, you might have to have a spell in a psychiatric clinic?

***G08BCF45:***

But not necessarily, because if you have, if you are being treated here, you’re looking at someone living on their own, and it depends on whether that person is just on their own, in which case, they might think they need to be in a safe place. So that they can administer whatever treatment, or whether that person has some family structure, whereby they could still remain at home, and receive care. I know that, here, in England, I should say here. In England, people seem to be, only talking about the nuclear family, mum, dad and the kids, because people tend to move away, and never see the grandparents, or, for [?]. But, I think things are changing now, because, the young family realise, they need the grandparents, to help them bring up, these children.

00:31:43

***G08BCM43:***

Babysitting.

***G08BCF45:***

They need them for the babysitting. So, at least you have, that stag there. You have the grandparents, and the parents, and the grandchildren. And you’re hoping that, should the grandparents, ever find themselves in a position where they are in need, that the parents, of the young children, would then come to their aid, in some way, even if they decide to put them in a home, but at least they’ll come to the aid, of these people. But I think, for medication purposes, they’re most likely to get it, in England.

***G08BCM47:***

And also the cost of it, because in a number of the countries, from where we come, you have to pay for medical treatment.

***G08BCF45:***

And that is why people don’t go to the doctor.

00:32:37

***G08BCM47:***

Yes, it could put some people off…

***G08BCF45:***

It is pretty expensive.

[Overtalking]

***G08BAF44:***

Where, here, or…?

***G08BCF45:***

No, back home

***G08BCM47:***

Back home, yea.

***G08BAF44:***

Yea, you know, I… I’ve forgotten now, that’s dementia setting in. I mean I did…Thank you G08BCM43. I think our understanding of dementia, and the ageing process, whether we are abroad, or here, still remains the same. That I’m getting old, that’s fine, I can get old, and I can lose my memory. We don’t, I think, we still don’t see the need, to actually go and seek medication, because it might slow the process down, depending on how old you are. If I’m 60, and my memory is going, then I will be really concerned, because I would consider myself to be young. If however, I was 70, or 80, as you were saying, you know, how old is the person, then I’m going to think hey, what’s the point in bothering myself with medication, I am getting old anyway, so…

***G08ICF46:***

and I may as well forget it…

00:33:37

[Overtalking]

***G08BAF44:***

And I’m bound to forget a few things, and that seems to be acceptable. And I think that is there, within the community. And I think, in a family situation, it really seems to work because we still respect our elders, that is our culture. And we look after our elders. Although, I know it’s changing. But, I think, within the community, that community support, it really is sad, actually, because the stigma, is so huge.

***G08ICF46:***

Absolutely, yes.

***G08BAF44:***

If you’re losing your memory, you will be shunned by the very people, who are supposed to be supporting you. Ooh, that one is going to bit, yes. You know, and we start in labelling people, and calling people…

00:34:15

***G08ICF46:***

That’s it. And if you’re institutionalised, well, that’s even worse.

***G08BAF44:***

Yes, so, that support, you are isolated, within that structure, that’s supposed to support you. And, I know, with working with some of the communities, I mean, they will be talking about someone, who’s within the group. And they’ll be saying, oh, we know someone who’s a bit, you know, funny, within… And that person is there, in the room. And, it’s just so negative. And I think, definitely, something needs to happen, in terms of raising awareness of dementia, and its impact, and its, the symptoms, and how it affects people.

00:34:53

***UCLRA01:***

I’m glad you brought up that point, of raising awareness, which my colleague, UCLRA02, is going to talk a bit more about.

***UCLRA02:***

It’s all, really, really interesting stuff. We could talk about it for ages. But we are just going to have to move the conversation on slightly, because I’m conscious of time, and I know that you have to leave. So, just building on some of the things, that you’ve already been discussing there, with UCLRA01, we just wanted to ask you a little bit more, about what your thoughts and opinions are, as to what you feel could be done, to try and help encourage, perhaps support people within communities such as your own, to seek help for memory problems, when they do first notice those symptoms. So, one of the things that we know, from a lot of research, is that, for those who seek help for memory problems, through their doctor, at an early stage, generally speaking, do better overall. So, these people are able to plan ahead for the future, they’re able to get better support put in place, and not only them, but their families, and their friends, around them, also, can be better supported, generally speaking, this is. So, I’d just like to start by asking, if someone close to you had memory problems, what kind of information do you think, would make it more likely, for you, and/or them, to seek help, for these problems? What kind of information, do you think would be good to have out there, available, to try and support people in this?

00:36:18

[Overtalking]

***G08BAF44:***

It’s very difficult, but I think, that borderline, we’ve already touched on that, at which point, you would consider it necessary, for someone to seek help. I think that information, needs to be available. As we said, we all accept that we forget things, but at which point, do you consider that someone needs to seek help, that information needs to be available, because it’s not there.

***UCLRA02:***

Okay.

***G08BAF44:***

I do think that.

***G08BCM47:***

Yes, I would say that, the information should be freely available, because although you may think, well, someone needs help, you need to know, exactly, what’s available, to discuss with the people, who are affected by it, so you can say, well, look, we can do such and such a thing, now. So, that information should be there. And again, it’s a question of educating the community. In that information, you spell out what the dementia is about, and that help can be provided, where that help can be obtained, etc. Then, we would be better equipped, to pass on to the people who we think, maybe affected by dementia, what we can do, about it.

00:37:49

***UCLRA02:***

Okay, thank you very much.

***G08BCF45:***

My addition to, and I mean, I support all that has been said before. But I sincerely, and I feel about this, quite sincerely, that, as you get older, you ought to get involved, in the things that are likely to stimulate you, mentally. I think mental stimulation, could go a long way, to easing that. And, what I find, is that, sometimes as people get old, all they want to do, is to sit. And do nothing, think nothing, and that’s part of, I don’t know if that’s part of your research, but maybe, those are the type of things, they can suggest, as we get older, these are the type of things, you could keep going, get involved in, keep going, to keep stimulating you mentally, because we need both mental and physical stimulation, and some people do nothing. They don’t do anything. And then, when it starts going, they say, oh, it’s my age.

***UCLRA02:***

Sure. No, these are…

00:39:00

***G08BCF45:***

I feel passionate about this mental stimulation. That people should be stimulated mentally.

***G08BCM43:***

Take up a language then, play chess, dominos.

[General agreements]

***G08BCF45:***

Yes, anything. Just to keep them thinking.

00:39:14

***G08BCM43:***

I think that’s lovely, what they just said, but to me, it’s, the majority of people I know, that suffer with, or having mental health, tend to be loneliness, they tend to be, maybe on their own, lost a partner, on their own, and then they deteriorate. But, amongst the BME, the black and minority ethnic communities, as I said before, many of them here are alone. So, when one partner died, they’re… you know if there’re two of them, they’re left on their own, and they seem to deteriorate quite fast. So, really, the early stages for them, is very difficult to report it, unless it’s an immediate family who’s going to report it. And they don’t necessarily live with immediate family. They’re only visitors, and I would imagine, if you’re suffering… I mean, I used to go and visit someone who was losing it…, and I used to joke to her, and said, that I’m losing it, as well, and joke, and give her examples of how I can’t remember things, and G08ICF46’s got to remind me of things, sometimes, especially appointments. And, we used to laugh and joke about it. We used to laugh and joke about it, and it’s, to me, it’s… you can’t, the early stage, it’s going to be difficult to report it, in the early stages. Because, the majority of black and minority ethnic people, are on their own. And, as you said, the family is not going to go and say, mum, come to the doctor with me, because this might be a stigma.

***G08BCM47:***

Well, to add to what you’ve said. Since a number of people from the BME communities are on their own, we need resources, such as, places like, where we can meet. So that those people who are lonely, have a place to go to, from time to time.

***UCLRA02:***

Absolutely. It’s a really good point, and in fact, if I can just expand it a little bit, I can throw it straight back to you. As you said, needing resources, and you’ve made, everyone’s made really good points, about what information you need, information about when should you seek help, where should you seek it from, what to expect. One thing I’d really like to get your opinions on, is to how should we get this information to people, and when I say, what kind of information, should this be in the form of leaflets, is that something that people would look at, and take note of? Letters, DVDs, what do you think would be a good means of communicating this information, to people out there, in the BME community?

00:41:43

***G08BCF45:***

I think, more visual. DVD.

[Overtalking]

***G08ICF46:***

DVD

***G08BCF45:***

Although, you could still have leaflets, but I think, just doing a film, or possibly talking, as well, you know, there are like three different ways, DVD, talk, leaflets.

00:42:05

***G08BCM47:***

Yes, I support providing leaflets, which can be distributed widely.

***G08BCF45:***

But, people might not read them.

***G08BCM47:***

Yes. No, but, this is one of several ways of tackling it. The provision of DVDs, and in addition to that, you’ll have talks you can invite people to. Now, when I mentioned resources, recently, what I meant, is like places such as this, BME, where BME people can meet, and where you can exchange ideas, and where you can have a talk, given to those who attend, as to what can be done. Because, if you haven’t got the knowledge, to know where to go, then, we’re not educating those who could get more help, that is…

***G08BAF44:***

Yes, I mean, we have had sessions here, with DVDs, remember. And we had one, that was sort of themed. Yes, remember that session, and one was, targeting I think black people, one was Asian, and we didn’t have one that was Chinese specifically, but it was really interesting, because people identified with that, if they saw someone like them, because usually, you might see a white person there. That’s not you, you can’t relate to that. But to actually see another African woman, sitting there, and saying… you relate to that. And we found, that had a huge impact, that day, because some people were saying, well, my children are saying, I’m going that way, and some people were actually talking about their own difficulties issues.

***G08ICF46:***

Some people were crying.

***G08BAF44:***

Some people were crying, in that session, yes. So, I think, things like that, are really important, where people can discuss, and we are normalising memory loss, or dementia, that way. And I think, personally, that’s what I took away from that session.

00:44:03

***G08ICF46:***

I think it’s the fear, I expect the next thing you’re seeing is that big door, when you’re institutionalised, in a mental home, which has got so much bad press…

[Overtalking]

***G08BAF44[?]:***

It’s not necessarily a mental home, you keep [bordering?] from that…

[Unclear] are all those with dementia in mental homes?

[Laughters]

***G08ICF46:***

Well, I don’t know, it’s a thin line.

***UCLRA02:***

Okay, do you think that, [unclear], you’re talking about, you’ve said about being institutionalised, and things like that, the way in which, perhaps, we deal with older people in this country. Do you think that fear amongst communities, such as your own, prevents people seeking help, from a doctor, because there is the fear of that happening?

00:44:41

***G08BAF44 & G08ICF46:***

I think so.

***G08BCF45:***

It could, yes. It could.

***G08BCM47:***

Well, this is why I’m saying, ignorance, if you have, if you’re ignorant about, where you can get help, and what, if the help will help you. That’s the…

***G08ICF46:***

Yes, I mean, when you take…I mean, they’ve shut down, so many of the homes, now. I don’t think there’s an awful lot left, that you can go to. But, it would be nice, perhaps, to get somebody that worked there, or if somebody’s been there, as a patient, and is quite happy to come and talk to people. That will open up, a little bit alleviating the fear, that people have got.

00:45:21

***UCLRA02:***

Okay, no, it’s really interesting stuff. I mean, just…

***G08BCM43:***

My… you see… oh sorry. I’ve got opinions, separate.

***G08ICF46:***

I’d be curious, also, to know, I mean, you’re targeting black, mainly minority, it would be curious to know, say Millview , which we’ve got here, how many black people are institutionalised there?

[Overtalking]

***G08BAF44:***

Loads!

***G08BCM47:***

It’s full of them. It’s full of them. Prisons, mental health. Yes.

***G08BAF44:***

But, not in nursing homes, where you’ve got older people, you don’t see black people there.

***G08ICF46:***

No, no no

***G08BCF45:***

That’s for mental health, isn’t it?

00:45:56

***G08BAF44:***

Yes, yes.

***G08BCF45:***

As opposed to dementia, that’s why I was separating it.

***G08BAF44:***

But, you know, it’s interesting, because I remember this really first, when we were talking about this, when we went to the South East, and I think the problem, whether you are going that route or not, in terms of dementia, not knowing , what’s going to happen to you, As you get older, it’s scary, for a lot of BME people. What’s going to happen to you? There’s no information out there. You just don’t know. You haven’t got that family, that will support you, or discuss with your children, and you’re really scared. The last thing you’re going to do, is go to the doctor, and say, I think I’m going a bit funny in the head, because you don’t know where you might end up. You might end up being locked up in some sordid place, because you just don’t know. That information is not there.

00:46:46

***UCLRA02:***

No, that’s a really good point, G08BAF44. Thank you very much for that. And if I can, just bring it back to the leaflet and DVD, I think, we were talking about. I mean, let’s start with the DVD, perhaps. Do you think, most people out there, have a DVD player, to watch these things on, that would be one question?

***G08BCF45:***

No.

[Overtalking]

***G08BCF45:***

I was talking about, a showing, to a group, not giving DVD to individuals.

00:47:11

***G08BAF44:***

No. Group, yes, group sessions. Because that would be scary anyway, on your own.

***G08BCF45:***

Like calling people together, and saying, we’ll be showing this. And it’s shown, once, twice, three times, or you know various times…

***G08BAF44:***

And we discuss it, and there’s support afterward, yes, yes.

***G08BCF45:***

And discuss, now that’s the type of thing I’m talking about. Not handing out.

***UCLRA02:***

Okay. No, that’s good to know, thank you.

***G08BCM43:***

Couldn’t you look at it the same way that the government looked at healthy eating, and smoking. I worked for the health authority, I mean, this healthy eating was my baby, you wouldn’t believe it. When I worked in the health authority. And, it was quite simple, really. They educated the children, and the children educated the parents. Smoke [unclear] response before all the parents stopping smoking, it’s going to kill your mum, it’s going to kill your dad. It was the children. Vegetarian, when I worked for the health authority, if you were a vegetarian, you were classed as a crank, you were classed as a crazy crank. And you go anywhere now, and ask for a vegetarian, there’s more vegetarian now, around. And these were the children, educating the parents. Smoking is a typical example of how we educate the children and the children educated… Until you start going into the schools, and teaching them history, for instance, they’ll never know their history, if you don’t teach them at school, because they don’t teach history at school, and it’s the same with… You have to, I feel you have to educate the children first, and the children will educate their parents. And you can do both, you can do both, but I think you have to get to the children.

00:48:40

***UCLRA02:***

Okay, so the information need to be available for all…

***G08BCM43:***

All around them, I think, yes.

[General agreement]

***G08ICF46:***

They might pick up the signs.

***G08BCM43:***

Yes, yes. Of course.

***G08ICF46:***

While you’re in denial, the kids will pick up the signs. Don’t tell me that everybody is not in denial.

00:48:51

***G08BCF45:***

When you’re talking about children picking up the signs. I think I’d bring it back to the project. This project is intended to focus on older people, people who might realise that they’re going there. Or, people who are travelling there. And, I think, I imagine, you are limited, in your budget, etc, so you can just about focus on us older people, and I think, the idea of the DVD, and the leaflets, would be something that possibly, you can concentrate on. But as G08BAF44 and the others have said, it should not, it should be a showing with a discussion, you call people together, and you show the film, and you relate it, as G08BAF44 said, whoever you’re using in the film, should be people that they can identify with. I support that. If you’re going to be talking about black people, then they should be black people in the film. So that, they can identify with them. Yes. And, I think those are the type of things, I would suggest. I mean, where the children are concerned, yes, but that’s another story.

00:50:21

***UCLRA01:***

Just one question. Leaflets, it’s a very good point. But we receive a lot of leaflets, and I don’t know if everybody is the same, but we tend to throw it away without even reading it. So, what would make you read the leaflet, pick it up, and actually read it?

***G08BCM47:***

It’s got to be simple. It’s got to be simple. For example, this is from Brighton and Hove neighbourhood care scheme, it’s broad, bold print, and simple. That will encourage people to, if you put a lot of, sort of, reading to be done, people are not that… it must be catchy.

***G08BCM43:***

I know, you won’t chuck away my leaflets.

00:51:07

[Laughter]

***UCLRA02:***

Okay, if you were to receive… Do you think you’d be more likely to pick up and read the leaflet, if this came through your door, for example, if it was accompanied with a letter from your GP, perhaps? Would that make any difference to you?

***G08BCF45:***

Yes, I think, well for me, yes, I would read it. I would ready

[Overtalking]

***G08BCM43:***

Mmmh, a letter from the GP, people would read it, more than a spam, if they consider it has come through… I think they would read it. But, they might not necessarily read a letter coming from the council, with a council stamp on it. There’s a difference. Or, they might not read it, if it’s got a police stamp on it.

***G08BAF44:***

Not, our council, yes.

***G08BCM43:***

Yes, you get what I mean. So…

***G08BCF45:***

So, if it comes from the GP, yes, it can be something that comes through the GP. But, as G08BCM47 said, it should not have a whole lot of words, because they’re not going to read it. It’s got to be…[knocking on table]

00:52:08

***G08ICF46:***

It should have pictures

***G08BCM47:***

A bit like this [Showing a leaflet]

***G08BCF45:***

Yes. So that when they look at it, and you’re saying, for, if you’d like further information, here’s where you go. That type of thing.

00:52:17

***G08BAF44:***

And another thing, if I saw a leaflet, coming through my door, as we say, we get loads, and there was a black face on there, I would look at it, because I’m thinking, oh, what’s this? You can relate to that. Because otherwise, it’s in the bin.

[General agreement]

***G08BCM47:***

Yes, yes.

***UCLRA02:***

Okay. That’s great. All, really, really interesting stuff. Is there anything else, at this point?

***UCLRA01:***

Yes. What if a letter from your GP is addressed directly to you and talking about memory issues?

***G08BCF45:***

That makes it relevant [?]

***UCLRA01:***

Would that worry you at all?

00:52:48

***G08BCF45:***

No. Oh well…[Laughter]

***G08BCF45:***

No, because I would see it as general information. I wouldn’t think, and they’ve addressed it to me, it’s like, they were talking about, when they write to me, and tell me about going for my jab, because I…

[Overtalking] [Laughter]

***G08BCF45:***

Because you haven’t taken up, this flu jab.

***UCLRA01:***

Yes. So, you’d be okay with that?

***G08BAF44:***

Yes, I think, that would…

***G08ICF46:***

And then your children can read it when they come to visit.

00:53:16

***G08BCM47:***

You put down and sit down, and read this? This is…

[Overtalking]

***G08ICF46:***

Yes, look at that.

[Laughters]

***UCLRA02:***

Thank you so much, everybody for all that, I mean, we could continue talking about this, for ages.

[Overtalking]

***UCLRA02:***

But we will stop there. We’ll just turn these recorders off, and there’s a few bits, before you all dash off, if that’s okay?

00:53:35