

Faces and Social Life in Age-related Macular Degeneration: A Conversation Starter

The information sheet *Faces and Social Life in AMD* describes some of the difficulties with faces and social interactions that can be experienced by some people living with AMD.

Not everyone experiences the same problems. Also, the problems they experience may change as their eyesight changes.

The following questions are designed to start a conversation between a person with AMD and their family, friends, and carers (e.g., nursing home staff).

The aim is to share information about **this person's** individual experiences in seeing faces, the impact this is having on their interactions and social life, and what they would like other people to do to help.

Questions can be read out loud by the family member, friend, or carer.

Seeing faces

- Do you have problems seeing faces?
 - How often? Just sometimes, or almost always?

- Can you see people's faces OK if they are close by? For example, if you stand or sit next to them and are having a conversation?
 - [Move to a conversational distance, i.e., 1-1.5 metres apart]*
 - What does my face look like to you now?
 - Is my face clear or blurred?
 - Can you see my facial features clearly? e.g., my eyes, nose, lips?
 - Can you see who I am?
 - Can you see when I change my expressions? *[make a sad then happy face]*
 - Can you see where I'm looking? *[shift eyes to left then right]*

- Can you see people's faces OK if they are further away, like on the other side of the room?
 - [Move to the other side of the room]*
 - What does my face look like to you now?
 - Is my face clear or blurred?
 - Can you see my facial features clearly? e.g., my eyes, nose, lips?
 - Can you see who I am?
 - Can you see when I change my expressions? *[make a sad then happy face]*
 - Can you see where I'm looking? *[shift eyes to left then right]*

- What lighting makes it easier or harder for you to see faces?
 - Do you like strong light? Or weak light?

- Are there other things that make it easier or harder to see faces sometimes?

Social interactions

- Do you sometimes make mistakes recognising people because you can't see their face clearly?
 - Have you failed to recognise someone you know, like walking straight past a friend, or not recognising a family member?
 - Have you ever said hello to someone you thought you knew, and then it turned out it was someone else?
 - When you make one of these mistakes, do you worry about what the other person might think?
 - Do you tell them about your vision problem?

- Do you try to use other information about people to help recognise who they are, like their hairstyle, or the way they walk, or their voice?
 - How often do these things actually work, so you can tell who the person is even if you can't recognise the face?

- Have you changed your behaviour?
 - Do you tend to wait for others to speak first because you can't recognise them?
 - Do you wait for others to get closer to you, or move yourself closer to them to work out who they are?
 - Do you smile at everyone to avoid offending people because you can't tell whether you know them or not?

- Are you sometimes unable to see other people's facial expressions, like whether they are looking happy, sad, angry, or bored?
 - Have you made mistakes understanding how someone is feeling, like thinking they are happy and only later realising they are sad?
 - Do you ever have no idea how others are responding to you, such as if they like you or not, or if they are enjoying your conversation or they are bored?
 - Do you sometimes fail to pick up on jokes because you can't see facial expressions?

- Do you try to use other information to help work out what people are feeling, like their tone of voice, or their body language?
 - How often do these things actually work, so you can tell how a person is feeling even if you can't see their face?

- Do you ever have trouble making eye contact with people, or telling whether someone is looking at you?

- Do you find it takes more concentration or mental effort to follow a conversation, because you can't see faces properly?

- If you lip read, do you find it hard to understand what people are saying because of problems seeing their mouth?

- Do you find it particularly hard to follow what is going on when you are in a group?
 - Why? Is it partly because sometimes you aren't sure who everyone is?
 - It is partly because you can't see everyone's expressions or where they are looking?

- Do these difficulties make it harder for you to fully engage in conversations so instead you sit quietly in social situations?
- Have problems seeing faces made social situations harder, or less rewarding?
 - Does it make it harder to join in, and to feel you are fully part of the group?
 - Does it mean you miss out sometimes, like missing out on talking to a friend because you couldn't see them at the back of the room and you didn't know they were there?
 - Are you worried others will think badly of you if you make mistakes, or accidentally ignore them?
- Do you ever just want to avoid social situations?

How would you like others to help?

[Replace 'Mary' below with actual name of the person with AMD].

- Would it be helpful if people introduce themselves when they approach, so you know who they are, like saying: *'Hi [Mary], it's Karen' ?*
- In group settings, would it be helpful if everyone says the name of the person they are speaking to each time, like: *'John, who do you think will win this weekend?' and '[Mary], how about you?'*
- Would it be helpful if I said the names of people to you, like: *'Here comes Bob', or 'David Smith is sitting at the back of the room with his wife' ?*
- Would you like me to tell you nicely if you've made a mistake, like laugh and say *'Actually that is Bob but he looks like David'*.
 - Would you want me to say this in front of the other person, or when we are alone later?
- Would you like me to tell you if someone is looking particularly emotional, like saying: *'Jill looks upset, she's crying'*. Or help you interpret people's expressions, like saying: *'I know you might think the doctor was a bit annoyed, but actually I think we was joking because he was smiling'*.
- Would you like me to explain your problems with faces to other people, so you don't have to do it all the time, or so they know you don't mean to be rude if you ignore them?
 - Who would you like me to explain to?
 - Who don't you want me to say anything to?
 - Would you rather explain yourself?
- Do you have any other ideas for things I, or other people, could do to help?
- Is there anything people currently do that **doesn't** help (including me!), and you would like them to stop doing?