

Faces and Social Life in Age-related Macular Degeneration

An information sheet for people living with AMD,
and their family, friends and carers

AMD can make it hard to see faces which may lead to some common mistakes:

Everyone is different, but depending on lighting and distance, faces can look blurred or distorted. Because faces can be hard to see:

You might not recognise people you know:

- The other day I didn't even recognise my son ... he was within a yard or two of me and I didn't recognise him.
- I pass by people in the street that I know very well.

You might accidentally say hello to someone you don't know:

- I went up to someone I knew very well and started having a conversation with them. They looked at me blankly, and I realised they were not who I thought they were. It was very embarrassing!
- I am more careful now and wait for others to speak first.

You might use other information to help but it doesn't always work:

- I look at the way people are walking, their size, their hairstyles ... and then of course if they speak it's voice recognition.
- I can make some terrible mistakes, the other information helps but it is certainly not fool-proof.

You might not see facial expressions:

- You can't see if you've wounded someone's feelings, so you don't realise 'oh I've hurt her, I shouldn't have said that'.
- I thought my doctor was upset with me and I couldn't work it out, but my daughter said he was having a joke just to crack the ice.

You might find crowds hard:

- I find social situations very difficult particularly in a crowded room
- I find crowds uninteresting ... if I can't see and can't place people then it's a bit of a waste for me.

Sometimes, these problems can start when your vision loss is quite mild.

People don't understand how AMD impacts my vision:

- It's difficult, they forget I have AMD.
- They don't realise my vision has deteriorated.
- I worry people think I am faking. They say 'your eyes look perfectly normal'.
- They wonder why I can't recognise people but I can walk around ok

Other people might think I'm rude or unfriendly:

Many people with AMD worry that others think they are ignoring them on purpose.

- People are mostly kind about mistakes (they help or laugh it off), but sometimes they do take offence: When I walked past Jenny and didn't recognise her, she yelled 'you don't even speak to me!'

Face problems can make social situations difficult:

Some people with AMD may appear passive or disengaged because they cannot see who is in a room.

- My old friend Tony was at the funeral and I would have loved to talk to him, but sadly I had no idea he was there.
- I sat there [at a social function] for fully two hours not knowing who the people at the table were, and that was pretty distressing.
- I find social situations can be a bit tricky when you can't see what other people are feeling.
- You can't feel completely part of what's going on.

Some people withdraw or lose confidence:

- I don't socialise anymore ... I would think I would hurt people's feelings ... they thought you were getting on famously and then next time you don't recognise them ... it's easier not to put yourself in that situation.
- I am more mousey now ... I go up to the social area and sit down quietly, whereas one time I would have been the president.

Most people want to keep a good social life:

- I don't give up!

Tips for people living with AMD

- Being open about having AMD can help in social situations and avoid offending others, e.g., say 'I'm sorry my eyesight's bad but come a bit closer, onto my right side, and I'll be able to see you better'.
- If you tell others about your vision loss, most people will respond positively if you make a mistake and are happy to laugh it off. This will help avoid feelings of frustration or embarrassment. You might need to remind people though, because they can forget.

How can family, friends and carers help?

- When you approach someone with AMD it is good to introduce yourself: 'Hi Mary, it's Karen from next door'.
- In a group conversation, say the name of the person you are talking to because people with AMD can't see who you are looking at: 'John, who do you think will win the football this weekend?'
- If the person with AMD wants help with recognising others, you could tell them who is in a room: 'John is in the back of the room with his wife', and say people's names as they approach: 'Hi Bob'.
- For facial expressions, you could say: 'Jill is looking sad today' or 'the doctor had a big smile on his face when he said that, he's having a joke'.
- Understand that the person with AMD is not faking it. It is normal for them to sometimes be able to see faces and sometimes not. It is also normal in AMD to have some peripheral vision (to walk around) but reduced fine vision (e.g. have problems reading, seeing faces, cooking).
- Everyone with AMD is different. Ask them to tell you how their vision is affected. **To get you going, see our Conversation Starter questions that you can work through together.** You can ask if they have problems seeing faces, if they make mistakes, at what distance and under what lighting conditions, how this affects their social interactions and confidence, and what they would like you to do (or not do) to help.

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