

Person-Centred Dementia Care – Webinar Q&A responses by Elaine Grisdale

PPE and COVID 19

This answer should cover the many questions that we received regarding Covid-19, social distancing and PPE during my presentation. I have been following what people in care settings have been doing regarding PPE. When we need to provide comfort and reassurance to dementia patients then PPE can be a barrier, confusing, intimidating and for some, distressing. I have seen some nursing staff produce a laminated pocket sized card which has their smiling photo on it and then words such as their name and their function.

We could produce one like this – you could maybe add the glasses image in case they have trouble with the word optician.



I am Elaine

I am an optician



This may help you if you have to wear a mask when introducing yourself. It will put the patient at ease. If the patient seems to be upset or agitated still, then using a transparent visor covering the whole face so they can see all your features will be more patient friendly. This falls in line with “making reasonable adjustments” for treating dementia patients.

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It has been reported that people living with a dementia are at a greater risk from Covid-19 exposure due to their cognitive impairment. Cognitive problems can make understanding and remembering any instructions regarding safety, difficult for them to process. They may also not want to wear a mask themselves or understand why this is necessary. See below, from a Position Paper on Covid-19 and Dementia published by Alzheimer's Disease International.

“Due to cognitive impairment, people living with dementia have a greater risk for Covid-19 exposure. Memory problems make instructions problematic to remember. For example, it can be difficult to understand instructions about social distancing (staying 2 metres from others), or hand hygiene, restrictions on walking outside, or reasons for wearing a mask. Eventual lack of insight can result in behavior that increases risk of exposure for themselves and for their families and carers. It is most important that society does not place any blame, stigma or guilt on people with dementia because of these risks, since it is a consequence of the dementia disorder. Nevertheless, awareness of these risks is important for the protection of people with dementia and those around them”

Reference: <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>

As far as telephone triaging is concerned, it might be that you have to ask the patient if you can speak to a carer or family member and get them to communicate questions to the patient to aid understanding which then will hopefully allow the patient to answer. This, only if you feel that the questions are not being properly understood.

Creating an information sheet (words and pictograms) explaining the appointment procedures in simple terms that can be sent to the patient by email or post, prior to any appointment may help with communication and reduce anxiety. It's important, as always, to allow extra time for the appointment. If you think that a patient can possibly wait for their appointment until the Covid crisis is less dangerous for them, then it might work in our favour that time isn't something that is managed well by some dementia patients. If you feel that it is safe to make them wait a little longer and is in THEIR best interests to wait for their eye examination to minimize the risk of infection and anxiety, then they may not mind the wait.

“People with mental health needs, a learning disability, autism or **dementia** may need additional support, including by making reasonable adjustments to care systems and clinical practice.”

Although this specifically comes from guidance for those in care settings, it refers to us as well.

Reference: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290-Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings-pdf>

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REFERRALS:

Many people wanted to know if we could refer to a GP if we feel that the person either is not aware of their possible condition or if a person we have known for some time is clearly showing signs of cognitive difficulty.

The short answer is “yes”. If it is in the **patient’s best interests**, we should act and raise any concerns we may have.

I would always try and have a conversation with the patient about how they are coping, firstly with their eyesight and optical appliances but that will obviously spill out into general well-being. Just as you can’t say to a patient that you think they have glaucoma or cataract (that’s a diagnosis), you can say that you want to refer them on to their GP for a bit of an MOT to see if we can make life easier for them based on the information they have given us. Always remember that people are frightened of this condition, as I mentioned in my webinar, it is the condition that has become the most feared medical condition of people over 40 so we have to be careful in how we talk about our suspicions.

You must always record in your patient notes exactly what you have said, what the patient said to you, why you think a referral may be necessary and what you did about it.

The test at the GPs for dementia is an MMSE – it is the standard test that they use and is based on questions that rely on memory. MMSE stands for ‘Mini Mental State Exam- cognitive assessment’. If you fail that, then you are referred into the hospital to a specialist department where further tests like brain scans are done and then onto a memory assessment service where medication may be prescribed (not as a cure but as a help with symptoms). You may stumble on a few questions or not reply quickly enough (although it’s not timed, the doctor will look for hesitation) and then they should call you back, say in 6 months to repeat the test. My Mum did it several times, it’s not a terribly accurate way to decide whether a patient should be referred as dementia can start with behavioural or vision problems and not memory and she’d memorised the answers! So, if you think there is a problem and it isn’t supported by the GP test, you should insist on a referral

Making a referral to the GP in the patient’s best interests does not contravene GDPR, we have to keep the safety and well-being of the patient at the fore front of what we do and this is a clinical decision. However, speaking to a family member without the patient’s consent does breach GDPR, unless that family member is identified to you as a carer. If they have brought their family member into the consulting room with them and are happy for you to speak in front of them about the findings of the examination, that is different. Even though the carer/ family member might be in the room for the test to help with understanding, you should check before the exam, that the patient is also okay with you discussing the findings in front of them. If the family member or carer is in the waiting room or at home, then you have to get the patient to agree to you sharing your concerns before you do so. A lot of people are frightened of losing their independence or becoming a burden and it is a very emotive and scary subject for a lot of people and the utmost sensitivity must be used.

To cover yourselves, practices should have a clause in their company privacy and GDPR policies/statements that they will share patient information under the lawful basis of **vital** and **public** interest, if they have a valid reason to do so. This will clarify matters for both staff and patients. See ref re ICO lawful basis vital and public interest :- <https://ico.org.uk/your-data-matters/does-an-organisation-need-my-consent>

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HELP and ADVICE:

Could colour overlays or filters help with reading issues?

There is no evidence to suggest that this is the case. If I had been more informed about my Mum's condition and the similarities the symptoms had with dyslexia, I would have been happy to try and help her through a colleague with more experience with colour overlays, but that is just a personal view and there would be no guarantee that it would work. You must be able to justify your actions in the patient's best interests in your note taking. A more appropriate course of action if reading issues cannot be resolved in practice and you think it may be due to brain vision rather than ocular symptoms, would be a referral to the GP suggesting onward referral to a neurologist for a PCA assessment.

Do diet and nutrition help to delay the progression of dementia?

Eating well is recommended by the experts to help with cognitive function.

Ref: <https://dementia.org> and <https://international-Academy-on-Nutrition-And-Aging>

Leafy Greens such as various types of lettuce, spinach and chard contain vitamin B9 which improves cognition. They also contain vitamin E which has positive effects on the brain.

Cruciferous vegetables such as kale, broccoli, cauliflower, Brussels sprouts are known to lower Homocysteine. Higher levels of Homocysteine have been linked to mental declines associated with Alzheimer's disease in elderly people.

Ref: <https://www.webmd.com/alzheimers/news/20030228/elderly-dementia-linked-to-homocysteine>

Beans are a source of Folate, Iron, Magnesium and Potassium and act on Choline which is a neurotransmitter critical for brain function.

Berries and Cherries contain Anthocyanin which is a phytochemical that protects the brain from damage caused by free radicals, inflammation and radiation.

Dark Chocolate contains Flavanol, the anti-oxidant in cocoa powder which improves blood flow to the brain.

Fish – Salmon, Trout and Mackerel are all sources rich in Omega 3 which is beneficial for brain function.

My Dad has Mixed Dementia. Do you have any showering tips for him as he is like a teenager and doesn't want to wash and also tips for getting him out of his bedroom to exercise?

Bathing and personal hygiene is a very personal thing and so it's often difficult to give advice. Mum wanted to do it on her own so it was different in our help. She didn't do the best job but we had to respect her independence. It was easier in her final 6 months when we had carers as she was more tolerant of accepting their help with personal care.

I've found a film from UCLA which is useful. <https://www.youtube.com/watch?v=sl3Dc1kERto> It is regarding a woman and they speak of creating a spa type scenario, but later on in the film there are things that the carer says and ways that she says them that might help with a man also.

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There's also excellent advice on a site called AgingCare ref: <https://agingcare> : What to do when a senior refuses to bathe and change their clothes. Take a read here and on their site - some good sound advice - not necessarily for a dementia patient but you might pick up tips.

Why Seniors Refuse Grooming and Personal Hygiene

Depression

*If a loved one who used to wear makeup, bathe regularly, or refuse to don a wrinkled shirt suddenly stops taking care of themselves, it's wise to rule out depression first. A simple checkup with a doctor is a good idea, especially if low energy seems to be part of this change in behavior or they just don't seem to be interested in much of anything anymore. Depression isn't always obvious to an observer, especially in seniors, so be aware of the **warning signs of depression** to look out for.*

Respect and Control

As people age, they lose more and more control over their lives. One thing that seniors tend to keep a tight grip on for as long as possible is their own personal hygiene. Caregivers and family members can nag all they want, but the more you pester them, the more they resist. They may react with a remark like, "This younger generation is trying to take over everything. Well, they aren't telling me when to shower, that's for sure!"

Dulling Senses

Your nose may easily pick up on the odours of urine, old sweat and faeces, but our elders may not even notice these stomach-turning scents. They are especially "nose blind" to their own smell and that of their home. This is because their senses are not as acute as they once were. With the aging process comes a weakening of the senses, especially one's sense of smell. Many seniors begin showering and changing less frequently because it is harder for them to notice the tell-tale scent of body odour or the stains on their clothing that indicate it's time for a wash-up and a load of laundry.

Boredom

Sadly, for many seniors, their days aren't marked with tons of activities as they were when they were younger. If there isn't something special about Wednesday, well, it might as well be Tuesday or Thursday. It can be easy to simply lose track of time and not realize how long it's been since they showered. (This can be compounded by actual memory loss, but more about that in a moment.) Furthermore, if there isn't company coming over or an outing coming up, then what's the point of exerting the energy to get all gussied up and just sit around the house?

Fear and Discomfort

The bathroom can be a scary place for many seniors. After all, it is entirely composed of slick, hard and often monochromatic surfaces—the perfect setting for a fall. Taking a shower or a bath was once a regular part of their routine that they didn't think twice about. But now, this basic act carries significant risks. The possibility of a bruised ego, a broken hip, or even a permanent change in mobility is enough to deter anyone from stepping into the tub.

Discomfort is another very common culprit. Seniors get cold much more easily. They may tire out quickly and lose the sense of balance and range of motion they once had. If someone must help them bathe, there is a loss of dignity involved. Joint pain and lower energy levels can make doing laundry and changing clothes a real hassle.

Cognitive Impairment

Poor personal hygiene is an incredibly common symptom of Alzheimer's disease and other types of dementia. Getting a resistant elder with all their faculties to bathe is difficult enough, but when dementia is

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part of the equation, it can seem downright impossible. Conditions that cause cognitive impairment are often accompanied by depression, difficult behavioural changes, sensitivity to stimuli and an inability to keep track of time. When these things combine, it can cause a loved one to refuse to bathe or mistakenly think that they have already bathed for days, weeks or months on end.

Fear and discomfort are often magnified by dementia as well. A loved one may not understand why there is water running on them or become afraid of it. They may hallucinate that the shower drain will suck them down. When it comes to bathing, dementia patients just don't understand what you are trying to "do to them." It can be a traumatic experience.

Furthermore, we take daily bathing for granted in this country, but when our elders were growing up, a weekly bath was likely the norm. Your loved one probably adopted more frequent bathing habits as they grew in popularity, but damage to their brain may cause old habits to re-emerge. A weekly shower may sound like a godsend for some caregivers, but it's difficult for dementia patients to actually stick to this schedule when they cannot recall when their last bath day was.

Don't insist on a full shower/bath and outfit change all at once. Breaking a task down into smaller pieces over a longer period can make it easier on both of you. Begin with just asking to wipe off your loved one's face. If they are receptive, gradually move to cleaning their under arms and other parts of the body, all while talking to them and telling them what you are doing as you go. Be soothing. If they fight it or say stop, then stop. You can always try again later. These little victories can function as a stopgap between full baths or showers

I think the trick for your Dad is to get him to buy into the process - bath or shower? - give him a choice (where no bath or no shower isn't one of the options). I like the taking it in stages approach above. Try and make it enjoyable and safe. Sometimes patients don't feel safe or warm or private and all these are important when undertaking personal care. Try and find out what he would like. Think of it as getting ready to do something or go somewhere. Maybe use it as a cooling down or warming up exercise rather than "washing". Try it in the middle of the day not necessarily first thing in the morning or at night. Maybe wearing shorts to bathe like at the beach might be fun! Also, see the comment above about older people not being used to having a bath or a shower every day, it was often once a week. If they are reverting to a past life, then complete bathing everyday may not be understood.

For exercise, Karen Hauer (from Strictly Come Dancing) does some great, gentle chair based exercises. I think her podcast / Instagram / Facebook class is called Hauer Power. It's something that could be done with a family member or carer. See if there is any music that he really used to like listening to? Maybe put that on to encourage him to move and lift his mood. Did he like dancing? You can kick a ball from a chair or throw a Frisbee and try and hit something in the garden. Did he like golf? You could make a little putting green? Maybe hitting the ball into a cup but have a number of cups round the garden or the living room like crazy golf. Even massaging his legs and a carer or family member manipulating them like in hospital to avoid bed sores and stimulate circulation, that could help. Maybe put a dartboard up in the garden - standing is also exercise and supporting the core helps the muscles to strengthen. Standing to cook - some men like cooking, probably with supervision depending on the stage of the dementia. Think of something he used to like to do Gardening? Could he kneel down and support himself to plant bedding plants? It's a case of being creative and tapping into something that could be enjoyable and not a chore.

Ref: <https://www.futurelearn.com/courses/dementia-arts> This is a course about sharing practice, developing understanding and enhancing lives. It looks at different strategies for engaging patients in the arts, music and dance.

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What do we do in practice if a patient is making a request and we think it is because they have a dementia, and that “normally” they would not make such a request?

I think that it all depends on what the request is and if you think that it is reasonable, in the patient's best interests and clinically necessary. If they insist, on say ordering something and it won't impact on them adversely clinically, you should do it but make notes. Dementia patients still have the right to make their own decisions and to cheer themselves up. I would ask appropriate questions as to why they are making the request. Use your professional judgement as to any risk for the patient.

What is the advice with regards to patients with suspected dementia purchasing glasses on a regular basis? We have had a couple of patients who live alone trying to buy specs every week convinced that they don't have any.

This is a tricky one. You must try and find out where their glasses may be and look at strategies to try and help them locate them such as having the big and bright glasses cases. Maybe a specific place in a room for keeping them and signposting this, maybe in a little book so it reminds them. Just re-issuing the order is not helping the patient and if we just do that it could be misconstrued as taking advantage. Obviously we can't leave them without glasses but equally we have to help them to find them. It also makes me think about cases in Posterior Cortical Atrophy where they can see but don't recognise where the object is in space, or in Dementia with Lewy Bodies where identifying figures that overlap is difficult so a pair of glasses on a pile of papers or a dull coloured glasses case in a bag might be easily missed. Bright coloured spectacles and spectacle cases, spectacle chains to keep spectacles around the neck can help.

Where do we stand if we suspect that a patient has dementia and keeps returning to buy more and more spectacles with patient confidentiality?

There is a fine line between respecting their privacy and flagging up any problem. See above for the strategy to check why a patient feels they need to buy more spectacles. If it is because it gives themselves pleasure to have more in different designs etc. then there isn't a lot you can do to object. It is different if they want to buy the same frame in five different colours at one sitting, then you can use an excuse that you want to check that everything is right with the new Rx, fit etc.

This links into another question I was asked wanting to know where we stand regarding a family member getting angry, stating the person had dementia and the carer wanting to cancel the order that the dementia patient had placed.

There are a number of laws relating to care of people with dementia that I mentioned in the webinar. Understanding them more will give you the ability to speak up if you feel that the rights of those living with dementia are not being protected or that the Act(s) is/are not being followed. They are:

The Mental Capacity Act

The Mental Capacity Act Code of Practice

The Care Act

Advanced Decisions Safeguarding Guide by NHS England

The Mental Health Act

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The relationship between a carer and the patient can have many blurred lines. Even without Power of Attorney, the carer does so much for the person that they inadvertently end up taking over and it becomes their “new normal” but also can be stifling for the patient who slowly loses any independence they may have had. The carer may be “in the driving seat” with all the best intentions but it's not always legal and can deprive the patient of their dignity.

As far as the law is concerned, a person is unable to make decisions if they are:

- unable to understand information relevant to a decision,
- unable to retain information
- unable to use or weigh the information as part of making decisions
- unable to communicate a decision (communication is not just verbal; it can also be non-verbal so they could be able to communicate but non-verbally)

The fact that a person is able to retain relevant information to a decision for only a short period does not prevent him/her from being regarded as able to make a decision.

So, if they are able to communicate / understand intermittently that is also okay for them to make their own decisions.

Just because someone has a dementia diagnosis does not mean that they do not have the right to continue living their life the way they want to. It's still their money and they should have the right to spend it as they please if the criteria mentioned above are fulfilled. What we have to be careful of is **not being ‘seen to take advantage’**. So, if they decide to order the same frame in four different colours and they only ever bought one pair before, it may ring alarm bells and you may want to try out one pair first. We have to always assess what is in the patient's best interests. We have to be careful as professionals (and carers) not to negatively discriminate by making unjustified assumptions as to what is in the best interests of the patient.

To demonstrate patient centred dementia care, we have to provide respect and include the person in conversations irrespective of the level of any communication impairment. You also need the patient's consent to discuss their treatment with the carer. You cannot have the carer then cancel the order without the patient's consent. If you thought the patient was able to understand and make their own decisions as quoted above, it is not for the carer to cancel the order. Whatever you do, you must always note it in full on the patient's record card and record your conversation in detail.

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GENERAL:

Do the experts know why dementia is on the increase?

The most widely quoted reason is that the number is projected to increase rapidly in the coming decades due to increases in life expectancy and population demographics in the UK.

Reference: <https://www.dementiastatistics.org/statistics/prevalence-projections-in-the-uk>

Worldwide, income is also thought to play a part and that could impact on poorer countries having a growing increase.

“Already 58% of people with dementia live in low and middle income countries, but by 2050 this will rise to 68%. The fastest growth in the elderly population is taking place in China, India, and their south Asian and western Pacific neighbours.”

Reference : <https://www.alz.co.uk/research/statistics>

How can you best convince them that they do not need another test? Do you just re-test?

I would try to explain that the NHS wouldn't sanction it unless there was a clinical problem. If they are adamant, then you might just have to “bite the bullet” and re-test to avoid stress to the patient and to respect their dignity – “make reasonable adjustments”.

How do we find out about the courses?

The links for the courses can be found in the webinar handout. There are a number of them on the Future Learn platform. I would start with The Many Faces of Dementia and then explore others.

<https://www.futurelearn.com>

I would have thought that dementia was related to aging?

The experts are very clear that dementia is in no way classified as an age-related disease. It is a progressive disease of the brain affecting cognitive function. Out of 850,000 people diagnosed with a dementia in the UK, 42,000 are under the age of 65.

Is it possible for a person to have more than one type of dementia?

Yes, 10% of all dementias are known as Mixed Dementia, the most common being the mix between Alzheimer's disease and vascular dementia, which in turn are the two most common dementias. There are however, over 100 different types of dementia.

Several of the symptoms are similar to those experienced by people with certain eye conditions e.g.

ARMD, how can they be differentiated?

I think that you are referring to the symptoms associated with PCA and the difference in ocular vision and brain vision. I am liaising at the moment with researchers at UCL to try and develop existing or new

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educational resources that might be useful to dispensing opticians and differentiation is something I want to look at. In the meantime, if you follow the link below and click all the way through (it's informative but you're not always sure if you are at the end, so persevere even past the film)

<https://www.raredementiasupport.org/wp-content/resources/pca/index.html> you will find a link to resources from the College of Optometrists. They have spoken about developing new resources and I am in contact with them about their progress.

Also a very good resource, and something to dip in and out of if you haven't got a few hours free all in one go, is the UCL and Vision UK Sight Loss conference, June 2018. The link can be found below.

<https://www.youtube.com/playlist?list=PLVXZs3D-CYLdaJKsinUi1WQ99FSByqvN>

<https://www.college-optometrists.org/resourceLibrary/which-test-is-best-managing-patients-with-posterior-cortical-atrophy-course.html>

Should we ask a family member to come with the patient when they come in to the practice if we know there is an issue with dementia?

You can only ask a family member with the patient's consent. It depends on how advanced the dementia is as to if help is needed. Look at your motives, do you want a family member to come with them because it is easier for you or because it is better for the patient? Many people with moderate to advanced dementia would probably be coming in with someone anyway given the potential problems with travel. Those who have made it on their own are usually capable of understanding what is going on and making their own decisions although it might take some time. Being accompanied has to be a decision for the patient to make. Some people would prefer to come with a carer and not involve family at all, so maybe talk to the patient and see if they feel confident enough to come in alone. Once they have someone bring them, it's not at all a given that they want them involved in their care, so that should be checked. Please see the link herewith of Barbara's story. She has dementia and struggles but is capable with the right care, of functioning perfectly well and she values her independence.

Reference: <https://www.youtube.com/watch?v=VFXirEnjTI>

What is the difference between Alzheimer's disease and dementia?

Dementia is an umbrella term for a number of different brain diseases which affect cognitive function which sometimes but not always involve memory. Alzheimer's disease is the most common of these, making up 62% of all the dementia diagnoses.

What advice can you give when dealing with a patient who is showing that they are anxious with their vision? And how can you ensure that the patient understands the prescription given by the prescriber is the best it can be?

I think that the explanation whether you have a dementia or not must be consistent and the same. The way you deliver the information will be key. Making sure you are in a calm and tranquil environment, connecting with the person using what you know about them, giving them autonomy and involving them in

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the choices for their vision correction. You can make sure you have done the best you can in the examination room by following some basic tips which will help with the efficacy of the examination and to build trust (which in turn will help with them understanding that the prescription is the best it can be): make sure all your explanations are clear throughout the examination and that they understand (this is why you will need more time), always tell the person what you are doing and if you are going to move in close to them, give them breaks from sitting still and concentrating too much, some may appreciate something to occupy their hands (a tissue maybe), allow carers/family if they would like, give them good advice for managing at home with their new prescription (take interest in how they manage with their vision at home and adapt your explanation).

Just as you cannot predict if a person without dementia will get on with a new lens type or a big change in prescription, so you can't predict if a person with dementia will get on with a new prescription (big or small) because the brain is involved in vision and you cannot assess what parts of the brain are damaged or where future damage might come from and when. I'm not sure putting any doubt into their minds about possible issues due to the brain seeing, would be appropriate without them discussing symptoms such as those seen on the film "Do I see What you see?", with you. Do suggest that they come back if they feel there are any changes in their vision. Giving advice about good contrast to help with locating images in space and the avoidance of using patterned flooring will help as you can mention this helping with their everyday quality of life. Be careful with lens choice and changing them for instance, I would avoid moving from two pairs of glasses (in case of losing them) to a pair of more sophisticated lenses (that they keep on their face most of the time) as this may be too much to cope with and lead to de-stability.

Reference : <https://www.youtube.com/watch?v=jekW8Z93LMw>