

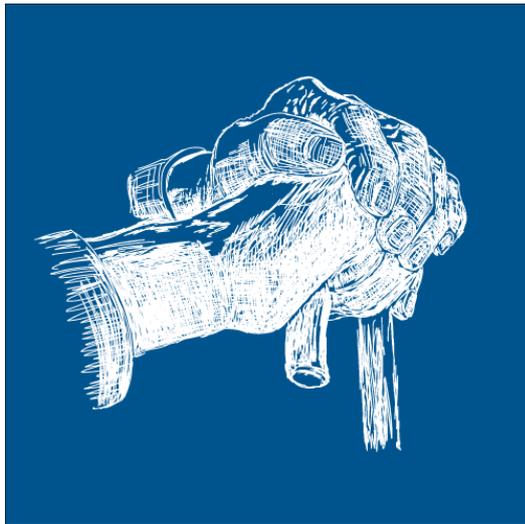


# The Old Age Psychiatrist

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Issue 81, September 2021

Old Age Psychiatry Faculty  
Newsletter



# The Old Age Psychiatrist

Issue 81, September  
2021

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# Update from the Editorial Team

by

Sharmi Bhattacharyya

Editor, The Old Age Psychiatrist, Royal College of Psychiatrists

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Hello from the Editorial team and hope you are looking after yourselves and keeping safe and well and enjoying the hot summer. Hopefully by the time you read this newsletter all restrictions are eased and you are enjoying the summer break. We do hope the articles in the newsletter will provide some food for thought and as always highlight the great work Old Age Psychiatrists do.

Sadly we lost another stalwart in Old Age Psychiatry – Prof Ajit Shah – his contribution to Old Age Psychiatry is highlighted in a tribute article which is truly moving.

Dr Amanda Thompsell, the National Specialty Advisor (NSA) for Older People's Mental Health (OPMH) at NHS England/NHS Improvement and Prof Alistair Burns provide an interesting '[Summer Hits](#)' for the newsletter. Please have a look at the 'Next Steps' website article too.

The Chair's report highlights relevant issues.

There are interesting articles on Court of protection and COVID 19 vaccines, WHO report on Ageism and [The Trieste Model](#).

This edition contains also contains our usual Cochrane corner and research update but also read about [the 'Understanding Dementia diagnosis'](#) project. There is also an interesting article on [Aducanumab](#) and the pros and cons of where we go with it.

As usual we round off with a film review by Dr Howard undoubtedly our Film specialist – the film she discusses highlights relevant issues and legal frameworks relevant to our practice. There is a book review in this edition too.

Our trainee Editor Nicole finishes her term in August 2021. She has written a moving article which is a must read for all. Thank you Nicole for all your hard work in the last year.

We also welcome our new Trainee Editor Dr Catrin Thomas, Higher Specialty Trainee.

The next newsletter is January 2022 so the last date for submission of articles is 15<sup>th</sup> November 2021.

Lastly but importantly, there is a [special request](#) from Dr Carmelo Aquilina, one of the original Editors for the Old Age Psychiatrist. Please email him directly if you can help.

As always let us know what you think of the newsletter, and feel free to email me on [drsharmib@gmail.com](mailto:drsharmib@gmail.com) with ideas, suggestions and of course articles for the future newsletter.

A special request from Dr Carmelo Aquilina.

*I am the original Editor for 'Old Age Psychiatrist' having founded the newsletter in 1995 when the front page article was 'Time for tacrine' in the prehistory of antimentia drug treatment.*

*When I moved overseas my copy of Issue number 50 went missing in the post. I would like to hear from anyone with a spare paper copy willing to sell or swap it.*

*I still have spare copies of issues 31,32,34,37,39,41,42,48 and 47 that I can give in exchange as well as the Conference supplements from 31,39 and 47.*

*Please get in touch directly to discuss this.*

*Email address is: [carmelo.aquilina@gmail.com](mailto:carmelo.aquilina@gmail.com)*

## View from the Chair

Dr M S Krishnan (Krish)



Dear colleague

We are continuing to work through the impact of the Pandemic both from outstanding clinical backlog as well as current challenges in the recent weeks. Across the country there has been continued pressure in various aspects of our service delivery to older adults.

Memory services are affected in various regions, thank you for providing leadership in your local areas to manage the surge and demand.

There has been continuous pressure on entire workforce and it is important that we promote support to our colleagues and also look after our own wellbeing. We had a presentation from our Psychiatrists Support Service team at our recent executive committee meeting. Please signpost colleagues about this service. This is a free, confidential and rapid peer support via telephone for colleagues.

<https://www.rcpsych.ac.uk/members/supporting-you/psychiatrists-support-service>

Our PTC also have developed Podcasts on wellbeing please share the links with your trainees.

<https://www.rcpsych.ac.uk/training/your-training/psychiatric-trainees-committee-supporting-you/supported-and-valued/You-Are-Not-Along-PTC-podcast?searchTerms=PTC%20podcast>

Hope you all had a look at the ARUK report. Our faculty expert reference group was led by Dr Barber in developing the report. Following the report, we are setting up a working group to look at future treatments.

We had our recent Faculty executive committee meeting this month. Josie our Vice-Chair has worked with Mohan our Academic Secretary and Sudip our Finance Officer to develop a short fellowship scheme for our trainees to support a project relevant to mental health of older adults. The details and application processes are being finalised.

Paul Rees our CEO attended the exec meeting and updated about college activities. We are one of the colleges to migrate everything online successfully during the pandemic including OSCE exams.

Our faculty trainees' conference will be on 10 December 2021. Thanks to our trainee reps for shaping the programme. The College is looking at a blended model for events for the next year and we will update the plans for our annual conference once we know the plans. We are also arranging a joint webinar on 8 September with RCGP (free) – you can find the [details on our website under Upcoming Events](#).

Please continue to engage with our Faculty twitter page @RcpsychOldAge.

Hope you enjoyed the recent warm weather. Lockdown has helped to explore several local outdoor places. Hope you all have some break during this summer and get some time to rest relax and enjoy with your friends and family. Thank you for your dedicated service to our older adults in these testing times.

Krish

Chair of the Faculty of Old Age Psychiatry  
@deliriumkrish

# Summer Hits by Alistair and Amanda

by

Dr Amanda Thompsell, National Specialty Advisor, Older People's Mental Health

Professor Alistair Burns, National Clinical Director for Dementia

I was cut to the quick by Amanda's genius idea at her top 10 - see below. The reference to "*Top of the Pops*" took me back, so I have taken the liberty of sharing at my own version (ten songs from my youth) in relation to key issues in dementia. They do reflect songs of a generation ago and so apologies if our younger readers feel excluded and have to search the internet for an explanation. People will think of better ones.

**Let's Stay Together** (Al Green, 1972). I think this relates to the issues around where dementia "*sits*" in our systems and several people have commented that dementia sometimes feels outside mental health and suffers as a result. I think for a number of reasons (professional and personal) that we are stronger together and Amanda and I work shoulder to shoulder on Older Peoples Mental Health (OPMH) and dementia. We both have links to other aspects of the system such as Primary Care, Personalisation, Ageing Well and Enhanced Care in Care Homes. The trick in our area is to ensure pope talk about OPMH and dementia when we have left the room (**Always On My Mind** – Pet Shop Boys 1987).

**Maybe I'm Amazed** (Paul McCartney, 1970). This must reflect the FDA decision around Aducanumab on which several people have opined. A BMJ piece describes the situation well (<https://www.bmj.com/content/374/bmj.n1682>) and the correspondence highlights a number of views. Perhaps, **The drugs don't work** by The Verve (1997) would align with some views. The discussions on Aducanumab mirror those around the introduction of the cholinesterases in the mid 1990's and will continue to divide opinion. We await the decision of NICE and the MHRA. What we do know is that there is an active pipeline of medications waiting for further testing and potential approval. So, as someone

put it, "Its not if, it's when" another agent may appear. I know the College is actively involved in discussions about this issue.

**Ladies Night** (Cool and the Gang, 1979) I attended a fascinating webinar which dealt with issues of gender and dementia highlighting this on a number of levels – differences in prevalence, carers issues and differential effect of head injury. An important area on which we will hear more in the future.

**A Good Heart** (Feargal Sharkey, 1985) Prevention is still key and Gill Livingston's landmark Lancet Commission piece is still very widely quoted. We have tried to repeat the messages ("*What's good for your heart is good for your head*"). My colleague Charles Alessi has written a book on this important aspect for the general public. <https://www.waterstones.com/book/increase-your-brainability-and-reduce-your-risk-of-dementia/charles-alessi/larry-w-chambers/9780198860341> (other booksellers are available!).

**Under pressure** (Queen and David Bowie, 1981) Everyone who reads this will relate to the pressure on services that everyone is experiencing at the moment with the backlog of people attending memory clinics and the need to maintain the quality of the diagnosis. I am always so hugely impressed by the innovation and experience that clinicians bring to bear on these challenges.

**You Should be Dancing** (Bee Gees, 1976). The work on personalisation and activities have been highlighted by Arts4dementia (<https://arts4dementia.org.uk/>) and emphasizes the role of the arts and physical activities and connections as part of that work in personalization particular in care homes and the benefits of activity the tour now enshrined in the personalization agenda we are taking Forward

**I'll be there** (Jackson Five, 1970) with the continuation of Zoom and Teams webinars it's never been easier for Amanda and I to be present meetings - if you have events where either of us could help we would be pleased to do so. Something recently I was involved in were re-articulating the simple messages (**Time after Time**, Cindy Lauper, 1983) around the importance of a dementia diagnosis and supporting people.

In order to emphasise how closely we work with colleagues in Geriatric medicine, attached is an image from our house where our Cockapoo got to the British Geriatrics Society (BGS) newsletter first.



Alistair Burns

[Alistair.Burns@manchester.ac.uk](mailto:Alistair.Burns@manchester.ac.uk)

### **Amanda's top ten**

So much is happening as so many organisations are now really getting to grips with Community Mental Health Transformation (CMHT). It is easy to miss some of the new policies and excellent guidelines that so many dedicated organisations have been producing.

In the spirit of Top of the Pops, here is what is charting in my personal Top Ten:

**Where do you go to my lovely?** (Peter Sarstedt -1969). We all know that we should be working together, but it can be difficult to know how to get hold of people in other organisations and to find out what else is planned in your area. But help is now at hand. If you want to get hold of your local CMHT plans or find out who is leading on older adults there is now a single point of reference who can point you in the right direction. Just email [vicky.cartwright2@nhs.net](mailto:vicky.cartwright2@nhs.net) and tell her which region and which Integrated Care System (ICS) or ICSs that you want contact details for. Remember that some Mental Health Trusts (MHTs) cover more than one ICS. It is best to see the plans from all the ICSs in your

MHT as there can be wide variation in the ambitions of the plans even within local geographical areas.

**Video killed the radio star** (Bruce Woolley and the camera club 1978). Thanks to Krish and Mohan, the Faculty ran a webinar that explored how to go about CMHT. This is still available on the Faculty of Old Age Psychiatry website under Community Mental Health Transformation and provides some useful insights.

**Help!** (The Beatles 1965). If you still need guidance after viewing the webinar, then you should consider the NCCMH reports [\*The Community Mental Health Framework for Adults and Older Adults published by Royal College of Psychiatrists \(rcpsych.ac.uk\)\*](#). Part 1 sets out the framework. Part 2 is about implementing the framework and has useful advice on the challenges and solutions from different perspectives and a section providing further helpful resources and outcome measures. The third report in this series is an appendix which has some positive practice examples for older adult services.

**You'd better shape up** (Olivia Newton John and John Travolta 1978). The 2020 Benchmarking data on your local older adult services is with your local mental health trusts and should be helpful in any assessment of your current capacity compared with your local identified needs. A national webinar was held in July discussing some of the recommendations that arise from this benchmarking data and this too can still be downloaded [OPMH page of the FutureNHS Collaboration Platform](#).

**We'll meet again** (Vera Lynn 1943). Local areas are addressing their local community mental health transformation in different ways but I have been struck by the difference made when one region brought together the OPMH ICS leads in their area to share local learning and best practice. See the *Futures* webpage for more details.

**I wanna be a Care Bear** (The Care Bears 2014). In July NHSE&I confirmed that the Care Programme Approach (CPA) has now been superseded by the Community Mental Health Framework. [https://www.england.nhs.uk/wp-content/uploads/2021/07/Care-Programme-Approach-Position-Statement\\_FINAL\\_2021.pdf](https://www.england.nhs.uk/wp-content/uploads/2021/07/Care-Programme-Approach-Position-Statement_FINAL_2021.pdf) (available at england.nhs.uk). The new approach is based on the following five broad principles which include meaningful



# Tribute to Professor Ajit Kumar Shah (1961-2021)

Shrenik Savla-Shah (BSc Construction Project Management)

Dr Sujoy Mukherjee, Consultant Old Age Psychiatrist & Executive Member,  
Faculty of Old Age Psychiatry.



The Faculty of Old Age Psychiatry has honoured a series of stalwarts for their extraordinary contributions to Old Age Psychiatry over the years. The most recent addition to this most coveted accolade was Professor Ajit Kumar Shah in 2020. It was a proud moment for him, his family and his trainees and everyone who has been a part of his extraordinary life. Unfortunately, little did we know that there would be an abrupt end to such a memorable journey so soon.

So, with the deepest sorrow in our heart, we share a glimpse of his life, his achievements, and his persona.

Professor Shah was a Kenyan Asian who migrated to the UK in his early teenage years. He qualified from the University of Liverpool in 1984 and started his training in psychiatry at Saint Mary's rotation in 1985. Having completed his high training in psychiatry in Royal Free rotation, in 1992 he emigrated to Melbourne to work as a Consultant Old Age Psychiatrist and Academic Associate at the University of Melbourne. On his return to the UK in 1994, he was then a Consultant Psychiatrist working in West London until his retirement from the National Health Service in 2010. His academic achievements blossomed during

these years. After a few years of being a Senior Lecturer (both honorary and full-time) in West London, he was appointed as Professor of Ageing, Ethnicity and Mental Health at the University of Central Lancashire in 2007. He was also appointed as an additional Professor of Psychiatry at Hallym University Medical School in Seoul, South Korea, between 2009-14.

In the 1990s, Professor Shah conducted pioneering research involving ethnic minority elders in West London. At that time, ethnic minority older people had a low profile, so many clinical services and clinicians often relied on the erroneous presumption that ethnic minority older people were well looked after by their families. A series of service evaluations in the West London Boroughs of Ealing and Hounslow highlighted service utilisation, strengths and developmental needs of old age psychiatric services in relation to minority ethnic elders. These were later published in peer reviewed journals and were quoted in textbook chapters. He also conducted other pioneering research with ethnic minority older people; ranging from exploring psychiatric terminology in the older Gujarati population, to the use of interpreters as well as the exploration of behavioural and psychological symptoms of dementia in ethnic elders.

Over a prolific academic career spanning almost 30 years, Professor Shah authored over 150 papers and many book chapters. He published over 50 papers on suicide in older people: suicide rates, age-associated trends, time trends in suicide rates, cross-national comparisons, identification of proximal (individual-level) and distal (societal-level) risk factors, and other miscellaneous areas of suicide. He recently published two pioneering papers: (i) global suicide rates in centenarians and (ii) global suicide rates in five-year age-bands after the age of 60 years.

Almost all his work on suicide has been pioneering. He was among the first to recognise the need to move away from linear correlations of distal risk factors with the risk of suicide. He did this by demonstrating that a whole range of distal risk factors (socioeconomic status, urbanisation, fertility rates, educational attainment, human development etc.) may have a curve-linear association with suicide rates (either a U-shaped or an inverted U-shaped curve following a quadratic equation). The work was culminated in development of an epidemiological transition hypothesis of suicide in older people and supported by

substantial evidence. It has changed the thinking on how population-based prevention strategies should be targeted. Recognition of this work resulted in invitations to speak at scientific meetings, writing editorials, book chapters and contributing to the development of suicide prevention policies.

Professor Shah was a keynote speaker in many national and international congress. He contributed to College reports on ethnic minorities and Old Age Psychiatry, served on the Board of International Affairs at the Royal College of Psychiatrists (2007-11), worked with the International Psychogeriatric Association, Department of Health in the UK, the State of Victoria (Australia) and the World Bank to name a few. More recently (2015), his work on costs of implementing Deprivation of Liberty Safeguards legislation (DoLS) in England and Wales has been extensively used in the current impact assessment exercise associated with the proposed changes to the Mental Capacity Act and DoLS. Equally, the same work has been used to provide unit costs for DoLS assessment in the health economist's "bible" 'Unit Costs of Health and Social Care'. He has recently also advised the Health Board of Northern Ireland on developing their costs for similar local legislation.

Professor Shah was a very popular trainer and he had scores of trainees who remained his lifelong admirers. He maintained long term relationships with many of them. Most of us achieved our coveted publications under his guidance and supervision. He was relentless until he could impress his discipline and work ethic upon the trainee and many achieved beyond expectation. He earned respect from all colleagues, patients and carers by his empathy, diligence and professionalism.

While all of his professional and academic achievements always stood tall, it never eclipsed the fun loving family man who was also devoted to sports of all kinds, particularly cricket. A keen cricketer himself, he became a well-known face at Lord's Cricket Ground and the MCC. He was also a spiritual person dedicated to his religion of Jainism, a lifelong vegetarian and a keen traveller. He supported a number of charities and contributed a lot to his local Jain community.

Professor Shah passed away after a short illness. He was due to take part in the "Lifetime Achievement" ceremony that was delayed because of the pandemic to the faculty virtual conference in March 2021, unfortunately he was too ill to attend. He leaves behind his beloved wife, only son, his mother and extended family, along with the scores of admirers who will always remember his legacy and contribution to our beloved speciality.

# The Court of Protection: Covid-19 vaccines and the older person

by

Dr Oluwasegun Amao – GP VTS trainee, Coventry and Warwickshire Partnership NHS Trust

Dr Martin Curtice – Consultant in old age psychiatry, Coventry and Warwickshire Partnership NHS Trust

## Introduction

This article reviews a Court of Protection judgment from early 2021 - *E (Vaccine)* [2021]. The case involved an 80-year-old woman, Mrs E, who was assessed and scheduled to have the Covid-19 vaccine. Her son, Mr W, objected to this. It describes how the Mental Capacity Act 2005 (MCA) was implemented in assessing this very topical treatment issue for older people in care homes who were offered the Covid-19 vaccine.

## Background

Mrs E had a diagnosis of dementia. She had also been diagnosed with schizophrenia about 20 years ago. She had lived in her flat in London for about 45 years where she received an extensive care package but this broke down in September 2018 when she required hospital admission. She was thereafter transferred to a few care homes before settling in her current care home in March 2020.

The Court had declared in October 2020 that she lacked capacity to make decisions about her residence and care. These proceedings had been hampered by Mr W's disinclination to allow the occupational therapist to assess his mother's flat and by not providing sufficient information about the care and support Mrs E would receive if she were to return home.

Mr W had always wanted his mother back home. He viewed the care his mother received in the care home as being under an 'abusive' regimen. Furthermore, he believed his mother was caught in a 'conspiracy of neglect and ill-treatment'. In doing so he espoused widespread criticism of those involved in the care of his mother e.g. local authority employees, carers, hospital staff, his mother's GP

and even the court process. It was against this background that Mr W raised objection to his mother receiving the Covid-19 vaccination.

Mrs E's legal representatives escalated the issue to the Court of Protection seeking a declaration under s15 MCA (Power to make declarations) that it was lawful and in Mrs E's best interests (s4 MCA) to receive the Covid-19 vaccine.

### **Mrs E's Capacity to decide whether to be vaccinated**

The Court reviewed a video consultation between Mrs E, her legal representative and her GP where an informal assessment of her capacity to consent to having the Covid-19 vaccination occurred. Whilst the court acknowledged the informality of this assessment, it was however satisfied that it was 'sufficiently rigorous to comply with section 2 and section 3' of the MCA. The GP had focussed 'with professional clarity on salient issues' was able to 'delicately' assess Mrs E's range of understanding whilst respecting her autonomy.

In applying s3 MCA, the court found that due to her dementia Mrs E was unable to consent to having the vaccine because she was:

- Unable to understand information about the existence of the Covid-19 virus and the potential danger it posed to her health.
- Unable to retain information long enough to use it to make a decision.
- Unable to weigh information relating to advantages or disadvantages of receiving the vaccine.

The judgment noted that evaluating capacity 'on this single and entirely fact specific issue' was 'unlikely to be a complex or overly sophisticated process' when undertaken by experienced GPs and with the assistance of family members or care staff who know the person well.

### **Mrs E's best interests in relation to receiving the Covid-19 vaccination**

The court, in applying s4 MCA – Best interests – needed to determine as far as 'reasonably ascertainable' her past and present wishes and feelings and her beliefs and values that would likely influence her decision if she had capacity (s4 (6)). Her son's views about what she would have wanted were also considered (s4 (7) MCA).

#### *Mrs E's wishes*

The court pertinently noted that prior to her dementia diagnosis, Mrs E had chosen to be vaccinated in line with public health advice. She had 'willingly' received the yearly influenza vaccine and the swine flu vaccine in 2019. This was regarded by the court as very relevant when assessing what Mrs E would ordinarily choose in relation to receiving the Covid-19 vaccine.

Despite Mrs E's lack of capacity to consent to the vaccine, the court noted her expression of trust in the views of the health professionals caring for her by saying repeatedly to the GP that she wanted "whatever is best for me". Though 'not a capacitous statement', this was however considered as an expression of her autonomy, which must be respected, and which was 'not eclipsed by her dementia'. Her 'straightforward and uncomplicated approach' resonated with the trust she had placed the medical profession over the course of her life in relation to having previous vaccines.

#### *Views of Mrs E's son, Mr W*

The court considered Mr W's views as a person interested in his mother's welfare and her best interests in this matter. He had doubts about the vaccine, was 'deeply sceptical' about the efficacy of it, the speed of its development and whether his mother's true wishes and feelings had been properly canvassed. He had not objected to the vaccine in principle, but believed this was just not the right time for his mother to be vaccinated.

The court respected Mr W's right to his own views, but regarded them as a reflection of his 'own temperament and personality' and not a reflective of his mother's 'more placid and sociable character'. In this context the judge opined 'It is Mrs E's approach to life that I am considering here and not her son's. Mrs E remains, as she must do, securely in the centre of this process.'

### **Particular risk presented by Covid-19 to Mrs E**

The court also considered Mrs E's characteristics which compounded her vulnerability to becoming seriously ill or dying from Covid-19:

- i) She was in her eighties;
- ii) She resided in a care home which had recent confirmed positive cases;
- iii) She has Type II diabetes; and
- iv) She lacked capacity to understand the nature or transmission of Covid-19 and would be 'inevitably challenged' in terms of complying with social distancing restrictions as many people with dementia were in care homes.

### **Conclusion of the court**

The judgment opined the vaccination reduced the risk of death 'dramatically' and the judge had 'no hesitation' in concluding it was in Mrs E's best interests to have it as soon as practically possible due to the Covid-19 outbreak in her care home. The judge acknowledged the wider context in that there was clear evidence of a 'statistically established vulnerability of the elderly living in care homes' including a 'particularly high risk of serious illness and death'. The judgment indicated this decision was relatively clear cut; the 'risk matrix' was not in the opinion of the judge, 'a delicately balanced one'. For Mrs E, and many others in her situation, there was a 'real and significant risk to her health and safety' had she not had the vaccine.

### **Further case law**

Following the above case there have been further Court of Protection cases involving older people living in care homes having the Covid-19 vaccine.

The case of *Re SD* [2021] involved a lady in her 70s with alcohol-related brain damage whose daughter objected to her having the vaccine. The judgment accentuated the key principle around respecting and promoting a person's autonomy within the best interests decision-making process. Relevant to the above case, it emphasised it was 'P's voice that requires to be heard and which

should never be conflated or confused with the voices of others, including family members however unimpeachable their motivations or however eloquently their own objections are advanced.'

The case of *Re SS* [2021] involved an 86-year-old lady with dementia. This case differed in that the objection to the vaccine came from the person themselves and not from the family. The judgment made a pertinent observation around a comment that the 'patient failed capacity assessment'. S3 MCA is not a test that someone passes or fails; it was an 'evaluation of whether the presumption of capacity has been rebutted and if so, for what reason' i.e. it is an assessment process of gathering information and evidence as to the person's decision-making capacity by applying the MCA framework until it is possible to reach a conclusion on the specific decision in question.

## References

1. *E (Vaccine)* [2021] EWCOP 7 (20 January 2021)
2. *SD v Royal Borough of Kensington And Chelsea* [2021] EWCOP 14 (10 February 2021)
3. *SS v London Borough of Richmond Upon Thames & Anor* [2021] EWCOP 31 (30 April 2021)

\*these judgments can be accessed in full for free via the British and Irish Information Institute website: [www.bailii.org](http://www.bailii.org)

# World Health Organisation – Global Report on Ageism

by

Joshuah Hill, Warwick Medical School student, University of Warwick

Dr Martin Curtice – Consultant in Old age psychiatry

In March 2021, the World Health Organisation (WHO) published their 'Global report on ageism' discussing the scale, impact, and determinants of ageism before highlighting different strategies to combat it. This article will outline salient issues emanating from the report.

## **What is ageism?**

The report defines ageism as the stereotypes, prejudice, and discrimination a person faces because of their age. This can occur on three levels:

- i. An institutional basis where a society unfairly restricts opportunities for people based on their age.
- ii. Interpersonal ageism which occurs between 2 or more people.
- iii. Self-directed ageism which is directed against yourself.

## **How prevalent is ageism?**

The WHO discuss how ageism is rife throughout society, being found in the workplace, media, legal system and even in healthcare settings. The report highlights a study that showed psychiatrists in the United Kingdom take sexual histories from middle-aged men much more frequently than older men. They go on to note the poor implications for early detection of sexually transmitted diseases (STDs) and the sexual health of older people. Another example of ageism in the UK is that in the financial sector, the Financial Conduct Authority noted that age is used as a risk factor when pricing financial products like insurance and mortgages, with the premiums usually being higher for older people.

## **What is the impact of ageism?**

To assess the impact of ageism, the WHO performed a global systematic review which found ageism was associated with worse health outcomes in all health domains. Interestingly, this association was strongest for self-directed ageism. Various studies looked at by this report found that ageism was associated with earlier death, with one study in China finding that those who were prone to self-directed ageism had a 20% higher chance of dying during the study. A further Irish study highlighted how self-directed ageism increased the likelihood of negative health behaviours like smoking and alcohol consumption.

Further to the report stating that psychiatrists are less likely to ask older people about their sexual health, the report continues to discuss how ageism contributes further to poor sexual health outcomes. Globally there is an increase in the rates of STDs in older people and the report states that older people may be at greater risk due to lack of information directed towards them as a group. This is further compounded by their exclusion from research regarding sexually transmitted diseases.

Ageism was found not to affect just physical health but people's mental health as well. The report cited 42 studies that found ageism influencing psychiatric conditions. In particular, ageism was associated with onset of depression, with 6.33 million cases in 2015 being attributed to ageism. The WHO report also discusses the effect of ageism on cognition, finding that negative self-perceptions of ageing accelerated a decline in cognitive processing speed. This goes hand in hand with a phenomenon known as 'stereotype threat' which arises when people underperform on a task due to worries about confirming a negative stereotype about their group e.g. an older person may do less well on a driving test or cognitive test due to anxiety about confirming stereotypes about older people being bad drivers or mentally slower. Several meta-analyses have demonstrated this important stereotype threat phenomena can affect older people who are exposed to negative stereotypes, regardless of whether they are conscious of it, such that their cognitive ability and memory can decrease.

Older people are also affected socially due to ageism, with all studies in the report showing a negative impact on older people's quality of life. For example, the report highlights how ageism increased isolation and loneliness in three key ways:

- i. Patients feeling unwanted and rejected leading to social withdrawal.
- ii. Older people behaving as they perceive they should, due to stereotypes.
- iii. Society creating ageist barriers to participation i.e., mandatory retirement age.

This was backed up in the report by another study reporting 40% of adults in the UK report experiencing loneliness which can have adverse effects on mortality and overall health.

The report describes how ageism affects older people's sexuality, the topic of which remains taboo in society. It states that older people are often portrayed as asexual and non-active. Again, this stereotype can lead to older people being reluctant to express their sexuality and sexual issues with healthcare professionals due to fear of disapproval. The report highlights the lack of health care provider training in the topic of sexual health of older people.

Ageism was queried to increase the risk of being a victim of violence, with 1 in 6 older people globally being subject to some form of abuse. It was postulated that negative stereotypes of older people de-humanises them, seemingly making violence more acceptable to the perpetrators.

Finally, the section on the impact of ageism discusses the economic impact. Although no evidence presented from the UK, the report referenced Australian evidence of ageist discrimination in employment processes increasing dependency on government funding, this is despite evidence showing positive economic impact of increased employment of the over 55 age groups.

### **What causes Ageism?**

The report focuses on the different and varied determinants of both self-directed and interpersonal ageism.

Interpersonal ageism was more likely to be committed if the perpetrator was younger, male and had a low level of education, the latter being the most poignant risk factor. However, the same characteristics were not found to affect ageism in health care professionals and being exposed to gerontological courses improved perceptions of older adults. Quite interestingly, the report posits that individuals with an anxiety and fear of death had increased ageist attitudes, although this has limited studies to support it, it was thought to occur as older

adults pose an existential threat to younger people as 'they serve as a constant reminder of one's mortality and vulnerability'. The report also identified certain characteristics that increased the likelihood of being a target of ageism. These included increasing age, poor health and increasing dependence with the report concluding that it may be the health and age of the older adult that causes certain perceptions of them.

Finally, self-directed ageism was found to be related to poorer mental and physical health whereas contact with grandchildren was found to have the opposite effect, with those with greater contact being less affected by stereotype threat. Another study, albeit with inconclusive results, reported that those with greater knowledge of ageing had more positive feelings about their own ageing.

### **What can be done?**

The report finishes by recommending three strategies and three recommendations to combat ageism. Firstly, they recommend improving educational interventions across all levels of education, the purpose being to help change misconceptions about age groups and decrease the impact and prevalence of ageism. Secondly, they state that we should aim to increase the amount of intergenerational contact, an example of how this can be implemented is shown on Channel 4's programme 'Old people's home for 4-year olds'. This would have the effect of decreasing ageism and stereotypes against younger people as well.

Finally, the report recommended that all stakeholders should aim to improve research and data about ageism, thus allowing greater evaluation of strategies and therefore a more evidence-based approach to combating ageism and as the WHO conclude to 'create a world for all ages'.

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# On Grief and Speaking More about Suicide

by

Dr Nicole Edwards, CT3 and Trainee Editor of The Old Age Psychiatrist

The 31<sup>st</sup> of August 2021 will mark three years since my mother died by suicide. She was 65 and had been off work following a car accident; I was 27 and four weeks into my first CT1 post in Psychiatry. She died in the coastal Welsh village where I was raised; I was 260 miles away in Newcastle. I write this as a way to reflect on what it was like to have a parent with severe mental illness, and to face that most painful outcome whilst also taking my fledgling steps in a career in psychiatry.

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My mother, Ruth, was a fantastic, funny, gentle and kind woman. She grew up in the beautiful Brecon Beacons of South Wales, developed a love of animals and a passion for languages, and ultimately studied French and Italian at Leeds University. She was intelligent and modest in equally large measures. She worked in many different jobs, but spent her last 14 years at Marks & Spencer's. I hated thinking about or writing these few lines. Not because I didn't know what to say or how to say it, but because I don't know how or when to stop. It can never be enough to describe a person thus, to see some facts about their life and opinions about their character typed onto paper; a vague line sketch of a vibrant human being. It seems important to introduce her, though, so that's what I've tried to do.

I spent many years growing up with a mother I knew was depressed at times, but had no concept of its depths or where it had taken her in the past. I don't know much about how her depression developed, but I have since learnt that it was recurrent and there were multiple suicide attempts before I was born, some of these in the postnatal period. She spent extended periods of time in psychiatric hospitals and received ECT.

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She had just taken some pills, my dad had said. Even without knowing the extent of her past psychiatric history at this point, there was no “just” in my mind when I received this news in August 2018. I rushed home and arrived in the middle of an assessment with a consultant from the older persons’ crisis team. (Although of course she wasn’t pleased that she fitted into the older persons’ team.) The rest of my immediate family were there, and my head was very suddenly swimming with the enormity of what had happened and how I had been wrenched from the privileged position of doctor, to relative of the patient, desperate to know and understand everything. She had been off work for 3 months following a head on collision in her car; there were no serious injuries but she was experiencing some symptoms of PTSD and a profound guilt emerged. Perhaps this triggered the recurrence of severe depression or perhaps it was a consequence. She stopped sleeping and eating, but didn’t like to bother anyone.

I spent the next few days trying not to leave her side; administering new antidepressant medication, cooking meals, playing mindfulness apps, walking the dog together. She couldn’t believe how silly she had been, she felt awful for dragging me all the way down here, and how had the first few weeks of the new job gone, you must get back soon... So I did. She stayed with the crisis team and I returned to the acute adult admissions ward; our roles very different.

And then; the phone call.

She didn’t “just take some pills” this time.

I had to be driven this time.

This time.

A couple of days after she died the consultant from the older persons’ crisis team, and one of the nurses, came to see us. They sat in the living room with us and told us how sorry they were. My dad pacing; me sat in silence. I’m not sure how it felt for them, but I was immensely grateful for this gesture. Sitting with us and tolerating the fresh, raw sadness and disbelief must have been incredibly difficult and it would have been much easier to phone us. Send a letter. But they chose to be there, and that mattered. I hold no feelings of blame towards them, or anyone else. As ever with hindsight, there were perhaps opportunities to

intervene, to do things differently, but without really knowing whether things would have been different, in the end.

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My training in psychiatry has been indelibly marked by these, and other, experiences. For a long time I worried about my own ability to carry out risk assessments and diagnose illness; how could I manage this in people I didn't know, if I couldn't detect it in my own mother? One of thousands of cruel questions that burrowed into my brain following her suicide, all of which require kindness when considered. I'll spare you the rest.

I write this now as I come towards the end of CT3, clearly with many years of learning and growth still ahead of me. I've learnt that it hasn't stopped me from being a good doctor; I think it gives me the opportunity to become a better doctor.

I've learnt that grief is both a formidable, crushing fatigue and a gentle, niggling reminder all at the same time; a constant ebb and flow in all directions.

I've learnt that clinicians working within mental health services are generally brilliant and compassionate people, but some unconsciously and unintentionally perpetuate stigma, and some still use phrases like "committed suicide". I know I don't have the answers to these complex issues, but I'm sure it starts with acknowledging we can always do better, myself included.

I've learnt that sitting quietly with someone and their grief and not trying to fix it is hard, but it can be a small, courageous act that might be remembered for years to come; as I do with the crisis team who sat with me.

I've learnt that, no matter how many CASC-approved empathic statements I master, I'll never understand what someone else's grief or distress or pain or experience of reality is *really* like, but knowing and accepting that can be the start of honest dialogue.

I've learnt that shame uses silence to trick us into thinking it's bigger than hope.

But it's not.

**Resources for clinicians and people bereaved by suicide:**

[Psychiatrists' Support Service \(PSS\)](#) from RCPsych provides confidential peer support by telephone for psychiatrists who may be struggling with personal or work-related difficulties.

[Survivors of Bereavement by Suicide](#) are an organisation who offer a national helpline as well as support groups.

[Facing the Future](#) is a service created by Samaritans and Cruse Bereavement Care to help support people who have been bereaved by suicide, and includes support groups (currently taking place online).

# Aducanumab Dis/Approval

by

Dr. Sharon Holland, ST6 in Dual Old Age and General Adult Psychiatry,  
PTC Representative for Northern and Yorkshire Division

As anyone working in the field of dementia assessment and management can attest, the treatment landscape for the past 18 years has been a sparse, grim domain. At present, in the UK, we have a paltry four medications at our disposal for the management of the most common cause of dementia, Alzheimer's disease. These are the three acetylcholinesterase inhibitors (Donepezil, Rivastigmine, Galantamine) and the NMDA-antagonist, Memantine. The first three seek to enhance acetylcholine neurotransmission, which is involved in memory and learning, while the latter aims to protect extant neurons from the excitotoxicity that can occur with mass neuronal death and glutamate release. None of these alter the longer term course of the illness, and as experience teaches us far too regularly, neither do they reliably offer short term benefit. However, compared to the vacuum of treatment options available prior to their development, they were a very welcome arrival to clinical practice and provided considerable benefit to some while, perhaps more potently, giving hope to the many people impacted by the illness.

The biggest obstacle to developing effective treatment, as in many areas of Psychiatry, is that the exact pathophysiology of Alzheimer's disease still remains the subject of hypothesis and theory rather than definitive fact. We know that there is generalised atrophy and degeneration of the brain, often with a predilection for the hippocampi and medial temporal lobes. We know that abnormal, extra-cellular aggregates of beta-amyloid plaques are present in affected brains. We know that abnormal phosphorylated tau protein neurofibrillary tangles are present. We know that genetic profiles and conditions that predispose to amyloid accumulation also predispose to Alzheimer's disease. We know that there is a long, sub-clinical period prior to the emergence of cognitive impairment and diagnosis, and the early detection of this is another keen area of research at present. However, we also know that amyloid can be present in the brains of people who do not show any evidence of cognitive

impairment. And we know amyloid can be the by-product of inflammatory processes, as we see in secondary amyloidosis. One of the most widely accepted theories of Alzheimer's pathophysiology is that of amyloid deposition causing a cascade of unstoppable neurodegeneration. Conversely, there are also theories that amyloid deposition may instead be a downstream product of another process entirely, such as inflammation, or that tau protein may be the true villain.

It is against this backdrop of desperation for better treatment, and uncertainty about causation, that the latest controversy has erupted in Old Age Psychiatry, and drug approval in general.

On June 7<sup>th</sup> 2021, Aducanumab received approval from the FDA under its accelerated programme, which is intended to allow earlier market release of medication to fill unmet clinical needs. Aducanumab (anti-A $\beta$  3-6) is a monoclonal antibody that targets beta-amyloid plaques and has been shown to successfully clear them from affected areas of the brain. It is given monthly via intravenous infusion and was developed by the US-based pharmaceutical giant, Biogen. It will be marketed under the brand name 'Aduhelm' at a cost of \$54,000 per year, per person. Its approval is based on the 'surrogate endpoint' of it being able to prove an effect on a biological marker of disease and they have been granted 9 years to confirm its effectiveness (or otherwise) in a Phase IV trial.

The controversy arises from a number of sources, but the majority of it stems from the trial data of their two Stage III trials, 'EMERGE' and 'ENGAGE'. By December 2018, Biogen themselves decided to halt both trials due to the preliminary findings that suggested futility. At this point, they had evidenced successful clearance of amyloid from the brain but, surprisingly and disappointingly, without any corresponding cognitive improvement. It was not until some post-hoc analysis was conducted, that they identified a statistically significant slowing of cognitive decline in the subset of patients receiving the highest dose of Aducanumab. However, this was only demonstrated in one of the two trials with the same subset in the other trial actually faring worse than those receiving placebo. When this data was presented to the FDA's Central and Peripheral Nervous System Drug Advisory Committee, in November 2020, they

voted against its approval. Three of these committee members have now resigned in response to the FDA's apparent disregard of their recommendations.

Perhaps of greater concern than inefficacy, approximately 40% in the treatment group experienced cerebral oedema and haemorrhage, termed 'Amyloid Related Imaging Abnormalities' (ARIA), with unpredictable clinical correlates and sequelae. This 'side-effect' will require routine MRIs for those receiving it, adding further costs to treatment.

There are concerns about the planned Phase IV 'confirmatory' trial for several reasons. The first is that it will be funded by patients and insurers, which is something that usually only occurs once evidence of efficacy has been demonstrated. The second is that Phase IV trials, in their messy 'real world' format, are usually intended to identify rare side effects and quantify effectiveness rather than provide the proof of efficacy that should normally have been demonstrated during Phase III. The third, and perhaps the biggest concern is that the FDA approval is for all shapes and sizes of Alzheimer's despite Biogen's trials having only included those with early stage disease.

Additional sources of controversy are the high cost with no proven efficacy, suggestions of impropriety or even corruption within the FDA due to the apparent irregularities in the normal approval process, the potential marketing of false hope to those contending with Alzheimer's Disease, and the diversion of money and attention away from what may be more fruitful avenues of research and drug development.

To understand the magnitude of money involved, the morning after the official announcement of termination in March 2019, Biogen's share price had dropped by almost 30%. The day after the FDA approval in June 2021, it rose by almost 40%. At time of writing, the share price stands at \$325. The maths is relatively easy; if just 5% of people with Alzheimer's dementia in the US were to take Aducanumab, Biogen would achieve revenues of \$17bn.

At time of writing, the Acting Commissioner of the FDA, Dr. Janet Woodcock, has requested an independent inquiry to be undertaken by the government in light of the above controversies.

Meanwhile, we await the European and British regulatory authorities' verdicts on Aducanumab but also, more importantly, we look forward to the eventual arrival of effective, safe, disease-modifying treatments for the full spectrum of dementias.

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- Aducanumab: Promising Alzheimer's drug or dangerous precedent? (pharmaceutical-technology.com)
- The Underside of the Aducanumab Approval | In the Pipeline (sciencemag.org)

# Trieste Model: Over 40 years on, can we still learn from this model?

by

Dr Catrin Thomas, ST4 in Old Age Psychiatry, Betsi Cadwaladr University Health Board.

Prof Alberto Salmoiraghi, Consultant Psychiatrist and Medical Director for Mental Health and Learning Disabilities, Betsi Cadwaladr University Health Board.

## **What is the Trieste Model?**

Trieste is a scenic seaport city in north-eastern Italy that has gained international recognition for its revolutionary changes in mental health care. Franco Basaglia, an Italian psychiatrist, founded the Trieste model of social psychiatry in the 1960s. The model was ground-breaking for its time and centred around deinstitutionalisation with an adoption of a person centred approach with social integration and inclusion into communities. Basaglia believed that the biological model of mental illness did not conceptualise the whole story but that illness is highly influenced by the social circumstances in which it develops<sup>1</sup>. His vision was to change mental health care from a clinical model of treating symptoms to a whole person, whole system, whole life approach. This is in contrast to how the UK system has developed which has a highly clinical service delivery model with many different specialisms.

## **Legislative differences between Italy and the UK.**

Central to Basaglia's vision of reforming mental health care in Italy was the introduction of Law 180. This legislation, introduced in 1978, mandated the closure of all asylums and the creation of community based mental health and social care alternatives<sup>2</sup>. Admission to hospital is allowed only if it can be shown that community-based treatment options are not feasible or have failed<sup>3</sup>. Psychiatrists in Italy do not have the legal power of detention and compulsory admissions have to be granted by a Judge. Compulsory admissions are initially for 48 hours, and can be extended for 7 days at a time by the order of local

Magistrates<sup>2</sup>. In contrast to the Mental Health Act in England and Wales, the power of detention in Italy has less emphasis on risk as we know it; being risk to health, risk to self and risk to others. Instead, they focus on risk to public safety along with emphasis on public protection. This fact allows a different approach to acuity that can be more easily treated in the community or in less restrictive environments.

### **Differences in community mental health care service models.**

Hospital admissions, including for older persons, are most often due to a crisis. Mezzina et al.<sup>4</sup> described a crisis within psychiatry as being linked to a behavioural problem and to social threat with the non-individualised response being to bring the person into an institution. With this logic, a crisis can be considered a social emergency. Many complex social problems cannot be resolved in hospital and remain present on discharge. This is especially true for the elderly population. Is bringing the person out of their own environment into an institution helping that person? Would it not be better to have a more preventative model of care that looks at the whole picture, including social needs, and treats the person in their own environment as opposed to lengthy hospital admissions that lead to institutionalisation? An integration of health and welfare resources under the umbrella of community mental health centres (CMHC) in the Trieste model makes this possible.

The Trieste model is based around a network of CMHCs which are open 24 hours a day, 7 days a week. The centres are open to drop-ins between 8am-8pm and provide crisis cover overnight. There are on average 6 open-door, short-term beds at each CMHC. The system, co-ordinated by the Department of Mental Health, also includes a small number of general hospital psychiatric units, a network of supported housing facilities, and several social enterprises<sup>2</sup>.

The CMHCs respond to all crises as they provide 24/7 working. There are numerous advantages to this, including a strong continuity of care which often leads to a more robust and individualised treatment plan as people are assessed by those who know them and know what their services can offer. In the UK, the community mental health teams are run as stand-alone services with only outpatient clinics and no, or very little, out of hours working which makes them ineffective in coping with acute crisis and cannot follow a preventative model of care which inevitably leads to the need for acute inpatient admissions<sup>4</sup>. Instead,

the Trieste model has shown that an integrated mental health care can be delivered in the community with very little inpatient beds required. This shows that a preventative model of care with a whole person approach can work.

A recent House of Commons report<sup>5</sup> on the treatment of people with autism and learning disabilities took note of the Trieste model and recommended the implementation of a number of its components. Many of the recommendations are easily transferrable to the care of people with dementia. Their main recommendations relevant to older persons mental health patients include: all new long-term admissions should be banned; for cases with severe co-morbidity any admission longer than three months should be subject to safeguard including weekly, independent, formal reviews for those detained longer than 3 months; and if a person is admitted for more than three months, due to a lack of appropriate community support and provision, then the funding from their inpatient stay should be used to find and set-up community provision within eight weeks<sup>5</sup>.

### **How does this relate to Older People?**

The Trieste model is an ageless service; however, many of the key components can, and in our opinion should, be applied to older people. This is particularly true for the integrated model of working that enables more preventative care. A lack of sufficient funding for care and community support is often a barrier to attempts to significantly reduce length of hospital admissions, especially for those with dementia. When the asylums were de-commissioned in Trieste, all of the funding was transferred to the community.

The Italian model also has numerous day centres and drop in clinics, many of which have closed down in the UK over recent years. These day centres offer an opportunity to relieve carer stress as well as monitoring of the person with mental illness, including dementia, and identifying any problems or concerns early on. As all relevant services are available under one roof at the CMHC, the day centres allow for a more rapid assessment by different professionals and volunteers to ensure a cohesive management plan.

There are some jointly funded health and social care community respite beds in the UK but their numbers are currently limited and don't necessarily mean that the person's problems are resolved more efficiently as they remain segregated

services. Should there be more of these respite or assessment beds available for people with dementia as an alternative to hospital admission? I am sure we would all agree that this homely environment is better for the person with dementia compared to the clinical environment of a hospital.

The Trieste model has demonstrated that, when services are well resourced, integrated, and supported by legislation, people with mental health problems can be safely and effectively supported to live in the community without the need for lengthy hospital admission.

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# IAPT Older People's Positive Practice Guide; Summary of main points

by

Dr Gareth Smith, ST6 Psychiatry, East London Foundation Trust

## **Introduction**

The IAPT practice guide was first published in 2009 outlining how local areas could deliver IAPT services for older people. This article is a summary of the main highlights from the most recent update of the IAPT Older People's Positive Practice Guide 2021. The formal document can be accessed from:

<https://babcp.com/Portals/0/Files/Therapists/Older%20People%20Positive%20Practice%20Guide%20-%20May%202021.pdf?ver=2021-05-11-100818-320>

## **Covid-19 and mental health**

Older people have been disproportionately affected by the Coronavirus Covid-19 pandemic. Symptoms of poor mental health that have increased over the course of the pandemic within the age group are reported to include depression, anxiety, bereavement and grief. Older adults may need help adjusting to the return of life pre-Covid-19. IAPT services will be required to be accessible, appropriate and flexible to the needs of older adults. Telephone and telecare service provision, as well as consideration of in-reach services to older people residents in care homes, will continue to be evolving areas of development.

## **Ageing and health**

Older people report overall higher levels of wellbeing and life satisfaction. It is important to differentiate ageing from being synonymous with a deterioration of mental or physical health. However, mental health and physical health comorbidities are common in older age. The experience of older adults with mental and physical health conditions is diverse. Older people with depression are at increased risks of frailty, functional deterioration and cognitive decline. There is a need for psychological therapists to become competent in supporting older people with complex health needs.

### **Making IAPT more accessible for older people**

Potential barriers to older people accessing IAPT services include; attitudes and beliefs of older people themselves, attitudes and beliefs of health care professions, and IAPT service flexibility. To address these barriers, services should provide self-referral routes, education and recognition of negative stereotypes, and age-appropriate advertising modalities. IAPT services could consider 'older people champions' and advisory groups to represent the needs for the older adult population within the provision of services.

### **Domiciliary visiting and psychological therapy**

Home visits offer enhanced assessment opportunities and the ability to engage hard-to-reach populations (for example mobility or frailty). Where possible, services should facilitate requests for home visits.

### **IAPT psychological therapy with older people**

Strategy approaches to the delivering of IAPT services to older people can include; Wisdom Enhancement and life skills, Selection optimisation with compensation, and a Trauma-informed approach to care.

### **Cognitive deficit and psychological therapy**

Changes to cognition and memory in older adults with dementia will require flexibility and adaptability of IAPT services. Older people with a primary diagnosis of dementia may require multidisciplinary care for depression and anxiety within an appropriate setting. It is important to approach care needs in a holistic manner, for example that some older adults will have primary carers involved in their care. Carer support including CBT is efficacious in reducing psychological distress in dementia caregivers.

### **Conclusion**

In summary, older people are a heterogenous group with different identities, needs and experiences of ageing. Mental and physical ill health is not a forgone conclusion of ageing. The delivery of IAPT services to this population will require a diverse and adaptive approach to meet these needs.

# New 'NextSteps' website developed to share sources of support for patients waiting for a memory assessment

By

The Dementia Change Action Network (DCAN) team

We are all too familiar with the impact of the Covid-19 pandemic and the distress that people and health and social care services experienced.

In memory assessment services, delays to appointments as a consequence of the pandemic left people feeling disconnected from formal and informal support networks, which negatively impacted emotional, cognitive, social and physical well-being.

To address this, we engaged people with lived experience and their carers to better understand their needs and what support would be most useful.

We also consulted with providers of support to identify resources and information that would best meet these needs.

The feedback gained through this engagement led to the development of [NextSteps.org.uk](https://www.nextsteps.org.uk), a new website to support people who are waiting for a memory assessment appointment, as well as their carers and family members.

## Who is the NextSteps website for?

- The Next Steps website is for anyone waiting for a memory assessment appointment as well as carers, family members and organisations who support them.
- A link to this website could be given to people by their GP at the same time that a referral to a memory clinic is made; or be included on an appointment letter from a memory clinic.



## What is the aim of the NextSteps website?

- Explain what to expect at a memory assessment;
- **Provide tools and resources to support wellbeing;**
- Connect people to available sources of support.

The website is divided into four steps:

Step 1: What to expect from the memory assessment process

Step 2: Taking care of your well-being

Step 3: Exploring available support

Step 4: Diagnosis

Information on the website is also available in a printable document, which can be downloaded from the site.

The website was developed by [DCAN](#) (Dementia Change Action Network) in partnership with NHS England and NHS Improvement.



For further information:

DCAN website: [dcan.org.uk](http://dcan.org.uk)

Twitter: [@DementiaCan](https://twitter.com/DementiaCan)

NextSteps website: [nextsteps.org.uk](http://nextsteps.org.uk)

# Understanding dementia diagnosis during Covid-19

by

Lindsay Kinnaird and Tom Russ

Alzheimer Scotland Dementia Research Centre, University of Edinburgh

Professor Alistair Burns highlighted the challenges the pandemic presented to our service in the September 2020 issue of this newsletter. One year on a small team of researchers at the University of Edinburgh are aiming to understand the impact of this rapid change in working practice in relation to the assessment and diagnosis of dementia.

The diagnosis of dementia can be challenging in normal times; the sudden shift to remote working made this even more complex. We are interested in how remote diagnosis is experienced by the person with dementia and if it is possible for it to be delivered sensitively with appropriate support.

This study will explore diagnosis by video-call or telephone in-depth from the perspective of both the person making and the person receiving the diagnosis. The rationale is to impact positively on the practice of remote diagnosis and, crucially, the experience of the person with dementia and their close family members.

The project arose from discussions within clinical services around what is considered ethical and best practice and consultation with the Patient Public Interest Group of NRS Neuroprogressive and Dementia Network. It also reflects the study's PI – Dr Tom Russ - struggle of balancing the benefits of a diagnosis with the imperfect way in which it may have to be given.

## **Study approach**

Informed by co-production principles, the study is being guided by a Research Advisory Group comprising people with personal experience of dementia. This Group is informing the research team throughout the research process, meeting

regularly with the University researchers to work collaboratively on planning, analysis, and reporting.

The study has two key approaches to gathering evidence: 1) interviews with clinicians and people with a diagnosis of dementia and 2) an online national consultation comprising a wide range of stakeholders.

We aim to interview approximately 30 people who received a remote diagnosis of dementia from the beginning of the first UK lockdown in March 2020. Learning from people who have received a diagnosis at a time of global pandemic will allow us to enhance practice for the future, including a more nuanced understanding of the ethical implications.

It is also essential to understand the perspective of the clinician and ensure this expertise is represented in the findings of the study. Therefore we are inviting Old Age Psychiatrists from across the UK to reflect on their practice during the pandemic. We would be very happy to hear from any Faculty member who would be interested in taking part. These interviews will take place by video-call or telephone and will be approximately 1.5hours.

The second phase of the project will bring together people with personal experience of dementia, professionals, and people working in dementia fields in an online national consultation. The findings from the interviews will be presented at this event and discussions held to allow participants to inform the outcome of the research project.

### **Outputs from the study**

The learning from the study will be shared as extensively as possible with several outputs including, a short animated film and podcast targeted at a general audience as well as clinical guidelines for practitioners, a briefing paper for policy makers and academic papers to develop the evidence base.

The project is funded by the Economic and Social Research Council as part of UK Research and Innovation (ES/W001349/1).

If you are interested in learning more about this project or would like to participate, please contact Lindsay Kinnaird ([Lindsay.Kinnaird@ed.ac.uk](mailto:Lindsay.Kinnaird@ed.ac.uk) or 07825 298 237)

## Cochrane Corner

by

Dr Jenny McCleery

Consultant Psychiatrist, Oxford Health NHS Foundation Trust

Joint Coordinating Editor, Cochrane Dementia and Cognitive Improvement Group

Featured reviews:

- Diagnostic test accuracy of telehealth assessment for dementia and mild cognitive impairment
- Non-pharmacological interventions for preventing delirium in hospitalised non-ICU patients

The pandemic has had many effects on our patients and their mental health, but one early effect was a sudden upheaval in the provision of services, including the rapid introduction of telehealth consultations. Among the questions raised by this change in memory clinics was whether diagnoses of dementia or MCI made using telehealth would be accurate. We knew that there was some evidence on this, mainly from settings that have an interest in providing services in remote and rural areas, and so two colleagues and I set out to review this evidence. Of course, a pandemic is not the only situation in which telehealth assessment could be important. Worldwide, the majority of people with dementia have no access to high-quality diagnostic assessment, with implications for individual and community-level access to health and social care services. The WHO has set a target that by 2025 at least 50% of the estimated number of people with dementia in 50% of countries should have had a diagnosis. This target will be challenging in many countries, and innovative ways to increase access to assessment will be needed. Telehealth might be one part of a solution.

In our review, *Diagnostic test accuracy of telehealth assessment for dementia and mild cognitive impairment*

(<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD013786.pub2/full>), we looked for cross-sectional diagnostic test accuracy studies in which

participants had both a telehealth assessment (the index test) and a face-to-face assessment (the reference standard) for dementia and/or MCI within four weeks of each other. The definition of a telehealth assessment was that all contact between the patient and the clinician responsible for synthesising information and making a diagnosis had to take place remotely, but some face-to-face contact with local health professionals (e.g. nurses) as part of the assessment process was allowed. We found only three studies with 136 participants to include in the review. Two studies (20 and 100 participants) took place in community settings in Australia and one study (16 participants) was conducted in veterans' care homes in the USA. All of the telehealth assessments were done using videoconferencing systems. Only the smaller Australian study (20 participants) used a pure telehealth model in which all aspects of the assessment were done remotely. In the other two studies, quite a lot of information was gathered in person by nurses and used in both diagnostic assessments; this poses a risk of incorporation bias, making it more likely for there to be close agreement between the in-person and telehealth diagnoses. The conclusions we could draw were limited by the very small amount of evidence and the application of our results to the pandemic situation was limited by the type of telehealth model used in the included studies.

In as far as they went, the results were reassuring for the accuracy of telehealth assessment, although all the evidence was of low certainty. We found that telehealth assessment correctly identified 80% to 100% of the people who were diagnosed with dementia at face-to-face assessment and also correctly identified 80% to 100% of people who did not have dementia. Only one study (100 participants) attempted to diagnose MCI. In this study, 71% of participants who had MCI were correctly identified using telehealth assessment, as were 97% of those who had any cognitive diagnosis (either MCI or dementia), but only 22% of those who had no cognitive diagnosis at face-to-face assessment. However, the latter result was especially uncertain because there were so few patients in this category. We found no data on the accuracy of subtype diagnoses.

Of course, two specialists seeing patients face-to-face will not agree about dementia and MCI diagnoses in all cases. Therefore perfect agreement between

telehealth and face-to-face assessments cannot be expected. The larger Australian study was interesting because it also included a group who had two face-to-face assessments; the authors found that agreement between telehealth and face-to-face assessments was no worse than agreement between two face-to-face assessments.

Clearly, accuracy is just one factor to be considered when deciding whether and how to offer telehealth assessments. Issues of acceptability, equity, sustainability and cost effectiveness are also critical and are likely to vary greatly between settings, so research on these outcomes within the NHS is very important if we intend to keep telehealth services going beyond the stage of an emergency response to the pandemic.

***Non-pharmacological interventions for preventing delirium in hospitalised non-ICU patients***

(<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD013307.pub2/full>) by Burton and colleagues is an update and adaptation of one of the Cochrane Dementia Group's most highly cited reviews. The 2016 version of the review included 9 trials testing non-pharmacological interventions. Seven of these were multi-component interventions, made up of between 2 and 13 distinct components, and there was moderate quality evidence that they reduced the incidence of delirium. This review set out not only to update the evidence but to use a component network meta-analysis to explore which components might be key to efficacy.

The current review includes 14 trials of multi-component interventions and strengthens the evidence that, among hospitalised patients outside ITU, these interventions reduce the incidence of delirium compared to usual care (10.5% incidence in the intervention group, 18.4% in the control group, risk ratio (RR) 0.57, 95% confidence interval (CI) 0.46 to 0.71,  $I^2 = 39%$ ; 14 studies; 3693 participants; moderate-certainty evidence). There may be little or no effect on inpatient mortality (5.2% in the intervention group, 4.5% in the control group, RR 1.17, 95% CI 0.79 to 1.74,  $I^2 = 15%$ ; 10 studies; 2640 participants; low-certainty evidence) but there may be a reduction in length of hospital stay (MD - 1.30 days, 95% CI -2.56 to -0.04 days,  $I^2=91%$ ; 3351 participants; low-certainty evidence). None of the studies looked at incidence of dementia as an outcome. In the exploratory component network meta-analysis, the components

most clearly associated with reduced incidence of delirium were re-orientation (including use of familiar objects), cognitive stimulation and sleep hygiene.

The review also includes 8 trials of 7 different single-component non-pharmacological interventions. There was no evidence of efficacy for any of these simpler interventions, which is perhaps not a surprise given the variety of risk factors for delirium. Clearly, a multi-pronged approach which systematically applies a range of delirium prevention strategies, including the less 'medical' strategies of re-orientation and cognitive stimulation, should be standard practice for all older patients in acute hospital wards. In their discussion of the implications of their results for further research, the review's authors highlight a need to focus in more detail on the content and implementation of multi-component interventions, and to study specifically patients with pre-existing dementia. They also suggest that outcomes related to incidence and progression of dementia should be included in primary studies.

# Research update

by

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## **Roberts et al., Accuracy of dopaminergic imaging as a biomarker for mild cognitive impairment with Lewy Bodies<sup>1</sup>**

This single-centre, prospective cohort study aimed to build on previous research looking at the accuracy of dopaminergic imaging in diagnosing prodromal dementia with Lewy Bodies (DLB) at the mild cognitive impairment (MCI) stage, which is referred to as MCI-LB. The specific type of imaging investigated was I-FP-CIT SPECT, more commonly known as DaTSCAN, and accepted as having high diagnostic accuracy at the dementia stage. Participants were recruited from memory services in the North East of England; these were individuals over the age of 60 with a diagnosis of MCI and the presence of core features of DLB and/or symptoms supportive of a DLB diagnosis.

Following clinical assessment and screening, the diagnosis of MCI was confirmed using a consensus panel of three experienced old age psychiatrists; acknowledged as the gold standard in living patients (but highlighted by the authors as a limitation of the overall study given ultimate confirmation of progression to Alzheimer's or DLB would come from histopathology following death). The I-FP-CIT SPECT images were assessed individually and then by consensus and all were blind to the clinical information; the decision on each image was either normal or abnormal, with mild balanced loss of dopaminergic uptake throughout both striata being considered normal.

The total number of participants who were ultimately included after screening and attending for scanning was 144. The overall accuracy of FP-CIT was 76% with sensitivity 66% and specificity 88%. The authors therefore argued that the use of dopaminergic imaging at the MCI stage of illness can be useful when DLB is suspected because it is five times more likely to for an abnormal scan to be

found in MCI-LB than MCI due to Alzheimer's disease. This is perhaps particularly pertinent at present as we see more research into disease-modifying treatments for the early stages of dementia.

**O'Sullivan J. L. et al. A tablet-based intervention for activating nursing home residents with dementia: results from a cluster-randomized controlled trial<sup>2</sup>.**

This cluster-RCT took place across ten nursing homes in Berlin, Germany, and aimed to assess the effects of a "tablet-based non-pharmacological" intervention for residents living with dementia. Their primary outcome in the study was apathy, which they argue is particularly important in people with dementia given its association with greater functional and cognitive decline. This was measured using the Apathy Evaluation Scale – Informant Version at baseline and 8 weeks. Secondary outcomes were also measured, including quality of life, use of psychotropic medications and depressive symptoms. Regarding the intervention itself, participants were randomly assigned to either "conventional activity sessions" or the tablet. The tablet included various tasks, which were designed to target cognitive and functional abilities, along with emotional self-regulation.

The study included 162 residents, although post intervention data were only able to be collected from 134. Unfortunately, the study did not support any benefit from the tablet intervention, and in fact quality of life improved more so in the conventional activity sessions. The use of psychotropic medications reduced slightly with the tablet group, however as the study authors highlight, their findings do not make it possible to draw an unambiguous conclusion.

The importance of finding effective and sustainable non-pharmacological interventions for apathy, depression, quality of life etc. in dementia is hugely important and while this study does not support the specific tablet-based intervention that was developed, it is encouraging to see more and more research of this nature.

**Oude Voshaar R. C. et al. A 6-year prospective clinical cohort study on the bidirectional association between frailty and depressive disorder.<sup>3</sup>**

The aims of this study included determining the prevalence of frailty amongst depressed older people, the impact of frailty on the outcome of depression and the impact of depression on the course of frailty. This was done with participants already involved in the Netherlands Study of Depression in Older Patients (NESDO), of which there were 378 depressed individuals and 132 never depressed individuals.

Data were collected at baseline, 2 years and 6 years, and this included a diagnostic assessment of depression using the CIDI (severity was also measured every 6 months using the Inventory of Depressive Symptoms) and the calculation of the individual's Frailty Index (FI). The study includes a helpful explanation of the development of an FI, essentially it is a ratio of "health deficits" (such as symptoms, signs, diseases, abnormalities in investigations etc.) present to the total number of deficits present, with an agreed cut off for frailty.

Perhaps unsurprisingly, depressed patients were more often frail and had higher frailty scores than those who were not depressed. Conversely, higher baseline depressive severity was associated with an accelerated increase in FI over time. The study gives more detail to our current understanding of the reciprocal relationship between frailty and depression, lending weight to the arguments for more multidisciplinary care models in later life that incorporate frailty and its impact on outcomes in late life depression.

Clearly, old age psychiatry has an important role in managing frailty and developing research relating to its intersections with mental disorders and this study was a helpful reminder to ensure this is incorporated into my CPD. In February 2020, the Royal College published a [position statement](#) on ensuring the best outcomes for older frail people, and this is an excellent resource for those who have not already read it.

**References:**

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## Film Review

### I care a lot, 2020

by

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Director J Blakeson

Released 2020, available to stream on Amazon Prime



Content warning: swearing, violence

This black comedy is not for the easily offended but is worth watching if only to feel smug and reassured that the English legal system still protects the rights of the vulnerable. Rosamund Pike won a golden globe for her portrayal of Marla Grayson, an ice-cold, ruthless legal guardian without a conscience enforcing draconian legal guardianship laws in the USA.

The film highlights the impact of legal guardianship meant to protect vulnerable adults unable to take care of themselves by having courts awarding wardships to court appointed legal guardians who can make decisions regarding their care on their behalf. But this film depicts how this has been privatised and monetised leading to financial abuse of the people the law was meant to protect.

A man begs entry to a care home in the film's opening scene, but this soon escalates to violence. The man has been barred from seeing his mother who has been placed in a care home without his knowledge by Marla who has been appointed his mother's guardian ,also, without his knowledge. Marla describes passionately how she had to step in at the courts behest to look after his mother

as she was no longer managing at home and has had to stop him visiting as this made his mother upset. The son's explanation, that he was respecting his mother's wishes to stay at home is ignored by the judge and Marla.

It becomes clear despite Marla's declaration "I care a lot" about her wards, the primary focus of her guardianship business is the money she makes charging her wards for her service by liquidating their assets. Marla is soon on the lookout for next victim and is helped by an unethical doctor who gives her the name of a patient, Jennifer (Diane Wiest), a well off older women with no family.

Jennifer is independent with an active social life and is shocked when Marla turns up with the police to escort from her home to a nursing home as the courts have decided that Jennifer can no longer look after herself. The court has made the decision on the report of one unethical doctor with no other evidence and as Jennifer points out, without talking to her.

Marla quickly liquidates Jennifer assets, putting her house on sale and while rummaging through Jennifer belongings finds an unregistered safe deposit key containing a bag of diamonds which leads to a battle of wills between Marla and the Russian mob who want Jennifer and the diamonds back.

The most harrowing part of the film for me was the complete control Marla has over Jennifer's life. Marla cuts off Jennifer's contact with her friends and family as well as reducing her pain medication when Jennifer refuses to talk to her. I had hoped this film was an exaggeration but when I tried to find out more about this, I found articles related to real life Marla Graysons' who had abused the legal guardianship laws and how families lost access to their loved ones.<sup>1</sup>

The film made me think of our patients in England and how they must feel when they are subjected to the mental health act or placed in care homes their wishes but feel slightly reassured that the legal frameworks are robust enough to protect the rights of vulnerable. These decisions can be challenged and this right to challenge needs to be protected no matter what, as the alternative could be far worse.

#### Reference

[How the elderly lose their rights, The New Yorker.Racheal Aviv](#)

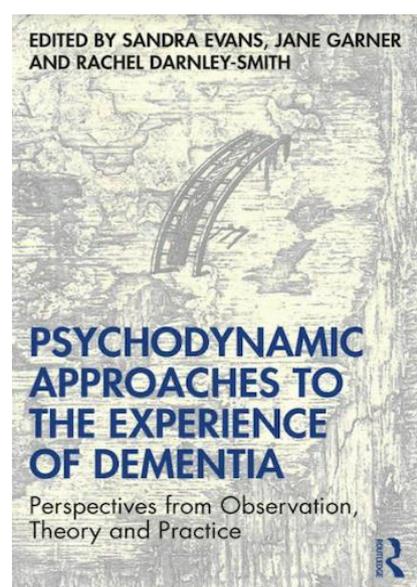
## Book review

# Psychodynamic Approaches to the Experience of Dementia: Perspectives from Observation, Theory and Practice

by

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Professor Sandra Wesenberg, Visiting Professor in Clinical Psychology, Alice Salomon Hochschule - University of Applied Sciences, Berlin.



Sandra Evans, Jane Garner and Rachel Darnley-Smith (eds.), *Psychodynamic Approaches to the Experience of Dementia: Perspectives from Observation, Theory and Practice*, Routledge: UK, 2019; 268 pp. ISBN: 0415786657, £22.41 (pbk)

While there is a large body of literature on psychodynamic processes in early life, this book is unique by applying psychodynamic thinking to late life and specifically dementia. To enable this the multi-author team courageously challenges a number of persisting beliefs, including Freud's famous assumption that people over 50 are too old for psychotherapy and that psychological therapies solely rely on language. The book invites a broader view of dementia and reminds the reader, that the dementia experience is shaped by much more

than neuropathology, but also personality, relationships, attachments, experiences predating the cognitive loss, as well as setting, milieu and the social network (caring relatives, professional caregivers, psychiatrists, etc.).

When examining dementia loss is a central topic. It is noted that making a proactive diagnosis of dementia could give an opportunity to mourn the losses encountered. In this context skilful advance care planning appears important, and it is described how psychodynamic approaches (chapter 4) can be helpful in preparing for such discussions many clinicians are dreading. The chapter defines advance care planning as an invitation to process dementia, and by naming the feelings the diagnosis and related losses evoke the person with dementia and their family can regain some sense of control.

Very thought-provoking is the discourse on the potential role of denial (chapter 5), offering the perspective that lack of awareness in people with dementia might not only be due to declining brain function, but also an active unconscious process to repress the painful outlook of the inevitable decline. While the absence of awareness of loss might lead to risk behaviours from overestimating abilities, this denial could put a much greater strain on relationships.

Attachment is a concept that many of us will remember as particularly important in early life. The book outlines how this remains important throughout life and becomes more important towards the end of life (chapters 9, 10). The loss of cognitive abilities leads to a person with dementia needing to rely more on being contained, either by external relationships or through internal representations of earlier ones. The caregiver's attachment can have a direct impact on the person with dementia's journey. While securely attached family members find it easier to accept declining abilities and provide care, anxiously attached caregivers might wear themselves out by caring beyond the needs of the family member (chapter 9). This is particularly challenging for couples (chapter 10) who contained each other for most of their lives, and the caregiver will not only lose their containing partner, but also increasingly need to act as container for the person with dementia. Hence the book highlights the importance of providing containment for the caregiver ('containing the container'), to make the caregiver emotionally available to the person with dementia and compassionate long-term caregiving possible.

These are only some of the areas the broad multi-disciplinary author team covers, others include psychodynamic aspects of art and music therapy, specific therapeutic approaches and concepts, general hospital liaison psychiatry, and also a medical student's 'encounter with dementia'.

This a book one could read from back-to-back, but also easily to pick out the chapter most relevant to a current clinical issue or ethical dilemma. Some prior knowledge on the major psychodynamic processes and concepts is required, but important theories are repeated without creating monotony. Most of it is not a handbook, rather includes illustrative case studies, and thereby encourages reflection. This reflection will enable clinicians to adopt a more personalised, or more 'human' perspective, on what people with dementia and their caregivers are experiencing and facilitate person-centred ways of providing care.