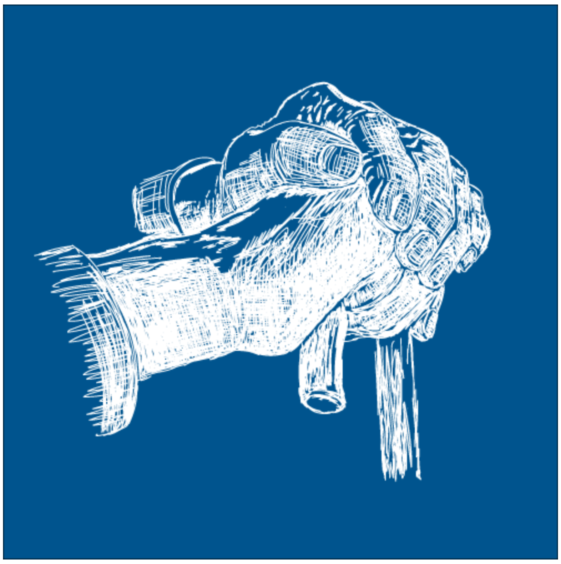
The Old Age Psychiatrist

Issue 76, January 2020

Old Age Psychiatry Faculty Newsletter



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Update from the Editorial Team

by

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It is January 2020 so Happy New Year to all and hope you had a lovely Christmas and looking forward to a fantastic year ahead.

We have had a bit of a reshuffle in the Editorial team and from this newsletter I have taken over as the lead Editor. Helen has led the team for four years now and it will be a hard act to follow - so thank you Helen for all your hard work. The editorial team of course remains the same (Helen, Anitha and I) with Victoria Jones as our trainee Editor.

It's a new year and a time for opportunities, new beginnings and we hope that you will be excited to read the variety of articles in this edition of the newsletter.

The features section is varied with several interesting articles. Dr Martin Curtice writes on Premier League football clubs and their work with older people in local communities. This is in two parts with the second part being published in May newsletter.

We also have an enlightening article by Prof Susan Benbow, a retired consultant on Life after NHS. In this current climate of pensions tax and annual allowance reviews maybe it may make us think of future after retirement. We would like to run a series on Life after NHS for retired or semi-retired psychiatrists. So please contact me if you are keen to write about this.

Please also read the Use of Force article in the features - it makes an interesting read but also very relevant to our everyday practice.

The Essay competition is open now so please write or encourage trainees, medical students and even other disciplines to write. The topic for this time is 'Through the Ages – History's Role in Today's Old Age Psychiatry'.

The usual updates such as integration insights, Cochrane corner and research updates make good contemplation. There is an interesting update on European Association of Old Age Psychiatry Conference held in Nottingham. As always, the Chair's update and Prof Alistair Burns update and quiz make an interesting read.

For more research orientated readers, the survey of Consultants on the use of CSF analysis in the diagnosis of Alzheimer's Disease might make you think of the future. The Faculty of Old Age Psychiatry has been commissioned by ARUK to explore these issues further – so there will be an opportunity via a national survey and focus groups for members of the Faculty to share their experiences on using CSF and other biomarkers too. The Joint Dementia research article by Bob Barber is also fascinating.

The faculty Conference is changing – please read the Academic Secretary's update on the format and programme. We hope you will join us at the meeting in London 18-20th March 2020.

As usual we round off with a book review, but we have more this time – a film review and a theatre review and although they are not specific to older people they do highlight relevant mental health issues for us to ponder over.

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

View from the Chair

by

Dr Amanda Thompsell

Chair of the Faculty of Old Age Psychiatry, Royal College of Psychiatrists

By the time this goes out it will be January. A happy new year to all my colleagues.

Writing this in November, I have the opportunity to look back on another 4 months of challenge and achievement for the Faculty. Once again I want to thank my Colleagues on the Faculty Executive who have worked so hard to ensure that we are responsive in relation to the many issues that we as a Faculty face.

Over this last year we have been working out in further detail how we fit in to the NHS Long Term Plan (LTP), and seeking to ensure that older people's mental health gets the recognition and resources that it deserves.

In this regard we have had a fair degree of success, for example in inputting into the NHSE Mental Health Implementation Plan to ensure a recognition of the need for physical health expertise in inpatient units is met (Our report "*Caring for the whole person*").

Our most major piece of work has however been the Faculty report "*Delivering the NHS Long Term Plan's ambition of ageing well: Old age psychiatry as a vital resource*"

This tells people about the essential role played by old age psychiatrists, and Older People's Mental Health (OPMH) services and is intended to support decision-makers responsible for implementing the LTP as it affects older people by showing them the importance of old age psychiatrists and OPMH services. Whilst I appreciate this is focused on England the arguments made are of value in the devolved Nations, and I hope that this report will inspire trainees to consider old age psychiatry with the variety that it offers and the importance of our role.

However, as well as this, much else has been going on.

The College on our behalf has endorsed The Care Home Charter for Swallowing and Medicines, a 1-page A4 document explaining what patients and what care staff should be expecting around medication administration.

We have also had a very successful European Association of Geriatric Psychiatry Conference in October with Colleagues from all over Europe.

We have been working on the code of practice of the Liberty Protection Safeguards and an update on this will be presented at the Faculty Conference, of which more below.

One new legal matter that came out of the blue has been our need to react to the Mental Health Units (Use of Force) Act 2018. This new act of parliament, passed quickly, having originated as a private member's bill and could greatly increase the need for bureaucracy when providing personal care interventions to patients of mental health wards and there will need to be great care in how this is implemented if it is not to cause a major resourcing problem.

Thank to those of you who commented when I emailed you about this issue as it helped us to make extensive comments on the draft implementation guidance. We have continued to liaise with the rest of the College and with CQC and hope to have a meeting with DH & SC in the New Year to discuss this further.

We are looking next year to consider updating our published Strategic Aims, when the new Chair is in place but meanwhile here is my usual round-up of some the things that have been going on since my last report that contribute to meeting those aims.

1. To enhance the profile of the Faculty's expertise in relation to the mental health of older people of all ethnicity

We have been working on a Faculty report on delirium which we will launch at the Annual Faculty Conference in March 2020.Thank you to those who have contributed good examples.

We also have in the pipeline a report on frailty, which should be published soon (early January 2020) – explaining the value of our role and giving service examples.

We have updated the College leaflet for those people living with memory problems to give them a better understanding of their illness.

Whilst we have had some media attention for older people with mental health issues I particularly want to thank my colleagues in Scotland and Wales who have also been raising our profile in the media – with an interview in Scotland around the value of music and another about access to PET scans for people in Wales.

2. To attract and retain within old age psychiatry the best doctors for every level of their profession

The College has launched its Choose Psychiatry booklet with supporting online video vignettes and Old Age is well represented in this, with this and also has a video featuring a trainee old age psychiatrist. There is also an excellent blog by a trainee. You can see these below:

- CHOOSE PSYCHIATRY | RCPsych Meets: Dr Manny Bhamra
- CHOOSE PSYCHIATRY | “I could see a future where I could be happier”
- Why my role is not just about dementia and slippers

The Masonic Charities have kindly financed a PHD award for research in older adults mental health, which is due to be awarded in December 2019 following stiff competition.

Members of the Executive and Faculty are continuing to do excellent work in developing the GMC curriculum for our speciality

We have gone back this year to giving trainees their own day at our annual Faculty conference. There is an exciting programme and I encourage all trainees to come to as many days as they can.

3. To focus on our Membership engagement

We have been working with Alzheimer’s Research UK on getting greater understanding of what services need to be in place if new treatment strategies come along. We have developed a survey on this topic and I encourage you to complete this please when it comes out as it will help articulate what we will need.

We are also about to repeat our annual survey about services in January 2020. We have developed better strategies to interrogate the qualitative data and we will be looking to use the results to highlight any service deficiencies.

We have put on our Faculty website information and tools that can help members support Join Dementia Research (JDR) which is a UK-wide service that allows people to register their interest in participating in dementia research and be matched to suitable studies. Central to the JDR service is a database of volunteers, representatives and studies with a front-end website.

Finally, as a result of feedback from our members we have changed and improved the format of our Annual Faculty Conference which will take place from 18 March in London. This is still open for booking. We are going to change the format of the Conference with the Wednesday and Thursday being of general interest and the Friday being specifically for trainees. We have got a fantastic programme with more international speakers and more time for workshops and we will be having a dinner!

4. To increase awareness of mental health conditions of older people of all ethnicities

We persuaded the College to support Public Health England's consensus statements on Healthy Ageing which talks about addressing challenging ageist and negative language, culture and practices wherever they occur, in both policy and practice. This builds on the themes we highlighted in our *Suffering in Silence* report last year.

Age UK launched a new campaign on older people's mental health aimed at older people on 4th November 2019 which is challenging common myths around mental health and we have supported this on social media.

We have inputted into the reports on the use of antipsychotics in dementia and provided an interview to Sky on the importance of getting social care sorted out. On World Mental Health Day we had a piece on ITN on older adults' mental health.

Final words

In these days when so much of the news is negative and people seem disposed to think the worst of one another it was a real tonic for me to attend the National Older People's Mental Health and Dementia Awards 2019.This was a wonderfully inspiring affair and the passion and commitment of the nominees and winners was amazing.

This was a reminder that we as old age psychiatrists should never lose sight of the importance and impact of the work we do and that we are amazing at developing innovative services. This is not a bad thought to carry into the New Year.

Update from Professor Alistair Burns

Professor of Old Age Psychiatry

University of Manchester

Although there are many things going on in the health service, in social care and in the country as a whole, the work on Dementia and Older People's Mental Health continues apace.

The Long Term Plan remains an important focus for NHS England / NHS Improvement (now combined at an operational level) and OPMH is a significant part of the mental health component. It is great that when general adult psychiatry is highlighted, older adults get a bespoke mention as well. Dementia and OPMH is a key part of the Ageing Well Theme. This theme has three related components – Urgent Community Response, Enhanced Health in Care Homes and Anticipatory Care.

The Urgent Community Response workstream will, in line with NICE guidelines, respond to the care of people at home with NHS 111 being an important point of contact. There is a two-hour standard for an urgent review in the community with a two-day standard for reablement and a commitment for a single point of access.

In Enhanced Health in Care Homes, the aspiration is to provide enhanced support with better-coordinated care, reablement and rehabilitation. We know that one person in seven over the age of 85 lives in a care home and 80% of people in care homes have dementia. The initiative is to extend the existing projects (known as the Vanguards) from about a quarter, to the whole, of the country. Core components such as a named GP, access to specialist, multi-disciplinary and medicines reviews are essential, as well as out of hours support and, importantly, end of life care.

With Anticipatory Care, the aim is to help people with complex needs stay healthy and functionally able, by making sure that proactive care in people living with complex health and care needs is given to maintain their health and function as long as possible. The development of Primary Care Networks will greatly facilitate this with a bespoke service specification to roll out this proposal.

There is an interactive site to allow people to keep up to date. In the Ageing Well theme, the aspiration is to change the pervading view of older people who are frail from "the frail elderly" to "an older person living with frailty", to change the late crisis presentation to timely identification and intervention, and to change hospital based episodic care to community based person centred with coordinated care. The time scales of these initiatives are that the accelerator sites (these used to be called pilot sites) will be chosen at the end of November 2019 with a national standard of response being delivered by April 2021 and a national framework being implemented by April 2022.

The Old Age Faculty, under the expert guidance of Amanda Thompsell, has produced an excellent report about implementing the Long Term Plan and everyone should read this. It provides a lot of good advice on how we can become involved with our local commissioners and providers to make sure that older people's mental health is fully embedded in plans. The chapter on mental health emphasises the issues of common mental illness in referral to IAPT services, severe mental illness and community care, crisis care and, of course, mental health liaison. There are a number of key service examples where things are being taken forward in a very innovative way.

In terms of other work, the care coordination aspect of the dementia work has recently been highlighted and dementia workers have been included in the Long Term Plan multidisciplinary teams, which will be aligned to the new Primary Care Networks. We continue working with three Sustainability and Transformation Partnerships (STPs): in London, West Yorkshire and Birmingham, to look at how unnecessary admissions from care homes can be avoided. We are at the process of final evaluation of these services which should feed into the work and align with the Long Term Plans. The team in London have demonstrated the positive benefits of integrated teams as have colleagues in Surrey Heath.

Anti-psychotic prescribing in people with dementia remains an area of much interest and the regular measures show that some 9.4% of people with dementia are prescribed an antipsychotic. There is significant variation from 4-16% across Clinical Commissioning Groups (CCGs). We have been tracking this now for 2 years and will allow us to assess longitudinally any changes that are occurring.

The dementia diagnosis rate continues to be a gradual upward trajectory, the latest figure being 68.8% and there have been steady increases now for some time. The ambition of 66.6% (two thirds) was realised four years ago and nationally has been consistently above that level for three years. As one might expect there is still regional variation, which we are paying some attention to. We still offer a dementia support offer to regions who wish some help and support in their diagnosis rate. I see this as an opportunity to engage with and help local services coordinate and collaborate in their work on dementia.

We held a Strategic Clinical Network day at the end of October 2019 focussing on dementia and the energy and enthusiasm in the room was palpable. The commitment across the country to fly the flag for dementia and continue with innovative ideas and proposals is fantastic. There is something unique and special in every region. One example is from the London Clinical Network where an audit of memory clinics has taken place. The results are due to be published in January 2020. Detailed analysis of some of the work in clinics was presented.

As we move from considerations of the dementia diagnosis rate to concentrate on post-diagnostic support, including the quality and timeliness of that diagnosis, waiting times in memory clinics are a key factor.

As always, any comments or suggestions for the newsletter please write to me at alistair.burns@nhs.net.

This month's picture quiz

Who is delivering the Keynote Speech at the Dementia Congress in Doncaster in November 2019?

Answer

Professor Steve Sabat, University of Georgetown.

Older people, toffees and forever blowing bubbles

by

Dr Martin Curtice, Consultant in Old Age Psychiatry

Coventry and Warwickshire Partnership NHS Trust

Introduction

As an avid sports fan I was intrigued when I came across a section on the BBC sports website profiling Premier League football clubs and their charitable work in local communities[1]. Amongst the many short videos, I found two about Everton Football Club ('The Toffees') and West Ham United Football Club ('The Irons'), which specifically described their work with older people. This got me thinking about the juxtaposition of the global multi-billion pound industry of the Premier League and their charitable arms (which are financially independent from the clubs) and how they engage with older people.

This is the first of two articles describing Premier League football clubs and their charitable organisations. This article describes visits I made to Everton FC and West Ham United FC looking at their charitable work with older people.

Everton in the Community (EitC)[2]

EitC was established in 1988 and employs 125 full-time staff and 204 volunteers across the organization (who themselves report improved well-being undertaking such roles). The annual turnover is £4.5 million needing strong and experienced leadership to establish wide-ranging projects. It provides 40 projects overall of which 10 are mental health projects[3]. EitC organizes an annual conference, in partnership with Edge Hill University, to showcase and network their projects. EitC are working towards having the football stadium being recognised as the first Dementia-friendly stadium in England by the Alzheimer's Society by providing awareness training to a range of frontline staff.

In terms of infrastructure EitC has invested heavily in the area close to the football stadium (this area being one of the most socially deprived areas in the country). The buildings are shown below.

I was impressed with all the buildings being in a pristine condition (rarely vandalized). They are recognized as an important part of the local community and are respected as such. These developments, along with a proposed new drop-in mental health facility, represent an £8million investment in the area. EFC helped in the purchase of land but the funding for all the builds was raised by EitC.

The 'Blue Base' is solely for the use older people and runs three programmes Monday-Friday. Over 220 participants are enrolled. The programmes have been developed in partnership with Edge Hill University to co-design and evaluate them (a Masters programme – MSc Sport, Physical Activity and Mental Health – has been specifically developed with EitC[4]). The three projects are:

1. Pass on the Memories

This pioneering programme supports people living with dementia and their carers. It began in 2012 in partnership with Mersey Care NHS Foundation Trust who initially funded it, but it is now fully funded by EitC. Referrals are only from local NHS services. It provides an 8-week programme for people usually over-70 with early onset dementia and their carers (who are provided respite, advice and support).

The aim is to increase well-being by using a range of interventions including sporting reminiscence workshops, custom-made life story memory books, visits to local historical places and sessions involving dancing and singing (there is a separate very popular Friday afternoon Dementia Choir group) and arts and crafts. At the end of the 8 weeks participants are offered signposting, toolkits and education about benefits and other social activities across the city. An important aspect is follow-up questionnaires at 3, 6, 9 and 12 months using scales assessing loneliness, social isolation and lifestyle behaviours demonstrating a positive and sustained impact of the programme.

The programme was so successful it has doubled to four groups each week; the additional two groups providing long-term engagement. This was in response to the questionnaires showing a clear drop-off in well-being at the cessation of the 8-week groups. Carers are welcomed back when their spouses/relatives die as it was recognised this is an important part of the bereavement process.

2. Stand Together

This unique programme was developed in response to local CCGs identifying social isolation over-75s as a major local issue. It was initially CCG funded but is now fully funded from a Premier League charity funding stream. People can self-refer as well as referrals from GP practices and other local organisations. A shuttle service is provided for those with mobility difficulties. Twice weekly sessions provide interactive and bespoke activities to improve social contact, engagement and social welfare knowledge.A befriending service is also part of this programme. Participants are also offered to attend screening programmes for conditions such as abdominal aortic aneurysm, AF and also flu vaccinations.

3. Aged Veterans

This weekly group, funded by the Royal British Legion, is for older people previously in the armed forces or who served their National Service. It aims to improve social isolation whilst also looking at other multiple social issues such as housing (the ‘Shelter’ charity also being involved).

In terms of the future, the next main £1 million fundraising project is for a purpose built mental health facility within the next couple of years called the ‘People’s Place’[5] for all ages with mental health issues. This is a proactive response addressing local mental health and suicide rate issues. The charity has been promised to be gifted land to develop where the current stadium is when a new stadium is built elsewhere (the charity is planning then for a projected annual turnover of around £10million).

West Ham United Foundation[6]

In 2015, having recognised the public health priority and need in the local area, West Ham United Foundation and Friends of the Elderly[7] developed a partnership implementing a social inclusion programme called ‘Any Old Irons’ (AOI), supported by the Premier League and the Professional Footballers’ Association[8]. By harnessing the power of football and leveraging the unique connection the club had with its community, the Foundation felt it was well positioned to access the community in a way that few other third-sector organisations could. This initiative aimed to address loneliness and social isolation in people over-65.

The five-week programme comprises various social events including stadium tours, digital learning and story sharing, meeting current West Ham United players (both male and female) and ex-players. Participants also work together using new-found I.T. skills to create a newsletter circulated to members and partners. People can self-refer and the club advertises locally and in the match day programme and word of mouth has helped the group to expand. The programme includes over 200 people across East London and Essex. After the initial five-week programme, all participants are welcomed to monthly meetings which includes events organised by AOI volunteers. It was to one of these meetings in East Ham that I was invited.

When I arrived there was a large group of people (readily identifiable in their claret T-shirts) waiting outside on the street as the pub which was the usual venue was not open as planned. The group rapidly repaired to another nearby pub for their meeting (quickly securing a large area with a few customers being cornered whilst still eating their lunch!). I was warmly greeted by the group making a brief talk about why I was there which included the mistake of owning up to my own football team allegiance! There was a wonderful, vibrant and noisy atmosphere. Everyone seemed to know everyone. My overriding memory will be the joyful camaraderie that suffused the group. Many wore T-shirts and pin badges designed by the group. Everyone I spoke with spoke highly of the group and the social stimulus and enjoyment it gave them. One lady had great joy in telling me she wasn't wearing her AOI T-shirt as she had forgotten to 'iron it'!

I spoke with people who had attended from the inaugural programme. Following the end of this first programme a few people continued to meet up in a working men's club and then a pie and mash café. From that a monthly meeting was developed which has successfully grown to on average 40-50 attendees each month. The group, being avid football fans, particularly like it when former players attend and speak to the group. The group has become so popular it has now formed its own committee and had recently had its first AGM (people join for £10 annual membership).

I spoke with Don, Chairman of the AOI Committee, who leads on planning and organising activities. He told me about the immense benefit he had from the programme and how his Chairman role had 'taken over' his life in a positive way, and how it had given him 'purpose' especially after a period when he had been very unwell which affected his sociability. He spoke of his immense pride at helping the group evolve from the initial programme which he also attended. As is usual, the group finished the meeting with a rousing rendition of the club anthem 'I'm Forever Blowing Bubbles'.

The second article in the next issue will look at other Premier League clubs and their varied work with older people and how they use social media.

References

1. Leicester City's young and old tackle loneliness together (video)
2. Everton FC in the Community
3. Everton FC Health and Wellbeing Projects
4. Edge Hill University - MSc in Sport, Physical Activity and Mental Health
5. The People's Place | A Mental Health Facility by Everton (video)
6. West Ham United - Moore Family Foundation news
7. Friends of the Elderly - Football Friends
8. How West Ham are bringing people together (video)

Acknowledgements

My grateful thanks to:

Mr Michael Salla (Director of Health and Sport) and Mr Lee Johnson (Older Adult Project Coordinator) from Everton in the Community.

Mrs Maria Abraham (Health Manager) from the West Ham United Foundation & Mr Don Adams from Any Old Irons.

Conflict of interest

The author is a dyed in the wool Evertonian (since aged 4).

Dedication

This article is dedicated to the memory of Dr Chris Vassilas *FRCPsych,* a former Consultant in old age psychiatry colleague and friend.

Palliative Care in Dementia

by

Dr Victoria Jones, Core Psychiatry Trainee, Greater Manchester

Bridget Willis, Mental Health Practitioner, Palliative Care in Dementia Liaison Service, Stockport

Alzheimer's disease and dementia were the leading cause of death in England and Wales in 2018[1], and the number of people living with dementia in the UK is projected to be over one million by 2025[2]. The challenges of providing palliative care (PC) for people living with dementia have been acknowledged for years[3], yet there is still a gap between care provided by mental health and by PC services to people living with dementia. As dementia progresses and symptoms develop, it can be difficult to assess what the needs of people living with dementia are, both from a psychiatric and a medical point of view. The NHS provides some useful guidance regarding care plans, advance decision-making and advance statements[4], but how feasible is it to apply this knowledge to practical everyday care? The Alzheimer's Society website[5] also provides information and guidance on managing end of life care in dementia, and highlights the different groups that may be involved – from GPs to carers, social workers to mental health staff, PC professionals to care homes. All parties can make a valid and important contribution towards planning for end of life; but it can also be quite disparate, and communication between different parties can be variable.

A recent systematic review highlights ongoing challenges around provision of PC in dementia[6]. Commonly reported issues included lack of training around providing PC in dementia, difficulties in assessing and managing symptoms, lack of care co-ordination across different specialities and care providers, and lack of care planning[6]. Guidelines are available to aid health professionals caring for people with dementia who are reaching end of life; for example the Palliative Care Guidelines in Dementia (2nd Edition) from NHS North West Coast Strategic Clinical Networks[7] are freely available online. The report contains advice and guidance on a multitude of topics, which include supporting carers of people with dementia, and insight on caring for people with dementia in final days of life. However, as many of us know, it is one thing to have guidelines, and quite another to put them in to practice.

A pioneering 'Palliative Care in Dementia Liaison Service' (PCiDLS) has been running in Stockport since 2015 with the aim of bridging the gap between guidelines and on-the-ground care. The service is nurse-led and works with the local PC team to provide collaborative end of life services to people living with dementia. Bridget Willis, a Mental Health Practitioner, currently leads PCiDLS and works with patients and their carers in the community, hospices and general hospitals. Bridget tries to challenge some of the myths around signs and symptoms in dementia, as outlined below:

'*People with dementia are at risk of poor symptom management at the end of life as 'dementia attribution' limits the wider holistic assessment of needs. Too frequently I hear a person is 'agitated' due to their dementia when they are clearly in pain. Terminal restlessness - a delirium which can occur as a person is dying - is also poorly managed in people with dementia. This is again due to this misconception that dementia causes agitation.'*

PCiDLS also works with Macmillan nurses to care for patients with more complex issues, for example having a dual diagnosis of cancer and dementia. This collaborative, shared-care approach helps patients and their families get the level of support they need. Furthermore, PCiDLS does a lot of work with families to provide education about progression of dementia, and how simple interventions like a hand massage or reading to a person can help bring comfort and increase wellbeing. PCiDLS also works to raise awareness of advanced care planning in dementia, and to have conversations with patients and families around planning for the future. According to Bridget, these conversations are '*crucial to both support our patients to feel in control of their health and wellbeing, and so we [health professionals] know their wishes if there comes a time they are no longer able to advocate for themselves.'* Stockport services have developed an advanced care planning document as a tool to guide these conversations, which are being offered from time of diagnosis.

In addition to advance care planning and education, PCiDLS aims to try and reduce, where appropriate, acute admissions to hospital for treatment and intervention when a person is reaching the end of their life. Bridget works with other professionals to understand prognostic indicators for dementia, and to advocate for best supportive care at home. Training around this is run in Stockport for professionals, and sessions are run with the support of people living with dementia therefore making it a more interesting, relevant learning experience. As well as supporting professionals, PCiDLS also spends a lot of time supporting carers. Bridget describes how '*many carers say they are grieving over time while the person is alive, because of the changes and losses the dementia causes.'* PCiDLS has set up walking groups for bereaved carers to facilitate ongoing support once their loved one has passed away.

PCiDLS challenges the misconception that the process of death and dying is exclusively within the remit of physical health specialists. Bridget's work in PCiDLS provides a shining example of how collaboration, communication, and a focus on providing the best life, and death, for service users, can help to make the journey through dementia the most positive experience possible. It is our duty as doctors and associated health professionals to get this right both for our patients, and for their loved ones.

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NHS Long term plan priorities for ageing well: How can old age psychiatrists contribute?

by

Dr Mohan Bhatt, Consultant Old Age Psychiatrist

Associate Medical Director, North East London Foundation Trust (NELFT)

Executive Member, Faculty of Old Age Psychiatry

Introduction

Earlier this year in January the Long-Term Plan[1] for NHS was published which sets out a vision for health services in England. It proposes setting up of integrated care systems in England by April 2021 to deliver the health services. These systems will be responsible for the local delivery of service transformation as specified in the LTP and will consist of collaborations between commissioning, provider and local authority partners. The LTP sets out clear goals for the development of both mental health and community health services, supported by significant transformation and baseline-uplift funding. There are multiple areas specified within the LTP that have direct relevance to the mental health of older people. Old-age psychiatry input will be fundamental in realising these goals.

What are the NHS LTP priorities for older person's health?

NHS Long term plan in its various chapters describes its health priorities with each chapter focussing on a particular area of health service.

Chapter 1 of the LTP (Ageing Well), promotes the development of community multidisciplinary teams to work with the older and frail population. It has a particular focus on:

- anticipatory care and urgent care for complex patients at risk of unwarranted health outcomes, and on helping them stay healthy, able and functioning, using collaborative models of care in the community that are centred around primary-care networks.
- enhancing healthcare in care homes where many older residents have mental health needs

Chapter 3 of the LTP outlines the mental health ambitions for the service and the mental health of older adults is specified in the LTP Mental Health

Implementation Plan as a ‘silver thread’ across all these ambitions described in this chapter.

What are the Opportunities and Risks?

LTP in its Chapter 1 discusses the following ambitions for aging well (See table below)

- Urgent community response: to meet the national standards’ two-hour response time for urgent care and a two-day response time for access to intermediate care/reablement
- Enhancing Health in Care Homes (EHCH)
- Expanded community MDTs delivering ‘anticipatory care’
- Increased recognition and support for carers
- Improved care for those who are frail
- Improved care for dementia and delirium
- Reduced inappropriate stays in hospital

LTP in its Chapter 3 discusses the following ambitions for improving the mental health services. (see table below)

- Development of IAPT services
- Development of Community services for Serious mental illness
- Mental health crisis
- Mental health liaison services.

Mental health services for older adults are currently provided in a heterogenous way across multiple service areas. As a result, when local and regional transformation is undertaken as part of the LTP implementation, the risks of overlooking the specific mental health needs of older adults are greatly increased.

The current Enhanced care in care homes framework does not include mental health expertise as part of its core multidisciplinary team. Hence future planning for EHCH services includes the provision of older peoples' mental health input as a central part of such services.

There is a growing demand for older-people’s mental health services which is not matched by recruitment and retention trends. Workforce planning must therefore be a key factor in transformation plans. There must be a move away from siloed working of old-age psychiatrists to integrated working across primary care, community health and hospital inpatient settings.

How can old age psychiatrists help?

Old-age psychiatrists will be central to the delivery of truly integrated community care for older people with mental health problems and realising the LTP ambitions. Their particular expertise is in the synthesis and coordination of complex care in older people with complex mental illness. They are clinical leaders with advanced skills in communication, education of others, legislative issues and understanding complex health and social care systems. They are experienced in working in a variety of settings in collaboration with health and social-care staff with a wide range of knowledge and expertise. Hence:

- Old age psychiatrists should be part of discussions in developing the ICS/STP (integrated care systems/sustainability and transformation partnerships) five-year plans for delivering the LTP ambitions and ensure that it includes explicit reference to how systems will support people with dementia and other mental health disorders in older age.
- Old-age psychiatrist representation will be key at newly developing primary-care networks (PCN) level. Systems must be aligned to ensure that older people's mental health is recognised within general mental health transformation (Chapter 3) and is also specified within community transformation through redesign of Ageing Well, particularly around ‘anticipatory care’ (Chapter 1).
- Old age Psychiatrists should take lead in research involving key areas in older people’s mental health to better inform and drive service design and practice in lines with the priorities of LTP. These should also include frailty in older people with mental illness and the efficacy of different models of care in terms of positive outcomes for older people with mental illness and their caregivers. They should also lead research to clarify which particular models of shared care/joint management with older people's mental health services and their health, social and voluntary sector colleagues work best across different settings in the community and hospital.

Where can the old age psychiatrist find guidance about this?

The Faculty of Old Age Psychiatry published a report[2] last month on how old age psychiatrists would be a vital resource in the implementation of the LTP ambitions. This report incorporates views from older people, service users, carers and a wide range of health and social care professionals and provides insight into:

- the essential role played by old age psychiatrists, and the Older People’s Mental Health (OPMH) services to whom they provide leadership, in delivering high quality outcomes for the health and wellbeing of the UK’s ageing population;

- the centrality of this to the Ageing Well agenda; and
- how best to support decision-makers responsible for implementing the NHS LTP as it affects older people

This report also summarises good practice examples of collaboration and innovations involving old age psychiatrists across different health and social care settings, and especially in care homes.

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Life after the NHS

by

Susan Mary Benbow

Director of Older Mind Matters Ltd and Visiting Professor of Mental Health and Ageing, University of Chester

As a member of the NHS Pension Scheme before 6 March 1995, I was one of the privileged ones. I qualified for Mental Health Officer (MHO) status and took early retirement from my NHS consultant post in 2009 (NHS Pensions, 2009). That's over 10 years ago now!

When the state pension was introduced in the UK in 1948 (Bozio, Crawford, & Tetlow, 2010), at 65 people were 'old'. Girls born in 1901 were only expected to live to around age 49 (45 for boys) (Hicks & Allen, 1999), but times have changed and by 1999 the life expectancy of newly born girls was 80 years of age (75 for boys). In the 21st century, people are living much longer in the stage of life that would previously have been 'post-retirement'. Age 65 is no longer 'old' (or at least I hope not!) and many jobs rely on thinking and knowledge rather than physical strength. People sometimes become 'serial retirees', retiring from one job and moving on to another, perhaps several times (Hansen, 2015). Others are 'unretired': they retire but then go back to work, often part-time and maybe in a somewhat different role (Kanabar, 2012).

The personal context

I didn't plan to take early retirement. I expected to go on banging my head against the brick wall of top-down NHS changes and writing angry letters after management meetings until the bitter end. Suddenly, and maybe impulsively, I decided I had had enough, and gave notice of my intention to retire. One curious consequence was that people who I thought had found me a thorn in their sides seemed genuinely concerned and talked about how much they appreciated me and would I change my mind? (It would be good if we told people how much we appreciate them before they decide to move on, but I guess we get bogged down in the day to day demands of work.)

Part of the context for the decision to retire from my NHS post, was that I had registered for a PhD by published work, so I had academic stimulation lined up and was engaged in other work with colleagues at the University involved. I called my transition out of NHS employment a lifestyle redesign (which people understood in a variety of ways and many seemed to find amusing). Anyway, I set up a limited company, and, immediately after leaving the NHS, focused on carrying out university work and concentrating on the PhD. In retrospect, I realise that this gave me time to think through what I wanted to do next, and also gave chance for people to approach me and ask me to do work that I had not anticipated. Planning ahead might have been a better way to proceed, but, as a systemic therapist, I am committed to things evolving and this worked for me.

I was surprised after ceasing my NHS role by a powerful feeling of burden lifted. I hadn't realized that I was carrying a burden, until it fell away, and I could hear the birds sing, go for a walk, and learn about things that I hadn't the time for as a full-time NHS consultant.

What next?

I found I missed the clinical team I had worked with. I probably missed the patients even more, particularly the privilege of hearing their stories and being alongside them and their families during their struggles with illness. Having trained as a systemic psychotherapist, I decided to set up in independent practice. (If you want to do something similar, I recommend that you plan it before retiring!) Getting this off the ground was both tricky and lengthy: where to base my practice, how to market it, how to deal with the money? I had several false starts, but eventually joined the team at a Psychotherapy Centre in South Manchester where I am now based one and a half days a week. Be warned, it takes some time to build up a practice, but I had been working in the West Midlands and I wonder if it helps to practise where your name is already known.

Alongside this I carried on with some clinical endeavours, becoming involved in a primary care memory clinic (which I love) and carrying out second opinions for the Isle of Man, which has its own Mental Health Act (living near Manchester airport it seemed a logical thing to do). Getting access to appraisals and revalidation was stressful and relatively expensive, but necessary, given the breadth of what I do and the need for flexibility in my portfolio practice.

My work now falls into six broad areas: systemic psychotherapy, clinical practice, research/ service improvement, teaching/ training, safeguarding, and consultancy (a catch-all for anything that doesn't fit under the previous headings).

Reflections

I have enjoyed the challenges of setting up a business and developing new interests and value opportunities to continue to learn and develop skills. In connection with my work portfolio, I've undertaken training in emotionally focused couple therapy, systemic supervision (a diploma course), and non-violent resistance. (I think I may be addicted to learning and firmly believe that learning contributes to well-being as we grow older.) In addition, I completed couch to 5k and now regularly take part in parkruns (strongly recommended). I windsurf at every available opportunity, go canal boating and have learned to identify dragonflies. (Being near or on water is essential to my mental health – you might like to try it.)

Some years ago I wrote a piece called Jam on the outside (Benbow, 2003) at a time that I was thinking about burnout, stress and workload in old age psychiatry and drawing on Handy's inverted doughnut model (Handy, 1994) – not a new concept but still useful (see Figure). For me life after the NHS offers more jam and less stodge.

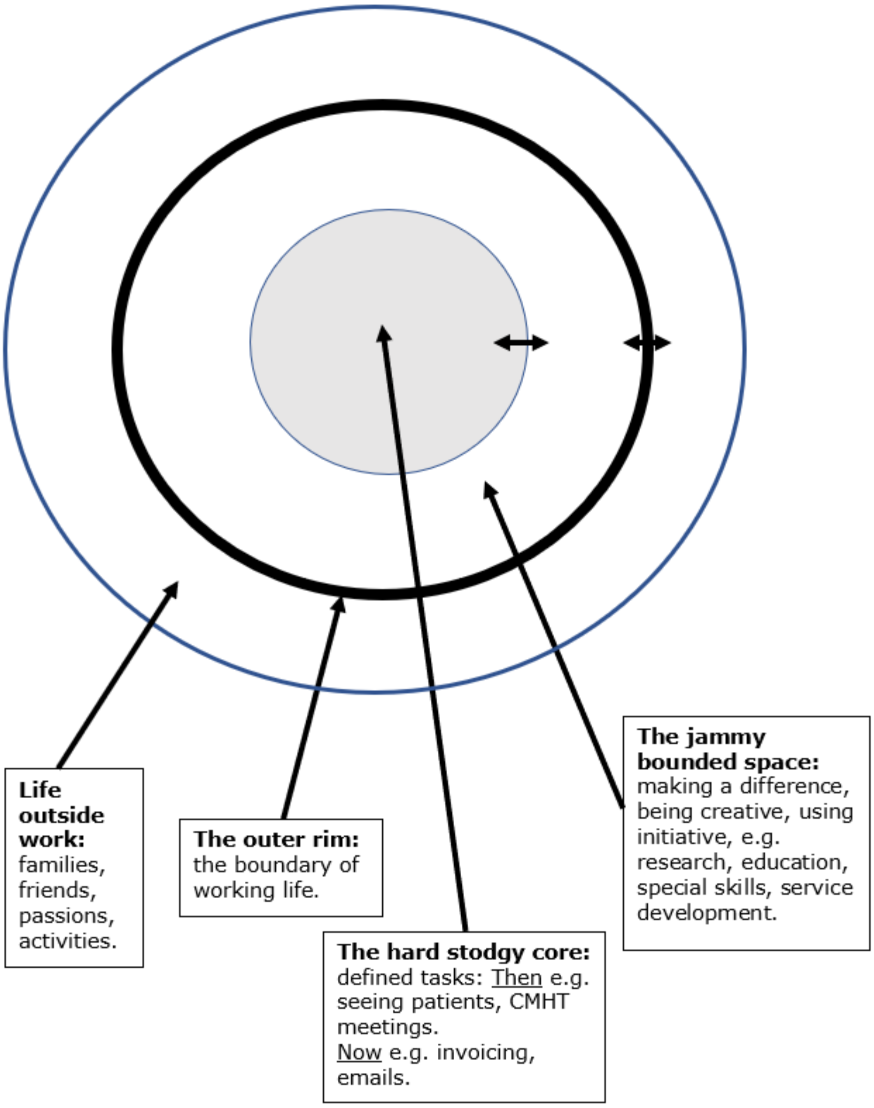

Figure: the inverted doughnut (from Handy, 1994)

This conceptual doughnut has a hard central core of dough (duty - the things we are required to do in our jobs) and a bounded space (potential - the work activities that make a difference) on the outside. An additional outer layer contains the things we do outside our jobs that influence both space and core. The boundaries between the layers are leaky ↔ and somehow we have to achieve a balance. 'A sensible job is a balanced doughnut'.

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Use of force in Mental Health Units: Impact of the new legislation?

by

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As parliament and the country remains preoccupied with a number of political developments, a little-known important development has sneaked through under the radar rather stealthily and is likely to have a huge impact on psychiatric patients in general and on old age psychiatric services in particular. A new mental health legislation has received royal assent becoming law. This legislation requires all mental health units to record the use of force within mental health settings. The push to reduce the use of patient restraint in mental health context has always been high on the government and CQC agenda, but there is now legislation in place, which specifically addresses this. The *Mental Health Units (Use of Force) Act 2018* was given Royal Assent on 1 November 2018.

The Act's provisions require mental health inpatient units to be compliant with new requirements around use of force policies, training and data collection. Whilst most mental health providers are likely to be complying with many of these requirements already, there are steps which organisations should now take to ensure they are compliant with the Act.

Here I look into more detail at this new legislation and its practical impact on organizations and services.

Background

The *Mental Health Units (Use of Force) Act 2018* started as a bill put forward by an MP following the death of one of his constituents after being restrained on a mental health ward by 11 police officers.

An inquest into the death found that the use of restraint was excessive and disproportionate, and the patient's family subsequently campaigned to bring in new laws about use of force, culminating in this new piece of legislation. This legislation is seen as the legacy to that patient and started its course as Seni's law.

What are the requirements of the Act?

The Act places new statutory obligations on inpatient mental health units - including NHS hospitals and independent sector units, which may provide NHS-funded services.

'Responsible person'	Organisations which run mental health units have to appoint a 'responsible person' for the purposes of the Act, to increase accountability in relation to use of force. Must be of an appropriate level of seniority and will have responsibility for ensuring compliance with the Act's requirements. Whilst they will be able to delegate any of their functions to another person the 'responsible person' will retain ultimate responsibility.
Policy	All organisations running mental health units must publish (and keep under review) a policy on the use of force by its staff. This policy has to set out what steps are being taken to reduce the use of force by mental health unit staff. There is a provision requiring the Secretary of State for Health and Social Care to publish a guidance to accompany the Act.
Rights information	As soon as reasonably practicable after admission, each patient must be given information about their rights in relation to use of force by staff.
Training	Mental health unit staff must be provided with training on appropriate use of force. The training should cover techniques for avoiding/reducing use of force, risks associated with use of force, the impact of any use of force on a patient's mental and physical health and how to involve patients in the planning, development and delivery of their care.
Record-keeping	There must be a record kept (for 3 years). Any use of force by staff which is more than 'negligible' (with the meaning of 'negligible' to be further defined in the accompanying guidance) must be recorded.

	Must include a detailed list of information in each case, including the reason for use of force, the date/place/duration, whether it formed part of the patient's care plan, the outcome of the use of force, efforts made to avoid it, whether any notification regarding use of force was sent to the person to be notified under the care plan, plus the patient's 'relevant characteristics' such as their sex, age, race, religion/beliefs and sexual orientation.
Incident investigation	If a patient in a mental health unit dies or suffers a serious injury in connection with use of force, regard must be had to guidance relating to the investigation of such incidents. In practice, this will mean complying with the existing national Serious Incident Frameworks plus CQC reporting requirements, which should already be happening regardless of the new Act.
Statistics	The information which mental health units are required to collect about use of force (see above) must be published each year in statistical form.
Annual report	The Secretary of State for Health and Social Care must review any 'Prevention of Future Deaths' reports relating to use of restraint which have been produced by coroners in the previous year He may review any other findings made in such cases - e.g. by the CQC or as part of serious incident investigations. Conclusions from these reviews must be published in the form of an annual report.
Police and body cameras	If a police officer attends a mental health unit on duty and is involved in assisting staff at the unit, the officer must wear a body camera and keep it operating at all times when reasonably practicable unless there are special circumstances at the time that justify not doing so.

What is the likely practical impact?

Failure to comply with its provisions could amount to a breach of the provider organisation's statutory obligations and, as such, could potentially be subject to governance mechanisms.

In practice, however, mental health providers are likely to be meeting the majority of the Act's requirements already because they are in line with existing

CQC requirements around restrictive practices in mental health. As a result, organisations that are CQC-compliant are likely to find that they are also already broadly compliant with the new Act, but provisions such as the responsible person requirement will be new. Further, the existence of new legislation focusing specifically on this issue is likely to raise public and patient awareness and increase scrutiny.

The main clinical issue that is likely to affect services result from the added burden or reporting lines created from the governance requirements.

What about the impact for Old Age Services?

In old age services in particular, there is a need to clarify the definition of ‘restrictive interventions’ as they are likely to directly impact dementia assessment units where challenging behaviours are routinely encountered during administration of personal care while maintaining the welfare, dignity and care of their hospitalized patients. The concern is the resulting burden of reporting and its impact on the much-needed time to care.

For example, it is not unreasonable to expect a person on a dementia continuing care unit to have 10 ‘reportable’ episodes of restraint per day or more. These arise often during the provision of personal care interventions to patients with aggressive and challenging behaviours; these being the reasons for admission to such units. Similarly, quite a few patients need frequent re-direction away from locked doors as they exhibit wandering behaviours in their dementia. Given the average time to record an episode on Datix is around 12 minutes (for an IT competent practitioner), one patient would add a recording burden of two hours. A typical continuing care unit would have 20 patients; giving a recording burden of 40 hours per day- equivalent to 5 whole time equivalent staff members. Such units would ordinarily have 5 staff members per shift, leading to an approximate doubling of the resources needed to meet the requirements of this legislation. With the existing staffing gaps and recruitment difficulties as it exists already, it is easy to see the levels of challenges this additional requirement poses.

How can psychiatrists influence the recording options for Old Age Services?

Influence by Old Age Psychiatrists has to be at national and local levels.

Nationally, we have to be actively involved in shaping policy, contribute to high level discussions and shape the options for implementation. Perhaps we need to debate the following options further.

One option would be to differentiate between ‘care planned’ and ‘unplanned’ restraint and only report ‘unplanned’ restraint. This would reduce the number of reports and would avoid duplication; ‘care planned’ restraint including the reasons for this would be in the in-patient care records and could be audited through other means. But this would mean that providers would not be regularly reporting on ‘care planned’ restraint although they may have local arrangements in place.

Another option would be to reduce the reporting requirement for ‘care planned’ restraint – for example for each patient needing this intervention complete one datix per inpatient episode or have a ‘once daily’ recording system. This would reduce the number of reports and would enable providers to report on ‘care planned’ restraint and would allow comparisons between providers. However, if providers wanted more detail on ‘care planned’ restraint, they would need to have a local system to collect this information.

A third option is to look at the definition of ‘negligible’ use of force for ‘care planned’ restraint. This could reduce the number of reports depending upon definition and would enable providers to report on ‘care planned’ restraint, allowing comparisons between providers. However, this could impact on the reporting of ‘unplanned’ restraint also and there is a need for clearly defining the term ‘negligible’.

At a local level, Old Age Psychiatrists have to be active in raising awareness within the local employing trust and canvass support regionally to make the issue be known wider. They have to work closer together with their nursing colleagues and their service managers to influence the development of local policies, seeking to minimize the burden of recording and governance without compromising the requirements of the Act. They need to be a part of local implementation committees and influence the implementation of local policies.

It is important that care professionals (especially nursing staff) are fully involved in ‘operationalising’ the work. The CQC, the Royal Colleges (including the Royal College of Nursing) and the Department of Health need to work together. Such twin pronged actions are likely to yield results that will safeguard and protect valuable clinical time that is needed to provide high quality clinical care for our patients.

Role of MELISSA and ERIIC: Raising delirium awareness in the North East of England

by

Dr Mani Santhana Krishnan, Jill Cassells, Professor Namita Kumar

Health Education England North East

Introduction

Delirium is often under recognised increasing the risk of mortality and morbidity. We found that Awareness, Knowledge and Skills are key components in raising the profile of Delirium. Community and care home settings are important places to provide training where the staff may not have the capacity to access training.

Method

As a region we proposed to acquire a training bus to travel around the North East and North Cumbria delivering training and promoting health education in hard to reach areas and hard to reach professions. The mobile facility has simulation equipment on board, and Europe's, and the UK's, first Brainarium; an inflatable educational resource, supporting Delirium education. We called the brainarium ERIIC (Educational Reource Inflatable Informative Cerebrum)

Launched in January 2019, MELISSA (Mobile Education Learning Improving Simulation and (patient) Safety Activities) has travelled across the patch showcasing the facility and engaging with both NHS and non-NHS workforce. The remit is to provide equitable access to training across all healthcare professions, including working with charitable sector, education providers and private sector healthcare providers.

Results

Since launch, to 1 July 2019, we have supported various conferences, health promotions, careers events, public awareness campaigns and training sessions.

We have had over 2000 visitors on board, and trained 450 healthcare staff, across NHS and private sector care homes, on a variety of topics, including catherization, Sepsis, Trachaeotomy and NEWS2.

ERIIC has been instrumental in raising awareness of Delirium and also we have delivered delirium education using our #icanpreventdelirium resources.

Conclusion

Mobile educational environment has made significant impact in reaching out to remote areas to deliver training. We are hoping to increase the resources available for further training.

European Association of Old Age Psychiatry Conference

by

Dr Amanda Thompsell

Chair, Faculty of Old Age Psychiatry, Royal College of Psychiatrists

Many of you will be aware that as members of the Faculty of Old Age Psychiatry you are also members of the European Association of Geriatrics Psychiatry (EAGP). One exciting development in this relationship has been the first conference by the EAGP and the Faculty. This took place in October in Nottingham and was aimed at Consultant old age psychiatrists with the idea that the small numbers would mean they could share their wide experiences and learn from each other.

There was a particularly varied and interesting programme put together in a workshop format with a wide range of speakers and attendees from Continental Europe and the UK. Having Senior Clinicians in the room meant the questions posed to the speakers were challenging and exhaustive.

The format was brilliant for illuminating the differences and similarities in practice in different countries, challenging assumptions that we might not even realise that we held. For example, one European speaker quite rightly challenged our use of words for example "treatment resistant depression v depression that is resistant to treatment." Various presentations were also made about different practices in Old Age Psychiatry around Europe (for instance a service focusing on the importance of sleep in recovery). A presentation about the similarity between frailty and depression which cannot be totally explained by symptom overlap made me reflect on the importance in articulating this association.

Perhaps the most interesting element was when we discussed case histories obtaining different insights on approaches to diagnosis. This again revealed different insights as to other possibilities to approach an issue, which made me reflect on my practice perhaps I am unconsciously missing cases of Lewy Body Dementia.

But this was not all about work. It was a chance to get to know our Colleagues in Europe socially and visit historic places in Nottingham including the oldest pub!

There will definitely be further such conferences in the future and the next one is likely to be in 2021 in continental Europe. More information on the EAGP and trainee events can be found on their website.

I came away from this event feeling refreshed and inspired with new knowledge that I have been able to use to the benefit of my patients .It also made me reflect that whatever happens with Brexit there is a role for us to work collaboratively with our European Old Age Psychiatry colleagues.

Annual Essay Competition

The title for this year's essay competition is:

'Through the Ages – History's Role in Today's Old Age Psychiatry'

Topics could include: how dementia has been portrayed over the course of history; a study of the origins of old age psychiatry; or something entirely different! We will accept all forms of writing, including essays, poetry, and short stories. We welcome submissions from Old Age Faculty members as well as core trainees, consultants and medical students.

We have got a fantastic panel of judges lined up, and the winner will be announced at the annual Old Age Faculty Conference in March 2020.

The winning entry, as well as runners-up, will be published in the newsletter in due course.

Entries should be no more than 1000 words long and should be submitted by no later than **1700 on 31st January 2020** to essaycompetition2020@gmail.com.

Please include your name, address and e-mail with your entries, and if you have any questions don't hesitate to get in touch using the above e-mail address. We can't wait to read your submissions!

When I was at Brain Camp…

by

Dr Anitha Howard

Consultant Psychiatrist, Bensham Hospitial, Gateshead

When I first heard of Brain Camp, I was intrigued as to how this was relevant to psychiatry. Brain Camp is part of the RCPsych Neuroscience project – a project looking at integrating neuroscience and psychiatry. Brain Camp helps trainers in teaching psychiatry to the trainees today so that they are prepared to deal with future changes in technology and neurosciences for example discussing genetics to patients.

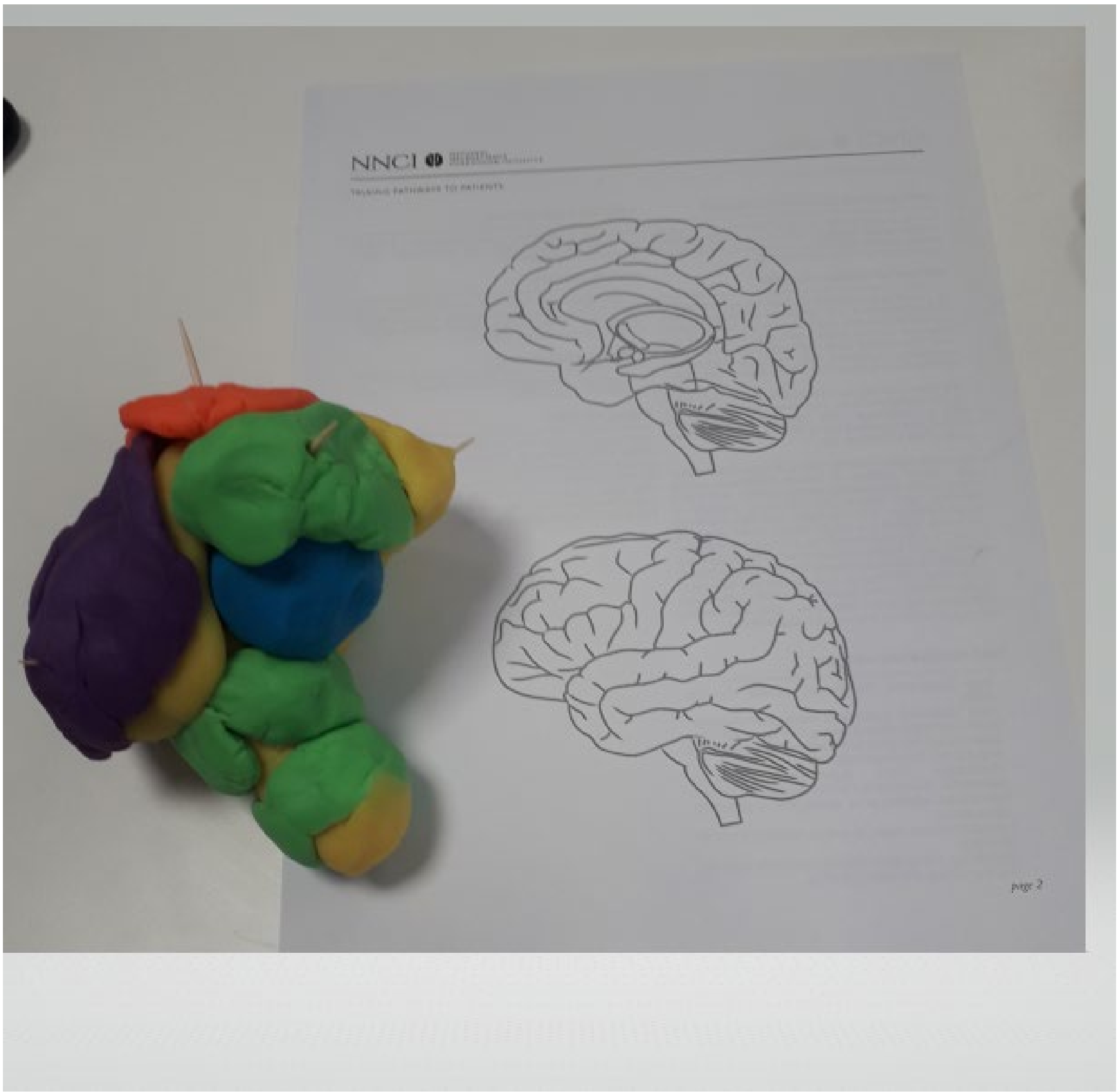
So when Brain Camp arrived in Leeds this September, I signed up to refresh my basic knowledge of neurosciences and also learn how to use this knowledge to improve training for core trainees as well as patients and their families.

The programme started off with a striking, visual 3D representation of white matter in the brain – an almost perfect fusion of technology and biology highlighting the importance of teaching neurosciences to our trainees. The session on the role of inflammation in the blood brain barrier in dementia was particularly interesting to me as old age psychiatrist; as was the talk on how genetics can explain why people respond to differently to medication and its side-effects.

The afternoon was an interactive session on how to use neuroscience to talk to patients about their diagnosis and medication. The techniques described in a short video shown at Brain Camp, taken from the National Neuroscience Curriculum Initiative, in discussing a diagnosis of borderline personality disorder can be translated in discussing common diagnoses in old age psychiatry.

The highlight of the day was trying to build the structure of the brain with just play-doh following instructions on a video.

I would recommend attending Brain Camp for anyone interested in updating their knowledge in neurosciences and learning how advances in neurosciences today could change our practice in the future.



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Upcoming event: Faculty of Old Age Psychiatry Annual Scientific Meeting

Wednesday 18 to Friday 20 March 2020

Congress Centre, London, UK

The faculty conference has been condensed to 18 and 19 March 2020 with a dedicated trainee conference on 20 March 2020.

All the days are packed with talks and masterclasses on wide range of topics. There will be a mix of speaker presentations and workshops with over 13 workshop/master-class sessions spread over two days.

Presentations include the keynote address by Prof Wendy Burn, President of the College and Prof Alistair Burns, National Clinical Director. Other interesting presentations include Trauma Informed Care and Update on New Liberty Protection Safeguards.

Workshops include Genetic Testing in Dementia, Data in Mental Health and update on Physical health assessment and ECG

On Wednesday 18th March 2020 we are delighted to have sessions from 3 international speakers from the EAGP faculty presenting on affective disorders in older adults

We will also be launching our faculty paper on Frailty best practice and new position paper on Delirium.

The National Old Age Psychiatry Trainees' Conference will be on Friday 20th March 2020. Presentations include improving the world of people with dementia through education, the nocturnal brain in older adults, integrated care for older people with alcohol use, update on Lewy body dementias, opportunities for private work, presenting to a tribunal in a breeze, old age psychiatry meets neuroscience, and football & dementia, all of which are relevant and important to trainees.

Full program is yet to be finalised but will be available on the website soon.

We look forward to seeing our faculty members in London. It would be a great opportunity to update and network.

#OAPsych2020

Integration insights

by

Dr Kapila Sachdev, Consultant Old Age Psychiatrist, East London Foundation Trust, Faculty of Old Age Psychiatrists, Elected Member

This time the article that I found interesting was "Health and wellbeing boards and integrated care systems" written by Richard Humphries[1].

What are Health and Wellbeing Boards?

Health and wellbeing boards (HWBs) were established under the health and social care act 2012[2]. The main role of the local health and wellbeing boards was to act as a forum in which key leaders from the local health and care work together to improve the health and wellbeing of their local population. They are a formal committee of the local authority although they had very limited formal powers.

Role of HWBs so far

Planning guidance on Sustainability and Transformation Plans (STPs) in 2015[3] considered it important for the success of STPs that there was active engagement with partners including the local government through HWBs. There has been little evidence that HWBs in most places have had much influence on the development of STPs. The CQC carried out a review of 20 local health and social care systems and found that there was variation in effectiveness of HWBs for producing change and it depended on the maturity of the HWBs.

Current progress

Over a period of time it has been found that HWBs are playing a stronger role in the emerging integrated care systems (ICSs) as compared to before. There has been a lot of joint learning and NHS has been able to draw on experience of local authorities experience in public engagement and benefits of working with elected members on working on controversial issues such as government reconfiguration.

The NHS long term plan[4] has created a sense of shared purpose because there are shared goals such as reducing health inequalities, prevention and improving population health.

Improved outcomes – what can help?

Strong leadership: A leadership style which is open, inclusive and engaging which includes understanding each other's challenges and respecting the differences and seeking ways to manage these differences. The examples include HWBs of Warwickshire and Coventry councils, West Yorkshire and Harrogate.

Governance is work in progress and there have been a number of challenges experienced by all the STPs especially when the ICS have a number of HWBs and NHS bodies.

Future

HWBs are more relevant than ever and their involvement in local ICSs is seen as really important. There has been a discussion of empowering the HWBs as a way of them making the ICSs accountable.

There has been suggestion of proposals for legislative change to improve barriers to collaboration

Learning from HWBs which have been involved in ICSs will help them to find ways of working together more effectively.

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Cochrane Corner

by

Jenny McCleery

Consultant Psychiatrist, Oxford Health NHS Foundation Trust

Joint Coordinating Editor, Cochrane Dementia and Cognitive Improvement Group

One of the questions I am most asked by patients to whom I have given a diagnosis of mild dementia is “What can *I* do?” At the mild stage of the illness, cognitive problems often dominate and, as we know, available pharmacological interventions have only very modest effects on cognitive decline. What about non-pharmacological interventions which target cognition? Might I advise my patients that they could help to improve or maintain cognition in the mild-to-moderate stages of dementia?

In the introduction to their review on *Cognitive training for people with mild to moderate dementia*, Bahar-Fuchs and colleagues describe cognition-oriented treatments (COTs) as a group of non-pharmacological interventions which aim to improve or maintain cognitive processes or to address the impact of impaired cognition on functional ability in daily life. They consider this group to include cognitive training, cognitive stimulation and cognitive rehabilitation, acknowledging that there can be some overlap between these categories.

Cognitive training (CT) can be viewed as the least ‘real world’ of these interventions, typically involving “guided practice on a set of structured - usually standardised - tasks, designed to train individuals on relatively well-defined cognitive processes and abilities such as speed of information processing, attention, memory, or problem-solving.” The intention, however, is still that the effects of training will transfer to the real world, thus bringing perceptible benefits to patients in their daily lives, although whether this can or does occur is hotly debated in the literature. The debate is heightened by the fact that many research groups have developed their own training programmes and that ‘brain training’ is now big business; hence both intellectual and commercial conflicts of interest abound.

Bahar-Fuchs and colleagues found 33 randomised, controlled trials (RCTs) to include in their review. Most were unregistered, parallel group, single site RCTs. Sample sizes ranged from 12 to 653 participants and the duration of the interventions from two weeks to two years. Risks of selection and performance bias were common in the included trials.

As always, the nature of the comparator is key to evidence of efficacy. In this case, there were 18 comparisons of CT to a passive control condition, such as a waiting list or standard care; 13 to an active control condition, which typically involved some kind of unstructured activity to control for contact with the researchers; and 15 to an alternative treatment, such as occupational therapy, mindfulness or reminiscence therapy. (Some trials included more than one comparator).

The review authors' prespecified primary outcomes of interest were overall cognitive performance at the end of the intervention and overall disease severity in what they referred to as the medium-term, 3-12 months after the end of the intervention. Thus, they hoped to detect both immediate cognitive effects and any persistent impact on both cognition and functioning.

The review found that, when CT was compared to passive or active control conditions, there was probably a small-to-moderate effect on global cognition at the end of the training period (standardised mean difference (SMD) 0.42, 95% confidence interval (CI) 0.23 to 0.62; moderate quality evidence) and that advantages over the control group were retained at follow-ups between 3 and 12 months later. However, there was no evidence that global cognition was better after cognitive training than after one of the various alternative treatment comparators (SMD 0.21, 95% CI -0.23 to 0.64; low quality evidence). Evidence was either lacking or of very low quality (very uncertain) for many of the authors' secondary outcomes, but they were moderately confident that CT had no advantages over alternative treatments for mood, behavioural and psychological symptoms, or capacity to perform activities of daily living.

This pattern of results is not uncommon in systematic reviews of non-pharmacological interventions for dementia. A structured, well-supported and stimulating activity is better than doing nothing very much, but it may not matter greatly what the activity actually is. Further research is certainly justified, but in order to inform clinical decision-making, comparisons between active interventions which focus on feasibility, acceptability, cost-effectiveness and patient-important outcomes would be particularly helpful.

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Research update

by

Dr Victoria Jones, Trainee Editor, RCPsych Old Age Faculty Newsletter, Core Psychiatry Trainee, Greater Manchester

Clinical and biological effects of long-term lithium treatment in older adults with amnestic mild cognitive impairment: randomised clinical trial

Forlenza et al, *The British Journal of Psychiatry*, Nov 2019 edition (online first)

There is limited controlled data about potential use of lithium in treatment or prevention of dementia, and this study aimed to determine benefits of lithium in patients with amnestic mild cognitive impairment. 61 older adults were randomised to receive lithium or place and were followed up for 2 years (double-blind phase), and then for a further 2 years (single-blinded phase). Primary outcome variables were the Alzheimer's Disease Assessment Scale (cognitive) and the Clinical Dementia Rating – Sum of Boxes (functional). Results showed patients on lithium remained stable for two years, whilst participants in the placebo group showed cognitive and functional decline over the study period. Lithium treatment was associated with better performance on memory and attention tests after 24 months, and a significant increase in CSF amyloid-beta peptide after 36 months. The study concludes that lithium can reduce cognitive and functional decline in amnestic MCI, and furthermore can modify CSF biomarkers related to Alzheimer's disease.

Negative Emotions and the Course of Depression During Psychotherapy in Suicidal Older Adults With Depression and Cognitive Impairment

Arslanoglou et al, *The American Journal of Geriatric Psychiatry*, Dec 2019 edition (online first)

This study examined the relationship between negative emotions and 1) non-emotional symptoms, and 2) the course of depression in suicidal adults treated with psychotherapy. A subgroup of participants with suicidal ideation were identified from a randomized controlled trial of two psychosocial interventions: Problem Adaptation Therapy and Supportive Therapy for Cognitively Impaired. These participants were followed up at entry, and weeks four, eight and twelve. The reduction in negative emotions among participants with suicidal ideation was significantly associated with the reduction in non-emotional symptoms of depression, and reduction in overall depression severity. The study states that negative emotions need to be targeted early in psychotherapy in order to reduce nonemotional symptoms and depressive symptoms. Ultimately this would improve suicide risk in older people.

Changing prevalence and treatment of depression among older people over two decades

Arthur et al, *The British Journal of Psychiatry*, Oct 2019 (online)

This study investigated whether prevalence of depression and antidepressant use in older people changed across two decades. The study analysed results from the Cognitive Function and Ageing Studies (CFAS-1 and -2); these are two English population-based cohort studies of older people with baseline measurements conducted two decades apart. CFAS-1 was conducted between 1990 and 1993, and CFAS-2 was conducted between 2008 and 2011. Depression was assessed at baseline by the Geriatric Mental State examination and diagnosed with the Automated Geriatric Examination for Computer-Assisted Taxonomy algorithm. Results showed that age-standard depression prevalence in CFAS-2 was non-significantly lower than in CFAS-1. Furthermore, in CFAS-2 the number of older people taking antidepressant medication had risen to more than twice that of the population in CFAS-1. Use of antidepressants also increased in care homes, though depression prevalence was unchanged. The study concluded that an increased proportion of people >65 years were taking antidepressants when comparing CFAS-2 to CFAS-1, however there was no evidence for change in age-specific prevalence of depression.

The use of CSF analysis in the diagnosis of Alzheimer's Disease: A survey of consultants in Old Age Psychiatry

by

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Dr Robert Barber, Consultant Psychiatrist in Old Age, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Since June 2018, NICE have begun including the analysis of cerebrospinal fluid (CSF) as part of the guidance for the diagnosis of Alzheimer's Disease (AD). Specifically, it suggests considering this test as an alternative to FDG-PET or perfusion SPECT in situations where the diagnosis is uncertain[1]. The core CSF biomarkers of neurodegeneration (T-tau, P-tau, and Aβ42) are strongly associated with Alzheimer's disease[2] and can be useful in the diagnosis of AD. In 2018 the National Institute on Ageing and the Alzheimer's Association (NIA-AA) developed a diagnostic method which included them[3]. Findings that would be indicative of possible AD are low levels of amyloid in the CSF, and elevated levels of total tau and phosphorylated tau. Importantly, these changes can be seen in the pre-clinical stages of disease, or when the individual presents with Mild Cognitive Impairment[4].

In order to evaluate the current usage and awareness of this investigation in every day practice, we created a survey that was disseminated in the first half of 2019 to all Old Age Consultants within Cumbria, Northumberland, Tyne and Wear NHS Foundation trust (CNTW). In addition to gauging awareness and interest in the diagnostic method, we also sought opinions on the potential development of a service within CNTW that would allow lumbar punctures, and subsequently CSF analysis, to be done. Examples of this elsewhere in the UK include the Cognitive Disorders Clinic at University College London, which has a dedicated lumbar puncture clinic for this purpose[5].

The survey was created electronically and consisted of ten questions. It asked about whether or not the respondents had ever used CSF analysis in their clinical practice, how important they felt it was that the investigation is available, which situations they thought it would be useful in, their estimates regarding how often it would be used if a service were available, and several questions looking at the practicalities of setting up a CSF service, and the barriers/benefits of this. The survey was sent out to all relevant clinicians via email and remained open for one month. There were two reminder emails sent during this time.

Of the 33 consultants who were sent the survey, 18 responded which corresponds to a response rate of 54.5%. Of these respondents, only one person reported that they had used CSF analysis in their clinical practice since the NICE guidance changed in June 2018. Unfortunately, this respondent did not answer the additional questions asked to provide context, so no further information was available. The overall view of the sample was that it was important that this investigation is available for patients, with 88.9% selecting either very important or quite important. Moreover, all 18 respondents agreed that further CPD on the subject of CSF analysis in AD diagnosis would be of benefit to them.

With regards to the situations where the test might be most useful, most of the respondents selected assisting with the diagnosis of AD in complex presentations under the age of 65 after routine investigations. This was followed closely by assisting with the diagnosis of dementia in atypical presentations (88.9%) and in the investigation of rapidly progressing dementias. The clinical situation with the fewest respondents (22.2%) was for differentiating AD from normal ageing. Additional situations suggested included differentiating from functional illnesses and for clinical dementia research purposes.

We wanted to estimate the likely demands of an LP service (in terms of number patients utilising it per year across) but clearly in the current context it was difficult to offer precise estimates. Responses ranged from 3 per year to over a 100 – though the majority estimated below 100 / year.

One half thought that the best option for delivering the service would be a specialist CSF clinic with external expertise such as an anaesthetist to assist with the practical aspects. 22.2% of respondents thought a specialist CSF clinic led by a nurse or physician associate trained in LPs would be the best option, and an equal number of respondents opted for a similar setup but with psychiatry trainees and consultants running the service. One respondent thought the service should be delivered through an entirely different trust. Other suggestions for how the service could be developed included: Shared model between psychiatry and neurology, central resource for those who can and generating local solutions on a case by case basis, pre-LP counselling, 2nd option of anaesthetic involvement for more complex patients e.g. with spinal issues

The two barriers to setting up an LP service in the trust which were most agreed with by the respondents were difficultly in accessing medical colleagues to perform procedures (72.2%) and managing adverse events post procedure (66.7%). 44.4% of respondents also agreed with the following barriers; difficulty in accessing training for staff, ambiguity in when it would be clinically appropriate, training in interpretation of the results, and patient reluctance to undergo the procedure. Further suggestions of barriers included the perceived need for a “culture shift” in that physical investigations should be seen as a central part to the "dementia work up", in addition to cost effectiveness and possible resistance from management for funding it.

Finally, the benefits of having an LP service in the trust that most respondents agreed with were more accurate exclusion of AD (based on negative results), advancing clinician understanding of new biomarkers in the diagnosis of dementia, and access to clinical trials/research (83.3%). There was also a high frequency of responses for the benefits of more accurate diagnosis of AD (based on positive results) (72.2%), earlier diagnosis of AD (72.2%) and patients more informed about their diagnosis (66.7%).

In conclusion, the use of CSF biomarkers is an area that is well established in AD research and has been shown to have a role in assisting diagnosis in conjunction with thorough clinical assessment and imaging. Outside of some specialist centres, however, it seems it is yet to permeate the everyday practice of clinicians who are regularly diagnosing AD. Our survey has shown that it is something Old Age psychiatrists view as important for patients, and furthermore that it is an area in which they would like to receive more training. There are a number of issues regarding how this might be practically done within a mental health trust, including concerns about financial aspects and access to appropriately trained staff. However, the benefits and uses of CSF analysis in day to day practice was well supported, in particular more accurate diagnosis and exclusion, and involvement in research.

Declarations

The project was undertaken under the Trust's process for baselining NICE guidance using an audit methodology with some supplementary questions.

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Opportunities for Faculty of Old Age Psychiatry to support Join Dementia Research (JDR)

by

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Background

Join Dementia Research is a UK-wide service that allows people to register their interest in participating in dementia research and to be matched to suitable studies. The initiative was developed and delivered by NIHR in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. Central to the JDR service is a database of volunteers, representatives and studies with a front-end website.

The service has been running for more than four years. Join Dementia Research is approved by the Health Research Authority and acts as a 'consent to contact' database. It works like a 'match-making service' between public volunteers and researchers. It does not commit individuals to take part in research. Researchers can use this service to get in touch with volunteers who may be suitable for their study but volunteers can choose which studies to take part in with no obligation, and they can change their mind at any time. Partner charity help desks can offer more personalised support for anyone registered or looking to sign up.

To date the service has successfully recruited large numbers of volunteers and placed many in studies, however, we need to work with health and care professionals to help raise awareness of the service as part of best care for people with dementia.

Why is JDR important

1. Patients want to hear about research opportunities

A recent survey of Join Dementia Research volunteers (most of whom have a diagnosis) showed that:

- 78% (62 out of 80 respondents) would want to have been told about Join Dementia Research as soon as possible after their diagnosis
- 58% (81 out of 140 respondents) thought the best person to tell them about Join

Dementia Research would be their healthcare professionals.

2. Talking about research meets the requirements of NICE and NHSE guidance

The need to share research opportunities and the use of Join Dementia Research are recommendations in:

- NICE Guidelines Dementia: assessment, management and support for people living with dementia and their carers,
- NHS England's Dementia: Good Care Planning Guidance.

Join Dementia Research provides a simple mechanism to meet these requirements as it matches registrants to relevant studies in real time.

3. It's a government priority

Join Dementia Research is an important tool in assisting the delivery of the Prime Minister's Challenge on Dementia and the Dementia 2020 Vision (published in 2012 & 2015) for which key aspirations include:

- Every newly diagnosed person with dementia and their carer receiving information on what research opportunities are available and how they can access these through JDR.
- All relevant staff able to signpost interested individuals to research via JDR.
- 10 percent of all people diagnosed participating in research from a baseline of 4.5%.
- 25 percent of people diagnosed with dementia in 2020 registered on JDR (currently estimated to equate to 116,450 people with dementia or MCI registered in 2020).

JOIN DEMENTIA RESEARCH
MAKES IT EASY FOR ANYONE TO TAKE PART IN ETHICALLY APPROVED DEMENTIA RESEARCH

VOLUNTEER REGISTRATION - YOUR PATIENT SIGNS UP ONLINE, BY PHONE, OR BY POST

STUDIES ADDED - RESEARCHERS UPLOAD STUDY INFORMATION

MATCHING - THE SYSTEM MATCHES REGISTERED VOLUNTEERS TO SUITABLE STUDIES

CONTACT - RESEARCHERS GET IN TOUCH WITH VOLUNTEERS TO EXPLAIN ABOUT THE STUDY

VOLUNTEER DECISION - VOLUNTEERS DECIDE WHETHER OR NOT TO TAKE PART IN EACH STUDY, WITH NO OBLIGATION

Tools that can help Healthcare professionals

- Short online awareness tool: taking just 10 minutes to complete, it is designed to help healthcare professionals understand why dementia research is important for their patients, and how talking about Join Dementia Research can help them deliver best care according to clinical guidance.
- Free promotional materials
- Toolkit of ideas for how Join Dementia Research can be promoted to patients

- Monthly data on CCG /STP progress towards recruiting 25% of people with dementia diagnosis on Join Dementia Research

Is there a role for the Faculty of Old Age Psychiatry to help?

The National Institute for Health Research (NIHR) has been working with NHS England, Alzheimer Scotland, Alzheimer’s Research UK, and Alzheimer’s Society to deliver the objectives but successful delivery needs local ownership and drive, particularly from Old Age Psychiatrists.

In particular can we as a Faculty help to strengthen, promote and support use of JDR (and research generally)? It could help Trusts to meet the new CQC requirements relating to embedding research in clinical practice.

Potential actions include:

- Promote JDR in local clinics (including meeting the MSNAP standards 1.2.6 and 1.2.7)
- Letting our trainees know about JDR.
- Promoting JDR in your services.
- Help to disseminate the online ‘LEARN’ tool and encourage trusts and individuals to use it
- Linking with local DeNDRoN team

Produced with the support of the JDR team

Film review: Joker

reviewed by

Dr Holly Fraser

Foundation Year 2, Queen Elizabeth Hospital, Gateshead

As a cinephile and a self-professed comic book ‘geek’, I thoroughly enjoyed Todd Phillip’s latest film ‘Joker’. Presenting a new twist on the backstory of the eponymous comic book villain, Phillip’s ‘Joker’ was a mesmerising and haunting piece of cinema. Visually striking with a timeless retro feel, provocative dialogue and iconic portrayal by Joaquin Phoenix, it’s no wonder that this film received a 7-minute standing ovation at the Venice Film Festival.

However, as a psychiatry F2 I found the film highly uncomfortable at points. Focusing more on real-life misfortunes than capes, crusaders and crass puns, this film gives a notorious comic-book villain an uncomfortably plausible backstory.

Throughout the film, I felt hopelessness for Phoenix’s Arthur Fleck and his inevitable spiral into his villainous persona, The Joker. Typically described as a ‘no rhyme nor reason’ psychopath in the Batman comics, Phoenix instead portrays a mentally unwell man battling with life events, failure of the welfare system and unrelenting insensitivity of a seemingly uncaring world. As more of his backstory was revealed, and further risk factors for deteriorating mental health were displayed, I felt increasingly helpless for Phoenix’s character – you wanted to reach out and help him but couldn’t.

Even before Joker had been showed to audiences, it had sparked several conversations about mental health. This is partly because the role of the Joker has become an infamous one, particularly following Heath Ledger’s Oscar award-winning portrayal of him in 2008 and his death later that year. Many postulated that this role had severely affected Ledger’s mental health and had spurred him to seek solace in prescription medication misuse, and subsequently led to his overdose. Even Ledger himself had acknowledged that during filming of “The Dark Knight” he was barely sleeping two hours a night, as he tried to emulate "a psychopathic, mass-murdering, schizophrenic clown with zero empathy". Phoenix has been questioned about this is in various interviews, particularly given the intense physical transformation he has undergone for this role, but has yet to comment on whether he believes his portrayal of the Joker will have any lasting effects on his mental health.

A component of the film that I found particularly striking was the loss of the community mental health support which Phoenix’s character had been receiving.

It reflected a scenario that unfortunately does happen in the UK, given that mental health services have been stretched and underfunded for years.

Mental health problems account for approximately 23% of the burden of disease in the UK, but reportedly only 11% of the NHS budget is allocated to spending on mental health services[1]. Furthermore, from 2012 to 2016, over 40 % of mental health trusts' budgets in England were reduced each year[2].

The disparity in funding and patient life expectancy between physical and mental health was raised in the Health and Social Care Act in 2012. It subsequently dictated that the NHS had a responsibility to deliver 'parity of esteem' between mental and physical health, and the government pledged to achieve this by 2020. Funding within mental health trust has reportedly since improved, however people who suffer with mental health problems still fail to receive the same access to services or quality of care as people with physical health problems, and the mental health workforce is still overstretched[2].

Overall, I would highly recommend Joker to any cinephile or comic-book fanatic. It is a singular and gripping origin story, with stylistic cinematography and a mesmerising performance from Joaquin Phoenix. However, there were many points throughout the film that I found difficult to watch as psychiatry trainee, especially the subtle commentary on the strain on and loss of mental health services, and the effect this has on the some of the most vulnerable members of our society.

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Theatre review: Reason to Stay Alive

reviewed by

Dr Cara Vincenti F1, Gateshead

Reasons to Stay Alive is based on Matt Haig's harrowing bestseller of a personal account of a 20-something year old man coping with mental health issues. The talented director of the stage play artistically generates a dynamic image of Matt - opening with a scene of him partying in Ibiza before capturing Matt climbing to the edge of a cliff to deliberate whether his life is worth living as he is suddenly overcome with crippling depression and anxiety.

The play follows with Matt's return home to England and cleverly depicts his battle of living and overcoming depression, while also expressing the struggles of his family around him, including his girlfriend Andrea as they try their best to support him. The dynamic and hectic movement of these broken-down segments around the stage embody the complexity of his thoughts and feelings throughout his journey with depression.

Throughout the production, the play successfully creates communication between younger Matt and older future Matt, who offers 'future-thinking' words of comfort to his counterpart - letting him know that he will be ok. The role of older Matt acts as a guide to pull him through his struggles and consequently allows some relief throughout the heart-wrenching production as both the audience and current-Matt is reassured.

In the short space of 75 minutes, the show explores the tormenting demon within Matt's mind, which forces everyday tasks to become almost impossible. Matt's emotional progression and regression show his slow journey to recovery which begin with baby steps such as walking to the shop alone to buy a carton of milk. This is celebrated by Matt and his family.

The writer of the production impressively creates a young man's emotional journey by skilfully threading acts throughout with elements of light-hearted humour. One act in particular explores "things people say to depressives that they don't say in other life-threatening situations" and follows to give a list of comical responses such as "okay. Yes. Yes. Maybe your parachute has failed. But chin up."

In conclusion, depression affects more than 20% of people at some point in their lives in the UK with the play being shown during Mental Health Awareness Week. For me personally, Reasons to Stay Alive was an excellent way to raise awareness and attempt to remove the stigma of mental health that we are all too familiar with.

The production left me thinking, as a young doctor, about the big changes we are going through in our lives and in our careers. On top of this, junior doctors are on the front line and often end up spending the most time with their patients in comparison to other doctors. As a result, we end up relieving a lot of our patients' emotional strain which is often therapeutic for them, despite having to take it all upon our own shoulders.

Doctors are always looking out for everyone else's mental health but rarely looking out for their own. So, ask yourself, when was the last time you reflected on your own mental health?

Book review: Dear Dementia: the laughter and the tears[1]

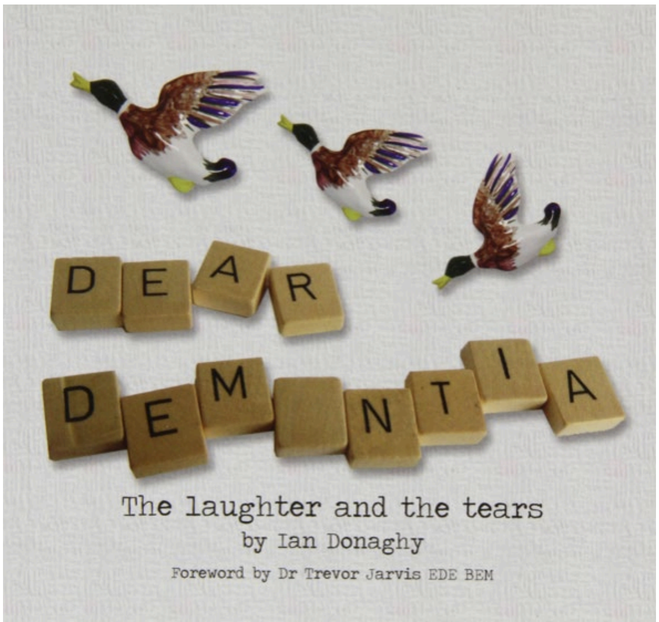
Author: Ian Donaghy

ISBN: 9781874790860

reviewed by

Dr Sophie Irwin, Foundation Year 2, Queen Elizabeth Hospital, Gateshead

This book is part of The Reading Agency's Books on Prescription for Dementia[2]. It is unique in regards to the composition of the book as it is comprised of pictures and small quotes. Dear Dementia gives you the opportunity to reflect upon what is drawn/written and allows you to reach your own conclusions regarding what message each page is trying to convey. A number of themes emerged when reading the various entries and upon reflection I felt that the majority of the quotes mirrored the stages of grief.



1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance[3]

I felt that a recurring theme of **empowerment** also resonated throughout this book.

The above themes are befitting in a book about Dementia. Dementia is a loss of cognition, loss of autonomy and ultimately the loss of a person's way of life. Dear Dementia, reminds the reader however, that all is not lost and to remember that Dementia does not become the person and to always treat the person, not the condition.

Denial

'Dear Dementia…

I hate shopping nowadays. "That'll be £15.67" I hold my hand out and hope for the best. Take my money, give me my shopping, give me my change. No questions please.

We have a big family. You've only got Dad so far. Why do I only see footprints in the sand whilst the rest bury their heads in it hoping you'll just go away?'

Denial often originates from a place of fear and a fear of the unknown. However, by armouring ourselves with knowledge the unknown becomes known and we can learn to manage and adapt. Even through reading these quotes and having the knowledge that these feelings are common could reduce the sense of loneliness one might have.

Anger

'Dear Dementia…

I've looked at activities in care home and activities in prisons…I'm off to rob a bank'

If a dictator was destroying the lives of as many loved ones as you, the world would flex its muscles to stop them at any cost!'

Anger can be expressed for a number of reasons in regards to Dementia. These quotes highlight the anger not only at the diagnosis of Dementia but at the services that are available. They remind us to always try to provide the best available care for those with Dementia and their loved ones.

Bargaining

'Dear Dementia…

You've turned my clock into a round picture on the wall. I still have "o'clock" and "half past". Please leave me with those...time is precious'

My autobiography's not complete. I still have chapters left to write. Don't send me to the printers just yet…'

Throughout the course of the disease, people are left with less and less as time ticks on. Therefore, it is understandable that people would clutch onto what they had left with all their strength to maintain their lives for as long as possible.

Depression

'Dear Dementia…

Having you with me is like playing 'snakes and ladders' . But you've stolen all the ladders.

My husband's gone. Never had children . it's just you and me together. Alone.'

With a progressive illness such as Dementia, feelings of helplessness, loneliness as described by the above quotes are commonplace highlighting the importance support has for those impacted by the condition.

Acceptance

'Dear Dementia…

We didn't invite you into our family but you're here now. We could totally focus on you but we're going to focus on Nana instead'

I'm so glad my wife celebrates what's left of me and doesn't dwell on what you've taken'

With the right support those living with Dementia and their loved ones could have the ability to move towards accepting the condition as part of their lives. By doing this it could improve people's quality of life as people may become more accepting of help and learning ways of adapting their lives to benefit them the most.

Empowerment

'Dear Dementia…

Everybody finishes my sentences. Every night I'm left with a bagful of full stops.'

She picks out my clothes, washes me, dresses me, makes my bed, cleans my room and ties my laces. So…what do I do again?'

Arguably the most important theme throughout this whole book. If people feel empowered they may be able to manage the other aspects of their diagnosis with less difficulty. Allowing them to feel more in control hence allowing them to accept their diagnosis and live with it rather than in fear of it.

Dear Dementia is a book that will resonate with those living with dementia and those who are caring for people with the condition. I think it is a very useful point of reference and therefore it is very appropriate that Dear Dementia is part of the Books on Prescription for Dementia. Through reading this book I felt I great sense of support, voices speaking out about their experiences and sharing what they have been through. In many respects it is alike to a support group of sorts, one in which you can have at your fingertips and engage with at any time – a vital tool in learning to live with Dementia.

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