Falling Off a Cliff at 65
Serious Mental Health Issues in Later Life

Notes from a second round table discussion with key stakeholders 3rd March 2021

Participants

Jan Beattie, Allied Health Professional Advisor, Primary Care Directorate, Scottish Government
Lauren Blair, Programme Engagement Officer, Voluntary Health Scotland (VHS)
Cara Cameron, Policy Manager,Mental Health Directorate, Scottish Government
Adam Daly, Consultant Psychiatrist in Old Age
Ashleigh Diverti, Policy Manager, Age Scotland
Caroline Docherty, Strategic Inspector, Adults Team, Care Inspectorate
Derek Goldman, Knowledge Exchange Manager, Open University in Scotland (OU)
Donald Macaskill, Chief Executive, Scottish Care
Sharon Mallon, Senior Lecturer, Open University (OU)
Jillian Mathew, Senior Manager Audit Scotland
Maureen O'Neill, Chief Executive Faith in Older People
Lindsay Paterson, Interim Director, Scottish Health Action on Alcohol Problems SHAAP
Arvind Salwan, Strategic Communications Advisor, Care Inspectorate
Frances Simpson, Chief Executive Support in Mind Scotland
Claire Stevens, Chief Executive, Voluntary Health Scotland (VHS)
Kathleen Taylor, Engagement and Participation Officer, Mental Health Welfare Commission
Jitka Vstekova , Senior Lecturer, Open University (OU)

Introduction

Claire Stevens welcomed participants and introduced the round table and its background. During 2019 VHS had collaborated with *Support in Mind Scotland* and *Faith in Older People* to explore what happens to people aged 65+ with serious mental health conditions (other than or alongside dementia). Two round tables were held, and two short pieces of evidence gathering were commissioned from NHS Health Scotland and Dr Adam Daly. A discussion paper and evidence briefing was published. Work then paused due to the Covid-19 pandemic, as a planned meeting with the head of the Scottish Government mental health directorate could not take place. In February 2021, VHS began working in partnership with the Open University (OU) to reinstate the work. Today is a follow up to a round table which that VHS and the OU held on 4th February 2021. At that, participants agreed that the situation for

older people with serious mental health issues has not improved at all since 2019, and has not been helped by the pandemic. Today's round table will explore potential recommendations for action and next steps, taking us beyond describing the issues and looking at the evidence. The format is four short presentations to provoke discussion.

Derek Goldman welcomed everyone and explained the OU's commitment to partnership working and to helping to progress this agenda.

Four short inputs from **Kathleen Taylor, Adam Daly, Donald Macaskill** and **Jan Beattie** followed, in order to stimulate discussion.

Kathleen Taylor, Mental Welfare Commission (MWC)

Noted that Kathleen also has relevant lived experience as an unpaid carer. One of the ways MWC fulfils its function to promote and protect the rights of people with a mental illness, learning disability, autism, dementia and other related conditions, is by visits to people around the country. These are often themed visits, the theme being flagged by topics coming up via advice lines or by local visits. The MWC report Older people's functional mental health wards in hospitals (April 2020) reports on visits in 2019 to all psychiatric wards in Scotland that provide assessment and treatment for older people with a functional mental illness. The visits aimed to see whether the recommendations of an earlier MWC report (2015) had been taken on board and improvements made – e.g. the need for more person centred care plans, better provision of activities, greater psychology support, better information for carers and advocacy. Pre-visit consultation with family members and staff helped shape the visits/questions asked.

The 2019 themed visits reviewed the files of all 145 patients, and MWC spoke to 95 patients as well as 23 family members/carers. There were also some mixed ward (i.e. functional mental health illness and dementia) visits/conversations with family members The visits enabled MWC to report on a large number of topics in detail, and there was a questionnaire for psychiatrists too. Issues raised included:

- inconsistency of approach to transition
- continued lack of psychology input
- need for staff to be trained in physical as well as mental health
- perception that older people's mental health gets a poorer response
- staff concerns about the issues of mixing functional mental illness support with dementia support
- need for better community support including in a crisis
- need for better hospital environments

Only seven wards had psychology support available on a regular basis. Dementia had an increasing profile on functional mental health wards, and patients with dementia admitted to functional wards posed a variety of challenges for staff. Kathleen pointed out that if the overall lack of psychology input was the situation in a normal adult psychiatric ward there would be more outrage. There should be dual

trained nurses. The report calls for clear protocols, that include social work, to be in place for patient transition from adult to old age services and for decisions to transition to be based on individual need, not on arbitrary age limits or the needs of the service. There were some positive examples of use of green space and volunteers in providing therapeutic and recreational activities for patients but there was room for improvement. There were some examples of allied health professionals being well linked with community facilities for when people were discharged.

The report says that people with dementia should not be admitted inappropriately to wards for older people with functional mental illness. Where wards are mixed the physical environment should be suitable for all patients, and staff should be suitably trained and resourced to meet the complex and diverse needs of both groups. Kathleen commented that, since the 2019 visits, they had heard that some wards have amalgamated their functional wards with dementia wards due to lack of space, and MWC very much hopes this will be temporary. **Donald Macaskill** commented in the Zoom Chat: *"very concerned that dementia wards are not amalgamated in medium or long term – pre-pandemic challenges will only be made worse, and sadly too much evidence of Covid and infectious risk when we have such mixed environments".*

Maureen O'Neill asked a question around transitions and community. Kathleen responded: this was a significant discussion point during the visits and all the psychiatrists flagged this as a difficulty. Adam Daly said he was relieved MWC is aware of wards being closed and amalgamated due to Covid-19/lack of space; this must not be allowed to become the norm and needs to be challenged. It is not in the interests of patients with functional illness like depression or schizophrenia, and it deprives people with dementia of the specialist skill sets they need. Kathleen commented that the visits revealed how stressful mixed wards are for staff, as they feel they are not able to give their best to either group.

Jillian Mathew, Audit Scotland

Audit Scotland is the independent auditor of all public sector bodies, including local government and NHS bodies. They have been doing work on various aspects of the Covid-19 pandemic, to highlight the main risks and issues for public bodies, which includes mental health issues. Jillian highlighted likely elements of their future work programme, to be published in the next couple of months, flagging areas where there was potential scope for Audit Scotland to contribute to today's subject matter. She emphasised the cross-cutting nature of themes and the scope to be flexible and pick up on emerging areas of interest or concern through a very short piece of work, without having to do a detailed audit on them. Such short pieces of work could even be in the form of Auditor General blogs to highlight issues.

One of five key themes for audit work going forward which is relevant in relation to today's topic is inequalities, with a focus on the impact of Covid-19 on different groups and how inequalities have been as exacerbated. This theme is likely to include looking at mental health. Another theme is policy priorities, and one topic within that likely to be social care sustainability.

Arvind Salwan highlighted the Independent Review of Adult Social Care chaired by Derek Feeley and the Health and Sport Committee's Social Care Inquiry, and asked if Audit Scotland has been able to come up with a definition of social care sustainability. Jillian replied that it was early days and that Audit Scotland were aware that Covid-19 had exacerbated some issues in the provision of social care that had already existed. One approach for the sustainable social care work strand might be to look at a particular theme, which could be older people.

Adam Daly, old age consultant psychiatrist

Adam explained he planned to be anecdotal and reflective today rather than presenting hard evidence. Mental illness is his specialist skill set. This time last year caused a sizeable bump for his profession: the pandemic meant things paused and went onto an emergency and urgent footing, as did other mental health services. We don't know yet if was the right thing to do, what the benefits and harms were, but it seemed the right thing to do at the time. One definite positive was the we learned that mental health services are different to other services in this emergency. Most services have not been scaled back and old age psychiatry is working as hard as ever but playing catch up on time missed and people missed. Some services weren't able to do what they normally do so there have been some negative impacts. The Scottish Government has produced tracker information on mental health via two reports so far and these do show some things have got worse, including the stress felt across the general population, increased use of alcohol, and the particular impacts on young people, women, and on those with pre-existing conditions. Older people who didn't have a pre-existing mental health condition have actually fared a bit better, some of the evidence suggests. But people who have been in intensive care have high rates of post-traumatic stress, and there is concern about the mental aspects of long covid.

The delay in presentations, noticed by him and colleagues, was not unique to mental health. The longer people have sat and absorbed their own illness, the worse the outcomes have been. Factors that have delayed clinical contacts include people's fear of covid, lockdowns, staff sickness, issues of access to clean buildings where social distancing can take place, and issues of access to technology.

Anecdotally, more people have been presenting as emergencies in both mental health and general services, and admissions are up. This latter is particularly upsetting because mental health admissions had been going down for long time. There have been some outbreaks of covid in mental health wards and some deaths, which has been very hard on families given visiting restrictions and hard on staff.

Services are now adapting and testing out new ways of working. There are some benefits to new ways of working, e.g immobile people who perhaps would have been excluded completely from services have the opportunity to attend appointments digitally. Interpreters are easier to access and involve remotely. Families can be included in assessment calls. It is a myth that older people are adverse to digital technology and communications, but the risk of digital exclusion is also clear. The

service response – whether face to face, telephone or video - must be based the person and their individual needs.

Adam commended the Scottish Government Covid-19 mental health transition and recovery plan published in October 2020 for mentioning older people. The plan discusses peer support, loneliness, bereavement and loss, digital exclusion, and evidence of impact. This is very welcome and very different from any previous strategic publication. It was also good that people with mental health issues were eventually recognised as a priority for the covid vaccination, although the delay mean that some older people did not benefit directly from this.

Frances Simpson commented on the tensions surrounding the use of digital technology. She endorsed Adam's statement that not all older people are afraid of technology. In rural areas digital has really opened things up and enabled many people to be reached without the need for travel. However, in Edinburgh *Support in Mind Scotland* lost contact with up to 30% of service users as they chose not to engage with the digital offer.

Maureen O'Neill remarked that there are now so many strategies, including A Fairer Scotland for Older People (April 2019) and that a good outcome from today would be if somebody could align the relevant strategies so that the impact of each is joined up. She reiterated the issue about not having enough people sufficiently dual trained and agreed with Adam that we need to be clear when we are talking about serious mental illness and when we are talking about mental wellbeing. Adam said that 20% of old age psychiatry doctor posts are jobs are unfilled, so the shortage is real. He said there are a wide range of people who can help with mental health problems (as opposed to serious mental illness), including the third sector, and asked whether put too much emphasis is put on the high end of professional help.

In introducing Donald Macaskill's formal input, Claire commended his blog, I need to be found - mental health and older age written ahead of today and now published on the websites of Scottish Care, VHS and Support in Mind and promoted in the Faith in Older People bulletin.

Donald Macaskill, Scottish Care

Donald explained he'd been invited to reflect on this last year, its impact on the mental health of older people in care homes, and his thoughts going forward. First, he said he wanted to 'tick' everything Adam had said. He added that the pandemic has put paid to idea that older people don't want to use technology and at the same time has highlighted that technology is not readily accessible to all older people, for example, for reasons of dexterity, visual or hearing impairment. Digital exclusion of older people will continue if we don't adapt the devices and technology and make them accessible.

Donald spoke firstly about care homes, saying they had been at the forefront of the most harrowing and distressing experiences of covid-19. It will be for another time to reflect on whether the measures taken to control covid-19 have stood us in good stead. Over and above those who died of covid-19 in care homes, another 13,000 have died in care homes and did so with minimal contact with their loved ones.

Remember that many relatives are themselves older people and they have been managing real distress. They are profoundly impacted by their exclusion from visiting loved ones in care homes: many are living with depression and with mental illness. With care homes now beginning to open up again to visitors, Scottish Care is hearing of relatives who are seriously upset by the deterioration they can now see for themselves in their loved ones, after over a year's absence, and who are castigating and blaming the care home staff.

Donald pointed out that pre-covid there was already a significant issue regarding the care of older people's mental health and that Scottish Care's 2018 report Fragile Foundations had argued that the dominance of delirium and dementia as a focus of attention was at the expense of other conditions in old age.

He spoke of the serious and long-lasting impact that covid-19 is having on care home staff's own mental health: there are cases of suicide amongst staff and numerous individuals who have attempted suicide during the pandemic. This he attributed in part to the sense of responsibility staff feel, coupled with negative media coverage and societal blame placed up care home staff. A related issue is bereavement. One staff group experienced 30 deaths in two weeks, of individuals they all personally knew. Donald chairs a cross-sectoral, national group that has developed the national charter on bereavement. Covid grief syndrome is increasingly recognised internationally, but less so here.

Anecdotally, Scottish Care members say there are profound implications for staff's mental health and wellbeing for those involved in the deaths of people in the community and the staff involved in their care and treatment. One of the major challenges for older people's health in the new pandemic era is how we support people to come to terms with bereavement and grief, given the absence of support, the experience of often very troubling deaths, and the removal of normal mechanisms and rituals for bereavement and grief.

Donald reiterated that family members are very often older individuals themselves. As homes start to open up again to visitors, relatives are expressing renewed distress at the deterioration in the health of their loved ones, including their cognitive deterioration – in some cases they are no longer recognised.

Derek Feeley's Independent Review of Adult Social Care offers us good prospects, in particular its call on us to reimagine what we mean by social care and social support and to focus on building a national care service that has wellbeing at the heart, including mental wellbeing, and focuses on autonomy and choice and rights. Donald said that a national care service must move away from a functional response and become preventative and focus on embedding relationships. One positive to emerge from the pandemic has been the level of partnership working: we can and must build on this. Training, learning, development, technology, person-centredness, prevention not reaction - it's all in the report, but we need politicians to be informed about the realities of social care.

Claire Stevens reflected on the opening of the Feeley report: the call to shift the paradigm, strengthen the foundations and redesign the system resonates strongly with today's discussion.

Maureen O'Neill questioned whether there will be enough political conviction to follow through on the Feeley report's recommendations. Donald said many involved in social care including carers, service users, disabled people and providers are increasingly distressed and angry. During covid-19 care home staff have faced demands from politicians with no insight into the consequences in practice e.g. to isolate a person with dementia. Older people's care and support have not been prioritised or well-resourced for 30+ years, but the arguments that have broken out over the proposal for a national care service do not bode well. The message to those defending the status quo surely is: "If everything was working well, if there wasn't an implementation gap, what have you been doing for 30 years?" The system is broken and needs transformational change, but the concern is that power games will work against this happening and that the loudest voices will win out. However, the pandemic has made most of us more determined than ever to overcome the political barriers and put support for older people's mental health and wellbeing at the heart of the development of a new national care service.

Jan Beattie, Scottish Government

Jan highlighted the cross-cutting themes that had been raised so far, and emphasised the commitment in the Scottish Government to join things up. She gave some examples by way of reassurance that work is underway to ensure connectivity between policy areas, and said there is lots of work underway concerning care homes. She agreed with Donald that the decline in older people's health and wellbeing this year, whether in care homes or the community, has been a major concern. She stressed that we all have the right to live with dignity, purpose and joy, whatever our age, and in a care home as much as in the community. Her particular focus as a AHP Professional Advisor to the Scottish Government is around the multi-disciplinary team in primary care, both within the GP practice and the wider wrap-around primary care service.

Jan pointed out that all occupational therapists are dual trained and qualified, regardless of where they work. From a community side of things the government's work is focused on how to ensure people get help at an early stage to prevent issues becoming acute or chronic. The mental health in primary care short life working group reported and made recommendations, leading to a new group (which has met once) now looking at next steps. The aim is that all the skills of the multi-disciplinary team will be used to ensure people have access to the support they need.

Jan said the workforce role and its wellbeing are really important, and she acknowledged that we don't have sufficient workforce capacity. Health inequalities and their relationship with poor mental wellbeing and with mental illness are part of the agenda, as is dementia. They are looking at dementia friendly connected communities and other ways to help people stay independent. The decline in people's physical and mental health during the pandemic is being actively looked at. For people with chronic pain the withdrawal of services during the pandemic has

resulted in mental as well as physical decline. The Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic (August 2020) stresses the role of all sectors and programmes. For example, the role of Care About Physical Activity (CAPA) in care homes; sports and leisure centres, and the third sector. The recovery and rehabilitation framework's Steering Group is developing an implementation plan and mental health will be a key element, so there is an opportunity there.

Lindsay Paterson asked what response is needed with regard to the impact of long-covid. Jan responded to say that there is a long-covid rehabilitation element to the policy work and that the inter-dependencies between mental and physical wellbeing are being included.

Adam Daly asked what primary care multi-disciplinary teams can do to persuade older adults with poor mental health to come forward? Jan responded to say that older people's mental health needs had not been separated out for specific attention in the work she had been talking about and that she will ensure this is looked at in implementation. She flagged the situation of older people who are carers for each other and holding each other up: if one falls the other falls. Conversations with people are crucial (e.g. via integrated nursing teams) to identify what support might be needed and wanted, and anticipatory care plans should not just be for end of care life.

Donald Macaskill referred back to the tracking work Adam had mentioned and cautioned against putting too much weight on tracking data, when the case is that older people's mental health needs are under-represented, i.e. because of lower numbers presenting. **Frances Simpson** commented that *Support in Mind's* experience is not so much that older people are reluctant to present but that when they come into contact with other services any mental health problems are not picked up on and assessed, especially anxiety and depression.

Wider discussion

Claire Stevens invited OU colleagues to offer their reflections. **Jitka Tsetekova** remarked that inequalities had threaded through the discussion, as had the vision for a redesign of systems and services. Was there a need for further research and if so what area should be prioritised? **Sharon Mallon** cautioned against research that simply describes the problems again, and argued for an activist approach to future research and academic involvement, welcoming any suggestions people may wish to make. She expressed interest in the areas of blame, culpability, stigma, bereavement and loss. How do we help people cope with their grief? Claire flagged the role the OU has in training the future health and care workforce as a potential area of OU activism that might be pursued.

Donald Macaskill agreed that there was a strong connection between the sense of blame and culpability that care staff and family members have been feeling and the high distress and trauma associated with Covid related bereavement and loss. Internationally we have begun to talk about a Covid stigma: namely, families who don't want others to know that their relative has had Covid or died of it. This

happened with the 20th century's Spanish flu epidemic, and the stigma associated with dying from the disease impacted on communities' ability to support each other. This might be one area of work worth exploring. A second piece of work would be around the ability of the care workforce to recognise mental ill-health and respond appropriately. For some people their home carer may be their only point of contact but this workforce is massively ill-equipped to recognise the signs and indictors of mental health and mental illness. **Frances Simpson** agreed with Donald there was little research/literature concerning this.

Jan Beattie commented on the need to overcome the misconception and prejudice that says poor mental and physical health are an inevitable part of ageing. All agreed with this.

Adam Daly reminded everyone that we have a bigger opportunity here and that we shouldn't focus only on the impact of Covid. We need to explore why older people get different care than other adults and why older people's mental health isn't an area that health care professionals seem keen to work in, despite it being such a rewarding area of work. We also need to ask why our health services are not picking up on older people's mental health issues, when our hospitals are very good at picking up on many other things.

Conclusions and next steps

Claire Stevens reminded people that the 'falling off a cliff' metaphor came from *Support in Mind Scotland* and described the issue by whereby some older people lose their existing mental health services at the age of 65. She said that we should not forget VHS's previous three round tables' focus on transitions as a key pinch point that needs addressed.

Claire summed up the discussion, saying that VHS, the OU, Frances and Maureen would reflect on the discussions at the two round tables and agree some next steps. One of those would be to seek to convene the meeting with Donna Bell, head of mental health in the Scottish Government, that Covid had seen postponed last year. She also welcomed Frances' suggestion that a third round table be held later in the year in order to ensure there is no 'unfinished business', and she suggested a paper might be the focus of that meeting. She pointed out that the round tables had been very cross-sector, that we all have a good degree of influence in our own right and should use it, and that we can capitalise on that and the momentum created. She invited **Derek Goldman** to close the meeting, which he did by thanking everyone for their contributions, adding that it had been a rich discussion and that the task ahead was to be action focused.