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TRANSCRIPT OF "FILE ON 4" - "PSYCHIATRIC DRUGS"

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“FILE ON 4”

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NORTHAM: Around the country, more than 100,000 elderly people with dementia are being given a range of dangerous drugs which may be doing them no good at all. The drugs are not licensed for the treatment of their condition and they can cause drastic side-effects.

RAMSAY: That's him after taking the drug and you can see how twisted his neck is.

NORTHAM: His head is bent right down to his chest.

RAMSAY: Yes, and sideways. And you can see how painful it is at the back of the neck here.

NORTHAM: It's not only agonising and irreversible disabilities. These drugs can also trigger life-threatening conditions such as strokes and pneumonia. Official figures reveal that 700 patients have died as a result of these drugs in the UK over the past five years, and that may be a considerable underestimate. Yet doctors continue to prescribe them widely for dementia patients.

KENDALL: It's horrifying to think that there must be some GPs out there – and it clearly isn't a small number - giving these drugs routinely.

NORTHAM: File On 4 has found that prescription rates vary widely among doctors. Some never use these drugs for dementia patients, others almost always do. And we've also discovered that two of the drugs are still popular with doctors, despite an official warning four years ago that they should not be used to treat dementia.

SIGNATURE TUNE

TUOHY: She was fully functioning during the day. She'd get up, dressed, she'd go to the local church, meet her friends, have coffees. I mean, a couple of weeks before the event she'd made loads of cakes and pies for the annual bazaar.

NORTHAM: Marion Tuohy's mother, Peggy, was 81 when last November she was admitted to hospital for assessment. The problem was that she had become increasingly confused, particularly following a recent urinary infection. She was living with her daughter and was generally in good health and full of zest.

TUOHY: The day before she was admitted to hospital she was out shopping with a friend and bargaining with one of the men in the shops because she thought it was too much what she was paying for. So she was compos mentis, you know, maybe forget where her glasses were or her keys or something like that, but not that we couldn't communicate with her at all.

NORTHAM: The day after she was admitted to hospital, Peggy had a visit from her friend, Jennifer Downey, and what she saw left her profoundly disturbed.

DOWNEY: Peggy was sitting in the corner and I thought it wasn't Peggy, I thought it can't be Peggy. She was sitting, spread-eagled, that's the only way I could ... with her legs apart and her skirt had moved round so she was sitting in a very unladylike manner, through no fault of her own, and falling down in the chair. So I went across to a man, who I think was a nurse, filling in forms and asked him what they'd given her. I said, "What's happened to Mrs Tuohy?" And he said, "Oh, she was agitated," and I

NORTHAM: The doctor said that to you?

TUOHY: The doctor said that to me in A&E.

NORTHAM: Were you consulted about her being given an antipsychotic?

TUOHY: No, not at all. I didn't really know anything was wrong until the Saturday, when my mum's friend went up to see her and rang me immediately and said, "Marion, your mum's out of it."

NORTHAM: Later, when she was returned to the ward from A&E, the hospital put Peggy back on antipsychotic medication and her daughter Marion says she became a 'zombie' again. Peggy died five months ago of a blood clot near her lungs, not thought to be a by-product of the drugs. We asked the Hospital Trust concerned, St George's Healthcare in southwest London, for an interview about Peggy's treatment and why she was given such powerful prescriptions. Nobody was available, but in a statement the Trust says:

READER IN STUDIO: Mrs Tuohy's clinicians prescribed a number of drug treatments in an attempt to ease her agitated state. It is true that we did not inform Mrs Tuohy's family of all the drug treatments prescribed, and for this we have apologised.

NORTHAM: The hospital also says that Peggy's treatment was monitored and reviewed by senior clinical staff, who found no reason to criticise it. But her daughter Marion believes that the antipsychotic drugs over-sedated her mother.

TUOHY: I'm not a professional, but I think it was the medication, because I can't see how you can go from somebody who is functioning, a complete chatterbox, great sense of humour - yes she was 81, but she was a very with-it 81 year old - to somebody who is just shrinking in front of you and just, I don't know, just not your mum. It was heartbreaking for me and her friends. They'd ring up. Some friends stopped going to see her because they couldn't bear leaving her there, because you just felt there was no improvement, no sense that she was comfortable, just that she was tormented.

NORTHAM: While they're not licensed for the treatment of symptoms of dementia, antipsychotic drugs are frequently prescribed for patients suffering them. A widely-accepted estimate of the use of these drugs has been calculated by Professor Clive Ballard of King's College London, who's Director of Research for the Alzheimer's Society. Professor Ballard's figures are adopted by the All-Party Parliamentary Group on Dementia and they point to a substantial national problem.

BALLARD: In the UK the best estimate is probably somewhere between 100,000 and 150,000 people with dementia prescribed anti-psychotics.

NORTHAM: And of them, how many do you believe don't need to take these drugs?

BALLARD: Probably about 70% of them don't need the drugs. The National Institute for Clinical Excellence, NICE guidelines on the prescribing of these agents suggests that they should only be prescribed for a severe and persistent aggression that hasn't responded to other treatments, and when there's a potential of risk to that person or others, and certainly from my own clinical experience it isn't the case that prescribing is usually restricted to the individuals with that level of need.

NORTHAM: That means 70,000 to 100,000 elderly people are being given these drugs who shouldn't be?

BALLARD: That would be exactly my estimate of the situation.

NORTHAM: Those are huge figures.

BALLARD: Enormous figures, and I think the perplexing thing about this large level of largely unnecessary prescribing is that, despite that many of the kind of hazards and risks of this have been clear for five years or longer, there has been very very little change in the rates of prescription.

NORTHAM: There are a total of nine atypical anti-psychotics in common use, and when the whole class of them was examined by the Government's

NORTHAM cont: advisory body NICE - the National Institute for Health and Clinical Excellence - it said they should be used only for people in severe distress or at immediate risk of harm to themselves or others. NICE's review was led by Dr Tim Kendall.

KENDALL: I would like to see a serious warning go out with these drugs, that the use of these drugs for people with dementia should be a rare event. We do say that these drugs should only be used in very limited circumstances, so you might say, for ordinary people with dementia you shouldn't be using these drugs - and we do say that. We say that in the routine treatment of people with dementia you shouldn't be using anti-psychotics. Now we know from some of the places we've seen round the country where they provide really comprehensive care for people with dementia, the use of these drugs is so low it's sometimes non-existent. Now if it's possible there, it should be possible elsewhere.

NORTHAM: File On 4 asked the research company, Medix, to question GPs throughout the United Kingdom about their prescribing habits with antipsychotic drugs for dementia patients. 355 of the doctors who take part in the company's research replied. Only fifteen of them say they would never use these drugs for such patients. The rest cite a number of symptoms for which they would - most often aggression, then inappropriate behaviour, disinhibition, wandering or being noisy. GPs tell us:

READER IN STUDIO: Nursing these patients can be very difficult when they are aggressive, violent, hurting other residents and staff. There needs to be some medication we can use, otherwise physical restraint may be the only measure.

READER 2 IN STUDIO: Sometimes some sort of sedating medication is needed for a while for everyone's safety.

READER 3 IN STUDIO: If we cannot use these drugs what are we supposed to do?

NORTHAM: Another finding from our questionnaire to GPs may cause some surprise. We asked what proportion of their dementia patients they give an antipsychotic drug. Their average answer is 15.7% - just under one patient in six. But the range of their answers is wide, from zero - doctors who don't give any dementia patient these drugs - up to 90% of such patients. Representing NICE, Dr Kendall finds this unacceptable.

KENDALL: It's horrifying to think that there must be some GPs out there - and it clearly isn't a small number - that there's a sizeable proportion of GPs who are giving these drugs routinely. I mean, if it's 90% of cases they're giving them out, is an awful indictment.

NORTHAM: What would you say to a GP who was prescribing antipsychotic drugs for 90% of their dementia patients?

KENDALL: Personally, I think it should be a professional matter and it should be the GMC. There is absolutely ...

NORTHAM: The General Medical Council?

KENDALL: The General Medical Council.

NORTHAM: You mean the doctors should be disciplined?

KENDALL: I think the doctors should be disciplined. A doctor prescribing for 90% of their patients an antipsychotic when there is enough guidance out there to say don't do it, it's unacceptable, and I do think that should be a disciplinary matter.

NORTHAM: The principal reason for NICE's caution about antipsychotic drugs for dementia patients is that their side-effects can be extremely serious, even fatal. Professor Clive Ballard argues that with many patients the risk of using them is too high.

BALLARD: There's now very good evidence that they can very substantially increase the risk of stroke, they almost double the risk of death while people are taking these drugs, and that they also lead to a number of other serious problems such as chest infections that can lead to pneumonia, that maybe some of the reasons why death is increased with these agents.

NORTHAM: And the risk of death is almost doubled for an elderly person with dementia?

BALLARD: Yes. There are a number of studies which show very clearly that the risk of death is about 1.7 or 1.8 fold increased compared to people not taking those drugs.

NORTHAM: Figures released to File On 4 from the Yellow Card scheme for Adverse Drug Reactions, run by a Government agency, show that the whole class of these drugs has caused 700 deaths across the UK in the past five years. And those are just the cases which have been reported. If antipsychotic drugs can cause life-threatening conditions like stroke or pneumonia, these are of particular concern for the vulnerable elderly. They certainly troubled the family of 86 year-old Lily Frost.

VICKERS: I have some pictures here taken two weeks before my mother went into hospital. She's laughing and joking. The young carer there, this young lad, she thought he was absolutely great, didn't she? They really got on.

NORTHAM: Last year, Lily's daughter Brenda became concerned about the condition of a surgical metal plate that had been put into one of Lily's legs. Lily was admitted to hospital, where visitors found her unaccustomedly drowsy. Unknown to her family, while she was on the ward, Lily had been prescribed the antipsychotic drug, Olanzapine.

VICKERS: I didn't find out until two or three weeks after she'd been discharged from the hospital, and it was because she went back to the residential care and the carers were concerned because she was a totally different person, she was sleeping all the time and I found that she was on Olanzapine.

NORTHAM: Did you know what that was?

VICKERS: Not at that point, no. I went home and looked it up on the computer and found out that it was an antipsychotic drug and that it should not be given to elderly patients with dementia, so I was extremely upset.

NORTHAM: What were your concerns when you discovered that your mother had been given this anti-psychotic drug?

VICKERS: Mainly the warnings that I'd read that it can cause strokes, pneumonia, and that it should not be given to elderly patients with dementia.

NORTHAM: And yet your mother was elderly and had dementia.

VICKERS: My mother was 86 and she'd been attending the memory clinic at the Countess of Chester hospital for about five years.

NORTHAM: The leaflet published by the manufacturer of Olanzapine warns that it is not recommended for elderly patients with dementia because of its side-effects. Brenda's concern intensified a few weeks later when her mother's condition took a sudden turn for the worse.

VICKERS: We received a phone call from the care home saying that my mother had been taken to hospital because it seemed that she'd had a mild stroke. So we went straight to the hospital.

NORTHAM: Was she suffering from anything else?

VICKERS: She'd had a stroke and she had pneumonia and hypothermia.

NORTHAM: So you knew that possible side effects of this drug were stroke and pneumonia and then your mother had a stroke and pneumonia?

VICKERS: Yes.

NORTHAM: And what did you think?

VICKERS: I was just so upset. All the doctors there knew that I was thinking that it was this drug that had done the damage.

NORTHAM: Lily Frost died last October, three weeks before her 87th birthday. Her death certificate records the cause as peritonitis - not her stroke or pneumonia. File On 4 asked the NHS Trust concerned, the Western Cheshire Primary Care Trust, to comment on her daughter Brenda's account of her treatment. Nobody was available for interview. In a statement, the Trust says:

READER IN STUDIO: The patient was treated with this particular drug because she was agitated. The doctor prescribed a very low dose, having carried out a risk assessment, and concluded that this was the most appropriate drug, because the benefits of prescribing it outweighed any risks.

NORTHAM: The Trust is unwilling to comment on Lily's stroke or pneumonia because her case is the subject of an ongoing complaint. Concern that these hazardous drugs may be extensively over-used reaches up to the Department of Health, where the Care Minister is Ivan Lewis.

Does the Government accept what a number of experts tell us, which is that these drugs are widely over-prescribed to people who don't need them?

LEWIS: Well, I think the Government accepts there is growing evidence to that effect and that it's not acceptable. There is clear guidance out there for GPs in terms of what drugs can be prescribed in these circumstances. If they're blatantly ignoring it, then in my view that's a breach of best professional practice and we cannot accept that.

NORTHAM: In the questionnaire that we sent out, which 355 GPs responded, some GPs make it clear that they use these drugs for most of their dementia patients, even up to 90% of their dementia patients. Is that tolerable?

LEWIS: Well, I think we need to separate out two issues here. First of all, prescribing drugs which are simply not acceptable in any circumstances, and clearly there can be no excuse for that. And then there is the inappropriate prescribing of drugs which are accepted but only in certain circumstances, and we have these two issues, frankly, coming together, and I am now focused on ensuring that the national strategy has to address this issue of inappropriately prescribing drugs.

NORTHAM: These concerns led to a recent inquiry by the All-Party Parliamentary Group on Dementia. It looked into the misuse of antipsychotic drugs in care homes. The Group's conclusion about them is summed up in the title of its report – 'Always A Last Resort'. The chairman, Conservative MP Jeremy Wright, also found the evidence persuasive that there is widespread over-prescription.

WRIGHT: Antipsychotic drug medication is being prescribed to keep people quiet. It's not being prescribed for a therapeutic purpose, it's not being prescribed even for a medical purpose, it's being prescribed because of the absence of other coping mechanisms. And staff who are overworked and will find themselves in care homes that are undermanned will resort to this, because it's the only way of dealing with potentially difficult people who live there exhibiting challenging behaviours of all different kinds.

NORTHAM: You say that staff may even exaggerate the problem they are facing with a particular resident in order to get the GP to respond with a prescription?

WRIGHT: Well, this is the evidence which we've had from some clinicians, and it's by no means, I think, an argument that this happens in the majority of cases. But I think it's easy to understand how staff at the end of their tether may say, "We need to do something here, we need to find a way of managing these people," and perhaps late at night, where it's very difficult to get access to any kind of specialist support, they do say, "We desperately need to have a prescription for an antipsychotic drug."

NORTHAM: The doctors who responded to our questionnaire suggest that it is often the case that the decision to give a patient an antipsychotic drug is taken not by a doctor at all. The drugs can be prescribed by GPs for care staff to administer 'as needed'. 144 (that's 45%) of the doctors who replied about this said they do prescribe antipsychotic drugs on this basis, leaving care workers to decide when the drugs should be given. Across England, the quality of care homes is monitored by the Commission for Social Care Inspection. Its Head Pharmacist, Hazel Sommerville, argues that significant cuts in prescription rates could be achieved - and have already been achieved across the Atlantic.

SOMMERVILLE: The Americans approach this from a two-fold angle, both are through federal law. Firstly, they've described a range of diagnosis that a doctor may prescribe an antipsychotic drug for, and they also detail the dose and length of treatment etc. It's really very precise clinical standard of management. But secondly, they have stated in law that everyone has the right to be free from chemical restraint imposed for the convenience of others. And to support that stance, they require the long term nursing facilities to arrange for a pharmacist to conduct medication review of every patient once a month.

NORTHAM: And what's been the effect of this legislation in America on the prescribing practice of these anti-psychotics?

SOMMERVILLE: Remarkable reduction, to about a third of the number of people who need these antipsychotic drugs. And I've read in many papers their description of people waking up, having a better quality of life.

NORTHAM: As it were, coming round?

SOMMERVILLE: As it were, coming round. But we have had a study in the UK that was conducted in Glasgow and they replicated the processes of the USA federal law in nursing homes around Glasgow and they reproduced the results.

NORTHAM: They got the same success rates?

SOMMERVILLE: They got the same success rates as ...

NORTHAM: A reduction to a third?

SOMMERVILLE: A reduction to about a third of what had previously been prescribed, and that was the number of people that it was felt relevant and appropriate to prescribe these drugs for.

NORTHAM: The project in Scotland found that 88% of antipsychotic prescriptions for dementia patients were inappropriate. The results were published in 1996, but had no impact on national practice. Improvements in two particular aspects of care home practice is thought to be vital in cutting the over-use of antipsychotic drugs. Better care planning for individual residents and better procedures for medication. Repeatedly, year after year, the Inspectorate finds that the worst performance overall is in precisely those two factors - care planning and medication. 40% of the homes inspected fail to meet the national standards. Independent care home owners are represented by the National Care Association. Is the Chief Executive, Sheila Scott, able to explain why standards of care planning and medication control seem so low?

SCOTT: The handling of medication is to me quite straightforward. Medication is prescribed, it's up to the care home to appropriately train their staff and make sure that the records are properly kept.

NORTHAM: And 40% of them are failing year by year. That's from the Inspectorate statistics.

SCOTT: That's a responsibility, there's a serious responsibility around that I'm not denying that. But it's the care planning that's of particular interest to me.

NORTHAM: And 40% fail that too.

SCOTT: Yes, and care planning is something that the National Care Association itself is concentrating on this year, and perhaps some care homes have failed to keep up with the latest developments.

NORTHAM: Well there's no perhaps about it. 40% of them are failing to meet the national standard of care planning and 40% are failing to meet the national standard for medication.

SCOTT: I'm not going to respond to that just for a moment, because I didn't know it was those figures.

NORTHAM: I've got the figures. Do you want me to show ...?

SCOTT: No, no, I've read the book, I've just

NORTHAM: Well let me put the point to you again, that 40% of care homes are failing on care planning, and 40% are failing on control of medication. Those are the two crucial areas to reduce over-prescription of these drugs.

SCOTT: The failures within medication, this is by and large a recording issue and it's something that care homes need to get a serious grip of. I'm not dodging that, and I do believe that by and large it's a failure to record properly, and I think the regulator would agree with that.

NORTHAM: Failures in the handling of medication aren't confined to the often-criticised care homes. A hospital and a respected charity are blamed by Lynn Ramsay over their treatment of her husband David, who was given an antipsychotic drug and then developed one of its recognised - and extremely distressing - side-effects.

RAMSAY: It caused something called tardive dystonia, and that means that your chin drops on to your chest and, in fact, in his case it also twisted at 90 degrees to the left.

NORTHAM: And gets stuck?

RAMSAY: It's absolutely irreversible.

NORTHAM: You've brought with you a couple of photographs, this one a portrait, that's before he was given the drug.

RAMSAY: Yes, yes, that's him looking normal.

NORTHAM: And this one?

RAMSAY: That's him after taking the drug and you can see how twisted his neck is.

NORTHAM: His head is bent right down to his chest.

RAMSAY: Yes and sideways. And you can see how painful it is at the back of the neck here and how taut all the muscles are.

NORTHAM: What did you think when you saw this happen to him?

RAMSAY: I was horrified. More so, because I had written to everyone. I understand that all medicine is risk management, and if there is a potential benefit for the patient then there might be an acceptable risk in giving medication, particularly as this medication has never been licensed for this disease, and when the medication was being trialled it is a known side effect. Had it improved his quality of life it might have been a risk worth taking. There was no chance this would ever improve his quality of life. It had a massive negative impact.

NORTHAM: The NHS Trust concerned, Oxleas Foundation Trust in southeast London, wouldn't be interviewed by File On 4. In a statement, the Trust says that David Ramsay was given Olanzapine to alleviate agitation and distress. It says, if the dystonia that affected Mr Ramsay was induced by the drug, then that is a very rare consequence of its use. One of Lynn Ramsay's main points of complaint is that she wasn't consulted or even informed about his being given the drug. The NHS Trust has told us that he himself understood and agreed to the treatment. But Mrs Ramsay says that her previous visit with him to another specialist hospital casts doubt on his capacity to make such a decision, because there she had to give consent for him.

RAMSAY: There is no way that he could have consented to have the drug. The day before, I had given permission for them to take some blood from him because he wasn't in a position to be able to give that decision himself.

NORTHAM: But the Hospital Trust is saying he gave consent to this antipsychotic drug being given to him.

RAMSAY: Well he wasn't present at the meeting when the decision was made. He was at the day centre. There was nobody at the meeting as far as I can make out who was there to represent him. I have no idea how they came to this.

NORTHAM: How long did he stay on the drug?

RAMSAY: He was on the drug about six, seven months.

NORTHAM: David was living under local authority care and attending a day centre. His wife Lynn is also concerned at the way he was given his medication. It's not uncommon for dementia patients to have drugs slipped into their food or a drink. If this is done with their consent, or a carer's consent, there may be nothing wrong with it. But Mrs Ramsay says there was no such consent in this case.

RAMSAY: He refused to take it and therefore they crushed it into a powder and put it in his yogurt without telling him.

NORTHAM: How did you find out that he was being given this drug and that he was being given it without his knowledge - covertly?

RAMSAY: I used to go and visit him every night and I saw this packet of medication there one night, and having found the medication I noted down the name and the very next day I rang the National Neurological Hospital saying, "What is this medication? "hy would he be given it, and is this a good idea?" And then the process started where I was told it was inappropriate treatment.

NORTHAM: Mrs Ramsay complains that the drug was slipped into her husband's yogurt at a day centre he attended run by the support group, MIND. We contacted MIND in Bromley asking for an interview. Nobody was available. But the organiser did tell File On 4 that they had investigated this complaint and a member of staff had admitted that she had concealed the medication in David Ramsay's food. MIND says this was unacceptable and the staff member was reprimanded. The drug David Ramsay was given, Olanzapine, was later the subject of an official warning sent out to UK doctors by the then Committee on Safety of Medicines. It considered the evidence of danger from two

MORRISON: It's advice, and they bring out guidelines and that's what they are. There are many circumstances in medicine where doctors use drugs out with guidelines, out with the evidence, and sometimes there isn't the evidence to tell you what to do.

NORTHAM: It seems odd, doesn't it, to have a national Government agency which looks into drugs and says these two specifically should not be used because of the risks they pose, and then doctors are still using them?

MORRISON: I'm not going to pretend for one minute that every single incidence of the usage of those drugs in the face of that advice is appropriate and, you know, I would say that training in the use of these drugs is absolutely key - or more importantly perhaps, training in the use of other things, including non drug treatments.

NORTHAM: The widespread use of these two named drugs came as little surprise to other experts we spoke to. When I asked them to name the most commonly prescribed anti-psychotics, Risperidone and Olanzapine were frequently mentioned. So how does the Care Minister, Ivan Lewis, respond to the news that these two drugs are still in common use for dementia, despite an official warning?

LEWIS: It shouldn't be happening. I'm not a doctor, I'm not a clinician, but as a minister I do have responsibility for ensuring that the guidance that is issued by professionals who do understand these issues is followed. What I have to do though now is decide on the most appropriate action to put this right.

NORTHAM: Well this has been going on for four years. Shouldn't the Government simply enforce a warning of that urgency that's put out by its own advisory council?

LEWIS: Well, for example, certainly that is one of the issues that I will be considering - how do we toughen enforcement in this area. But equally I think I have a responsibility to get to the bottom of the scale of the problem. You have produced some very powerful and damning facts this week. The all party group has done so also within the last few months. Primary Care Trusts, for example, are supposed to keep an eye on the prescribing patterns of GPs within their areas, so we do have an audit trail potentially back to look at where GPs are inappropriately prescribing.

NORTHAM: Is it time to start punishing GPs who over-prescribe these drugs?

LEWIS: Well, it's time to say that any profession must be accountable for its action, and if we send a message that somehow older people with dementia don't matter, and GPs can behave in, frankly, in some circumstances, in an unprofessional way, what are we saying about the way we care about such vulnerable and frail older people? It cannot be accepted. So, of course, if people do not uphold best professional practices, then there should be disciplinary consequences.

NORTHAM: The Government's National Dementia Strategy is expected to be finalised by the autumn. The Minister agrees that the continuing use of antipsychotic drugs is simply indefensible for many of the rapidly-growing number of people who merely slip into dementia in their final years.

LEWIS: This is about my mother and father, your mother and father, other people's. We wouldn't tolerate it for our families. We shouldn't tolerate it for people, many of whom are in care homes, some of whom won't have any family members involved in their lives any more. Last summer I said that I was committed to bringing dementia out of the shadows. Far too many families had been let down by the system. Till now, it's a condition that, frankly, we haven't given sufficient attention to – not just as a Government, but as a health service, as a society. We are stepping up to the mark now and the question of antipsychotic drugs is clearly one of the most important issues – in terms of the human rights of people with dementia, let alone the peace of mind of family members.

SIGNATURE TUNE