



Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

Cofnod y Trafodion The Record of Proceedings

[Y Pwyllgor Iechyd, Gofal Cymdeithasol a
Chwaraeon](#)

[The Health, Social Care and Sport Committee](#)

21/09/2017

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Motion under Standing Order 17.42 to Resolve to Exclude the Public
from the Remainder of the Meeting

Cofnodir y trafodion yn yr iaith y llefarwyd hwy ynnddi yn y pwyllgor. Yn ogystal, cynhwysir trawsgrifiad o'r cyfieithu ar y pryd. Lle y mae cyfranwyr wedi darparu cywiriadau i'w tystiolaeth, nodir y rheini yn y trawsgrifiad.

The proceedings are reported in the language in which they were spoken in the committee. In addition, a transcription of the simultaneous interpretation is included. Where contributors have supplied corrections to their evidence, these are noted in the transcript.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Rhun ap Iorwerth Bywgraffiad Biography	Plaid Cymru The Party of Wales
Jayne Bryant Bywgraffiad Biography	Llafur Labour
Caroline Jones Bywgraffiad Biography	UKIP Cymru UKIP Wales
Dai Lloyd Bywgraffiad Biography	Plaid Cymru (Cadeirydd y Pwyllgor) The Party of Wales (Committee Chair)
Julie Morgan Bywgraffiad Biography	Llafur Labour
Lynne Neagle Bywgraffiad Biography	Llafur Labour

Eraill yn bresennol
Others in attendance

Tim Banner	Fferyllydd Ymgynghorol, Bwrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro Consultant Pharmacist, Cardiff and Vale University Local Health Board
Yr Athro/Professor Sue Jordan	Athro, Coleg y Gwyddorau Dynol ac Iechyd, Prifysgol Abertawe Professor, College of Human and Health Sciences, Swansea University
Helen Payton	Gweithiwr Cymorth Dementia, Cymdeithas Alzheimer's Cymru Dementia Support Worker, Alzheimer's Society Cymru
Sue Phelps	Cyfarwyddwr Gwlad, Cymdeithas Alzheimer's Cymru Country Director, Alzheimer's Society Cymru

Sarah Rochira Comisiynydd Pobl Hŷn Cymru
Older People's Commissioner for Wales

Suzanne Tarrant Seicolegydd
Psychologist

Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol
National Assembly for Wales officials in attendance

Amy Clifton Y Gwasanaeth Ymchwil
Research Service

Sarah Sargent Dirprwy Glerc
Deputy Clerk

Sian Thomas Clerc
Clerk

Dechreuodd y cyfarfod am 09:30.
The meeting began at 09:30.

Cyflwyniad, Ymddiheuriadau, Dirprwyon a Datgan Buddiannau
Introductions, Apologies, Substitutions and Declarations of Interest

[1] **Dai Lloyd:** Bore da i chi i gyd a chroeso i gyfarfod cyntaf y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon y tymor newydd hwn. O dan eitem 1, a allaf i groesawu fy nghyd-Aelodau? Rydym ni wedi derbyn ymddiheuriadau oddi wrth Dawn Bowden ac Angela Burns, ac nid oes neb yn dirprwyo yn eu lle. Mae hefyd Julie Morgan wedi datgan ei bod hi'n mynd i fod yn hwyr y bore yma. Bydd hi'n ymuno efo ni maes o law. Nid oes neb angen datgan buddiant, rydw i'n cymryd. A allaf i bellach egluro bod y cyfarfod yn

Dai Lloyd: Good morning to you all and welcome to the first meeting of the Health, Social Care and Sport Committee of this new term. Under item 1, may I welcome my fellow Members? We have received apologies from Dawn Bowden and Angela Burns, and we don't have any substitutions. Julie Morgan has also said that she is going to be arriving late this morning. She will be joining us soon. Does anybody need to declare an interest? No. May I now explain that the meeting is bilingual? Headphones can be used for

naturiol ddwyieithog a gellir defnyddio clustffonau i glywed cyfieithu ar y pryd o'r Gymraeg i'r Saesneg ar sianel 1, neu i glywed cyfraniadau yn yr iaith wreiddiol yn well ar sianel 2? A allaf i atgoffa Aelodau i naill ai ddiffodd eu ffonau symudol ac unrhyw gyfarpar electronig arall, neu eu rhoi nhw ar y dewis tawel? Yn bellach, a allaf i hysbysu pobl y dylid dilyn cyfarwyddiadau'r tywyswyr os bydd larwm tân yn canu?

simultaneous translation from Welsh to English on channel 1, or to hear contributions in the original language better on channel 2. May I remind people to either turn off their mobile phones and any other electronic equipment or switch them to silent? Further, may I inform people that we should follow the directions from the ushers should we have a fire alarm?

09:31

**Defnydd o Feddyginiaeth Wrthseicotig mewn Cartrefi Gofal—Sesiwn
Dystiolaeth 1—Comisiynydd Pobl Hŷn Cymru
Use of Antipsychotic Medication in Care Homes—Evidence Session 1—
Older People's Commissioner for Wales**

[2] **Dai Lloyd:** Felly, gyda chymaint â hynny o ragymadrodd, symudwn ni ymlaen i eitem 2, ac ein hymchwiliad i'r defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal. Dyma sesiwn dystiolaeth rhif 1, y sesiwn dystiolaeth gyntaf, ac o'n blaenau ni mae'r comisiynydd pobl hŷn, Sarah Rochira. Croeso. Bore da i chi. Rydym ni wedi derbyn eich papur, yn naturiol, ac wedi ei ddarllen mewn manylder ac wedyn, fel yr ydych chi'n gwybod erbyn rŵan, mae yna gyfres o gwestiynau wedi cael eu paratoi, ac felly byddwn ni'n mynd yn syth i mewn i gwestiynau, gyda'ch caniatâd. Felly, mae'r cwestiynau cyntaf o dan ofal Rhun ap Iorwerth.

Dai Lloyd: So, with those words of introduction, we'll move on to item 2, and our inquiry into the use of antipsychotic medication in care homes. This is evidence session 1, the first evidence session, and before us we have the Older People's Commissioner for Wales, Sarah Rochira. Welcome. Good morning. We have received your paper, naturally, and we have read it in great detail and, as you know by now, there are a series of questions that have been prepared, and therefore we'll go straight into questions, with your permission. The first questions are from Rhun ap Iorwerth.

[3] **Rhun ap Iorwerth:** Diolch yn fawr iawn, Cadeirydd, a bore da. Mae'n werth nodi eich bod chi, bod Comisiynydd Pobl Hŷn Cymru, wedi datgan cryn bryderon ynglŷn â'r sefyllfa o ran defnydd cyffuriau gwrthseicotig yn y gorffennol, gan gynnwys yn yr adroddiad 'A Place to Call Home?' yn 2014, ac wedi ysgrifennu at y pwyllgor. Ond tybed a allech chi grynhoi eich prif ganfyddiadau chi yn ogystal ag unrhyw ddiweddariadau ers i chi fod mewn cyswllt efo'r Cynulliad yn y Cynulliad diwethaf ynglŷn â graddfa'r broblem yr ydym ni'n ei hwynebu?

Rhun ap Iorwerth: Thank you very much, Chair, and good morning. It's worth noting that you, as the older people's commissioner, have stated a great deal of concern about the use of antipsychotics in the past, including in the report 'A Place to Call Home?' in 2014, and have written to the committee. But could you please summarise your main findings, as well as any updates since you've been in contact with the last Assembly about the scale of the problem that we're facing?

[4] **Ms Rochira:** Okay. Bore da, good morning. Thank you. Perhaps what I might do by way of answering that is just very briefly take us back to the original review and what I found, because where we started on this was important, and then what I can do is provide you with an overview of the issues that came up in my follow-up work. Okay, so, just to take us back to where this began, very briefly: three years ago I published 'A Place to Call Home?' It was focused into the quality of life of older people in our care homes. I focused on that very carefully because I wanted to focus as much on the emotional as the physical aspects of their life. We all talk about well-being now, but at the time nobody was really talking about well-being, particularly in relation to care homes.

[5] I was deliberately open in my approach. I wanted to hear from people living in homes, people working there, professionals, and others what they thought the issues were. So, I didn't pre-empt any outcomes. I spoke about a whole range of things, good and bad, in the report, but I made a number of key observations within that. These seemed to me, if you like, the stark facts that sat above what I was finding. One of those was that the emotional needs of older people weren't fully understood or recognised. Too many older people faced an institutionalised approach—task-based approach—to care. The value base that we would expect to see was missing. I spoke about emotional and communication needs often being misunderstood or neglected—a lack of meaningful social contact. I spoke about many being afraid, bewildered, grieving, distressed, but too frequently being labelled as

‘challenging’ or ‘difficult’. And wherever I use the phrase ‘challenging or difficult’, please take it to be in parentheses. It is our observation, not necessarily their experience. I spoke about a managerial, controlling culture rather than an enabling culture.

[6] Now, in part, one of the reasons I drew that observation was because of the evidence that I received in relation to the use of antipsychotic drugs. So, I received evidence from professional bodies, I received evidence from my rapporteurs, who came back to see me—particularly those who had clinical pharmacology backgrounds—and also, I took evidence, which I was very taken by, from 1000 Lives Plus, who said to me that they felt this wasn’t, but it needed to be, a top priority for health boards. They felt that good practice wasn’t spreading fast enough, and their view, in line with many published reports, was that up to 70 per cent of prescribing was inappropriate. Now, it’s not just the level of inappropriate prescribing, it’s the impact upon people, and I’m very happy, after this question, if you want to ask about the impact, to talk about that, because that’s really, primarily, where my focus is—scale, yes, but impact. So, what I did when I published my report was I focused two of my requirements for action around this area. One was in relation to health boards publishing data about the use of antipsychotics, but that data needs to be benchmarked against the good practice guidance we have, which is the National Institute for Health and Care Excellence.

[7] The other one was a slightly wider, but intrinsically linked, issue about the importance of medication reviews, particularly when somebody comes into a home, and on a regular basis. So, it was a hugely disturbing finding, and antipsychotic drugs sat, if you like, in no small part at the heart of that, and were a reflection of what I found. When I published the review, I made it very clear I was looking for stronger corporate prioritisation, more effort and action, and a stronger focus on outcomes. I’ve worked with people over subsequent years, but I was also very clear I would come back and look at this again. I’ve just finished that piece of work. I’ll be publishing it in the next few months. It would be inappropriate, probably, to comment on individual health boards, but there are, I think, some very significant observations that hold true in no small part across Wales. So, if I might, I’ll share those with you.

[8] So, let’s start with the positive. Well, all the health boards responded to me. All the health boards confirmed that they do follow NICE guidelines. That is positive, although one might argue one would hardly expect them to say otherwise. All health boards made reference to some activity in respect of

reviewing prescribing in relation to antipsychotics, and things such as training of care home staff in relation to non-pharmacological interventions—so, psychosocial interventions. Some made reference to multidisciplinary approaches—very important. One health board made reference to the development of inreach community psychiatric teams—good practice, really important. Some health boards are now beginning to develop—and this is particularly important—preventative services, and there was some encouraging evidence about training and education for staff, and I don't take away from that.

[9] However, there was little evidence of activity taking place across health boards. Where it was there, it was small area work, limited in scope, not sufficient scale. A small number of examples of good practice does not equate to really robust, strategic roll-out of good practice, and I have concerns that there's not an equitable approach in terms of the interventions that are taking place between nursing homes and residential care homes. Furthermore, I thought there was generally little evidence about the benefits or impacts of the interventions upon individuals, and I was really clear in my request for evidence that's what I was looking for and that was what it was all about. I didn't see a strong enough focus on the use of skills of allied health professionals. So, if you think about things like communication difficulties, which often sit behind so-called challenging behaviour—the role of speech and language therapists, the role of occupational therapists and many others—I didn't see enough focus on skills sharing and leaving a sustainable legacy within care homes, where knowledge and competencies were raised, not just while the intervention was taking place, but on a sustainable basis overall. And, finally, I got little sense of oversight at a strategic or senior corporate level, and almost no evidence of data being collected that would enable us to answer the question once and for all: actually, what is the scale of the problem? But, as I say, it's not just scale, it's impact—not sufficient by way of a Welsh approach, I have to say.

[10] **Rhun ap Iorwerth:** And, in terms of outcomes, you have previously stated that Wales should be following England's lead in setting very ambitious targets of cutting inappropriate use of psychotic medication by two thirds. Is that something you still think is an achievable aim?

[11] **Ms Rochira:** I'm not sure I've ever said we should follow England's example. Actually, I think what I do say is we should set ourselves the very highest standards that are in line with, actually, our Welsh values. These are some of the most vulnerable people, some of the most voiceless, powerless

people I have met in my five years as commissioner. We should be at our very best for all of them. I'm really clear on what the final outcome in relation to this should look like. If you're living in a care home, you should be receiving antipsychotic drugs—if you do receive them—in full line and full compliance with NICE guidelines. And I guess, in a sense, that's my ultimate question to health boards, Welsh Government and others: when will we be compliant in Wales with those NICE guidelines—full compliance?

[12] **Rhun ap Iorwerth:** And, in terms of the picture throughout Wales, you've already said that you think that there's evidence that this is a problem throughout Wales. Is the inadequacy of response also equally spread throughout Wales?

[13] **Ms Rochira:** Pretty much so, I would say, and I was very careful when I sought the additional evidence. Sometimes it's really difficult to know what somebody's asking for, so I was very clear in terms of what I was looking for. I gave people a pro forma; I gave people guidance notes; I also gave them a worked example in relation to another area about what a good response would look like. So, pretty much across the board, the responses I received were not good enough and, I would say, pretty much across the board I didn't get a sense of strategic prioritisation: limited action—some good action, but far too limited—and almost no hard data. And the hard data we did have was really meaningless in terms of being able to interpret it and learn anything from it.

[14] **Rhun ap Iorwerth:** And we will learn more about this in depth when you publish your review within a few months.

[15] **Ms Rochira:** You absolutely will. Everything that I have received, everything that I send, is placed in the public domain, but every individual health board will have detailed feedback from me as well, making clear both my future expectations, but also trying to assist them in where I think they need to improve.

[16] **Rhun ap Iorwerth:** Okay, thank you. Diolch.

[17] **Dai Lloyd:** Diolch. Mae'r ddau **Dai Lloyd:** Thank you. The next two gwestiwn nesaf o dan ofal Caroline Jones are from Caroline Jones.

[18] **Caroline Jones:** Diolch. Good morning, Sarah, and thank you for your

evidence. You recommend, in your evidence, that multidisciplinary team services are made available to all residents in care homes. What is the current situation regarding access to a range of allied health professionals such as speech and language therapists, and are you aware of any particular issues in different parts of Wales or in relation to certain professionals, for example?

[19] **Ms Rochira:** Thank you. You are absolutely right. I do, and I have highlighted the crucial role of allied health professionals and, as I mentioned earlier, particularly people like speech and language and occupational therapists, but others as well. They are one of the preventative front lines that we have to avoid the use of antipsychotic drugs. Now, I haven't done a detailed audit across Wales. That was not my role and outside of my gift, but I can share with you some of the observations that people have shared with me.

[20] So, talking to many professionals across Wales, they know there is far more they can do and would like to do, but they are not resourced to do it. I suspect, as with most things, it is hugely variable; it will depend on where you live within Wales. But also quite telling are conversations I had with a consultant and a GP, who said to me, 'Sometimes we know that perhaps prescribing this antipsychotic drug is not the best thing to do, but we have nothing alternative to offer. So, in terms of acting in the best interest, this is what we can do. It is not what we would like to do, it is not what we think we should be doing, but it is for the lack of anything else to offer.' So, in terms of what do we need to improve and change in Wales, we absolutely need to invest in those wider support multidisciplinary teams that are wrapped around the home, if you like, so the home can access those on that preventative level.

[21] Now, I know some people will say to me, 'Oh, you are talking about investment again, commissioner. We live in times of severe resource constraint.' Well, my answer to them is, 'Actually, I don't accept that.' We are spending a huge amount of money on antipsychotic drugs, both directly and indirectly, because of the negative impact they have on people's health. I read some really interesting research—I'm really happy to share this with you—that said, for every £1 you spend, you save up to, I think it was, £3.50. Now, that's just direct costs. If you think about savings in terms of lack of strokes, people who then don't fall—. We're spending a fortune on poor practice; far better, in my view, if we spent less money on good practice and better outcomes for individuals.

[22] **Caroline Jones:** Yes, and because you've said about the holistic approach, haven't you, with the multidisciplinary teams, so—

[23] **Ms Rochira:** And I would say what's so interesting about the preventative, multidisciplinary, non-pharmacological, psychosocial approach is how low cost much of it is, and, if I may, I'll just share one example. Would that be all right with you—just to make it real? Because there's a lot of jargon in this, which I can't really avoid, but it makes it real. So, I was told about a gentleman in a care home. This is what good practice looks like. A gentleman in a care home, he seemed very distressed, very agitated, very angry; he was banging his head against a glass door constantly. Nothing the staff seemed to do would calm him down. He was becoming a risk to himself and a risk to others. So, at this stage, you might start to think that maybe there is a role for antipsychotic drugs, but a canny member of staff began to question why it was the same door every single time—nowhere else; it was just this area where he became agitated. So, to cut a long experience short, it turns out, when they spoke to his relatives, that this gentleman had been a keen gardener all his life. He had a greenhouse; it was the love of his life; it was the place, I suspect, he snuck off to when everything else was too much and too noisy. It was his safe place. So, he goes into a care home; he's frightened, he's distressed, he's anxious, and he sees through the door a greenhouse—the one place he's not allowed to go, because he's not allowed to go out the business. So, instead of prescribing antipsychotics, they helped him go back out to the greenhouse, and it became his safe place in a world of turmoil and horror, in no small part, for him, and his behaviour changed completely. That's what complying with NICE guidelines looks like, and I do not believe that that costs anywhere near what it costs to support continued poor practice in Wales. And I've so many other examples I could share with you like that, but I hope that makes it real for you—

09:45

[24] **Caroline Jones:** It does.

[25] **Ms Rochira:** —because it is about the impact on people's quality of life and their rights as vulnerable, voiceless, powerless people.

[26] **Caroline Jones:** Thank you for that. My next question is about that health boards are, despite promising it, not publishing audits of the use of antipsychotic medicines or their evidence that it is being monitored. The committee asked the Welsh Government about progress for this and they

were told it was a matter for the health boards. So, would you like a more direct lead from the Welsh Government on this? And what are your next steps regarding this issue on data?

[27] **Ms Rochira:** I talk quite a lot about data, and there's a danger that you make it sound easier to do than it is, I have to say. But the complete absence of any data coupled with the impact of this on people is a hugely worrying issue. I don't hold that view—I absolutely think there is a leadership role for Welsh Government here. I actually had a very productive conversation with the new chief pharmaceutical officer. We both agreed it was hard but that, actually, the benefits in terms of getting it right were hugely important, and I look forward with anticipation to building on that positive conversation with him. There absolutely is a role for Welsh Government in this. It is not right and proper, I think, that we have different approaches to what we collect developing across Wales. Having said that, ultimately, I think, health boards are accountable for the practice that goes on in their areas because it's not just about data; it's what you ask of that data, what key interrogation you place upon it, that's important. I hold the view that, actually, what we should develop is a self-scrutiny toolkit for health boards, something that helps them ask some really quite simple inquiring questions. I mean, I know what I would ask if I were sitting around a health board. It shouldn't be variable across Wales. Now, others will follow after me who are far better at talking about things like national prescribing indicators and how you link those back to read codes and small area data. It is quite complex, but the position that we're in now is not tenable. The lack of data, I think, is leading to and supporting that lack of strategic prioritisation.

[28] **Caroline Jones:** We definitely need an audit trail—

[29] **Ms Rochira:** A role for Welsh Government; a role for health boards as well. And I would also say that I strongly hold the view that information should be in the public domain. I believe that transparency and openness are key ways to drive up quality, key ways to hold to account public servants who are paid out of the public purse.

[30] **Caroline Jones:** Thank you.

[31] **Dai Lloyd:** Ocê. Mae'r **Dai Lloyd:** The next questions are cwestiynau nesaf o dan ofal Lynne from Lynne Neagle. Neagle.

[32] **Lynne Neagle:** Thanks, Chair. Morning, Sarah. Can I just ask you to expand a bit on what you see as the main reasons why antipsychotics are prescribed to people with dementia inappropriately?

[33] **Ms Rochira:** I think it is multifactorial, and actually I think it's more complex than we think. The way I look at it is by way of, I suppose, layers around the individual. So, when you're in a care home as a vulnerable individual, you need care and support to be wrapped around you. So, at the front line, we need people working in care homes who've got the right skills and competencies to see past the behaviour to see the person, to understand the person. And that's, in no small part, what my whole care home review was about. We need really good person-centred care planning there and we need sufficient levels of staff as well. So, training and skills of staff—. And there is a lot of work under way. So, things like the national dementia training framework are a really important step forward. But we need to get that part right first of all, and we've still got a way to go.

[34] Then, around that, we need to have what we've just spoken about a moment ago: those specialist multidisciplinary teams that can reach in and provide that more intensive support when it's needed. Around that we need more specialist clinical support. So, when those first two lines of defence against the use of antipsychotics don't work, we've got that more detailed clinical support. I have to say I think there's a lot of it in Wales, but we also, I think, need to see a better focus on things like the commissioning processes that health boards and local authorities undertake. This needs to be referenced explicitly within those so we're very clear, when we're commissioning care, what good quality looks like.

[35] I think we also need to ensure that we focus more on this within the regulatory and inspection system that we have. So, if you think about nursing homes in particular, a decade ago they were in the NHS; they were part of the hospital. There were community hospitals and long-term care of the elderly wards. They sat at the heart of a fairly tight regulatory system. Because the sector has changed and the basic provision has changed I'm not convinced yet that that's tight enough around them. So, the reason I share all of those is that I don't think any one in and of itself is sufficient, because you can fall through the net and become a recipient of antipsychotics for the lack of any one of those. So, it truly has to be, I think, a joined-up multi-agency approach to that. But what I've said is, at its heart, it has to start with an absolute determination to uphold the rights of vulnerable people and comply with that NICE guidance. At its heart has to sit ambition, and behind that has

to sit a proper acknowledgement of the detriment being paid and faced by older people.

[36] **Lynne Neagle:** You mentioned staffing and what it used to be like in nursing homes, and, of course, lots of people with dementia who would be considered to have challenging behaviour are cared for by people who are not registered mental nurses, who don't have the skill set. To what extent do you think that is a particular problem in the whole care home sector?

[37] **Ms Rochira:** I think it's still part of the problem. I think we recognise that. Certainly, if you look at what would be the move towards registration, which would be mandatory training, the work of Social Care Wales, we have a much stronger focus, I think, on the skills as well as the qualifications that people working in homes need. But it's a work in progress, and, as I say all the time, a beginning is not the same as doing the job. Doing the job goes back to the outcomes that I wrote in my care home review the first time around, and I was very careful to specify what those outcomes would look like. So, when all staff working in care homes have got the right skills, knowledge, and competencies, they've got the right back-up support that they need, and they've got the right levels of staffing that they need, that's the front line of protection. But sometimes it is just too difficult and complex to see past the behaviour. That's why you need those other services wrapped around it. So, it is actually more complex, I think, and more interlinked than, on the face of it, it looks. But I keep going back to the detriment being paid by older people. It is so significant that that should really drive our ambition. And that's my point, Rhun, about I don't really mind, at one level, what England's ambition is; I know what our ambition should be in Wales.

[38] **Lynne Neagle:** We've had some evidence that GPs and other clinicians feel under pressure to prescribe antipsychotics, and also that there's resistance then in care homes by staff to actually stop their use. Is that a view that you recognise?

[39] **Ms Rochira:** It's certainly a view I've had shared with me. I think everybody, in a sense, is struggling. I've not come across anything that suggests that anybody wants to default to these. It's just where people end up for the want of the other things that they need to provide alternative care. I've not found any want of good intent. What I've found is lack of knowledge, resource, and support behind this.

[40] **Lynne Neagle:** Okay. And if I could just—. I'd like to ask another

question. Alzheimer's UK drew to our attention the fact that it's only risperidone that is actually licensed for treatment of people with dementia. To what extent do you see a range of other antipsychotics being prescribed that aren't licensed for that? Have you got any data you can share with the committee on that?

[41] **Ms Rochira:** I don't. I try very carefully to only speak about those things that I have an evidence base for. I'll probably defer that to some of my clinical colleagues.

[42] **Lynne Neagle:** Okay. Thank you. Just finally, then, can you tell us about the availability of alternative non-drug treatment options? You have referred to a few today, but if there's anything you'd like to add, and maybe comment on access to things like psychological therapies for people with dementia.

[43] **Ms Rochira:** Again, one of the big issues that I raised in my original care home review was about what I saw was differential access to these other support services. So, if you lived in your own home, you still might struggle to access them, but the chances are that you would access them. If you lived in a care home, you may well not access them. I thought it was inequitable, discriminatory provision of access that people were facing. I think that is still true, in no small part, across Wales. I think, in no small part, across Wales, what you can access will still depend on where you live and which 'sector'—whether it be your own home or in a residential care setting. In fact, in some areas, I think that may well have become exacerbated as well. You know that my view has always been that it shouldn't matter where you live, where you call home; you should have access to the care and support you need. It's good for you and, actually, it's good for the public purse as well.

[44] It goes back to the point about data, doesn't it? Sometimes, it's like looking through a dark glass. So, that's why I think the evidence from professionals working in the field and the evidence from older people themselves is so important and it's also so powerful as well.

[45] **Dai Lloyd:** Okay, Lynne?

[46] Symudwn ymlaen i'r Moving on to the last questions from cwestiynau olaf, felly, o dan ofal Jayne.
Jayne.

[47] **Jayne Bryant:** Thank you, Chair. Good morning.

[48] **Ms Rochira:** Good morning.

[49] **Jayne Bryant:** You've explained clearly to us this morning your vision on this, and you've said that you'll be feeding back to health boards following their evidence that they've given to you in your inquiry, but what do you think are the priority actions that are needed to reduce the inappropriate use of antipsychotics?

[50] **Ms Rochira:** Well, I suppose I spoke a moment ago from the person's perspective—you know, what they need to see and feel being wrapped around them. But I also have, I suppose, a system critique of it, as well. I think the first thing that we need to do—and I've spoken about this a couple of times—is focus on this as a national priority. It should be up there with those other big-ticket issues that we have in Wales. There is clearly a role for Welsh Government in relation to that. We have a new dementia strategy and vision being developed for Wales. I expect this to feature in it, but more than that, I don't expect it just to feature, I expect us to set ourselves some ambitious targets and be open and public about the extent to which we're delivering on those. And, as I said, fundamentally, the question that I have for everyone is: when will we comply with NICE guidelines in full in Wales? You'd be amazed at how hard it is to get a clear answer to a simple question. Well, maybe you wouldn't, but it is.

[51] So, the prioritisation it deserves. I think we need to get better at rolling out good practice and I think there's a role for Welsh Government, but health boards as well, in sharing and developing that. I'd like to see some more guiding control, perhaps, let's say, in relation to that; better self-scrutiny from health boards—that openness and transparency that I spoke about. And, I think, a recognition that, when we invest in these preventative services, we are benefitting not just the individual, but the public purse, as well.

[52] If I might, can I just segue way that into impact, so that it makes real, kind of, where the cost is falling in relation to this? Because I did want to say just a few words about that. So, I look at the impact of the inappropriate use of antipsychotics at a number of levels. So, the individual. You will have other evidence about this, but when you receive antipsychotics, you are at greater risk of significant health problems, so, things like a stroke, for example. That's hugely bad for you as an individual, hugely costly to the public purse.

You're also at greater risk of what I call catastrophic events, like falls—hugely damaging to you, it can lead to death, and again, to the public purse.

[53] But just as worrying—and this is a really important point—is that if you fail to really realise what's sitting behind so-called challenging behaviour, you leave the person with something that is unaddressed, and that includes pain. We know that pain is a big issue that can sit behind perceived challenging behaviour. And other physical health problems; you leave them with unresolved depression and mental health problems; and you leave them with emotional pain as well. So, not only do you unnecessarily prescribe, but you fail to treat the issues that really sit behind it as well. So, that makes it of double concern.

[54] It also, I think, if we allow this situation to continue, runs directly contrary to some of our big public policy drivers. I'll just share with you some of those. It's not just NICE guidelines; section 27 regulations—I think it's section 29 within that—on control and restraint.¹ I cannot see how the current position is compliant with that. The national outcomes framework that we have for Wales: I cannot see how that is being made real for these people and it seems to me an example of what prudent healthcare is not. This is one of those perfect examples of something that is bad for everyone but worst of all for some of our most vulnerable people for whom our duty should have been highest. So, I think there are a whole range of resources that can go into the system, but it starts with that strategic prioritisation, getting a grip on the data, interpreting that properly, and setting real, ambitious targets for us here in Wales, but, underpinning it all, knowing what a job well done looks like— compliance with those NICE guidelines. I cannot see how that is too much to ask for people who can't ask it for themselves.

10:00

[55] **Jayne Bryant:** Thank you. Finally, do you have any evidence about the inappropriate use of antipsychotics in other care settings?

[56] **Ms Rochira:** I don't, because that wasn't really what I was looking at. But, just a couple of observations—because, obviously, in looking at this, you look at other peripheral issues—in relation to hospitals, particularly the move from a hospital to a care home and also a good practice example in hospitals

¹ The commissioner wishes to note that these are regulations under the Regulation and Inspection of Social Care (Wales) Act 2016.

as well. So, a couple of observations about the hospital sector: there seems to me to be a far stronger focus on this in the hospital sector than there is in the care home sector—one of the reasons that I've been trying to highlight this issue as much as I have. I'm not saying it's perfect, but when you can find a report, you can pretty much guarantee it's talking about a hospital. When you can find data, you can pretty much guarantee it's talking about hospital care as well. So, we seem to have managed to exclude, within Wales, a population of, potentially, 23,000 people living in the care home sector. It doesn't seem equitable, right or fair.

[57] Another observation I would have is that this is the transition point. Often, when people go into hospital, they can go in because they are in crisis, so they may well be prescribed antipsychotics then. But, when you move into a care home, you may well be out of crisis, and if you weren't then, you should be by the time you've settled in and received a different kind of care and support. That's why the regular review of medicines matters so very much. One of the big issues that came up when I was reading about this was the length of time, because the length of time is a key part of the inappropriate use of antipsychotics. That seemed to be a key issue.

[58] But perhaps I'll just share with you a good example. I visited a ward in a local community hospital. The people, again, were really struggling to cope, in crisis. I went in and I couldn't see anybody. There were no patients there. So I said, 'Well, where is everybody?' She said, 'Oh, they're in their bedrooms', and this was about 10 o'clock in the morning—an interesting use of a term, not 'in the ward' but 'in their bedrooms'. She said they'd been up all night, most of them. She said, 'They're absolutely shattered, so we don't get them up at 7 o'clock. We get them up when they want to get up.' She said that it's amazing the difference it's made in their behaviour, because, quite simply, they're not tired. I thought it was a brilliant example of getting it.

[59] So, I think there are absolutely issues across sectors. I think more of a focus on that sector—although I don't think it's perfect by any means, but there are others, I'm sure, who will speak in more detail about those sectors.

[60] **Jayne Bryant:** Thank you.

[61] **Dai Lloyd:** Hapus? Dyna ni. **Dai Lloyd:** Happy? Then that's the Wel, dyna ddiwedd y cwestiynau. A end of the questions. Do you have oes gyda chi unrhyw sylwadau cyn any further comments before closing,

cloi rydych chi eisiau eu dweud, yn further to what you've already said,
 bellach at yr hyn rydych chi wedi ei Sarah, before we bring the session to
 ddweud eisoes, Sarah, cyn inni ddod a close?
 â'r sesiwn i ben?

[62] **Ms Rochira:** Just two very brief comments, really. One is to say 'thank you' for doing this inquiry. I raised this as an issue. I said I'd come back to it as a follow-up review, and, certainly, when I publish my findings, I'm not only going to feed that back to health boards, I'm going to feed that to Welsh Government and others, who I expect to take this forward with further drive in future years. But it's also to thank you on behalf of those who don't have a voice, because if we don't have a voice for them, then who does? For all the reasons I just spoke about in terms of how we should do this because it's good for the individual and we should do this because it's good for the public purse, we should also do this because it's morally right, and, sometimes, you have to stand up and do the morally right thing, regardless of what duties there might be laid down in legislation. For me, that goes to the heart of what our roles are. So, diolch yn fawr, and a heartfelt thank you for doing the inquiry.

[63] **Dai Lloyd:** Wel, diolch yn fawr **Dai Lloyd:** Well, thank you to you for
 iawn ichi am eich tystiolaeth your written evidence, which we
 ysgrifenedig ymlaen llaw a hefyd y received beforehand, and also your
 dystiolaeth ar lafar y bore yma. Wrth oral evidence this morning.
 gwrs, yn ôl ein traddodiad, byddwn ni According to our tradition, we will
 hefyd yn danfon trawsgrifiad o'r also be sending you a transcript of
 cyfarfod yma i chi gadarnhau ei fod this meeting for you to check for
 o'n ffeithiol gywir. Gyda hynny o factual accuracy. Thank you. We'll
 ragymadrodd, diolch yn fawr iawn have a short break now until 10:15.
 ichi. Gallaf i gyhoeddi i'm cyd- Thank you.
 Aelodau y cawn ni egwyl fer rŵan tan
 10:15. Diolch yn fawr.

*Gohiriwyd y cyfarfod rhwng 10:04 a 10:17.
 The meeting adjourned between 10:04 and 10:17.*

**Defnydd o Feddyginiaeth Wrthseicotig mewn Cartrefi Gofal—Sesiwn
Dystiolaeth 2—Cymdeithas Alzheimer’s Cymru
Use of Antipsychotic Medication in Care Homes—Evidence Session 2—
Alzheimer’s Society Cymru**

[64] **Dai Lloyd:** Croeso nôl i Aelodau i ail sesiwn y bore. Rydym ni’n symud ymlaen i eitem 3 ar yr agenda, parhad o’n hymchwiliad i’r defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal. Sesiwn dystiolaeth rhif 2 ydy hon. O’n blaenau, mae Cymdeithas Alzheimer’s, ac, yn benodol felly, rydw i’n hapus iawn i groesawu Sue Phelps, cyfarwyddwr y Gymdeithas Alzheimer’s yng Nghymru. Yn ôl ein harfer, rydym ni’n diolch i chi am y papur gerbron, y dystiolaeth ysgrifenedig, ac, yn ôl ein harfer, awn ni yn syth i mewn i gwestiynau, gyda’ch caniatâd, ac mae’r cwestiynau cyntaf o dan ofal Rhun ap Iorwerth.

Dai Lloyd: Welcome back to Members to the second session of the morning. We move on to item 3 on the agenda and the continuation of our inquiry into the use of antipsychotic medication in care homes. This is evidence session No. 2, and, before us, we have the Alzheimer’s Society Cymru, and, specifically, I’m very happy to welcome Sue Phelps, the director of the Alzheimer’s Society in Wales, and, as usual, we thank you for your paper that’s before us, the written evidence, and, as usual, we’ll go straight into questions, with your permission, and the first questions are from Rhun ap Iorwerth.

[65] **Rhun ap Iorwerth:** Diolch yn fawr iawn, a diolch i chi am eich tystiolaeth ysgrifenedig. I ddechrau, a allwch chi roi ryw drosolwg o’r hyn rydych chi’n ei weld ydy graddfa’r broblem o gam-ragnodi meddyginiaeth wrthseicotig mewn cartrefi gofal yng Nghymru?

Rhun ap Iorwerth: Thank you very much, and thank you for your written evidence. To start, could you give us some kind of overview of what you see as the scale of this problem of inappropriate prescribing of antipsychotics in care homes in Wales?

[66] **Ms Phelps:** For me, the use of antipsychotics as a default position is what’s the biggest issue here—that, where you have somebody with behavioural or psychological problems relating to their dementia, to routinely prescribe an antipsychotic medication without looking at what is underpinning those behaviours and causing them is wrong, and it does, as I say, seem to be the default position, which needs to be addressed. There are

so many more non-drug interventions that can be explored before going down the medicated route, in my view. And, although I can, to a certain extent, sympathise or empathise with the reasons why medications are used, one of which—the main one—being that it takes time to really get to know, to understand, the individual, what makes them tick, and what potentially could be causing the problems, the behavioural problems, that time to me is worth spending, and, long term, is a sound investment, not only for the individual, obviously, who's the most important person, but also, I believe, it would help care home staff, nursing staff in hospitals, in the care of that person and take away some of the stresses and the issues that they face in terms of somebody not being able to dress or to feed themselves or even take themselves to the toilet or becoming immobile. That makes it more difficult to care for somebody, so if you can support somebody not to be medicated to an extent where they can't do any of that for themselves, then, I think, as I say, it helps the individual and the care home staff.

[67] **Rhun ap Iorwerth:** And it's clear to us, from the evidence that we've taken in our consultation, where we are in the here and now, and that this is something that needs to be addressed. Are you able to measure whether this is something, over the past, say, decade, that has got worse or, conversely, whether there are signs that this is an issue that is beginning to be addressed?

[68] **Ms Phelps:** It's difficult to say, because it's in patches. So, in certain places—parts of Wales—I think there has been improvement and there's more understanding where investment has been made into training of staff and understanding the issues. So, for example, I know that Cwm Taf Local Health Board have got a care home intervention team. So, they've been concentrating a lot on upskilling the knowledge and skills of their care home staff to take that more person-centred approach. So, there are pockets where it is better than others. But, as with many things, it's not consistent, and it's certainly not as we would like to see. When you consider that a statistic is that, with 77 per cent of those people with dementia who are prescribed antipsychotics, it's an inappropriate prescription, that, to me, is unacceptable, and should be addressed.

[69] **Rhun ap Iorwerth:** And ongoing assessments could take place, if there were regular medicine reviews. What's your assessment of the use of medicine reviews—the regularity of medicine reviews that take place?

[70] **Ms Phelps:** Actually, I've got personal experience, although my mother

lives in Shropshire. She has dementia. She's on a number of drugs and I actually had to go, in the last two weeks, to insist on a drug review. So, she has been on the same medications—six different drugs—and hasn't been reviewed for 18 months, and her symptoms have dramatically changed. So, you know, I don't understand—for someone who is quite clearly deteriorating with her dementia. And she's not the only one.

[71] We had a case study, for this inquiry actually, from a member of staff whose father was in a care home in Caerphilly. He hadn't had an appropriate review either. It shouldn't be the case, because, actually, there could be medications that are counterproductive—you know, you can take one that can react with another—but also, as I say, the symptoms of dementia change, therefore, the levels of medication should change accordingly. And it may be that, from the point of diagnosis, an inappropriate diagnosis of a particular form of dementia has been made. So, if somebody has been diagnosed, let's say, with Alzheimer's disease, but then their symptoms become more in keeping with something like Lewy body, if an antipsychotic has been prescribed, that is completely inappropriate and dangerous—life-threatening—for somebody who has Lewy body dementia. So, for that reason alone, there should be some synchronicity between diagnosis, type of dementia, and review of medication.

[72] **Rhun ap Iorwerth:** And you're making it clear that you believe, as a society, there should be mandatory monitoring.

[73] **Ms Phelps:** Yes.

[74] **Rhun ap Iorwerth:** Could you tell us a little bit more about why you think that's the way forward, and perhaps even suggest what the frequency is, ideally, of these reviews and the publication of, or preparation of, written statements and so on?

[75] **Ms Phelps:** The NICE guidelines suggest it should be 12 weeks. I wouldn't disagree with that, certainly in terms of what the society provides in their service delivery, whether it be an information support worker or a befriending service, we review that person every 12 weeks. So, that's outside—[*Inaudible.*] So, I'd certainly say that we need—. Currently, we're in breach of NICE guidelines, so that is something that we can do fairly quickly.

[76] I absolutely support Welsh Government's intent in their national dementia strategy—the recommendation that there should be national and

local audits of the use of medication. In order to make that meaningful, I think what needs to be done is some pre work, really, in terms of establishing a benchmark. At the moment, we don't know. If we're going to set a target, it has to be SMART and we don't really know what the use of medication is in care homes and in hospitals, in particular antipsychotics, so we need to establish that benchmark first. I think that could be done fairly quickly. I think multidisciplinary teams, as a matter of routine, could go into care homes and support—so, not just in terms of training and supporting staff to understand what the repercussions of medication are, but also what the alternatives to drug intervention could be. I think that could be something practical that could be implemented fairly quickly. And, as I say, more intensive training for staff: understanding dementia, understanding what works, the person-centred approach first and foremost, before then looking at exploring the use of medication.

[77] **Rhun ap Iorwerth:** And addressing the culture that perhaps we have now that suggests this kind of monitoring and reviewing is optional, wherever that exists.

[78] **Ms Phelps:** For me, it has to be mandatory, of course, yes. Yes, absolutely. Yes.

[79] **Dai Lloyd:** Océ. Mae'r ddau **Dai Lloyd:** Okay. The next two gwestiwn nesaf dan ofal Julie questions are from Julie Morgan. Morgan.

[80] **Julie Morgan:** Diolch. Bore da.

[81] **Ms Phelps:** Bore da.

[82] **Julie Morgan:** I wonder if you could say a bit more about why—. You said that 77 per cent of dementia patients are prescribed antipsychotics, and I think, when you started off, you said it was the default position. How much is that due to lack of training, for example, which you've mentioned, or is it anything to do with lack of resources or lack of alternatives? Could you talk a bit more about why we are in this position?

[83] **Ms Phelps:** I think it's all three of those things. So, it is lack of training. It is easier to prescribe something that will quite quickly calm a person's behaviour, which makes them then potentially easier to care for. So, I think more training and understanding of what is happening in a person's brain—

so, more understanding of dementia, and not necessarily the clinical aspects of dementia. Something like—. I don't know how many of you have taken or been involved in a Dementia Friends information session. That is very basic, for want of a better word. It's non-clinical, but, goodness me, you come away with an understanding of what makes that person tick. So, something as small as that, I believe, can make a huge difference. I think resource—and resource, I believe, is more about time. It's about having the time to be able to invest in effective support planning, individual support planning.

[84] I think possibly the use of something like 'This is me'. So, the Alzheimer's Society produce a document—I don't know whether you're aware—called 'This is me', which was introduced primarily for hospital admission. So, a carer or the person themselves could complete hobbies, dislikes, et cetera, et cetera, what they prefer to be called, and their history. Now, that can be used, I believe, more effectively in residential care and nursing homes, and should be. I don't see any reason why that can't be. If a person with dementia doesn't have a carer, then I think there's a role to play then with advocacy or somebody, a key worker, who can help support them to complete that form. So, resource is an issue, more in time, I think, than anything, because, actually, I don't know the cost of drugs, but I would suggest it's probably more expensive to prescribe an ongoing prescription of drugs than it is to invest that time in support planning.

[85] And, in terms of non-drug, pharmacological intervention, there is lots of evidence out there that if you take the time—. It could be something as simple as somebody's in pain and they can't articulate their pain. So, investment in speech therapy—so, somebody who is unable to communicate, then they have a speech therapist that can help them, and an advocate, as I've said. So, address underlying pain. Address—there could be an infection that's causing a behavioural problem. Let's rule that out. Hearing. Sight loss or hearing loss. Something as simple as reviewing their hearing aid, having their sight prescription checked, having their teeth checked—dentistry is really important here—to rule out all of those other possible causes of somebody being distressed or agitated. But then use of—. Years ago, there was a massive use of, or an attempt to introduce, what they called Snoezelen therapy—so, lights, or calming music, or oils, and there is research to show that, if you put somebody in a room with sensory equipment, that can calm somebody down. We use, in one of our—. In a day centre in Cardiff, there's an aquarium, and actually sitting somebody in front of a fish tank—. It sounds very, very basic, again, but it can be hugely beneficial. Introducing pet therapy. You know, somebody who has always had a dog or a cat at

home, they've moved homes, they're now in a residential care setting. They miss that interaction with an animal. Bring a cat. Ten minutes stroking a dog on their lap can make a huge difference.

10:30

[86] Children—we know that intergenerational work is happening across Wales. There are pockets of that where it's brilliant. We've got schools up in Brecon who go into a local residential home and befriend the residents—help them garden, take them for walks. There are so many things that can be done. As I say, there is good practice out there, we just need to share it and spread it.

[87] **Julie Morgan:** So, in terms of training and knowing all the things that you've told us now, how much of that training does actually go on? In a care home, how many of the staff would know all this?

[88] **Ms Phelps:** Probably not many. I don't know the percentage. I know that good work is being—. I've got a meeting later this week with the reablement team that's now part of Social Care Wales and they're very much looking at training and upskilling the staff in care, but also out in domiciliary care, the home care field, as well, about exactly this. So, it's work in progress. I don't think there is anywhere near enough at the minute. There are agencies, not just the Alzheimer's Society but other agencies who can go in and work with care homes. That, going back to your point around resource, could be an issue because budgets are tight. Probably training is one of the areas that slips under the radar when you're trying to set a budget—there are other things that take precedent. I think we need to switch that if we're going to make improvements, because, as I say, I think the investment in good-quality training will be massive in the long run for the individual but also for care homes. We know there's a huge problem with retention of care home staff. I think if people felt more able to provide this person-centred care, to get a reciprocal relationship with somebody that they're caring for, to really understand, I believe that they'd be more confident then and would possibly stay in their caring roles.

[89] **Julie Morgan:** You've given us some good examples of practice that is going on. How wide would these practices—? For example, the pets, being able to stroke a cat or a dog—is that widespread?

[90] **Ms Phelps:** No. One of the reasons is risk aversion as well. You can

speak to some staff and they'll say, 'We can't bring a dog in to somebody with dementia, they don't know what they're doing.' There is this—I don't know. We've got to get over this myth—somebody with dementia is actually still an individual—that just because they've got dementia they don't want to feel and experience everything they have done in their—. And it's not a risk—it wasn't a risk when they didn't have dementia to look after a dog, for 30 years, so why is it suddenly a risk now? So, there's an element of risk aversion to it and just the trouble of, I guess, having somebody else coming in to the care home environment. It's around risk-assessing that intervention, health and safety—all of those things can play a part, and they shouldn't. It's breaking down those barriers, really.

[91] **Julie Morgan:** And how do you think that these barriers could be broken down, and how could this good practice be shared throughout Wales, really, if it's so sparse?

[92] **Ms Phelps:** I think you're absolutely right: this is about sharing the good practice, because that peer support, where you can see it working practically somewhere, can give confidence to try it elsewhere. So, whether we have some sort of information portal that we can share, or we share it through an agency like Social Care Wales—but make sure that good-quality case studies are out there—whether we use practitioners and have champions who can go from care home to care home and say, 'Well, this has worked here, why aren't you—?' I'm sure there are ways of doing it, but spreading it is crucial. Use organisations like Alzheimer's Society as well. We've got teams of carers out there who potentially have seen the benefit of what's happened in a care home environment for the person that they were caring for—we can use them and volunteers much more effectively, in my view.

[93] **Dai Lloyd:** Jayne—cwestiwn **Dai Lloyd:** Jayne—supplementary atodol. question.

[94] **Jayne Bryant:** I just wanted to come in, following what Julie's just asked you, regarding music in care homes. I think that's an important way where there's no need for a risk assessment in that and there's no reason not to use music, which can really help people in that setting. I don't know—is that something that you would say was widespread in care homes?

[95] **Ms Phelps:** Music and dance are probably two of the areas that are used and are more popular, because, as you say, it's easier to bring

somebody in to play the piano et cetera. So, yes, I would say that's probably one of the more common interventions. One of the areas that, again, is hugely beneficial but could be explored is life history work and reminiscence. I know there's a seminar going on next week, I believe, presenting what can be done through reminiscence and life and digital storytelling. That, I believe, is where we can use younger people really effectively. So, for example, students in media or digital IT could go into a care home and work with people to tell their story, and then to share that and then re-enact it in groups. So, we do know that there are care homes that use that. They have a dressing-up box, and they'll have sessions where everybody can put a hat on, and then everybody takes a part. That is hugely beneficial and could be—. Again, it's back to spreading the word. But music, I would say, yes, is probably the most popular.

[96] **Jayne Bryant:** Because it is really quite important—you know, there's no money involved in that: you can play music, you can listen. I know that there's a great project going on at the moment with the Forget-me-not Chorus, which are looking to get people's songs, and they can then remember why they were interested in those songs. Something like that doesn't have a cost implication either.

[97] **Ms Phelps:** I tried this, actually, with my mother-in-law, who also has dementia. We had taken her out for lunch, and she came back and was particularly distressed. It turned out that it was a corn that was playing up. We got to the bottom of what was causing the problem and it was the pain. But I had my phone with me and just downloaded, through iTunes, a series of songs. So, it was Tom Jones and Doris Day and, you know, the usual suspects. We sang for an hour and a half, and it was fantastic; so easy to do.

[98] Going back to effective support planning, when somebody is admitted to a care home or into hospital, if the time is taken through 'This is me', and the time is taken to review any medication that they are on at the time—. That sometimes happens—somebody will come into a care home, they are on medication, and the review doesn't happen at the outset, never mind when they are in there. So, that needs to be—. And then the support planning could include, 'So, what music do you like?' You could put together an individual playlist. It's so easy to do. Again, going back to the care home staff and motivating them to provide good-quality care, what a lovely time—to spend half an hour with an individual, playing songs and putting together a playlist for that person, which can then be used when an individual does become a little bit distressed or agitated.

[99] **Dai Lloyd:** Diolch. Mae'r ddau **Dai Lloyd:** Thank you. The next two gwestiwn nesaf gan Caroline Jones. questions are from Caroline Jones.

[100] **Caroline Jones:** Diolch, Chair. Good morning. You mentioned the use of multidisciplinary team services in care homes. Can you tell me what the current state of access is to these services and health professionals? Are there any issues regarding any parts of Wales that you can highlight or discuss regarding these services?

[101] **Ms Phelps:** Particular issues? I mean, I can't be specific, but I do know from feedback that therapies such as occupational therapy, physiotherapy, speech therapy, dietician, chiropody—all of those services that you can access when you are living out in the community, and services via the multidisciplinary team, through your social worker or your individual community psychiatric nurse—tend to stop if you go into residential care. I don't understand that, as I know that the older people's commissioner has said, and I was part of the review into residential care—. She always said, and still says, that it's simply a change of address. All you are doing is changing your postcode. So, whatever you had to support you living in the community should follow you when you go into residential care. So, all of those therapies should be in place. From my point of view, and from the feedback that we've had from people living with dementia and their carers, in many instances, it stops. So, it's hard to get a visit from the dentist or from a physio, and that, to me, is crazy.

[102] **Caroline Jones:** Yes. So, you say it's difficult. Is it more difficult in some parts of Wales than in others—in rural areas, for example?

[103] **Ms Phelps:** Well, yes, rural areas. Some of that we will be exploring in some of the work that we are going to be doing around rural dementia. But, yes, absolutely, it is more difficult there.

[104] **Caroline Jones:** Okay. So, we have got to combat that, then, haven't we?

[105] **Ms Phelps:** Well, I think so, because again it is about long-term investment. If you can get those support interventions in to support that individual—. Physiotherapy: we know that one of the biggest problems is falls for older people and people with dementia. So, if we got physios going in then we can hopefully stop inappropriate falling as well. So, the knock-on

effects are quite significant.

[106] **Caroline Jones:** Another point that I would like to ask about is your recommendation that staff training in care homes should incorporate speech and language therapy. So, could you explain to me the importance of staff training incorporating this, and can you give me any examples of good practice?

[107] **Ms Phelps:** Examples of good practice—I can't think of any examples of good practice, however, in relation directly to speech therapy, I can point to where the use of advocacy has helped. So, an advocate for somebody who has lost the capacity or lost the ability to be able to communicate can be really beneficial. So, we, the Alzheimer's Society, for example, have got a team of what we call 'non-instructed'. They're trained in non-instructive advocacy where they can be the voice of that person. So, if they are experiencing any issues with their care then they can be supported to articulate that.

[108] I think, in terms of training for care staff, it may not be so much around—. Because obviously it's a specialism—speech therapy is a specialism—it's more about taking the time to communicate, spend the time with the individual, to understand their likes, their dislikes et cetera, and how they prefer to be communicated with. It might be via music, it might be through writing. It could be lots of different ways, depending on the individual. So, taking that time to understand how you can communicate is really important. What I will do, actually, is go away and see if I can find out if there are particular examples, through our own services, where that sort of intervention has made a difference, and we can bring that back to you.

[109] **Caroline Jones:** That's lovely, thank you.

[110] **Dai Lloyd:** Diolch yn fawr. **Dai Lloyd:** Thank you very much. The Mae'r cwestiynau nesaf o dan ofal next questions are from Lynne Lynne Neagle. Neagle.

[111] **Lynne Neagle:** Thanks, Chair. Morning, Sue.

[112] **Ms Phelps:** Hello.

[113] **Lynne Neagle:** We've had some evidence to say that GPs and clinicians may feel under pressure to prescribe antipsychotics. Is that something you

recognise, and if it is, can you just expand on what you think those pressures might be, where they're coming from?

[114] **Ms Phelps:** I think some of the pressures come from, for want of a better phrase, a quick win. If somebody is—. And sometimes I think, if you're caring for somebody with dementia, as many of you will know, it's not an easy task. So, I think some of the pressure could come from care in the family. If somebody is exhibiting quite difficult behaviours, if they are agitated, if they are aggressive, et cetera, et cetera, then sometimes the plea is, 'Can you please do something? I need to get some sleep. I need a break. Can you calm this person down?' So, I think there is pressure sometimes from carers and families and, actually, similarly, from care staff, to make life easier. And I sort of understand that in some ways. But I think the flip side of that is that it is because there is a lack of understanding of what could be done as an alternative, so—. I don't know what the stats are in terms of GP prescribing, but in terms of pressures, yes, I do believe that there are—.

[115] **Lynne Neagle:** You've referred in your earlier answer to maybe weaknesses in the training that's made available to staff working in care homes. So, I won't ask you to expand on that but, as you know, that was something that was flagged up several years ago in the commissioner's report, 'A Place to call Home?' I just wondered, have you seen any improvement led by Welsh Government policy in that area since the commissioner published that report?

[116] **Ms Phelps:** I would say, yes, that there has been improvement. Again, it's in pockets, so you get some places better than others. In the feedback that we get, it is a bit hit and miss. But, overall, yes, I think it is in people's consciousness now, and that there were very clear recommendations, actions laid out in that residential care review, and I think, where care homes have seen the benefits, then the practice has continued and they have been prepared to explore. So, for example, where music has been a rule of thumb, they are the very care homes that would then look at—'Well, okay, if music works, then dance might work' or 'Let's introduce a group of schoolchildren', or 'Let's introduce cooking'. Those are less risk averse because they've tried it once and, 'Oh, yes, it really does help', but we're back to, then, spreading that good practice. So, I would definitely say there has been improvement, but there is still a significant way to go.

10:45

[117] **Lynne Neagle:** Okay, thank you. And you've referred to the need to involve the person and their family in medicine reviews, and to provide informed choice over treatment. Can you just tell us what you think good practice in terms of these medicine use reviews would look like in Wales?

[118] **Ms Phelps:** Well, I think taking a step before the review, actually when you're looking to introduce medication or a drug, whatever it is, you should be talking that through with the individual that you're going to prescribe it to, and, if necessary, with the carer or friend who knows that person well, so that the person has some sort of say and influence and choice as to what they're going to be taking, and, crucially, an understanding of what difference it will make. Because, I have to say that there are situations—. We had a case study as part of pulling together information for this morning, from one of our advocates, actually, where the use of diazepam had been hugely beneficial for a lady who had—it was a lady with dementia who was experiencing domestic abuse—to be taken in, for her own safety, to care. She didn't want to be taken in to care, absolutely not, and became very aggressive. She couldn't understand why she was there; she didn't want to be there. But she had to be there for her own safety. She was resistant to taking the medication. But the advocate worked with her and explained, 'If you don't, and your behaviour continues as it is, then there is a strong likelihood that you could be sectioned', and explaining all of that to her, helping her to understand the medication and the reasons why.

[119] So, that needs to happen, and, then, once there is an understanding of why an intervention has been prescribed, the review should continue to reinforce the benefits, or not. It could be that the benefit of the drug is not evident, so, therefore, you have to explain to a person why we're withdrawing this and why we're trying something different. So, that does absolutely need to happen, and really robust medicines management. And, as part of the review as well—. Obviously, one of the issues with dementia, as you know, is people forget. And it's all very well prescribing one, two, three, four five, six, you know, multi medications in some instances—and they all may have tremendous benefit, but, if the person's not taking them, they're going to have no benefit at all. So, part of the review is making sure that the person is supported to take the medication as and when it's required for it to be of any use, and I don't think that happens either—you know, perhaps weekly prescriptions instead of sending people their monthly supplies and they're stockpiled on the side in the kitchen and completely useless if they're not being used. That has to be incorporated in all of this: ultimately, a review of how we manage medicines.

[120] **Lynne Neagle:** Alzheimer's UK have highlighted with the committee the issue of off-label prescribing, so prescribing antipsychotics that aren't actually licensed for people with dementia. Is that something you're concerned about and how widespread do you think that is in Wales?

[121] **Ms Phelps:** I'm not sure how widespread it is. We can certainly try and find out for you. It certainly does happen. Our position on that is that, yes, there are some drugs that you can take off-licence. Again, it's back to understanding what that drug can do, and it's so individual, prescription, so, I think if a drug does provide benefit to that particular individual for a particular length of time, and this is again going back to—it's not just routine prescribing, it's very well-judged prescribing and it's checking in at six weeks, 12 weeks, regularly, to make sure that it's still effective. So, there could be a place for a non-licensed drug, but, again, it could only be done under the umbrella of very strict review.

[122] **Dai Lloyd:** A'r cwestiynau olaf, **Dai Lloyd:** And the final questions are o dan law Jane Bryant. from Jane Bryant.

[123] **Jane Bryant:** Thank you, Chair. You've mentioned about the collection of data and the importance of that, and publishing audits. But, just to clarify, how do you think that should be driven? Do you think that should be driven by Welsh Government or by local health boards?

[124] **Ms Phelps:** Well, I think from Welsh Government to local health boards—to go back to the mandatory point, that it's not an option, really. I think it should be made mandatory, and then local health boards then to—. And, you know, it could be that local pharmacists could be used. We've worked very closely on this with the Royal Pharmaceutical Society Wales. That's absolutely what they would recommend—they're very well placed and they have the knowledge and the skills to be able to go and support that type of review and monitoring, so let's use organisations like that, and experts like that, far better.

[125] **Jayne Bryant:** Brilliant, thank you. You've touched on other settings where antipsychotics could be a problem—or inappropriate use of them. Do you think—? Can you explain a little bit more about that in other types of settings? Do you have any evidence on that?

[126] **Ms Phelps:** Well, I think they're used in hospitals as well as care

homes. I know we're focusing on care homes here, but I do know that they're used. Again, we've got a case study from somebody who was admitted to hospital and was difficult—difficult to manage. No account, really, was made of the fact that, actually, that person had gone into a very unfamiliar environment, didn't know why they were in hospital, didn't want to be there, very scared, frightened, and were prescribed an antipsychotic, which essentially rendered that person unable to feed themselves. They were immobile, became bed bound. When they did put that person in a chair, their carer went to visit—in this instance, it was this gentleman's wife—and he was slumped in a chair, not able to speak, in her words, 'Dribbling into his lap', and he'd gone into hospital for a problem unrelated to his dementia. So, that is completely unacceptable and it does happen, because it was easier for the nurse to manage, I guess.

[127] **Jayne Bryant:** Okay, thank you.

[128] **Dai Lloyd:** Iawn.

Dai Lloyd: Okay.

[129] There we are.

[130] Dyna ddiwedd y cwestiynau.

Well, that's the end of the questioning.

[131] Have you got any concluding remarks you would want to say before we bring this session to a close?

[132] **Ms Phelps:** I think, for me, we've spoken about a lot, and thank you for bringing this to the fore and for taking the trouble to enter into this inquiry. I think we've got the key messages around: let's move away from routine prescribing; let's ensure that there is regular review at least 12-weekly; that there needs to be some sort of national, local audit to benchmark where we are, so we can set some very clear, SMART targets. So, we know all of that has to happen. For me it's also, alongside that, growing our knowledge and understanding of dementia—what it is potentially that can make a person with dementia and what's happening in their brain that then manifests itself in behavioural or psychological symptoms that do not necessarily have to be—. There doesn't have to be a prescription of an antipsychotic to improve those behaviours. Let's focus on the person-centred approach—that would be what I would say. Let's look at everything else that we can do, which probably wouldn't cost an awful lot in terms of human and financial resource.

[133] **Dai Lloyd:** Diolch yn fawr iawn i chi. **Dai Lloyd:** Thank you very much.

[134] **Ms Phelps:** Diolch yn fawr. **Ms Phelps:** Thank you very much.

[135] **Dai Lloyd:** Diolch am eich presenoldeb y bore yma. Diolch am gyflwyno tystiolaeth ysgrifenedig o flaen llaw, a hefyd am eich tystiolaeth ar lafar y bore yma. A dyna ni ddiwedd y sesiwn yma. **Dai Lloyd:** Thank you for attending this morning and for presenting the written evidence beforehand, and for your oral evidence this morning. And that's the end of this session.

[136] Gallaf i gyhoeddi i fy nghyd-Aelodau fe gawn ni egwyl fer nawr, a dod nôl am 11:05. Diolch yn fawr iawn i chi. **I can announce to my fellow Members that we'll now have a short break and return at 11:05. Thank you very much.**

*Gohiriwyd y cyfarfod rhwng 10:53 a 11:05.
The meeting adjourned between 10:53 and 11:05.*

**Defnydd o Feddyginiaeth Wrthseicotig mewn Cartrefi Gofal—Sesiwn
Dystiolaeth 3—Yr Athro Sue Jordan
Use of Antipsychotic Medication in Care Homes—Evidence Session 3—
Professor Sue Jordan**

[137] **Dai Lloyd:** Croeso nôl i bawb ar ôl yr egwyl fer yna i'r rhan ddiweddaraf o'r Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon yma yn y Cynulliad. Rydym ni'n symud ymlaen rŵan i eitem 4 a pharhad o'n hymchwiliad i'r defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal. Rydym ni wedi cyrraedd sesiwn dystiolaeth rhif 3 rŵan, ac o'n blaenau mae'r Athro Sue Jordan o Goleg y Gwyddorau Dynol ac Iechyd, Prifysgol Abertawe—croeso, bore da—a hefyd Timothy Banner, **Dai Lloyd:** Welcome back to you all, after that short break, to the latest part of the Health, Social Care and Sports Committee here at the Assembly. We move on now to item 4, and the continuation of our inquiry into the use of antipsychotic medication in care homes. We have reached evidence session 3 now, and before us we have Professor Sue Jordan from the College of Human and Health Sciences, Swansea University—welcome to you, good morning—and also Timothy Banner,

fferyllydd ymgynghorol Bwrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro. Bore da i chi'ch dau. Nawr, rydym ni wedi derbyn eich papur gerbron ac yn naturiol mae Aelodau wedi ei astudio gyda manylder—eu manylder arferol, yn naturiol. Felly, mae gyda ni res o gwestiynau eisoes, felly, gyda eich caniatâd, awn ni'n syth i mewn i'r cwestiynau. Mae gyda ni rhyw hanner awr, felly bydd y cwestiynau yn fyr, ac, yn naturiol, disgwylir i'r atebion fod yn fyr ac yn gryno hefyd. Felly, Rhun.

consultant pharmacist, Cardiff and Vale University Local Health Board. Good morning to you both. Now, we have received your paper, and naturally Members have studied this in detail, their usual detail. And therefore, we have a series of questions already, and, with your permission, we'll go straight into questions. We've got about half an hour, so the questions will be brief and we expect, naturally, the answers to be brief as well. So, Rhun.

[138] **Rhun ap Iorwerth:** Diolch yn fawr iawn, Cadeirydd. Rydw i wedi cael y cyflwyniad gennych chi mewn digwyddiad yma yn y Senedd o'r blaen ynglŷn â sut mae'r ymyriad rydych chi wedi ei ddatblygu yn gweithio. Tybed a allwch chi egluro yr egwyddor y tu ôl i'r broses fonitro yma rydych chi wedi'i datblygu, ac yn benodol sut y gall hynny fod yn ddefnyddiol o fewn y cyd-destun meddyginiaeth gwrthseicotig?

Rhun ap Iorwerth: Thank you very much, Chair. I have had the presentation from you at an event here before in the Senedd about the intervention that you have developed and how it works. Could you perhaps explain the principle behind the monitoring process that you have developed, and, specifically, how that can be useful within the context of antipsychotics?

[139] **Professor Jordan:** How it works—. We're asking the nurses or the people closest to the patients to spend time recording a lot of what they actually know about the patients and to take the same approach, really, as the World Health Organization did on its previous challenge of safer surgery because when the safer surgery challenge was announced by the WHO, the solution became—and has been effective—a check-list approach, and this worked. Now, we've got the next WHO challenge: safer medicines, and our approach is quite similar in concept. You have to be thorough, you have to put everything on to one single document, and you have to communicate across the multidisciplinary team. So, what we're asking is for the nurses to engage with the multidisciplinary team and record all the potential problems of the medicines so that when the pharmacist or the prescriber sees the patient—and many of the patients we're working with here are non-verbal—

they have an overview of what's happening to the patient, and that, in our trials and our implementation work, is helping them to see what medicines are needed, where the problems are, how they might be solved, and, yes, we've got some trial evidence, we've got some other evidence, that it works, and, even in the acute sector, that we can save lives this way.

[140] **Rhun ap Iorwerth:** Ac mae hwn yn berthnasol ar draws yr holl ystod o ddefnydd cyffuriau. Nid oes yna ddim gwahaniaeth yn hynny o beth rhwng unrhyw gyffur arall â chyffuriau gwrthseicotig mewn cartrefi gofal o ran y broses rydych chi'n ei datblygu.

Rhun ap Iorwerth: And this is relevant across the entire range of the use of drugs. There is no difference, in that regard, between any other drug and antipsychotic drugs in a care home in terms of the process that you're developing.

[141] **Professor Jordan:** Sorry?

[142] **Rhun ap Iorwerth:** The approach, the intervention that you have developed, is across the board in terms of the use of medication. It is equally appropriate in, equally relevant in, the context of antipsychotic drugs in care homes as it is with any other. It's the monitoring process that's important.

[143] **Professor Jordan:** Most of our work has been in care homes, yes. Yes, we think it can work across the board. We've had some spectacular results in the acute sector. We've got a randomised control trial in care homes and we've got ongoing work in care homes.

[144] **Mr Banner:** I think that the—. To answer your question, there are certain drugs that have got recognised monitoring parameters, which we would monitor according to their licence, the *British National Formulary* advice, et cetera, and pharmacists, medics, et cetera, doing that—. It's been highlighted that antipsychotics are a high-risk area, and there isn't necessarily the monitoring ongoing that NICE guidance recommends should be happening with antipsychotics, which is where the tool comes in then as being an ideal more observational monitoring tool, coupled with the more medical monitoring of blood tests, et cetera, to ensure that the antipsychotic is doing minimal harm to the person and having maximum benefit as well. So, I think that's where the antipsychotic element really suits this tool then.

[145] **Rhun ap Iorwerth:** Yes. And especially, perhaps, because the overuse of antipsychotics is a cultural issue as much as a lack-of-monitoring issue.

[146] **Mr Banner:** Potentially, yes. In answering one of your other questions that you posed in the literature, we don't know the levels of prescribing of antipsychotics within care homes. We don't know what is appropriate, what is inappropriate. Anecdotal evidence is there is a degree of inappropriate prescribing going on, going back to 2009 with the Banerjee report. So, there is going to be some use for antipsychotics. We just haven't got a gauge of what is appropriate and what is inappropriate at this point in time, and this tool should help to weed out some of the more inappropriate usages or people who are starting to suffer from side effects associated with the antipsychotics.

[147] **Rhun ap Iorwerth:** Okay, thank you. Diolch.

[148] **Dai Lloyd:** Hapus? Mae'r **Dai Lloyd:** Are you happy? The next cwestiynau nesaf gan Lynne Neagle. questions are from Lynne Neagle.

[149] **Lynne Neagle:** Thanks, Chair. Can you tell us a bit more about why you think nurses are best placed to lead these medicine reviews? And can you expand on your point that research suggests that consultant-led medication reviews and pharmacist-led reviews are ineffective?

[150] **Professor Jordan:** That's entirely based on the literature. There have been a couple of Cochrane reviews in the area, which have shown no change in patient outcomes. What we're advocating is a multidisciplinary approach, because there was certainly one expensive trial that was pharmacist only, which was the RESPECT trial, which showed no difference. So, I think we need to learn from that and work in a more multidisciplinary way and look at patient outcomes. It's the people closest to the patients because it takes time to ask people about all their signs and symptoms—whether their bowels have been open, et cetera—and when the prescribers and the pharmacists come in they don't have as much time with the patients as the nurses do in the care homes, and it's the nurses working with the care assistants as well, because that is how care homes are staffed. These are the people who spend 24 hours a day with the patients and know them very well, and some of them are not able to communicate.

[151] **Mr Banner:** I think the nurse is closer to that person for more hours of contact in a day than myself, as a professional going in to review a care home resident, would be. I go in as a very small snapshot. My questions would be led by what they are prescribed, what their GP has documented, so my questions would be more directed towards that than necessarily what the

nurse is observing. So, in a large care home, to have the time to have all those observations coming to you would be a challenge, and for the nurse to remember to tell you everything as well would be a challenge. I think it's become recognised professionally that multidisciplinary working is the way that has the most benefit, certainly.

[152] The Royal Pharmaceutical Society report, 'Your Care, Your Medicines', is moving pharmacists away from the dispensing element towards this multidisciplinary care and putting the person at the centre, in which case we need the nurses, we need the psychiatric support, and the GP then to effect change in this area.

[153] **Lynne Neagle:** Okay, thank you. You note in your evidence that there have been many UK recommendations and costly initiatives to reduce prescribing of antipsychotics, including the national dementia strategy in England, but these have failed to have an impact. What are your views on why they have failed?

[154] **Professor Jordan:** I think they've just exhorted people to reduce antipsychotic prescribing rather than shown people how you might do it. I think it's been a bit of an interdict coming from above instead of engaging and saying, 'This might help you do this a bit differently.'

11:15

[155] **Mr Banner:** I think, professionally, it's a very challenging area to reduce or de-prescribe antipsychotics. I think, as alluded to earlier, they're initiated because that is the option. It's the whole wraparound of holistic care of the therapy support prior, the training of staff to be able to support the individuals better, and the challenge and the aim of the development of non-pharmacological intervention plans. It's not as simple as focusing on the antipsychotic prescription because that's the problem we're faced with at the moment, but the solution is probably earlier down the river—that we need to be supporting these residents earlier on in their symptoms and thinking outside the box of different ways of dealing with it. The drug isn't the answer, but that's the problem we're faced with at this point in time.

[156] **Lynne Neagle:** And you'll be aware that we're waiting in Wales for the final publication of our national dementia strategy, so have you got any observations on what you think should be in that to address this?

[157] **Mr Banner:** My personal view from this area is there needs to be more of a system, a process, in place prior to needing the prescription of the medication. I think we're focusing on antipsychotics, whereas that seems to be the symptom of the system problems. Having worked with brilliant occupational therapists about diversion tactics, et cetera, when people are starting to exhibit the behaviour that challenges, it can be done in a much more beneficial way, for the person and the staff who are involved as well, rather than just giving them a prescription for antipsychotics.

[158] **Lynne Neagle:** Okay. Thank you.

[159] **Professor Jordan:** What I'd like to think is that we have a strategy and we have a way to address the problem that has been through clinical trials. So, what we'd like to see would be adoption of an evidence-based intervention as a concrete proposal, as opposed to exhortations, which is what we already have. So, some practical help, practical guidance. And we think we're part of the way there, because we have shown that this does reduce prescribing.

[160] **Lynne Neagle:** Okay. Thank you.

[161] **Dai Lloyd:** Océ. A'r cwestiwn **Dai Lloyd:** Okay. And Caroline Jones nesaf gan Caroline Jones. has the next question.

[162] **Caroline Jones:** Diolch, Chair. Good morning. Could you tell us, please, more about why you believe it should be mandatory to provide documented evidence of medicines monitoring for older people prescribed mental health medicines to CSSIW? Thank you.

[163] **Professor Jordan:** Well, I suppose this goes back a long way. There's an undertaking to do no harm. There is prudent healthcare. We heard the Minister last week say prevention is what we need, and we are actually a preventative strategy. If we can pick up a potential fall early, that's a huge saving to the individual. So, this is about prevention. The recommendation to feed back whether the medicine is agreeing with the person is in the Royal Pharmaceutical Society guidelines for prescribing, which have been adopted across the board. So, there is an obligation there. In the response to the Andrews report, Welsh Government put in an obligation to monitor the patients as a result of their medicines and to feed back. So, what we're doing is we're saying, 'We've already got the policies here; let's formalise it, let's organise it, and make sure that it's shared across the team.' Because I think

without that sort of regulatory support, even mandation, it's not happening. As I said, all we're asking is actually nothing more than is already there.

[164] **Caroline Jones:** Yes. You just want to enforce it. Okay. Thank you very much.

[165] **Dai Lloyd:** Océ. Diolch, **Dai Lloyd:** Thank you, Caroline. Julie Caroline. Gan symud ymlaen, mae'r Morgan has the next question. cwestiwn nesaf gan Julie Morgan.

[166] **Julie Morgan:** Diolch. You're talking about—you want evidence-based intervention. Is there any of that going on at the moment?

[167] **Mr Banner:** In what respect? In the de-prescribing of antipsychotics or the monitoring element?

[168] **Julie Morgan:** Well, in terms of practices that are based on evidence, but don't involve prescribing.

[169] **Professor Jordan:** Yes, understood.

[170] **Mr Banner:** I suppose it's probably outside of the sphere of the adverse drug reaction tool that Professor Jordan is bringing to the table. The Older People's Commissioner for Wales searched for the evidence of good practice through her report, 'A Place to Call Home?' and the subsequent follow-up to that report, of which I believe she submitted the introduction, or the summary of the findings, to the committee as a paper exercise.

[171] I think there are some—. From my understanding, sorry, there are some good localised applications of what I alluded to earlier—the therapy, the development of non-pharmacological action plans, et cetera—but it's not wholesale across the board. It's either in a certain locality or a certain home setting, be it nursing or residential. I think there is a lot more work to be done to pick up on that good practice and really promote and push it forward across Wales, then.

[172] **Julie Morgan:** Are there mechanisms, in your view, when this good practice can be shared?

[173] **Mr Banner:** That's probably what we struggle with a little bit. I think we've probably all got a responsibility to do this. For me, working within

health, there seems to be a lot more cohesive working between the health boards now than there perhaps was previously. I think that cohesive working is leading towards the changing behaviours. I think the commissioner setting down the challenge for the health boards around antipsychotic prescribing in her initial report and her subsequent report should, hopefully, focus health boards more to be looking at what is working out there and bringing that in. I believe the commissioner is going to cite good example practice in her publication as well, which, hopefully, we will learn from then as well.

[174] **Professor Jordan:** I think our intervention works alongside psychosocial interventions. It's certainly not an alternative. It is different and there's a lot out there, with varying degrees of evidence, and they're very expensive to introduce in terms of staff time. And sometimes—this is only from the literature—people are busy or they don't buy into the intervention and then it doesn't happen, so it's a bit patchy. And, as I say, some of it's evidence-based, some isn't. There are several reviews out there as to what some of the barriers are.

[175] **Julie Morgan:** Thank you.

[176] **Dai Lloyd:** Océ. Diolch, Julie. **Dai Lloyd:** Okay. Thanks Julie. The Mae'r ddau gwestiwn olaf gan Jayne final two questions are from Jayne Bryant.

[177] **Jayne Bryant:** Thank you, Chair. You've highlighted the importance of working in multidisciplinary teams. What do you think would have the greatest impact on reducing inappropriate use of antipsychotics? What's the main priority?

[178] **Professor Jordan:** Well, I would say our intervention tool. [*Laughter.*] We've actually shown we can do it.

[179] **Jayne Bryant:** Yes. So, you'd say implementing that on a—.

[180] **Mr Banner:** I think implementing the tool is a definite in respect of safe use of antipsychotics. And it probably goes some way to answer the appropriate/inappropriate use. I think it's ensuring that people who are prescribed these medicines aren't suffering from side effects or starting to deteriorate and suffer from side effects. And we're also picking up more holistic health concerns around the resident using the tool.

[181] I suppose what is appropriate and what is inappropriate is very much a case-by-case basis. If someone's transitioning from the secondary care setting to a care home, it may be appropriate for that short space of time. It's the ongoing monitoring and review by the multidisciplinary team that then would term it appropriate to continue or inappropriate to continue. There is only the one antipsychotic licensed for the indication of behavioural and psychological symptoms of dementia, and that is risperidone, and I believe the licence is only for 12 weeks, and there's very limited evidence that, after 12 weeks, the drug does have an effect. So, in a way, if that's what the evidence is saying, we could argue that any prescription after that length of time could be termed inappropriate, though we know in practice there is still a use after that. So, the tool will go a long way to supporting the safe use of antipsychotics. The appropriateness question is probably subtly different and needs that clinical expertise, reviewing that person, coupled with all the other support and training for the staff to be appropriate in managing that resident as well.

[182] **Jayne Bryant:** So, what are the next steps for implementing the tool, then? What are the next steps for the intervention that you've got?

[183] **Professor Jordan:** Can I come back to the other question? I think if it was mandated, that would bring all care homes up to the standards of the best, because I think they're all saying that it's very patchy. That's definitely what we've seen; it's very patchy. So, making this more enforced, or more highly recommended, would bring them all up. The best are already fine—some of them are already doing it. Sorry, and the other question—?

[184] **Jayne Bryant:** My other question was about what the next steps are for the tool.

[185] **Professor Jordan:** Well, in some ways, that's up to you, really. [*Laughter.*] We're hoping that you will support at least encouragement to use the tool. In terms of the research, there's an education initiative that we're hoping to start, although we've got a study that we're finishing off now, and that's going to take us at least until the end of the year, so we're very busy with that, then we're hoping to do a small education initiative.

[186] Our next funding, which starts next month, is to look at taking this approach, with the Health Foundation, to the common medicines and primary care, because when we see the patients, they're not only using antipsychotics, they can be using another 17 or so medicines, and some of

these other medicines are causing problems, whether it's low blood pressure or bleeding, falls risk—all these, we need to prevent and nip in the bud while they're still on our tool, before they end up going into secondary care for bleeding, falls et cetera. I know antipsychotics are a big issue, but we're trying to widen the approach a bit, because it's still a fact that 5 per cent of in-patient beds are filled with people who've had adverse effects from their medicines. The aim here—. We think we've got a way of preventing at least some of this.

[187] **Mr Banner:** I think we have got a wide vision for the use of this tool across primary care, care homes, community mental health teams—we feel that way it will have a great benefit everywhere. We are starting with the care homes because it is a controlled population, but we know there is a definite benefit to be had across the community.

[188] We are looking into the technological side of it, to move away from a paper-based model, in line with the more electronic systems that are utilised in primary care. So, I have made contact with the NHS Wales Informatics Service about trying to look at ways of making the tool more user-friendly in relation to the computer side of it. We're also, potentially, in the future, going to look at some of the electronic medication administration record systems that are currently operating within care homes. The health technologies fund funded a Beacon Digital project a couple of years ago in the Abertawe Bro Morgannwg University Local Health Board area, so we're going to pick that up to see if there is scope to be working with a company like that to see if there's something we can do on the technology side to make it simpler, away from the paper-based version as well. I think we have got a grand vision for it—we're having lots of conversations, but it's how we get traction on a national level to really drive and, hopefully, promote and, potentially, mandate this tool to be used in all settings.

[189] **Dai Lloyd:** Océ. Rhun, a oedd **Dai Lloyd:** Rhun, you had a gyda ti gwestiwn atodol? supplementary question.

[190] **Rhun ap Iorwerth:** Pushing you just a little bit further on the potential barriers to the rolling out of this tool, I have no reason whatsoever to question the effectiveness of your intervention tool, on the contrary, but is it the case that if there is a real appetite now to deal with this issue of the overuse of antipsychotics, are the powers that be able to pick and choose from a series of intervention tools, off-the-shelf, or do you perceive that you are genuinely filling a vacuum where there isn't, as far as you know, another

tool that offers the same potential outcomes?

11:30

[191] **Professor Jordan:** We've looked in the literature—our last student reviewed it last year—we haven't found anything that fills the gap in terms of the guideline support, being nurse led, and it's all very well finding the problems on a piece of paper. We're telling people how to action this. We think we're unique. There are other tools. Some are much shorter—they deal with a single problem. For example, they might just look at the posture and movement problems, but that won't help our person who's hopelessly sedated on diazepam. And because we're nurse or carer-led, we're unique, and the range of drugs that we cover and try to unify—. Unlike the other, we have a trial.

[192] **Rhun ap Iorwerth:** Diolch. **Rhun ap Iorwerth:** Thank you.

[193] **Dai Lloyd:** Can I just ask, as a sort of final question: nurse-led intervention—what has been the response of the nurses? Do they like your tool, as it were, or have they misgivings?

[194] **Professor Jordan:** Some are using it. I think they all like it in theory. It's time. And that's why we need, I think, your support to bring those who think they don't have time up to the level of those who think they do. It is a slightly different way of working. A lot of nursing homes don't liaise closely with pharmacists, for example, and we're asking them to do that for the first time. So, we're asking to sort of look at new things. They're often surprised that the patients, when they answer a directed question—. I was sitting with somebody very near me, and she said she had chest pain, and the nurse said, 'You didn't tell me that—I've been working with you for several months', and she said, 'You're such a nice person, I didn't like to bother you', and she had chest pain. So, that now has to be explored, because chest pain is potentially serious. And the tool helped the nurse and the patient, then, to work together, beyond being nice people and having a very good relationship, to reduce the chest pain, which is waking the lady up at night, if nothing else.

[195] **Mr Banner:** I think it focuses on the more subtle deterioration. When the nursing staff are close to the residents, over a period of time, they may not notice a gradual decline in functioning, or, say, a development of a slight tremor, whereas this tool does focus the direct questions of, 'Have they got a tremor? What are their blood saturations? What is their blood pressure?' And I

think putting it all together in that one place has really focused—. But, as Sue said, it's the time of filling it in that is the problem. But when it's all down there on one side to see, 'These are the actual problems that are going on with the resident', it can say, for example, 'Clearly demonstrates extrapyramidal side-effects of an antipsychotic', which, in isolation, hadn't been detected previously. And I think, from myself reviewing the reports as part of this research, it's been quite a shock to see some of the symptoms that are being picked up, or not being picked up more precisely, that we feel warrant fairly urgent intervention. So, yes, I think the tool does definitely have a place. It's the timeliness of filling it in, which is why we're looking at trying to find a quicker, simpler way of filling it in, and then to be reviewed by the professionals.

[196] **Dai Lloyd:** But there was an acceptability of the principle rather than—. There was no outright objection saying that it was completely unworkable or anything.

[197] **Professor Jordan:** [*Inaudible.*]—they've been using it for five years, and they say, you know, once you get used to it—. They need to look at the whole of the documentation as well. Some will like it more than others certainly, but—.

[198] **Dai Lloyd:** Grêt, diolch yn fawr. **Dai Lloyd:** Great, thank you very much. That's the end of the session. Dyna ddiwedd y sesiwn gwestiynu. Diolch yn fawr i chi am eich Thank you for your written evidence tystiolaeth ysgrifenedig ymlaen llaw, beforehand, and thank you very a hefyd diolch yn fawr iawn am ateb y much for answering the questions cwestiynau mor fedrus y bore yma this morning. That is the end of the hefyd. Dyna ddiwedd sesiwn y bore, morning session. I can announce to yn wir. Gallaf gyhoeddi wrth fy my fellow Members that there will nghyd-Aelodau fod toriad nawr am now be a break for lunch, and we will ginio, a byddwn yn ailymgynnull am reconvene at 12.30 p.m. Thank you 12.30 p.m. Diolch yn fawr iawn i chi very much. gyd.

*Gohiriwyd y cyfarfod rhwng 11:35 a 12:33.
The meeting adjourned between 11:35 and 12:33.*

**Defnydd o Feddyginiaeth Wrthseicotig mewn Cartrefi Gofal—
Sesiwn Dystiolaeth 4—Suzanne Tarrant
Use of Antipsychotic Medication in Care Homes—Evidence Session 4—
Suzanne Tarrant**

[199] **Dai Lloyd:** Croeso nôl i Dai Lloyd: Welcome back to this gyfarfod y prynhawn yma o'r Pwyllgor afternoon's meeting of the Health, lechyd, Gofal Cymdeithasol a Social Care and Sport Committee Chwaraeon yma yng Nghynulliad here at the National Assembly for Cenedlaethol Cymru. Rydym yn Wales. We move on to item 5 on the symud ymlaen at eitem 5 ar yr agenda and the continuation of the agenda a pharhad yr ymchwiliad i'r inquiry into the use of antipsychotic defnydd o feddyginiaeth wrthseicotig medication in care homes. This is mewn cartrefi gofal. Hon ydy sesiwn evidence session 4. Members will dystiolaeth rhif 4. Fe fydd Aelodau yn remember that we've had three cofio i ni gael tair sesiwn dystiolaeth evidence sessions on the same ar yr un pwnc y bore yma. subject this morning.

[200] Felly, o'n blaenau ni y nawr, So, before us now, I'm very pleased rwy'n falch iawn i groesawu Suzanne to welcome Suzanne Tarrant, who is Tarrant, sydd yn mynd i adrodd ei going to tell us her story and her hanes hi o'i phrofiad hi a'i theulu experience and her family's ynglŷn â'r pwnc yma a sut mae trin a experience of this subject and how to thrafod yr henoed efo dementia â treat older people with dementia with meddyginiaeth gwrthseicotig. Felly, antipsychotic medication. Welcome, croeso, Suzanne, ac mae'r llwyfan i Suzanne, and the floor is yours. chi.

[201] **Ms Tarrant:** Thank you. Can I just start by confirming that I'm here in my personal capacity? I do work for one of the university health boards in Wales, but I'm here representing myself and my family.

[202] **Dai Lloyd:** You're here in a personal capacity to tell us your story.

[203] **Ms Tarrant:** That's right.

[204] **Dai Lloyd:** And we've got roughly 28 and a half minutes to get through that.

[205] **Ms Tarrant:** I'm sure that's going to be plenty of time. Thank you.

[206] My experience is in relation to my mother, Margaret, who is 78. A fabulous woman, she was very good at watercolour painting, pottery, and a fantastic cook. She suffers from mixed dementia. She was diagnosed a number of years ago, and her diagnosis is Alzheimer's, frontotemporal dementia and vascular dementia—so, all three together. Her deterioration has been quite significant over the last year, but up until February this year, she was still at home. My father was her full-time carer, with my support, as and when I could, and then, very sadly, on 9 February, she fell at home and fractured her hip and had to go into hospital for emergency surgery.

[207] She had the surgery and was admitted to the hip fracture unit, and my experience really is around her care and stay on that unit. So, it's about her care in hospital, as opposed to being in a care home, but I think you probably are already aware of that. Mum is now in a care home, because, following discharge from the acute hospital, she was actually transferred under section to an elderly mental health unit for a number of months, and then into residential nursing care, because she's not able to go home.

[208] So, after mum's surgery, she was admitted to the acute hip fracture unit, which is a very busy unit in the hospital—quite cramped, low ceilings, very busy, very noisy, and not suitable for someone who has dementia. There were many things about the environment that I could see very quickly were going to be quite challenging for her, not only in terms of how she would be normally, but having gone through a very traumatic experience and suffering all of the effects post-operatively. So, my dad and I were visiting my mum on a daily basis, trying to work with the staff to help them understand her unique needs, and I have to say that there were many instances in which the staff demonstrated compassionate, fantastic care, and we were feeding that back and working with them to try to ensure that mum was okay and had the best experience possible, because it was awful for her and it was horrendous to see her going through that. And my dad really struggled as well. He's 83. He really struggled to see her in so much pain and so much distress. And there was no doubt that the effect of the fall and the operation had a huge impact on her mental health, which she's never really recovered from. But, after a number of days—I can't be specific about times; I'm sorry about that—we noticed that mum's mental state seemed to be deteriorating, in that she was very, very drowsy, had very slurred speech, a very poor attention span, didn't seem to be able to connect with us in the way that she had been, even post-operatively, through the trauma and the pain, and certainly not in the way that she had been prior to her fall. She also had a fall on the ward,

where she just fell forward out of a chair and hit her head on the table going down. Fortunately, it wasn't a serious fall, but there were a number of things that were going on like this, the kinds of experiences that I've just mentioned, that we were confused about. We didn't know why her mental state was deteriorating in this way. And it was only by accident, from my dad asking questions of the staff, I think, to do with some of her medication, that it was then disclosed to us that she had actually been on antipsychotic medication for 10 days without us being informed, without there being any discussion about that at the time. So, she was prescribed quetiapine and diazepam at the same time, and that was obviously why she was experiencing the drowsiness, the slurred speech, and I think that both of those things led to the fall that she had out of her chair.

[209] When I became aware that she had been prescribed the antipsychotics, and I tried to make sense of what we were noticing in mum, I then started discussing that with the staff, raised my concerns with the staff, had a meeting with the sister on the unit and with the psychiatric registrar—no, sorry, not the psychiatric registrar, the orthopaedic registrar—who told me, 'Well, this is how we do it here'. That was the reason given for mum being prescribed antipsychotic medication. It wasn't clear at all if any record had been kept of the so-called target behaviours prior to the medication being started or even after it having been started.

[210] So, there was no way of ascertaining whether the use of the medication, which had been prescribed to control her behaviour—because she was resisting personal care and she did become quite violent and aggressive towards staff when they tried to approach her and deliver the personal care—and it was because of that that she was apparently prescribed the antipsychotic medication, to basically sedate her and make her more manageable to the staff.

[211] But, what I could see when I was there and witnessed staff interacting with her was that it was perhaps due to their ignorance, staffing levels, their lack of understanding about what the triggers for mum's behaviour might be—that there could have been some other ways of dealing with her that wouldn't have required her to be sedated in the way that she was.

[212] But I asked for this meeting with the sister and with the registrar to find out why the medication had been prescribed. Other than being told that that was how they did things, I just had the feeling it was being used as a chemical straitjacket to control mum for the benefit of the unit and the staff,

rather than taking mum's needs into account. When I raised concerns about the side effects and the impact on her stability—I mean, my mum is like a baby bird, she's a little skeleton with skin wrapped around it, she's very frail, very thin. She was very unsteady on her feet prior to the fall that she had at home. Certainly, post-operatively, she was very unsteady. She has osteoporosis as well.

[213] So, any medication that was being given to her that was going to increase the risk of falls, to me, was a big issue, and should have necessitated a full risk assessment and proper management plan. There was no evidence of that in her record. I've asked to see it and I've never been shown it, and there was no record of the target behaviours before medication and post medication either.

[214] I was very grateful that, after raising my concerns, the medications were both stopped, at my request. Diazepam was then given on a PRN basis but the antipsychotic medication was withdrawn. Mum's mental state did improve quite quickly as soon as that was taken out of her system. She was no longer so drowsy, she was no longer slurring her speech.

[215] So, I have raised my concerns, and that's an ongoing process, but from my perspective, in terms of what happened to mum with the antipsychotic medication, I just really felt that it was used as a matter of course—as the registrar said, that's how they do things—to control mum's behaviour, to make it easy for the staff to deliver generic care, without taking mum's specific needs into account.

[216] I think that if there had been a more appropriate environment for mum that took into account her specific needs and given her—mum's also visually impaired. Sorry, I forgot to mention that. She's only partially sighted. If the environment was able to be more appropriate to her individual needs, if staff had a better understanding of dementia and the skills to be able to respond to her needs arising out of her dementia, and if the team were working together with an individual care plan in mind, with my mum at the heart of it, I do believe that my mum's experience while she was in hospital could have been quite a different one.

[217] We couldn't wait to get her out of there. She was medically fit for discharge but had to stay on longer because there was nowhere to move her to. She was under section and then the ward was closed due to infection control, so she had to stay there far longer than was required. All the time,

during her stay, the issue around personal care was a major issue because staff were struggling with her. I was undertaking as much personal care as I could, partly because she knew me, but I was able to respond in ways that didn't trigger aggressive behaviour. But we were very relieved to get her out of there, and I was very relieved that she wasn't put on the antipsychotic medication again.

[218] So, my intention in coming along today in sharing this with you is that I hope, and I'm guessing there's going to be some learning experience from this, that other families and other dementia patients wouldn't have to go through a similar kind of trauma. It was very traumatic for my mum, and for me and my dad to see her go through that—not just the fall but the way that it was handled and the impact of this medication on her mental state.

12:45

[219] **Dai Lloyd:** Okay, thank you for that. There might be the odd question.

[220] **Rhun ap Iorwerth:** Thank you very much for being so open. It's quite distressing listening to your experience. I can't imagine how it would have been for you as a family, and I note you were told that, 'This is how we do it'. Were you given any indication at that time, or perhaps since, of how long they would have continued doing it—how long they had intended to, had you not intervened?

[221] **Ms Tarrant:** No.

[222] **Dai Lloyd:** Lynne.

[223] **Lynne Neagle:** Thank you for sharing your experience with us. We do appreciate it. You mentioned that when you were helping your mother with her personal care that obviously things were much better. Was there any attempt by the staff to actually engage with you, as the person who had most expertise, really, in helping your mother in terms of what they could have done differently to manage her personal care without needing to resort to antipsychotics?

[224] **Ms Tarrant:** There was, to some extent. Trying to work with the sisters on the unit, they certainly were very keen to do that, and I think they were doing their best within very difficult circumstances. They've got a very large group of staff, so there's a high turnover. So, in terms of who was delivering

care to my mum, or undertaking the personal care, it could have been any one of 30 or 40 members of staff, because of the shift pattern. So, yes, there was an attempt, but it didn't seem to be working well enough and there were just occasions, again and again, where I could see that there were small things that were really important that weren't being communicated—so, the fact that my mum is partially sighted but has very good hearing. So, to go right up in front of my mum and talk in a loud voice was completely inappropriate and was very distressing. She would then react aggressively. To suddenly come from the side of her and ask her to do something was disorienting because she couldn't see, so she wouldn't know what that was about. So, there was some willingness, but it was difficult. I could see that it was difficult for them.

[225] **Lynne Neagle:** When your mother was admitted, did they do the 'This is me' thing where you have a form and they go through with the family things like, you know, to find out if there are any particular issues, like with her visual impairment? Did they go through any of that with you when she arrived on the ward?

[226] **Ms Tarrant:** I did fill out some forms that were about my mum in terms of her history and her likes and her dislikes, but in many ways, all of that information was quite irrelevant because it was meaningless to talk to her about, for example, her love of watercolour painting because she just had no recollection of it whatsoever, because of the deterioration in her mental state. Because, in a way, her needs had become so—well, they changed. On admission and post-operatively they were quite different. On admission, in a way, we were giving information based on how she was before that, not based on her needs after admission, which were quite different. But we did fill out the forms. I'm not quite sure where they were after that.

[227] **Lynne Neagle:** Okay, thank you.

[228] **Dai Lloyd:** Okay. Julie and then Caroline.

[229] **Julie Morgan:** You mentioned how you helped your mother with her personal care. Were you welcome at any time on the ward? Were there restrictions on when you went onto the ward?

[230] **Ms Tarrant:** No, there were no restrictions at all. Even when the ward was closed in terms of infection control, which was quite tricky, we were able to work with the staff, and as long as we were following the infection control

procedures, we were very welcome to be there as much as we wanted to, which was lovely because it meant that we could be with mum as much as was possible.

[231] **Julie Morgan:** So, there weren't any sort of visiting hours or things like that.

[232] **Ms Tarrant:** No, which we are hugely grateful for.

[233] **Dai Lloyd:** Okay, Caroline.

[234] **Caroline Jones:** Diolch, Chair. Thank you for sharing this with us. Looking, now, into the future, what do you think you would recommend, after your experience, that could help other people? Do you think staff training in a particular sort of—to care for people with dementia—or additional training? You said about the surroundings and so on. So, if you could tell us what you think would help, for future reference. Thank you.

[235] **Ms Tarrant:** There are probably three main areas, and you've mentioned two of them. So, the one is that I think, when someone like my mum is admitted into acute care—for my mum it was because of the fall and then the surgery—because of the extent of her dementia and her individual needs, it would've been far better if she had been in an appropriate physical environment: much quieter, not as cluttered, not as busy. Because all of that was overstimulating, overwhelming for her and, I think, added considerably to her distress. I'm sure that you couldn't have a separate ward, because then you'd have a separate ward for every particular specialty, but certainly to have a bay or an area that was able to meet the needs of dementia patients would have been really welcomed. So, mum was in a bay of six beds, away from the corridor, over by the window, which was lovely because it had light, but she couldn't really see out of the window anyway, but she was surrounded by busyness 24/7, which was very, very distressing for her. So, the environment is really key.

[236] Then the second area is in terms of staff training and staffing levels, so having the right level of skill and skill mix. My perception was that there weren't enough staff, and whilst there were some who perhaps did have the right skills, not enough of them had a sufficient level of skill to be able to meet my mum's needs consistently. There were a few who were fabulous. One of the student nurses, Nancy, was like a little angel. I was delighted when I saw her there in her purple, because she just knew how to work

with mum, and that was really lovely.

[237] **Caroline Jones:** So, how do you think that this student nurse could work with your mum and the trained, experienced nurses couldn't? What do you think?

[238] **Ms Tarrant:** I don't know. It was probably, I don't know, something to do with personality factors, or just in terms of her approach. Maybe she wasn't feeling as stressed as everybody else, but she was just able to take the time, and her approach was very obviously based on compassion; it was from the heart. So, that was the second area in terms of the staffing and their approach to mum—just being more responsive to her and her needs. I think that could be greatly improved.

[239] And then the third area is in terms of the liaison with the family and sharing of information, because we felt really let down by what had happened. Because my understanding—and I don't know whether it's correct, but looking at information on the NHS website and in the NICE guidelines—is that when antipsychotic medication is prescribed for dementia patients, it should be fully discussed with family members or carers first, and it wasn't. And we felt that that was done to my mum's detriment, because of the falls and the loss to her health and well-being. So, there's something there around including the family in the care plan and decisions made about medication, and also a willingness to consider alternatives, rather than seeing medication as being the only option because that's how they do things, regardless of what the individual needs.

[240] **Dai Lloyd:** Okay. Jane.

[241] **Jane Bryant:** Thank you, Chair. Thank you so much for coming here today, because hearing your personal experience is just so important for us for the inquiry that we're doing. As Rhun said, it's very emotional for us all to listen to what you've had to say today. That doesn't go anywhere near to what you've experienced. But, I just want to talk about the personal experience your mum had on the ward, and you as a family. Did you feel, after, you know, you'd made lots of interventions, you know, you were able to speak with staff—did you feel that anything had changed after you left, on that ward? Do you think that anything had been learned by other members of staff on that ward? Would they look at discussing with other patients the use of antipsychotics, as they should, or do you feel that you've left that ward and nothing's changed from that experience, from them?

[242] **Ms Tarrant:** Honestly, probably the latter: that nothing has changed. I think that the willingness of the nursing staff is certainly there to do the best that they can, and I think I remember the senior sister was organising specialist training. I don't know whether that has happened yet or not, but in terms of the overall approach and the environment and the decision-making process, I have no awareness that anything has changed for the better, and my concern would be that it's just business as usual, actually.

[243] **Jayne Bryant:** Okay, thank you.

[244] **Dai Lloyd:** Okay. Everybody happy? Can I thank you very much indeed, as everybody else has? It's been very impressive and, as others have said, quite emotional, so we're very grateful for your attendance and for your evidence, which will feed into our inquiry, and you've already formed the basis of some of the recommendations in answer to some of the questions. Thank you very much indeed for your attendance here today. Diolch yn fawr.

[245] **Ms Tarrant:** Okay, thank you.

12:56

Papurau i'w Nodi Papers to Note

<p>[246] Dai Lloyd: Wrth symud ymlaen i'r eitem nesaf—eitem 6, papurau i'w nodi—bydd Aelodau wedi sylwi bod yna naw llythyr yn fanna. Mi fyddwch chi wedi'u darllen nhw mewn manylder. Hapus i'w nodi?</p>	<p>Dai Lloyd: In moving on to the next item—item 6, papers to note—members will have noticed that there are nine letters there. You will have read them in great detail. Are you content to note these papers?</p>
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Cynnig o dan Reol Sefydlog 17.42 i Benderfynu Gwahardd y Cyhoedd o Weddill y Cyfarfod

Motion under Standing Order 17.42 to Resolve to Exclude the Public from the Remainder of the Meeting

Cynnig:

Motion:

bod y pwyllgor yn penderfynu that the committee resolves to

*gwahardd y cyhoedd o weddill y exclude the public from the
cyfarfod yn unol â Rheol Sefydlog remainder of the meeting in
17.42(vi). accordance with Standing Order
17.42(vi).*

*Cynigiwyd y cynnig.
Motion moved.*

[247] **Dai Lloyd:** Symud ymlaen i **Dai Lloyd:** We move on to item 7, and
eitem 7, a chynnig o dan Reol a motion under Standing Order 17.42
Sefydlog 17.42 i benderfynu to resolve to exclude the public from
gwahardd y cyhoedd o weddill y the remainder of the meeting. Is
cyfarfod. Pawb yn gytûn? Pawb yn everybody in agreement? Yes. We go
gytûn. Fe awn ni i mewn i sesiwn into a private session.
breifat felly.

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 12:56.
The public part of the meeting ended at 12:56.*