BREAKFAST CLUB

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TREATING FATIGUE & SLEEP DISTURBANCE FOLLOWING BRAIN INJURY WITH COGNITIVE BEHAVIOUR THERAPY

Speaker: Dr Adam McKay

Thank you to the Summer Foundation for inviting us to speak today, so it feels quite apt, talking about fatigue and sleep problems when you have to get up so early for a morning breakfast.

Hopefully, this doesn't put you to sleep.

So I'd just like to start with getting a sense of who's in the audience, and I'm just wondering if you can put up your hands if you do treat or help people with sleep and fatigue problems in your work.

Okay, most of you great, and I'm just wondering who of those use CBT as part of their work.

(Pause):

Okay, a few not many, a few.

So actually, Di and I ran this as a workshop at a brain injury conference earlier this year, and after the workshop, we had a few people come up and give some feedback, some nice feedback.

But interestingly, the person who was most excited about the workshop was the tech guy in the back of the room who was doing the slides, as he said he'd always had sleep problems and now he had some techniques to go home with, so we hope this is actually useful for your clinical work, but if it's helpful personally as well, that's great.

We work as part of a broader team, so I just want to acknowledge the rest of our research and our clinical team, so particularly Jennie Ponsford and Sylvia Nguyen who have led the research side of this, and Kate Frencham who is one of the neuropsychologists wo delivered the therapy along with Dana and myself.

So fatigue and brain injury, as I'm sure this is what you see a lot in your work, but what is it?

There are lots of definitions, but broadly speaking, fatigue is a subjective and usually very unpleasant symptom that people experience and it has, and it has a range.

It can range from tiredness to complete exhaustion.

It's both mental and physical and I think when you talk to a lot of your clients, you'll notice that they talk a lot about their mental fatigue and that's something that they really notice as being quite distinct from how things were before, and this really just really interferes with their ability to function, to sustain or initiate activities that they want to do, and I quite like this description which is from a therapist who works with people with brain injury.

So she says the fatigue that they experience defies description, going far beyond and far deeper than anything a person with no brain injury would consider as profound exhaustion.

So when you talk to people about their fatigue, they just say it's just so overwhelming and a sense that people can't really understand how bad it is and something that they've never experienced before.

In terms of sleep problems after brain injury, these are really quite wide ranging, from formal sleep disorders such as insomnia which is simply difficulty falling asleep or maintaining sleep, hypersomnia which is an abnormal need for sleep, or a lot of sleep, sleep apnoea, narcolepsy, but also just general sleep complaints that essentially, people find it hard to fall asleep or they wake up too early, the quality of sleep, their quality of sleep is not very good, partners talk about snoring, so lots of different complaints will report, and I'm sure that what we know and that what you know is that it's very common, so we're looking to at least a third to a half of people with brain injury who will report problems with fatigue or sleep, and often they will report having both problems.

So our groups of interest are people with traumatic brain injury and stroke, but this applies to other ABI's such as MS.

So these problems are far greater than what you would see in the general population, and in terms of the underlying causes of these problems, this is really an area of growing knowledge and development, so there are proposed particular regions of the brain that are important for sleep function for arousal, neurochemical systems such as melatonin, and physiological processes, so I'm not going to focus a lot on this, but really, this is an area that we're trying to understand a bit more.

What we also know is that there are a lot of secondary causes of fatigue and sleep problems, so problems such as anxiety and depression, chronic pain, the cognitive problems themselves, so these issues which often do co occur after a brain injury often can contribute or lead to people having poor sleep and fatigue during the day.

Now where this becomes important is that if we're trying to treat these issues, it can be important to try and work out how we treat these secondary factors because if we can improve these other things, then we might be able to improve their sleep and fatigue as well, so this is where we think CBT as a treatment approach shows some promise because it has shown that it's effective for treating these other issues.

So to date, there is no evidence base or guidelines around the best way to treat fatigue and sleep problems after a brain injury.

So medications have been trialled for both of these issues, but the efficacy has been limited and there are also issues with side effects from these medications, particularly cognitive side effects which obviously, if you have a group who already have cognitive problems, the last thing you want to do is introduce more cognitive issues for them.

Exercise therapy has also been started to be trialled, and on the face of it, it seems like a good idea and I think a lot of us recommend this.

In terms of traumatic brain injury itself, there isn't a lot of evidence that it does actually help with fatigue.

There is some evidence in stroke, that it does assist with fatigue, but it's still an area that needs further investigation.

Light therapy where people get exposed to blue light has shown also a little bit of promise in helping fatigue, but unfortunately, it seems that the effects don't seem to last beyond when people stop using the light therapy, so maintenance of the effects has been limited in some early studies.

So this is why our group has turned to cognitive behaviour therapy, to try and look at treating some of these issues.

So for those of you who don't know CBT, I'm sure you've heard of it, so it's really a talk based therapy, where the focus is it's trying to change patterns of behaviour and patterns of thinking that are contributing to symptoms and with the aim of improving or reducing symptoms, improving a person's function and quality of life.

So CBT has been around for a long time now and we know it's effective in treating a wide range of emotional and health related conditions, and importantly, it has shown that in the general population, it has been effective for treating sleep problems like insomnia, but also fatigue in chronic fatigue syndrome.

But at the moment, there's limited evidence that CBT's effective in treating these problems in people with ABI, so CBT is somewhat cognitively demanding therapy and we can't assume that it necessarily will be efficacious if people have these cognitive issues.

So this is why we embarked on a trial to look at CBT for treating sleep and fatigue problems to see if it was effective in people with stroke or TBI.

So this was led by our student, Sylvia Nguyen, and we conducted a randomised controlled trial by involving thirty nine people with either a stroke or TBI, and there was a range of severities from mild to quite severe.

So they presented with either having poor sleep quality or fatigue, and most of them had both of these complaints.

The CBT involved eight sessions, and that was compared to a treatment of a usual group who just got whatever they were normally getting in terms of their therapy.

For some of them, that was nothing, for some of them, they were still involved in rehab as well.

So the CBT was delivered by Dana, myself and Kate, so neuropsychologists, and importantly, the treatment, and we think this is an important part of it, focused both on the sleep problems and the fatigue problems, because they co-occur so frequently, we thought that was quite important.

So we'll unpack the treatment a little bit later in the talk, but broadly speaking, what we were aiming to do is to change patterns of sleep, and patterns of activity during the day, but also changing people's misconceptions about sleep and fatigue and how best to manage them because a lot of people develop ideas about the best way to manage these issues which may not actually be helping them, and often it was that change in their ideas about the best way to manage things which was really important to lead to behaviour change.

So we've also been doing CBT for other issues such as anxiety, depression and what is clear is that you really need to adapt CBT for people with cognitive impairments.

You have to simplify a lot of the materials, you have to provide repetition, you need a lot more visual handouts and reminders, and a lot more active planning, so when we delivered the therapy, we did modify it quite a bit to suit our group and Dana and I will talk a bit more about how we did that when we give you some of the descriptions of the treatment.

So all I'll say about this slide is that it's a mix of people with TBI and stroke.

Most of them were further down the track, so on average, at least two years post injury, but we did have some people who were earlier, but most of these people were further down the track.

So I just want to briefly present some of the results, so here, we have their sleep outcomes, so baseline is before they started treatment, two months after they finished the intervention, and four months is a two month follow up.

So up the top, we have a measure of sleep quality and down the bottom, we have a measure of insomnia symptoms and lower scores represent better sleep, essentially, and what you can see is that the CBT group in blue improve at a much faster rate than the treatment is usual group in terms of both sleep quality and insomnia symptoms, though probably the most important thing was the difference was maintained at follow up and actually was increasing in terms of the effect.

So CBT is a skill based program where really, you're teaching people new skills and habits, and it's potentially that over time, these can actually become more effective.

When we looked at the fatigue outcomes, they weren't as strong, but there definitely were some improvements.

We had two different measures of fatigue, and unfortunately, they showed different things in the two different groups, but we do think that the fatigue might be slightly different in people with TBI and stroke.

With a lot of the stroke cases, there was a greater physical component than in the TBI group, and it's possible that that explains some of the differences because the two different measures might be picking up different things, so overall, there was an effect and some of these effects were maintained at follow up, but there were some things we need to unpack and understand.

Although we weren't actively treating anxiety and depression, we had quite large effects for in terms of improving their mood, so both their anxiety and their depressive symptoms reduced across the treatment and on follow up, so it seems that this treatment was also addressing those secondary factors which is likely to help their sleep and fatigue.

So in summary, the CBT did seem to have a strong effect on their sleep, so we were focusing really on insomnia and hypersomnia, primarily.

There was some reduction of fatigue, but it was a bit more complex in terms of understanding what was going on which we need to unpack a bit more.

There were secondary improvements in their mood, but most importantly, these effects were maintained and that's what we're really looking for in a treatment like this.

But really, I think what we're going to do is unpack the treatment a bit more to give you a sense of actually what we're doing, so I'm going to hand over to Dana who's going to talk a bit about that.

Cool. Now?

Now.

Sure.

Or am I doing the first-?

No, either way.

Shall I keep going?

(Laughter):

Seamless, okay, so we had eight sessions, but essentially, we had six modules of intervention, so each module focused on a particular aspect of either sleep or fatigue, and importantly, these were interspersed throughout the whole treatment, so we were concurrently trying to treat both issues, as I talked about what the focus was.

So this is what the modules looked like, and just to, we're not going to go through it module by module, but we're going to focus on, Dana's going to talk a bit about assessment of formulation, and then talk about specifically about the fatigue interventions and then I'm going to talk about the sleep interventions themselves, but this is what the program looked like across the whole eight sessions.

We also ended with a review of therapy and relapse prevention which is really a core part of CBT is giving people strategies to avoid relapsing.

Now I'll hand over to Dana.

Speaker: Dr. Dana Wong

Okay, so as Adam said, I'm going to talk now a little bit about assessing where people are at when they start the intervention and setting the goals, coming up with a formulation and then leading in to the fatigue interventions.

So as part of the study, but in the general clinical practices, there is also a good idea.

We did do a range of different psychometric assessments of fatigue and insomnia, so that included measures of sleep and fatigue as Adam described before.

I haven't got copies of them on these slides, but I'm happy to send them to you if you would like copies of them, and as Adam presented in our research, we found that they were sensitive to change, the fatigue measures in different populations, but the sleep ones have been shown to pick up that improvement, so they're good to use in clinical practice, also, I think.

So also then, when we start therapy, we did a clinical interview to assess their experience of fatigue and sleep disturbance during their daily lives and get a good picture of what their

pattern tends to be during the day and their routines of sleep at night or lack thereof, and in doing that, we really wanted to explore how the brain injury and other factors associated with their fatigue and sleep difficulties were contributing to the whole picture, so things like their mood, any pain that they were experiencing, and what their activity levels were like during the day, so we got a really good thorough picture of what their day looks like.

Then we'd set smart goals, so these tended to be particularly, a lot of people came in to this program wanting to increase their activity, and do more, so sometimes that was about kind of reshaping that to look at what activities were most important to them and looking at goals for enhancing the quality of what they were doing rather than the amount, so that was, I'll show you an example of that in a moment, and as part of that, we're also looking at importance and confidence ratings which is a concept kind of borrowed from the motivational interviewing, so we would ask them to rate out of ten how important it was for them to make changes to improve their sleep and fatigue, and how confident they were to make those changes.

So a pretty common pattern would be that they would be rating their importance quite high so that it was important to them to feel less tired and to sleep better, but they weren't always very confident that they could make the changes necessary to do that, and then also, in, after the first session, we would set them a homework task to fill out sleep and activity diaries which we'd then use in the second session to look at what their patterns were and sort of identify targets for the intervention.

So the formulation is a really key aspect of CBT.

You really want to be identifying all the background factors and triggers that are contributing to their symptoms, and then in particular, all the factors that are maintaining their symptoms and it's the maintaining factors that we really target in CBT.

So this is an example of a formulation that might be quite typical of somebody who's experiencing insomnia, so at the top there in the different coloured squares, I don't know if you can see that very well, but there are four different categories of triggers, so we've got social in red, so things like unemployment and less social activity.

It might mean that there's just less going on for them socially, the less connected with people, so in the health category in green, shoulder pain and medication might be contributing to that lying awake at night in pain or medication might be affecting their sleep cycle, emotional, so perfectionism or being a worrier.

This was really common for the people who came through the study, so a lot of people coming in with being used to very active, busy lifestyle and it was very difficult for them to adjust their expectations of what they should be able to achieve during the day following a brain injury or a stroke, so a very common pattern that we saw, and then environmental demands, so lots of chores, so often, after a brain injury or stroke, there might've been a work reduction or stopping of work, which meant that there are more domestic duties to be done at home, so sometimes there was a sense of being a bit overwhelmed by all the things that needed to be done and worked out at home.

So then down the bottom, maintaining factors, so in relation to the presenting symptoms of insomnia, so there might be problems getting to sleep or waking up in the middle of the night and not being able to get back to sleep, so then at the top of the circle there, you've got

sleeping in to catch up on sleep, so let's say this person's laid awake for a long time trying to get to sleep, they don't get to sleep till two o'clock in the morning, and then they sleep in till eleven or twelve to catch up on that.

Then they might worry about their daytime functioning if they haven't had enough sleep, they think, I'm not going to be able to manage all the things I'm supposed to do today, so they then, as a consequence, do less, so they don't do as much, and they think they won't be able to achieve as much, then they feel guilty about that, they feel quite hopeless about themselves, they feel exhausted from worrying, so that emotional energy that gets expended from worrying about what you need to do and what you haven't done is quite exhausting, so they might take a nap and then they might wake up feeling quite unrefreshed and guilty about wasting time.

Often, naps and rests are viewed as quite a waste of time in people who are used to be perfectionistic and active, an so because of that, they might drink more caffeine to feel more alert, and worry about the night's sleep ahead, so then when they go to bed, they're tossing and turning and worrying about getting enough sleep, and then the cycle continues.

So then you can see in that, a number of different factors that are contributing to maintaining that pattern that you might be able to target in CBT, so we'll go through that in a moment.

This is a specific case example of somebody who I did actually see and give this program to.

So Sue, I'm going to describe in a bit more detail because you'll see a couple of videos of me working with Sue, so she was a seventy three year old woman who suffered a left partial stoke three years before she came and did the treatment program.

She was high average, pre morbidly and had a very active lifestyle, so she was a phys-ed teacher and also ran a number of different physical kind of education programs for older adults and different populations.

She was one of these women who would spend their whole life helping other people, so she was widowed a few years earlier, her children were spread all around Australia and were quite busy, so she didn't see them a lot, but she did have a good relationship with them and she lived alone, so that was one thing that she identified as a factor that in that it was up to do everything at home.

There was anyone else to show the load with.

She did play a lot of bridge and golf, so she was quite busy during the day doing those things, she tried as much as possible to keep her days quite full, and then she would usually crash at night and around seven o'clock, fall asleep in front of the TV.

So then when she woke up and went to bed, it was then hard to get back to sleep because she's already had a fair bit of sleep in front of the TV.

If she was tired, she sometimes napped during the day, otherwise usually, she would rest by actually doing quite active things like emailing, doing computer games or watching TV, and that was a really common pattern of people who we saw in the study was that their concept of rest was actually not very restful, so they would be doing things like playing word games on their phone or doing crosswords or getting on the computer and doing something and that to

them, even watching TV, they would consider a rest break, whereas they were activities that they were still cognitively demanding.

They were still using quite a lot of cognitive functions to do that and had to focus their attention and process words and problem solving and so on.

So she was having difficulty getting to sleep and she would often wake up during the night for up to two hours and lie there, tossing and turning.

She had some pain from a previous elbow injury, she drank about six to seven cups of tea a day, another trap where people often don't realise the caffeine content in tea and have a lot of tea that they don't sort of process as being having any affect on their wakefulness, and then her baseline scores on these initial measures, she had very poor sleep quality, clinically significant fatigue and the impact of that fatigue was severe.

So this is her sleep diary from the first week after the first session of therapy, so I'll just pick out the fact that she had quite a varied sleep pattern, she wasn't going to bed at a very consistent time, and she was having quite a variable amount of sleep.

Her sleepiness during the day was generally reasonably hard particularly when she didn't have very much sleep and she was waking a fair bit during the night, so not an ideal pattern of sleep, and then this is her activity diary, so this is just an example from one day, just to highlight that she would really fill her time by, so she had a bridge group, bridge lesson in the morning, then she had an art lesson, then she came home and did her emails, she crashed for thirty minutes at that point because her fatigue levels were up to nine out of ten after all that activity and then she went out again at night and did more bridge and was quite tired then, too, so not very surprising that she had a fair bit of fatigue.

So this is the formulation that I shared with Sue, and you'll see me doing that in a moment, I just wanted to, I won't go through the maintaining factors because you'll see me doing that on the video with her.

But at the top there, there's, you can see in the social category, the fact that her best friend actually is living in Queensland, so her really close group weren't living close by, so she didn't see them very often, and her family had limited availability, so socially, she wasn't quite as connected as she would've liked.

Her health, so she obviously had the stroke, and she had the pain from the shoulder injury and her medications, she was having some statins which were messing with her a little bit, and then emotionally, she had some occasional stress, particularly from things like her strata title and things, she had a few audio issues, and also just loneliness, she was feeling quite lonely at times, and then living on her own in terms of her environmental demands, she had a lot of responsibilities.

So now I'm going to show you a video of me describing with her the maintaining factors, so this is a real therapy session, warts and all, so I'll just, I might need to go to the computer.

Do you want me to-?

No, that's all right.

Video:

So I've got the idea that there's more, but before that, maybe we'll draw just then a little bit of a formulation of what we talked about last week and put that in to an idea of how I think it could be used. Would you like to go through that?

I'd love to.

So from that, so this is just my idea of your, what you know best, so please, if anything comes out, we can then change it.

So again, was there ones in Sydney up here?

I don't think that he did.

Okay, so this is how we will perpetuate, so if there is one thing that's clear and being part of all this and have you to it?

Yeah, pretty much.

And now it's not?

Yeah, a different change in role.

Yeah, and that was back when your sense of identity was very strong and so that made you very productive as a provider when it's changed and that can really shape your sense of who you are and how you value yourself, so that how you treat people in a crisis and stuff like that and you're going to be going with that and you used to be the most confused person, but not anymore.

Yeah, it's just not there.

Yeah, and the fact that you have now those things, you have to have it where you're faced with the fact that you can't do things as you used to, so whatever happens has not really changed, I discovered, with all the emotional energy, so I don't really care about some things because you're not spending excess emotional energy on it, but I would be triggered from time to time, but whenever that happens, I do it a little bit, but what happened this morning, I suddenly found that I hadn't touched it and it would've if I had wanted to, so I was thinking over the years that it could've been very different or much worse, so I am encouraged by it and of course, I am always encouraged and I try to do that because I want to get there and I feel better afterwards as I'm always looking for an outcome, but that motivation is there for activity or productivity is quite close in particular, so one of the things during productivity is passive aggressive which is quite uncomfortable and there are lots of therapies for that, but you feel that it's a far cry and not in this aspect, as you feel you need to do, and there's still a tiny bit of guilt there, and having to tick these things off, so that's when I feel I don't do anything productive, particularly with that.

So do you feel you've been doing it a bit later.

Yes.

Yeah, and because of that, maybe you keep pushing yourself even if it's, you don't use that time watching TV, but you might, you do keep trying to do as much as you can possibly do until you're really too tired, so you won't be kind of practically having a rest, knowing that there might be times when you'll just keep going.

Yeah, it depends for how long, but it's pretty common.

Yeah, and I suppose then you also crash in front of the TV because you've gone all day and then by the time you sit down to rest, you're actually quite exhausted, so you fall asleep which then might disrupt your sleep at night as you fall asleep quite early in front of the TV and then you'll actually go to bed, you've already had a fair bit of sleep which will then affect how well you can go off to sleep after that, so then if you have disrupted sleep, you'll feel tired in the morning.

Yep, so I think that pretty much sounds okay.

(End of video):

Okay, so I think that sort of process of sharing the formulation is a really key kind of part of setting the scene for therapy because you can see she's noticed that I've described the situation in a way that resonates with her which helps her feel that we're kind of on the same page and I understand what's going on for her, and then also it provides a rationale for the treatment, so she had this goal to be not watching as much tv and increasing her activity in other ways, so she wanted to be doing more art and gardening and seeing her friends more often, as opposed to kind of crashing at home in front of the TV and she was in the category of feeling that that was a really important change to make, but not being very confident about making it.

In terms of the things that, so when we do those importance and confidence ratings, we use the motivation interview and technique of saying, okay, so her importance rating I think is eight out of ten, and I said, I think her confidence rating was six out of ten, which is a better example, and I said, so what makes it a six out of ten rather than say a four, so she said, well, I know that if I'm kind of told to do something or if you're kind of suggesting a treatment program to me, then I'll follow through with it, and I'll do what I say that I'm going to do, and in terms of what will help it bring it up higher than six out of ten, she said, well, the things that probably get in the way are I might be too tired to do it, so that was the main barrier for her, is just that concern that her fatigue itself would prevent her from actually following the treatment program.

But with this kind of person, you can see that she's quite articulate and her language function is quite intact, so that, from the point if view of doing therapy, there wasn't, I was using quite kind of high level vocabulary and wasn't adapting the way I described quite high level concepts very much, but of course, this isn't all of our treatment population for a young guy with not as articulate verbal skills.

You would need to be describing some of those concepts in a different way and I'll talk a bit more about adapting that therapy in a moment, so now I'm just going to work through some of the modules on fatigue interventions, and these are kind of spread throughout the program.

The modules three and five are the main modules that focus on fatigue in our manual, but the relaxation techniques from the sleep module I think are also very relevant for the fatigue management, and also in the second module, we do a bit of psycho education about the body battery which I'm going to show you in a moment and that also is crucial, I think, with the fatigue intervention, so I'll go through each of these elements now.

So as I mentioned, this body battery idea is one that I have used with every single person I've done this intervention with and I think it's a really important concept, too, as a base for understanding the notion of regular rest breaks, so it's the notion that your available energy is like a battery, so we all have a battery of a particular capacity, but after injury, your battery might have a more limited capacity and is also drained more quickly, so it's like a kind of Aldi brand battery.

So if you drain your battery all in one go, it's also going to take longer to recharge, so a bit like if your phone goes right down to 2%, you plug that in, it's going to take longer to get to a hundred than if it was at a 50% when you plug it in.

So to keep the battery working when you need it, you always need some in reserve, so it's a good idea to have and keep the battery in the green rather than letting it go to the red, and to keep it in the green, it's the best way of doing that is having regular top ups.

Now of course, the tech focus people, when you talk about it, they say, well, if you recharge your battery often, it drains, it damages the battery and that's where you say, well, it's not exactly like a phone battery, but that's generally the idea.

Yeah, so I think just having that concept of keeping your battery in the green is immediately kind of reframes the idea of a rest break because you can see Sue, we were talking about how when she had a rest break, she felt quite uncomfortable about that, she was feeling lazy and she just was a bit restless with the notion of resting, but when you talk about resting as actually recharging your battery, it has a more positive and kind of productive flavour to it already.

So then when you plan the initial activity program, the key to this is really introducing much more regular and shorter rest breaks, so that idea of topping up your battery much more regularly, so as a rule of thumb, I tend to suggest, so you use as a basis for this, the activity diary that they've filled out, so you could see Sue's one, she was doing whole chunks of activity without any rest in between, so to address that, my general rule of thumb that I use is five minutes of rest for every hour of activity, and that includes both physical and mental activity, because mental activity is crucial as well, and it's something that often people don't think about as something that should be tiring, but in fact, it is extremely tiring as we know for people with a brain injury.

So it's not always possible to have five minutes of rest every hour, so if you're in the middle of a bridge game and your partner's there and waiting for you to have a turn, it's not always feasible to have a break in the middle of that, so that's where I think using that rule of thumb flexibly is important, so if you can't have a rest on the hour, then you might have ten minutes every two hours or fifteen minutes every three hours, but trying not to go much more than two or three hours without having a rest break.

So this initial plan, you do have to kind of be quite specific about what the strategies are going to be to actually trigger the person to start and stop their rest because particularly for someone like Sue, she's not used to doing this regularly.

It's not part of her general pattern and it's easier to then just get carried away with whatever you're normally doing and not stop and rest, so that's where using some strategies like alarms or reminders is sometimes quite important because otherwise it just won't happen.

But I think this acts a little bit like a script and for people who are quite perfectionistic and like to do what they're told by an expert, then it can be quite helpful because it's where this is your prescription for what to do with your rest breaks and it also actively targets the potential barriers to introducing those rest breaks.

So then in the session after that, once they've had a go with trying out those rest breaks, you then need to review and see how often they've managed to actually implement them, so this is a little table to help guide the percent of success and the potential reasons for non-achievement, and then what you might do in response to that, so sometimes it's about actually, when they might have thought about rest, but they sort of thought, no, I'll be right, or I don't, there's still that sort of entrenched belief of rest is unproductive might get in the way, so the beliefs about rest you might need to address as the next port of call or there might just be forgetting to, as they're just sort of not in the habit, so they've forgotten to implement it, so there are some memory strategies or some organisational strategies that might need to come in to play a bit more and then also, you might need to sort of work out the balance of physical and mental activity, too, so if they're doing each of those in long chunks, spreading them out and having more of a balance of physical and mental activity also might be useful.

So in working out the best way to rest, as I mentioned, a lot of people would tend to use screens or other mental activities to rest naturally.

I'm guilty of that myself, spending a bit of time with friends or something like that or scrolling through Facebook, but it's actually not very relaxing and still quite mentally stimulating for many people with a brain injury, so I think I see it as a skill that you're introducing is actually learning how to relax and truly give yourself a rest, so for that, we often, with almost everyone who I did it, will introduce some relaxation techniques, and in particular, I think progressive muscle relaxation tends to be a really useful one to do with this group, because it is quite, it's a bit more like a sort of physical exercise.

You're going through the different parts of the body, clenching and relaxing in turn, so there are some things for the mind to focus on a sort of sequence of movements that are relaxing and that differs from, say, a slow breathing exercise which might last for five to ten minutes and it's just breathing where it's easier to lose your focus and get distracted and feel a bit bored or frustrated, so I like using the progressive muscle relaxation for that reason, and I think it's in general, quite useful for everyone, brain injury or not, to have a recording of that relaxation to use it to guide them, so you can either have a recording that you've just done yourself and can give them, or you can actually record it in session, even on their phone, using voice memos, so then they've got something to actually guide them at home because if they have to take themselves through it, it's really easy to lose track, and relaxation exercises can be quite difficult and quite frustrating when your mind keeps wandering and you can't keep focused on it, so the more that they've got a guide to follow, the easier it is, I think.

Okay, so now this is another little video of me working through some barriers to the activity rest with Sue, and also reviewing some options for rest breaks and summarising her homework, so it's sort of addressing some of the sort of logistics, I suppose of making sure the activity program is in place.

(Video):

And that's another important factor, that it was the day that we didn't get really much of a chance to have a break, with a lot of activity and at that point, you crashed out, you had the batteries.

And that day, physically, it just didn't work that way, I was just too weak, but I think often, after a stroke, if that mental activity then can in a small way a bit more relaxing, then that will mean it gets that much down there, so that makes a lot of sense, because I needed a lot of that regular recharging to a certain extent, at night, right down at 5% battery level and crashing in front of the TV and sleep later.

Yeah, so anything that we could do to be incorporated then? No, because I was out socially and I would sit there and take it in.

So sometimes, some things that are suggested are go to the bathroom, or all my clients will do that, so how do you have breaks?

Well, you don't have to do a full ten minutes, you can just sit and have breaks, just a sort of mini pause, but that's sometimes enough just to recharge for a top up, so I', wondering whether that might be something.

And if you're getting in the car to go to the next place, it doesn't have to be a long one.

Yeah, well, that worked that day, in the car, it actually worked well.

Yeah, good.

I never thought of a break in a social situation but there's no reason why you can't.

Yeah, so you don't even have to say that, just do it while you're there and you've got the options, I suppose, too, like a relaxation CD or just relax on the couch or think about having a bath.

Yeah, okay, well, that's another thing, and probably that's something after bridge, maybe another sort of relaxing thing to do to sort of winding down.

Okay, does that sound like it's going to work? What might be hard?

Yeah, I've been quite impressed with it, yeah, and I'm already thinking, this might be working, so if I could keep going on the same to recharge the battery, then it will be effective.

Yeah, excellent, so it's sometimes part of the others, so then it's finding a way through those barriers, so taking those little opportunities and you can go to the toilet or whatever and then just try to have a really short break and there are the things that will help refine this plan. Yeah, but it's great that you have those, because that will keep it healthy.

Absolutely, and yourself motivated.

Yeah, well, it's good to hear that you're travelling well and the tweaking this week with a bit of relaxation and afternoon rest, taking the opportunities.

Okay, that's wonderful, excellent.

(End of video):

I'm finding that all very straightforward, but I think really crucial to be doing that work on potential barriers to implementing these breaks and also, the gender setting and summarising of homework at the end of really, really important elements of CBT so that the session is quite structured and it's clear what you're setting out to achieve in each one and at the end, you're reviewing that and making sure the plans for the homework are really clear and there's a clear rationale for that and there's a plan for how to implement it and remember to do it.

So I'm aware that I'm chewing up some time, so I'm just going to go through this fairly briefly, but in restructuring the thoughts and many of the thoughts that come through in this work are around resistance, I suppose, to changing the entrenched patterns, and the rigidity, the cognitive rigidity that comes along with brain injury means it's sometimes quite hard to shift some of those beliefs, so you do have to be quite careful in how you go about doing that and doing it in a way that's different to what it would be for people without a brain injury.

So here are just some brief ideas for adapting some of the cognitive restructuring techniques that are a core part of CBT.

So in traditional CBT, there's the idea that you're using kind of socratic questioning to elicit the thoughts from the client and get them to come up with alternatives, but that's not always possible in a brain injured person, that coming up with different ways of thinking about something in a flexible way can be really challenging, so that's where the role of the therapist sometimes needs to be a little bit more directive or proactive in helping the client prompt the client to come up with a different way of thinking about the situation.

So I'd sort of like to think of that process as a bit of a scaffolding or increased level of structure as needed, so you might start off with just asking an open question about is there a different way to think about this, and then gradually provide a little bit more prompting as needed if they can't come up with anything or they're quite stuck in a certain way of thinking, if you had a friend in the same situation, what would you say to them, so stepping outside your own experience to see it from a different perspective, then offering a choice of one or two other thoughts?

Well, what about if you think about it in this way or how would it feel if you thought this, so you're offering a couple of options and then finally, just directly offering a specific thought that you think might come in handy, so I've got an idea about a different way of thinking about this, would you like to hear it, so you're still asking for their permission, you're still involving them in the process, but you are also more directly suggesting particular thought about it, so just to put that in a context, here are some sort of common unhelpful thoughts about particularly fatigue, so just take a moment to have a think about how you might restructure these, so if somebody who you were working with expressed these thoughts, so when I feel:

Okay, I need to push myself to get everything done, resting on the couch is lazy.

If I don't do all the things I need to do, I'm worthless.

I need to keep my brain active or I won't get better.

If I can't do the entire job in one go, there's no point in starting.

If I miss out on doing things, I'll lose my friends.

So are these thoughts that you've heard clients express?

So it's good to have in your kind of toolkit some different takes on these thoughts so that you do have something to offer if a client is stuck on this perspective, you've got some things to offer, or if it comes to directly suggesting an alternative perspective, you have one to come up with, so just have a moment to think what you might say in response to these, and these are what I have come up with.

There's no right or wrong answers, but here are some options, so if rest is unproductive, instead rest recharges me, so again, coming back to that body battery idea. It's kind of giving you that fuel.

If I do less, I can do each thing better, so quality rather than quantity.

I need to give my brain a rest or I won't get better, so that rest is something that your brain needs to repair itself.

One step at a time is better than none, so you do get a lot of people kind of seeing a whole stack of things that need to be done and going, I just cannot do that at all, it's just overwhelming, the thought of doing it, so breaking that right down in to smaller steps and thinking about each step as an achievement.

Then if I do things when I'm tired, I'll crash afterwards and miss out on more things, so that cost of pushing yourself too much.

Okay, so just very briefly, the final part of this fatigue intervention is about the cognitive and physical fatigue and some strategies around that, so it's about kind of with physical fatigue, finding some different ways of doing things, making sure that the tools that you need are all there, that you're organised for the task that you need.

I did this with an electrician sort of with a process that he needed to follow and we worked through all the tools that he needed and the steps that he needed to follow, which meant that he wasn't kind of going all over the place and walking back and forth from his car all the time to try and get himself organised which is tiring, and then with mental fatigue, really breaking tasks down in to steps, ticking them off as you go, using memory strategies.

So for one of my clients, really learning how to use her phone and putting in calendar alerts was one of the most active ingredients for the interventions because she was just spending a lot of time trying to remember what she needed to do, and just having that trigger helped her feel much more in control and less tired with the effort of trying to remember, and then also allowing enough time to do things.

So sorry I skipped through that a little bit quickly, but I now want to hand over back to Adam, so he can talk about sleep and I'm sure you might have questions, but we'll perhaps save them to the end.

Thanks, so has everyone had a go for about ten minutes?

Yeah, so is that all right?

Okay, so our sleep intervention was mainly focused on insomnia because that was the main problem people were presenting with, so difficulties falling asleep or maintaining sleep, so

CBT for insomnia or CBTI is really the first line treatment if anyone just presents with insomnia in the general population, so this is the list of techniques that would form part of CBTI and really, we just use those and adapted them for our group.

So I'm just going to go through probably the key ones, just given the time.

So sleep education actually was really important in validating the symptoms, but also reducing some of the anxiety because anxiety about not sleeping becomes a huge barrier.

You don't want people to get in to bed and think, my God, I'm not going to have, I'm not going to get to sleep again, it's going to be a terrible night, and that's really going to inhibit their ability to fall asleep.

So just two things that were quite reassuring for people:

The first thing was that it's actually quite normal to wake up through the night, because sleep goes in cycles and phases, it goes from lighter stages down in to deeper stages and then comes back in to lighter and that cycles throughout the night.

So when you come up in to a lighter stage of sleep, a lot of people actually wake up, but then fall straight back to sleep.

Now people who aren't used to that start to equate any waking during the night as a sign of poor quality sleep, when actually, if people can fall back to sleep easily, then the quality of sleep actually can be okay and they're quite reassured by that.

The second thing is deep sleep is seen as the restorative aspect of sleep that restores our bodily functions.

Now most deep sleep happens in the first two or three cycles of the night, so if people even get four or five hours of sleep, they're still getting most of that restorative aspects of sleep.

Again, that can be reassuring for people, that even if they're getting that, they can still get those, that restoration.

Another key thing to educate people about is sleep inertia, so this idea of when you first wake up, you can feel quite groggy and not quite with it, and we all feel that.

But after a brain injury, this can be really extended, so people can talk about feeling this way for half an hour or an hour or even longer after they first wake up.

Now the issue is that people, when they wake up and feel that inertia, feel that must mean I haven't had a good night's sleep, I need to sleep in more. I have to go back to bed.

But often, a lot of people will say that if they can push through that first half hour or an hour, they really wake up and they feel much better.

So what we're trying to educate people that this is a normal thing and a normal process and maybe if we can set you up with a routine to get you through that first hour, you're actually going to feel much better, and in the end, people talk about that actually, sometimes they sleep in and it actually doesn't make them feel any better anyway and they feel like they've actually done less for the day and they feel worse.

So I'm sure everyone's heard about sleep hygiene, so really, this is just a collection of habits, things to do within an environment that you sleep in, to help promote better sleep.

If you went to probably a GP or someone, that's the first thing they would give you, are some sleep hygiene tips or if you Googled it, what we know about chronic insomnia is that that alone isn't that effective in treating insomnia.

But in our clients, what we found is because potentially, the sleep issues weren't so entrenched or it wasn't their only problem, they actually hadn't had a lot of that basic sleep hygiene to date, so we found that some of these basic sleep hygiene techniques were actually quite effective for our group.

So in the red box is just a list of common things that we would go through with people, and again, if you looked it up on the web, this is what you would find.

So sleep hygiene was really our first intervention because these were the least invasive things that we would do with people.

Interestingly, a lot of these things are actually surprising to people, they hadn't thought of them.

There was some reluctance to use some of them if they were different to what they would normally do, so I had a guy who liked to have a few whiskies before bed because he felt it would send him off to sleep.

But then he would wake up after an hour or two and find it difficult to back to sleep and we talked about the impact of alcohol on sleep, so you had to often provide a lot of justification and rationale around why he would change these before people would implement them.

The other thing is you have to spend quite a bit of time planning how they're going to do it, so I think in a group of the clients, just giving them a list of strategies often that may not be that effective and you have to spend some time working out how you're going to implement that.

So for example, not looking at the clock is something which we'd often recommend because people then get anxious if they're not sleeping and they keep looking and get more anxious, but how to stop yourself from doing that is something you need to plan and work out because sometimes just turning the clock around isn't enough. You might need to actually take the clock out of the room.

Okay, so people who can't sleep who have insomnia start to associate being in bed with fear of not sleeping, and that can lead to arousal and perpetuates a problem of falling asleep.

So if stimulus control is doing everything to strengthen the link between being in bed and being asleep versus being in bed and trying to sleep, being awake.

So this includes a range of strategies, and I want to focus on two, so the first one is only go to bed when you feel sleepy.

So rather than prescribe a time when you go to bed, we talk about a window of going to bed, so it might be let's go to bed between ten thirty and eleven thirty, but wait till you actually

feel sleepy before you turn the light off, because if you turn the light off and are still awake and aroused, then it's going to be harder to fall asleep.

I'll talk about three.

Having a consistent wake up time, though, we do think is important because that helps set the Circadian rhythm for the day, so if people have varying wake up times, it can interfere with your Circadian rhythm which is a key physiological process that impacts on sleep.

The last one which is really important in terms of this approach is that if you're not sleeping and you get in to bed and you're trying to sleep is to actually get out of bed after about twenty minutes, go and do something else in another room, read, listen to some music, do relaxation exercise and then when you feel sleepy, go back to bed.

So most clients like the idea of the consistent wake up time because they felt like it got them going for the day, so they could then get on with their goals, but getting out of bed was another story and I don't know if you've ever tried to do this, but it's quite hard to motivate yourself to get out of bed when it's particularly cold and often people would think, well, if I'm not in bed, there's no chance I'm going to sleep, but then you talk and look at their sleep diary and say, well, you were awake for two hours in bed, maybe it's worth trying something different.

Now the clients who were willing to try this actually found it was really successful, and sometimes they only had to try it once for it to work, but it also took the pressure off this so they felt like they now had something they could do if they were lying awake, so it sort of had this anxiety reducing affect as well.

It was also very important to engage the partner if there was one because a barrier for some people getting up is they don't want to disturb their partner, but of course, the partner is often wanting them to get out of bed because they're tossing and turning, but if the partner was able to say, look, you've been here for a while, why don't you get up and go and read in the next room, then that was actually quite effective.

So a common thing with people with sleep problems is that they will often try and sleep in to catch up on sleep or they will nap a lot during the day to make up for that lost sleep which as I mentioned before interferes with things like Circadian rhythm and other sleep processes.

Sleep restriction is quite an invasive technique, but it involves essentially restricting the amount of time the person spends in bed, so if for example, they're only on average getting five hours a night, but they're probably in bed for eight hours trying to sleep, the intervention would be to actually set that they're only in bed for five hours for that night.

So the idea is that what you're inducing is a better quality sleep, you're taking away that anxiety of trying to get to sleep, and the idea is that over time, you would build how much time they're in bed, presuming that their sleep quality has improved, and in terms of chronic insomnia in the general population, this is seen as the standalone sort of gold standard of treatment, and if you thought they were reluctant to get out of bed, they're even more reluctant to restrict how much time that they're in bed, and this was more of a second step if other things hadn't been working because it is quite invasive and you also had to think about how they would manage the fatigue during the day because it could make them more tired because sleep does fluctuate.

Sometimes people will get four hours, but other times, they will get eight, so you need to plan it if they're going to have a night where they're not having as much sleep, how do they manage that fatigue during the day, and that's where some of the strategies done are talked about are important to discuss.

In terms of relaxation, a key really was to establish some wind down period before bed where they would be more relaxed and more likely to fall in to a good sleep, so we'd often talk about what are you doing in the last one or two hours before bedtime to help that process, and that would include a range of different techniques or strategies that we would go through.

But in the end, it was really important and this is the basis of CBT to look at what are their underlying beliefs about sleep and how they're managing it.

So a lot of people would have fears that if they don't have a good night's sleep, they won't cope tomorrow and it'd be a complete disaster, so that would encourage them to start looking at the clock more to make sure are they getting to sleep and that anxiety would build and then they would actually find it harder to fall asleep.

When you challenge some of those ideas and get them to think, well, actually, how did you go the next day when you didn't get, you only got four hours' sleep that night, and often, they'll say, actually, it was pretty hard, but it was all right, I sort of managed, it actually wasn't too bad.

So they really start to challenge some of those entrenched things that they have when they're lying in bed and that's what you're trying to do, trying to set up some alternative ideas to lessen the anxiety they have when they're actually trying to fall asleep.

So these beliefs around sleep and this anxiety around sleep was really common and we've all had it when we're trying to get to sleep, but in people who have chronic problems, they become intensified, so we did use a range of things to try and address that and I think if you're trying to create behaviour change, you really need to understand what are those beliefs underlying those patterns?

Lastly, I just want to talk about hypersomnia, so this is excessive sleep, so people who sleep for nine or ten hours or longer, yet still feel very sleepy during the day.

We incorporate a lot of the interventions that we do for insomnia, but key things are actually having scheduled naps during the day, so rather than napping when people just feel tired, actually trying to pre-empt those periods of sleepiness by scheduling naps.

We limit them to about fifty or thirty minutes because we don't want people to fall in to a deep sleep and then have really extended sleep inertia when they wake up, so if they have an hour's sleep, they might feel so groggy for the next hour or two that they actually can't do anything, so we try and keep it quite short.

But again, addressing some of the beliefs were helpful, so some people will believe that they just need more and more sleep to feel better during the day when in fact, when you look at their experience, actually sleeping longer doesn't tend to make them feel better or function better, so we try and limit that night time sleep, but come up with better techniques during the day to help them manage that sleepiness and that seemed to be more effective for them.

Okay, so our belief and I think that the research has showed from what we did that CBT can be effective for treating both fatigue and sleep issues.

We do think, though, it's important to treat them concurrently, because there are no medications involved, it avoids some of the side effects that you can have with medication based treatments.

But with all these treatments, we need to adapt them to our client group and if people have cognitive difficulties, you need to think how to best implement them, so that's what you need to think about when you're implementing these techniques.

So sorry I sped through that, but hopefully, we have some time for questions if there are any

So thank you very much, Dana and Adam.

(Applause):

Let's open up the floor for questions.

Q Hi, I'm Wes Jerry, I'm a regular physician, I noticed at the beginning that you, in your actual research, you had pain in both groups, the treatment as usual and the CBT groups, there seemed to be more pain in your treatment of usual group, even though that maybe wasn't statistically significant, it could be clinically significant, I wondered if you thought that might've had an impact on your results and also I wondered if you ended up having to do pain management with the people in your groups who had pain because that's obviously going to impact a lot of sleep disturbance.

A Yeah, so it's possible, so we only had thirty nine people, so it's a small enough sample that you can get some differences like that, pain was definitely a factor for a lot of our clients and we had to, it wasn't a direct focus, but we definitely talked about it and talked about how to manage that pain when they were trying to sleep particularly, around using relaxation, so we used the techniques that we had in the program to focus on pain, I don't know if Dana had a few people particularly.

A2 Yeah, and I think that particularly one of the things is that the impact of pain on sleep, there are the direct effects of just being focused on the pain, but also there's the anxiety around the pain and how it's going to impact on sleep, so I think with our intervention, we did tend to focus more on that, so looking at the beliefs about how pain is going to impact on sleep and their daytime functioning and they're trying to sort of shift some of those and reduce some of the anxiety around the pain, yeah, we didn't have the scope to do a full pain management program obviously within this, but it's a question that's been raised before and it's a really crucial thing that I think would probably need to still happen in concurrently with a program like this, but certainly the beliefs and the anxiety around pain, we can address as part of this.

Q Hi, I'm Batten, an OT, I also have done some research in this area and the thing that I grapple with still is around outcome measures and you've used the fatigue outcome measures and because fatigue is so multifactorial, I'm just not sure that the fatigue measures that we have are accurately capturing the changes because you've obviously had some significant changes in your group and I guess I wonder, clinically

researching, we should be looking more at that to be a participation level rather than if they say changes on the fatigue scales, I'm not sure of your comments on that.

A Yeah, so we didn't record the activity levels through the diaries, the problem is it's quite hard to get people to accurately fill those out, but I agree that there are limitations with the existing measures, so we try to use a range of different things to understand what is going on with the person, and we also do exit interviews for the people as well and just ask them all, how has this been for you in terms of your fatigue, but also your goals, so we do set out more functional goals at the start of the program to work out what do you want to do if your fatigue is less, so we try and focus on those as well.

Q But it may not be that fatigue's necessarily less, but if they're managing it better, so they can respond to their activities more and be able to fulfil their activities that they want to be able to do.

A2 Absolutely.

A Yeah, and that's what we talk about, that your symptoms actually may not be less, but you may be able to do more because you're coping better with it, yep, definitely, and that's why I think you have to look beyond symptoms and look at function as well.

Q I guess just having those as your key outcome measures, it's difficult then to look outside those.

A2 It's such, Jenny Ponsford often talks about this because it's such a problematic thing to measure because it is, like you say, you highlighted that it's so subjective and multifactorial and really difficult to pin down, we don't have good physiological marker of mental fatigue, so yeah, it's really tricky.

Q Because generally, your interventions hake significant results on not some, but all of it, but whether those are picked up on.

A2 Yeah, and it might be that because of the depression, as we had a really strong affect on depression symptoms, so that also can be sort of tapping in to some of that apathy and sluggishness and the fatigue kind of related symptoms, too, that that might be one of the signifiers that fatigue is improving.

Q My comments might sort of overlap a bit about the measures, too, thank you for a really, really useful presentation for me as well, I do a lot of this sort of sleeping stuff, so some of it is quite informative as well, just with the measures, I was interested as sometimes in my clinical work, I have previously used actigraphy, I find with the sleep diaries, while that gives me really good clinical, I sense a lot of clients think is happening, I've had cases where hiring actigraphy for a couple of weeks has then been able to get a lovely graph and show the client, well, actually, you feel you're awake for seven hours a night, it turns out look, here, you actually didn't move between this and that time, and that itself can be quite helpful, but also then from the sleep timing stuff, but I haven't found anyone, for the people we've used for actigraphy have been useless recently, so I need to find out if there's anyone else who can, or find other patients.

A2 Absolutely.

Q So I find that a little bit awkward, and as you talk, well, actually, it's the clients' experience of it, really, it doesn't matter how many moments they're sleeping or not, it's how they feel about how they're sleeping.

A Well, I think it can be helpful, though, to educate them, but I had a few clients who had the strong belief they weren't sleeping at all, so I had one client who would come every week and say, I haven't slept again for another week, so it's twenty weeks in a row, I haven't slept, and presented all the evidence on the actigraphy and it didn't make a difference and really, we had to, I tried to rationalise that and in the end, we sort of shifted completely away from the sleep, we sort of just moved on to function and said, okay, well, if this is happening, it sounds like nothing's changing, let's just focus on what you want to do in your life, and moved away from the sleep, because for some people, it becomes this, and I think for a lot of people, it actually becomes, they link sleep to all their problems, they actually, it's particularly for people who don't have insight in to their brain injury and acknowledgment of it, but I think sleep becomes a socially acceptable reason for their problems, so they tie on to, well, if I fix my sleep, it'll all be fine.

Q Yeah, and one of the interesting ones I think was once, even when you show them that sleep study or the actigraphy, they still do not believe that their experience correlates with what you can show them, that's physiologically going on.

Q Yeah, I had one lady and she hadn't slept for years and it turned out that she would wake up every hour and look at the clock and it would say seven, ten PM, eleven PM, midnight, she slept with the radio on and the news bulletin would wake her up and that would affect her sleep limitation where you're drifting off and it's almost real, but it's not quite real. If you wake someone up in stage one or two sleep, they'll often say, no, I'm not asleep, I'm just lying here, and that's what would happen to her, she would sort of wake up slowly and then go, I've got another hour, another hour, another hour, but sorry, my other question, just about the idea of five minutes' rest in an hour for physical and mental activity, I love that idea, I like that for myself, I haven't done that so much and I will think about incorporating that in my work, I often tend to suggest people have a rest sort of in that post lunch, that Circadian dip period as siesta time, but I would sort of go for a bit of a longer, as I find that's really-?

Q Did you find that five minutes to-?

A2 Look, it's a rule of thumb and not meant to be a sort of set, it would have to be this-.

Q But if you've used it with people, then I would've thought that it's sure after an hour, it would be effective or it's elective.

A2 Sometimes it's just about what's practical, so for somebody who is working or doing a lot of activity during the day, having a nap for half an hour is not usually feasible in most workplaces.

Q And the lady said about having a nap.

A2 Yep, and just the notion of short and often, a bit like the idea of snacking regularly during the day rather than having massive meals and then having a sugar high and then a crash, it's just maintaining that really even energy level that's kind of maintained across the day rather than going up and down and I think the nap thing, so a lot of people did also need a nap, so then it's just really making sure that it's timed for a less than thirty minutes, so ideally, about twenty minutes, and having a strategy to wake up after that time, so I would've said, it's not, you don't need to ban naps all together, but they do need to be, just the most recent evidence is that at least kind of ten hours before bedtime, ideally, which would be just after lunch, and then no more than twenty minutes, I guess.

Q And set an alarm or something.

A2 Exactly.

A But I think that's a key.

Q But if they've got an activity plan, they've got to jump up and do that.

A Yeah, and that's when I suppose with more severe people, you really need the input of a family and the carers and support network because sometimes it needs to be them that makes it happen. It's very hard for some people to do it on their own.

Thank you, a really great presentation and it sounds like a lot of really helpful things to incorporate which a lot of people will as well, is this a program and strategies that are being published or available?

A2 Yes, good question, so there are already some papers out and there is a manual that we will publish, but we're now doing, we didn't get to that, Adam's sort of leading this a bit.

A So we're continuing the research, so we have published three papers based on that initial group of thirty nine people, Sylvia has led that, so they're available in various journals, so we'll just search for Sylvia or our names, they should come up, or we can email them, but we're commencing a new program now, using the same CBT intervention, but comparing it to a control, an active control group, so before it was just treatment as usual, but we really need to show that CBT is better than just having client contact, so often, you just get a lot of benefit from seeing a professional and talking about things, so we want to show that it is actually more effective than that, so we're comparing CBT to providing information about brain injury, stroke, but sleep and fatigue issues, but more just information versus the active CBT, so if you do have any clients with TBI or non-progressive ABI's, please contact us or Lucy is probably the best person to contact, she's the person leading the research trial.

A2 And also it reminded me, I just wanted to just plug Brain Span if you're not a member of Brain Span yet, please join, there's the website there, it's a new, multidisciplinary network for clinicians and researchers in the field of brain impairment, so all of you would fall in that category, so if you're not a member, it's just a matter of joining up to the group and hopefully, it's a good source of information about new research and things that are happening in the field, resources, things like that, so please do join.

Q I just had a question, thanks very much for a great presentation, I really enjoyed it, with the sleep diary, did you have any issues with that making people worse because they've got to think, my way, my sleep, this, that, did any of that go on?

A I didn't get a lot of that feedback, I think we contained it to only at the start and the end, I've definitely sent in clients who are doing it all the time who become so obsessed by it that it does interfere with their sleep, so I agree, I think you need to do it in bursts to see what is going on and if things are changing.

Q Did you get many filling it in at the appointment for the whole week, with one pen and the whole thing?

A Look, I think with a client, you can always tell, but really, I think very early on, if you felt like you weren't getting reliable information, I would always call the partner and get their input and particularly about, where there were clients who would come to us and say, no, I don't have any fatigue issues, and you would talk to their partner and say, they just really crash, they're really tired, they're irritable, they fall asleep before dinner, so getting that informant history was really important.

A2 Yeah, so I think the key with the sleep diary is to enhance awareness for the clinician and the patient about what's going on without it becoming an obsession, so just using it sort of moderately, I suppose, and sometimes they just haven't quite realised the amount of variation in times that they're going to sleep and waking up, so even just seeing that and pointing out the impact of that on Circadian rhythms and things can be a helpful step.

Q How long to cure, eight sessions for an hour?

A2 Yeah, so an hour, but that again could be flexible, so if there was significant fatigue during the session, for example, so sometimes I would actually just do a relaxation in the beginning or middle of the session, just to break it up and give them sort of model of fatigue management within the session, too, in generally an hour.

Q So we've talked, just a quick question about that as well, what proportion had sort of comorbid chronic substance abuse issues and the self-medicating around their sleep in terms of utilising substance and prescription meds as well and how did that kind of interact with the effect on the CBT as well?

A2 We had that as an exclusion, didn't we? I think we had an exclusion as a major substance dependence, there were probably quite a few people with signs of significant alcohol use and some with other drug use, but if they were really dependent, they were excluded, we probably, yeah, I personally didn't work with a lot of people with obviously an issue in general practice, but the study didn't have a lot of people who were really dependent on say benzos or other medications or substances.

A So generally, there's an exclusion, but I think, I have to recall, but for some people, for example were taking melatonin, so we allowed that, but they had to be on a stable dose and couldn't change it throughout the study, so we talked to them at the start, if you feel that with your doctor, you need to change it, then just let us know and we can work out whether you need to stay in the study, but generally, people-.

A2 We had quite a few on sleeping medications, and they were allowed to stay on those, but just couldn't change it during the course of the study.

A But most people actually wanted to be off them, they didn't want to be on them, so we're happy to stop using them, so I suppose we talked about, well, this might give you something that would avoid having to use those.

Q Thank you very much, Dana and Adam.

(Applause):

END OF TRANSCRIPT