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**THESE MINUTES ARE EMBARGOED UNTIL  
FRIDAY 5 SEPTEMBER 2008 AT 1.00PM**  
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**WESTERN HEALTH AND SOCIAL SERVICES COUNCIL**

**Minutes of One Hundred and Sixty-second meeting of the  
Western Health and Social Services Council  
held on Friday 6 June 2008  
in the Committee Room, Library Headquarters,  
Spillar's Place, Omagh, Co Tyrone  
at 6.00pm**

**Present:**

<b>Mrs V Brown</b>	<b>Mr E McGrade</b>
<b>Mr J Campbell</b>	<b>Mr M McIvor</b>
<b>Councillor M Carten</b>	<b>Mrs M McKeague</b>
<b>Councillor M Hamilton</b>	<b>Mr V McKelvey</b>
<b>Mrs S Hogg</b>	<b>Councillor J McKeever</b>
<b>Councillor B Johnston</b>	<b>Mrs F Robson (Vice-Chair)</b>
<b>Mr I Maguire</b>	

**Apologies:**

<b>Councillor M H Durkan</b>	<b>Mr P McGowan (Chairman)</b>
<b>Mr G Foley</b>	<b>Mr R McIntyre</b>
<b>Councillor R Hussey</b>	<b>Councillor B Page</b>
<b>Councillor R Lynch</b>	<b>Mr D Sutherland</b>
<b>Councillor M McColgan</b>	<b>Ms M Trimble</b>

**In Attendance:**

<b>Ms M Reilly</b>	<b>Mrs M Gormley</b>
<b>Mrs K Loughran</b>	<b>Miss S Forbes</b>

**1 member of the Public in attendance.  
1 member of the Press in attendance.**

**Chairman's Business:**

Mrs Robson welcomed everyone to the 162<sup>nd</sup> meeting of the WHSS Council. She said she would be chairing the meeting in the absence of Mr McGowan.

Mrs Robson introduced and welcomed Mrs Sandra Campbell, Development Officer (NI) for the Progressive Supranuclear Palsy Association (PSP).

Mrs Campbell thanked the Chair and members for inviting her to present to the Council.

## **Presentation by Mrs Campbell:**

Mrs Campbell said her work involves raising awareness of a devastating disease called Progressive Supranuclear Palsy (PSP). She said she works at every level throughout the Health Service and with the public in general.

She has been working with the PSP Association for the past 10 years - the first 6 years as a volunteer. The Association received funding from the Department of Health to strategically raise awareness of PSP through the media and the Health Service.

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Statistically worldwide PSP and Motor Neurone Disease (MND) have the same prevalence in any population across any race, gender or culture.

With most conditions when someone is told they have a terminal illness they usually are told what has to be done, what support there is available to them, and what is going to happen to them. However with PSP when patients are diagnosed they rarely receive any information except maybe by chance when a Neurologist may just happen to have a leaflet beside him and gives it to the patient directing them to the PSP Association. Usually following diagnosis of PSP the patient will leave the Consultant with nothing but a sentence hanging over them and nowhere to turn. Most GPs have not heard of PSP and the PSP Association has found the patient experience is that when they tell their GP they have been diagnosed with PSP the GP may ask them if they have been given any information about it. This can lead to difficulties for patients across Northern Ireland as they may not receive the appropriate care due to a lack of information.

A major part of the PSP Association's role in raising awareness is trying to ensure that patients diagnosed with PSP will from the very beginning receive appropriate care, support and palliative care for themselves and their families.

### **What is PSP?**

The presenting symptoms for PSP are very complex in nature and it is a progressive condition. 'Supranuclear' refers to the difficulty with eye movement. This can very often help a Neurologist with the differential diagnosis of PSP and Parkinson's Disease. The presenting symptoms of PSP are very similar to Parkinson's Disease and Alzheimer's or a mixture of both.

A Neurologist described PSP as the worst feature of all neurological conditions put together. In PSP there are symptoms also associated with

Alzheimer's, Parkinson's Disease, Motor Neurone Disease and Dementia all wrapped up together. 'Supranuclear' is the one thing that defines PSP because it refers to the eye movement. Patients develop problems in moving and aiming their eyes particularly in the downward axis. 'Palsy' refers to the weakness in the body. In PSP the patient falls backwards and not forwards as in Parkinson's Disease.

PSP can be described as BESS i.e. Balance, Eye movement, Speech and Swallowing.

Very often diagnosis will not be made until possibly 2-5 years into the actual onset of the disease. By the time patients register with the Association they may have had a diagnosis of Parkinson's Disease, Alzheimer's or dementia because of the complex range of symptoms. In fact the patient will have PSP and will have had a very difficult journey before a definitive diagnosis is made.

### **PSP:**

- Comparatively rare neuro-degenerative brain disease;
- Aggregation of Tau protein causing neurofibrillary tangles in various regions of brain – general atrophy;
- Progressively affects vision, balance, mobility, speech and swallowing. Order of symptoms depends upon region of Tau aggregation;
- No effective treatment and no cure;
- Life expectancy typically 5-7 years from onset;

### **Frequent misdiagnosis**

Prior to referral to a Neurologist, GPs would generally diagnose patients with Parkinson's Disease, Depression, Stroke, Balance disorders or other unknown disorders. GPs in general do not know about PSP and this proves very difficult for getting an early diagnosis. If and when a patient registers with the PSP Association the Association will liaise very closely with the patient's GP and make sure referrals have been made to the relevant health professionals.

### ***Diagnoses prior to referral***

Parkinsons - 29%

Balance disorder - 21%

Stroke - 10%

Depression - 7%

Other - 33%

### **Prevalence in Northern Ireland**

There have been 36 cases of PSP diagnosed in Northern Ireland. Currently only 16 of the 36 cases are registered with the PSP Association. The PSP Association wants to support every patient with PSP but because of Data Protection issues they have to wait for patients to come to them. Often it is only following a traumatic fall or a crisis of some description that a family member might discover PSP through the internet and find out that the PSP Association exists. The Association is working very hard to change this so that following diagnosis patients are immediately signposted to them in order to get the immediate support and information that they need.

The PSP Association has a 24 hour helpline and they want all patients to be able to access support.

Patients diagnosed with MND are usually directed to an MND Nurse Specialist and get immediate access to the MND Association for support. Currently in Northern Ireland there are no PSP Nurse Specialists and instead patients with PSP rely on a Parkinson's Disease Nurse Specialist. The PSP Association are hoping to receive funding in the near future to employ a Nurse Specialist to assist patients in Northern Ireland. At present patients in Northern Ireland are supported by telephone contact with a PSP Nurse Specialist based in Liverpool and by attending meetings held in Belfast.

### **Balance Problems**

Balance problems are a common feature of PSP and patients often fall backwards without warning. They may not have had a dizzy spell or tripped but could be just walking from A to B at home or at work. A person with PSP may be driving their car and all of a sudden will fall backwards and will almost blank out and possibly crash. Very many of the Association's patients have had quite horrific car accidents before a diagnosis of PSP is made.

People with PSP typically develop an arched neck in the backward flex so they cannot see down. This means when they are walking along they are not going to see objects on the floor. Their peripheral vision is very poor and they may trip and fall because they have a balance disorder. Patients with PSP do not have the ability to steady themselves and cannot save themselves because they are falling backwards not forwards.

Shortly after registering with the PSP Association two patients had fatal falls in their own homes. One patient fell and banged his head on a table resulting in a fatal injury and another patient fell through a glass door in his own home. This occurred shortly after they were diagnosed and they did not

understand the risk of severe falls. Very often patients will develop what is called the “Rocket Sign”. An example of this is where the patient goes to lift an object off a table; instead of walking carefully they think if they go quickly they will not fall. Patients with PSP have a tendency to rush and are impatient, reckless and uncoordinated so they suffer very serious falls resulting in severe injuries. There are many admissions to A & E with traumatic head injuries in particular. A patient with PSP may be well generally, their health may be very good but their balance can be extremely poor and they may need head protection from a very early stage. Depending on how bad the balance problem is the PSP Association may recommend a shield for the head.

## **Visual problems**

Visual problems with PSP are very complex. We ordinarily blink about 60 times a minute without thinking about it but PSP patients lose their ability to blink. They struggle to blink and push their eyes down losing their entire ocular movement. In struggling to blink their eyes will become very dry and they may suffer from corneal ulcers. Because they are not blinking the eyes fill up with water which runs down their face from the tear ducts. Although they would appear to have watery eyes their eyes remain dry because all the water is running down their face. Patients need a lot of support from Ophthalmology to try and help them with different visual aids and also support from the Royal National Institute for the Blind (RNIB) and other agencies. Sometimes patients develop a stare and a frown as they almost over-compensate and struggle to keep their eyes open. This is a very defining feature of PSP and is often called the “Mona Lisa” stare. Conversely their eyes may just close up and they cannot open them. There may be balance problems, some memory loss and problems with speech. Dementia may be diagnosed but the patient may in fact have very little dementia. Dementia is not a feature of PSP so it is important to be cautious with patients who seem to be disinterested and sleepy looking. They are not asleep but simply cannot open their eyes. Sometimes patients may require surgery and need a stitch in the side of their eye. Changing lenses makes no difference whatsoever as the problem is with eye movement and not visual acuity. All these symptoms help in the diagnosis of PSP. When talking to health professionals the PSP Association will ask them to look out for these signs in patients with neurological conditions in case there has been a misdiagnosis. Patients with PSP can register as partially sighted or blind and have access to visual aids through RNIB.

In a quote from Charles Dickens (The Lazy Tour of Two idle Apprentices 1857) “A chilled, slow, earthy, fixed old man. A cadaverous man of measured speech. An old man who seemed as unable to wink, as if his eyelids had been nailed to his forehead. An old man whose eyes – two spots of life – had no more motion than (sic) if they had been connected with the back of

his skull by screws driven through it, and riveted and bolted outside, among his grey hair. He had come in and shut the door, and now he sat down. He did not bend himself to sit, as other people do, but seemed to sink bolt upright, as if in water until the chair stopped him". This is a very vivid description of a patient with PSP.

Because of these type of symptoms the PSP Association is concerned about furniture in patients' own homes or in nursing homes. Patients with PSP tend to just flop into a chair and they jump out of the chair to rush to get things. If the chair is not a heavy, solid chair they will fall backwards and very often that is how injuries occur.

## **Speech and swallowing**

Speech and swallowing are probably the most difficult aspects of PSP that patients have to cope with. With the deterioration of mobility there are aids to help people e.g. walking aids, wheelchairs, electric chairs, pillow elevators and a lot of OT support. For eye problems patients can get support from RNIB and from Ophthalmology.

Patients tell us that difficulties with speech and swallowing are the most difficult things to deal with. Their mind is fully intact but their speech is deteriorating and they cannot communicate. Their swallow is also deteriorating and they will very often need PEG tube feeding which is a very significant and ethical decision for patients and their families to have to make.

Patients with PSP have a weakened cough and swallow reflex. They have a lot of mucus sitting at the back of their throat and they have not got the ability to cough properly. They cough, they drool a lot and are in a lot of discomfort causing embarrassment and social withdrawal. In America this is often called the "Dirty Tie" syndrome; as the patient cannot look down and see the food on their plate their co-ordination is poor and food may go all over their clothes instead of into their mouth. All this usually happens before they even know they have a neurological condition. It can be very difficult and very distressing for a patient when eating out with their family or at home.

Speech and Language Therapists need to be involved from a very early stage to make a baseline assessment of the patient following diagnosis. They need to monitor the patient and assess them and help them with exercises in order to maintain some strength in the muscle. Dieticians also need to work with patients to keep their fluid intake high; keep them well hydrated and make sure they are not at risk of choking, They also give advice on pureeing food and food consistency etc. Again very often PSP patients do not get this service until quite later on in their illness because no one knew to make the appropriate referrals. Sadly communication aids do not work very well because often a patient cannot speak and because of complex eye problems and even blindness usually accompanying PSP they may have no vision to allow them to access communication aids.

Because of choking aspirational pneumonia can be very common and can cause death. Some patients have not had information that their food was of the wrong consistency and could cause choking.

### **Other changes**

There is a huge cognitive change in patients with PSP and families would say it is like living with a stranger. With PSP patients can become very withdrawn, not wanting to communicate and depression can set in. Patients sometimes can have inappropriate behavioural problems, similar to Parkinson's Disease where they speak, laugh or cry inappropriately. Families struggle to come to terms with why their loved one is changing so much and what is going on in their life. They describe it as a living bereavement for the whole family. It is a loss of a person bit by bit.

### ***WHSC Trust and PSP***

In Northern Ireland the Western Trust has the lowest diagnosis of PSP. Mrs Campbell said the PSP Association has an emerging group in Omagh as most of their patients in the Western Trust are from Omagh. The real difficulty for patients she said is in knowing what services they need to access. Some of the PSP Association's members who are registered in this locality are getting services where they are needed. Because of the complex needs of the patient it takes two carers to work with a patient. Patients in rural areas are really struggling with getting two carers to come into their home to provide care. A full package of care following diagnosis is required which usually requires four care visits per day. Some sitting services are also required and again this is particularly difficult to access in rural areas. When a patient registers with the PSP Association the Association calls the patient's GP and mostly the GP asks for information to be sent to them as they do not know what PSP is. Once patients are diagnosed and contact the PSP Association it is very pro active in working on their behalf. The PSP Association wants to make sure there is continual assessment at all stages

and this is not because health professionals do not want to do it but because they just do not understand what is needed in PSP. Hopefully the Association will be able to identify the patients in the Western Trust; at the moment they have six patients which is very low.

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### ***Members' Questions:***

#### ***Mrs Brown***

Mrs Brown asked if PSP was more prevalent in men or women and if there was any particular reason why it was occurring in Omagh?

Mrs Campbell said it was the same for both genders and thanked Mrs Brown for raising the issue of why it was occurring in Omagh. She said that normally when clusters emerge it is because there is a very good Neurologist in the area who is picking up the patients. This happens in big cities such as Dublin, London, Birmingham, Liverpool and Manchester where there are excellent neurology services. She said there is one Neurologist in the Western Trust but it was not this Neurologist who diagnosed any of the PSP Association's patients. Mrs Campbell said several were diagnosed through video link to Belfast which is not ideal but at least the service is up and running. Some patients went privately to get a diagnosis fairly quickly. She said they cannot explain why there is a cluster around the Omagh area and it could be just coincidence because it is not like some other diseases where there is a familial or genetic link. She said there is no genetic link in PSP.

#### ***Mrs Hamilton***

Mrs Hamilton asked if a number of people could have PSP but think they have Parkinson's Disease?

Mrs Campbell said this was definitely the case.

Mrs Hamilton then asked if doctors were currently being trained to recognise PSP?

Mrs Campbell said the PSP Association works with the Northern Ireland Medical and Dental Training Agency. Every three years they run a neurological masterclass for GPs and PSP awareness training is included. She said more work needs to be done with GPs within Practices because they find it very difficult to get away from their surgeries for training. As PSP is often diagnosed as Parkinson's Disease the PSP Association works very closely with the Parkinson's Disease Society and with the Parkinson's Disease Nurse Specialists. The Parkinson's Disease Nurse Specialists

receive regular training in PSP so they are aware of what to look out for and very often they refer patients to the PSP Association. Mrs Campbell said if there was a PSP Nurse Specialist in Northern Ireland there would not be the same need to rely on other services.

### ***Mr McIvor***

Mr McIvor said he has an interest in the field of dementia. He said he was not convinced there was a difference between what Mrs Campbell was talking about and some varieties of dementia. He referred in particular to Lewy body dementia. He asked Mrs Campbell to explain the difference between what he knows as Lewy body dementia and PSP.

Mrs Campbell said Lewy body dementia is quite similar to PSP but with Lewy body dementia there would not be the same problem with the downward eye movement. There may not be the same extent of problems with balance but she said she is aware that speech and swallowing difficulties can develop. In Lewy body dementia the problem is more at the frontal lobe and behavioural problems develop which would not be as common in PSP. There would also be more emotional difficulties in Lewy body dementia than there would be with PSP. Mrs Campbell said PSP is really defined by the balance, eye movement, speech and swallow.

Mr McIvor asked Mrs Campbell if she would agree that a lot of dementia patients do not see their food on the plate especially if it is a particular colour. He said they may eat very untidily and they can be aggressive. He said PSP sounds very similar and he had not heard about it before but he certainly knew about dementia.

### ***Mr Carten***

Mr Carten enquired if PSP was diagnosed in certain age groups or could it affect all age groups?

Mrs Campbell said that typically PSP strikes in the early 60s but there are exceptions. She said they have a patient in his 40s and a lady of 84 who has just been diagnosed.

Mrs Campbell said following a correct diagnosis and the proper support patients' lives can be turned around. The condition cannot be cured but a big part of the PSP Association's work is to improve the patient's quality of life.

Mrs Robson thanked Mrs Campbell for her comprehensive presentation and wished her well in her work for the future.

### **WHSSC Business continued:**

Mrs Robson read to members a letter from Mr Patrick McGowan giving notice of his resignation as Chairman of the WHSS Council. Mr McGowan said he regretted that he could no longer commit the time required to the role of Chairperson. She said Mr McGowan will remain with the Council as a member until 31<sup>st</sup> March 2009. In his letter Mr McGowan wished every success to the new Chairperson and to the staff in carrying on the good work of the Council.

Mrs Robson made a proposal to suspend Standing Orders so that a matter of procedure could be discussed in a confidential session. She asked both the member of the Press and the public to leave the meeting for approximately 20-30 minutes in order for the discussion to take place.

### **Confidential Session**

Following the discussion Mrs Robson brought the confidential session to a close and invited the member of the public and the Press to return to the meeting.

Mr Campbell proposed that the Council make an amendment to the Standing Orders in relation to the procedure for election of Chair of the Council and Mrs Brown seconded it.

### **Minutes of Previous WHSS Council Meeting:**

The Minutes of the previous WHSS Council meeting held on 8 May 2008 were adopted on the proposal of Mr Mclvor and seconded by Mr McKeever.

### **Matters Arising from Previous Meetings:**

Members were provided with a written update on Action Points carried forward from previous Council meetings.

#### **Action Point AP: a/05/08 – WHSCT to provide WHSSC with:**

~ **copy of Trust's Prevention Infection Control Committee's Annual Report**

Awaiting Response.

~ **Three year Action Plan**

Awaiting Response.

~ **Action Plan following WHSS Council's Bugwatch Survey.**

Copy received and included in Member's pack.

Mr McIvor asked if there was a timetable for the repeat Bugwatch Survey to be held at Altnagelvin?

Ms Reilly said the repeat Bugwatch Survey will be carried out when the Trust has implemented their action plan. She said that quite a few of the actions were reported as having been implemented and she commended the Trust for their early work. Some of the actions are not expected to be in place until the end of July.

Ms Reilly said an invitation had been received from WHSC Trust for herself and a Council member to attend the Ward Sisters' Charter seminar to be held on 8<sup>th</sup> July 2008. She said she has another commitment on that date and

Mrs Gormley will deputise for her. Mrs Robson agreed to also attend the seminar.

**Action Point AP: b/05/08 - WHSS Council to arrange a repeat Bugwatch Survey at Altnagelvin.**

Work in Progress. Visit will be arranged after Trust has completed actions.

**Action Point AP: c/05/08 - WHSC Trust to provide WHSS Council with a copy of a description role for a Link nurse and job description for Infection Control nurse.**

Awaiting Response.

**Action Point AP: d/05/08 - Chief Officer to write to Ms Mason to confirm arrangements for presentation to WHSS Council at November meeting.**

An e-mail has been sent to Ms Mason to confirm the arrangements for the November meeting.

**Action Point AP: e/05/08 - Information available from Sub-group meeting with WHSC Trust on 15/5/08 to be forwarded to all members.**

Due to time constraints it had not been possible to discuss the SCEP Programme at the meeting on 15<sup>th</sup> May 2008. It was agreed to re-schedule this for a later date. Information received regarding the new Hospitals has been distributed to members.

**Action Point AP: f/05/08 – Mrs Rosaleen Harkin, Assistant Director Learning Disability Services, to report back to WHSS Council on the hydrotherapy pool issue.**

Awaiting further response.

**Action Point AP: g/05/08 - WHSS Council to continue to monitor this situation and the outcome of the Trust's reappraisal of options.**

Awaiting further response.

**Action Point AP: h/05/08 - Chief Officer to contact WHSC Trust in relation to workshop being held re Ballycann replacement.**

WHSC Trust has been contacted and asked to ensure that WHSS Council is included on distribution list for future invitations regarding change in services.

Mr McIvor said he had also spoken to the Trust following the previous meeting and they indicated they would send an invitation to the Council. He reported that there was some confusion as the venue had been changed from the MDEC at Altnagelvin to the Waterside Hospital but attendees had not been informed.

Ms Reilly said the Council had contacted Mr Vincent Ryan. She explained that Mr Ryan had returned her call but unfortunately she was out of the office at the time. She said she would follow up on this.

**Action Point AP: i/05/08 - WHSS Council to contact WHSC Trust regarding the phone system at Riverview (former Foyle Trust HQ).**

A letter has been sent to WHSC Trust raising the Council's concerns about the phone system at Riverview. Awaiting response.

**Action Point AP: j/05/08 - WHSS Council to re-issue information to members regarding ICE (In Case of Emergency) Campaign.**

Information on the ICE Campaign has been forwarded to all members.

**Action Point AP: k/05/08 - Send out nomination forms to members for the election of Chairperson at June meeting.**

A letter and nomination papers for election of WHSS Council Chairperson have been forwarded to all members.

### **Comprehensive Spending Review (CSR):**

Ms Reilly said over the next three years the WHSC Trust has to make a total of 9% savings. She said that Mrs Way had indicated to her that she would like to meet with the WHSS Council to talk about the Trust's CSR plans. Ms Reilly said there are two options for this – (1) the acting Chair and she could

meet with the Trust and then pass the information to the members or (2) a sub-group of members could meet with the Trust to receive the information and put forward their questions.

Ms Reilly said a meeting had been arranged for Friday 13<sup>th</sup> June 2008 at 2.00pm at Trust Headquarters and asked any member who is interested in attending to please contact the office. A notice will be sent to all members to confirm the details of the meeting.

### **Dental Services:**

Ms Reilly said the WHSS Council had carried out a telephone survey of all Dental Practices (50 in total) in the WHSS Board area last month. She said the Council was already aware that there was a serious problem for adults in accessing NHS dentistry. However, she said the Council was hearing that there was also a very significant problem for children getting access to NHS dentistry. The Council repeated the telephone survey in May and the problem has in fact become worse in that one month. In the April survey there were six practices registering children and in the May survey there were none. The only caveat to that she said is that occasionally practices do open their books again for registration but only a very small number in any given month. She said the Western Board area has one of the highest levels of dental decay among children and also has some of the highest levels of deprivation in all of Northern Ireland.

Ms Reilly said following the WHSS Council's survey the four Health Councils jointly raised their concerns both with the Health Committee and directly with the Minister. The Minister offered a meeting to the four Chief Officers with the Acting Chief Dental Officer and his civil servants as he was unavailable which was held on 3<sup>rd</sup> June 2008. The Chief Officers reiterated the concerns and issues around access to NHS Dentistry. Ms Reilly said she provided them with a copy of the survey the WHSS Council had completed. She said that sometimes there can be a variation between the information the Boards have and what the WHSS Council were able to find out from the dental survey. Ms Reilly said the Department officials confirmed to her that the Western area is the worst for access in the four Board areas. She said as expected the Eastern Board area is less affected because it is the main centre of population with most dentists operating from there. Ms Reilly said there is an out of hours pain clinic operating at Craigavon Area Hospital and this is something the Western area does not have access to. In the Western area dentists operate an out of hours rota primarily for their registered patients.

At the meeting with the Chief Dental Officer the four Chief Officers expressed their concerns about the length of time being taken in the negotiation of the dental contract. Ms Reilly said they were also aware that money had been given to employ six salaried dentists in the Western area. She said it is her

understanding there have been two unsuccessful attempts to recruit. She said in the Northern Board area they were able to attract three salaried dentists who are now working in that area.

Ms Reilly said the Minister had announced that money had been set aside for a new initiative to tender for NHS dental services from the independent sector. However, she said, this can only be seen as a short term solution. The long term solution remains the negotiation of a robust contract that will attract dentists into providing NHS services. Ms Reilly reminded members that there had been a 'blitz' exercise carried out for Orthopaedics and Ophthalmology and questions had been raised about the quality of these services provided by the independent contractors.

Ms Reilly drew to members' attention comments from one of the practices included in the survey. She said that the practice stated that if a £100 registration fee was paid treatment would then be carried out under the NHS. She said she had raised this directly with the Director of Dental Health at the Board and questioned if this was an ethical position. Ms Reilly said this response was re-checked during the May survey and the dental practice was still saying the same thing. She said the Director of Dental Health at the Board has written to the Dentist concerned to ask him to clarify the position. Ms Reilly said she will keep members informed when a response is received from the Board.

**Action Point: AP a/06/08**

Chief Officer to keep members informed when a response is received from the Board.
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A member of the public asked if he could address the Council and was granted speaking rights by Mrs Robson, Acting Chairperson.

He thanked the Chairperson and introduced himself as Mr Barry McGonigle a dental practitioner in Omagh. He said he was the newly appointed spokesperson for the local dentists in the Omagh area.

He said he was a member of the Dental Association and belonged to various Committees in Belfast but he was speaking tonight as a local person.

Mr McGonigle said he had not seen the Council's survey but was broadly aware of what Ms Reilly had just said. He said that he felt Ms Reilly's summary of the problems accessing dental services in the West was a very accurate and clear picture of what the situation is and she was obviously well briefed and had her research done.

He said in Omagh and in most of the Western Board practices, dentists cannot take on more patients. Mr McGonigle said he could not say that he has not taken on an NHS patient in the last two months but he could certainly say he has not taken on more than ten as there is not the capacity. He said he could also say that he probably could not take on more than approximately fifty patients of any description as he does not have the capacity. He said dentists only have one pair of hands and dentistry involves direct physical intervention which needs qualified personnel. That he said is the key issue. He said dentists are not actually looking for more money to be spent on the service for themselves but they want the service expanded; they would welcome more dentists.

Mr McGonigle said he shares the WHSS Council's concerns. He said that the commitment of dentists who are brought in on a short term contract is not going to be as high as people who have provided a lifetime of service to the community.

Mr McGonigle said opening a dental facility required premises to purchase, plans to be drawn up and planning permission passed by building control. This process he said could take anything up to 18 months or 2 years.

Mr McGonigle said he had attended a meeting of dentists earlier today and they had received a briefing from Mr Brian Bailey of the Department of Health. Mr Bailey told them they were due to have the next meeting of their tendering group later this month and then they will hopefully be progressing to actual tenders. At the moment he said it is just an expression of interest. Mr McGonigle said he cannot see a tooth getting filled under this scheme for 2-3 years. He said there is a short term crisis in dentistry and it is not fair to the public. He said it is not fair for someone who may move job to Omagh and not be able to register themselves and their children with a local dental practice. He said this is giving dentists a bad name.

Mr McGonigle said he had come along to tonight's meeting to say to the WHSS Council that dentistry affects us all. He said it is a universal disease so there is a universal need for treatment and dental decay and periodontal disease is the commonest disease in the world. He said that someone can come along and get a tooth out because they are in pain but that doesn't mean they have had dental care. Mr McGonigle said just providing an emergency service, although necessary, is not the answer.

Mr McGonigle thanked the WHSS Council for allowing him to address the meeting.

Mrs Robson thanked Mr McGonigle for his contribution and for his comments regarding the Council's survey.

## **Members' questions:**

Mr McKelvey said that he appreciated Mr McGonigle coming along to the meeting. He asked what happens to people who are in severe pain?

Mr McGonigle said dentists have the same obligation as anybody else to treat people fairly. His time he said is scheduled from 9.30am on Monday to 5.00pm on Friday and he has to squeeze in additional appointments which frequently leaves him running late. He said they have taken the view in his practice that they will prioritise children and that is what they are doing with their NHS capacity.

Mr McKelvey said there are approximately 100,000 people from Eastern Europe in Northern Ireland and asked how they are being dealt with?

Mr McGonigle said dental practices receive no subsidy or start up costs. The building is paid for by the practice as are staff, equipment, drugs and medication. There are some small grants but the vast majority of costs are paid for by the practice. He said if he is overwhelmed by demand for his business he has got to decide on the mix of business he is going to do and how much he can afford to devote to the lowest paying part of the business which is the NHS. He said the NHS has the lowest fees - they are bizarrely low compared to Southern Ireland and are a multiple lower than most private fees. To answer the question he said if a non-national comes along they are treated the same as anyone else as a private patient. If they want urgent treatment they will be charged a premium for that.

Mr Carten said he also appreciated Mr McGonigle coming along to the meeting and asked if young dentists coming up would get a place in Omagh and could he fit them in? He said he has a major concern about the NHS not paying dentists.

Mr McGonigle said dentists earn a decent living as they should; considering they are highly trained professionals with a five year university degree. He said the running costs including buildings, insurance and employment have taken off in the last five years. He said there is a failure to invest by the Health Service.

Mr McGonigle said as had been mentioned earlier, a lot of dentists, including young dentists, are based in the Belfast area. He said they go to Dental Schools in Belfast, Liverpool or Scotland and they get a taste for metropolitan life. He said he has three other dentists working in his practice but they often have to wait six months to recruit. They offer a good job, well trained staff and still they struggle to recruit.

Mr McGonigle said Scotland has put in processes to offer 'golden

handshakes' to young dental students and the real tragedy is that a significant proportion of the undergraduate student intake in the two Scottish Dental Hospitals are from Northern Ireland. He said it is not huge money (£20,000 or £30,000 if they stay for four years). If they leave before the four years is up they lose a proportion of the money.

Mr McGonigle said he would share information on the Scottish process with the Council.

Mrs Hogg said she also appreciated the fact that Mr McGonigle had attended the meeting. She said she was particularly interested in children because it is very important that they get a proper start with their teeth. She asked if there is a School's dental service and if so does that pick up on children in a slightly different way?

Mr McGonigle said the School's dental service no longer exists as we would have known it. It became the community dental service and that still exists. The community dental service has now defined their remit as dealing with children with special needs i.e. those with severe disabilities or medical problems. He said dentists are struggling at times to get children who are difficult to treat seen by the community dental service whereas ten years ago that was a core part of their business. Now the community dental service see it as something they will only do if they have spare capacity and there is no spare capacity.

Mr McGrade also thanked Mr McGonigle for coming along to the meeting. He asked Mr McGonigle if there was anything the WHSS Council could do to influence the Minister or those in a position regarding policy, for example to look at what is being done in Scotland?

Mr McGonigle said dentists believe that there are innovative solutions and gave an example of where the Board could come to an agreement with a new dentist starting out to pay half of the start up costs for a certain volume of activity.

He said the new dental contract is not going to deliver extra dentists which is what is required.

Mr McGrade thanked Mr McGonigle and suggested that the Council could take some of his suggestions and put them together in a short paper. This could be submitted to the Department to ask them to look at using new initiatives or innovative ways of delivering dental services.

Mr McGonigle asked if he could make a presentation to the WHSS Council at their next monthly meeting.

Ms Reilly said the Council's next meeting would be held in September and the Council would welcome a presentation from him.

Mr McGonigle said it is important that the voice of the people from the West is heard.

Ms Reilly said this was one of the reasons that motivated the WHSS Council to carry out the telephone survey particularly in relation to children.

She said this had highlighted the disparity between the situation in the Western area and the other three Board areas.

Ms Reilly said the Council felt strongly that children in particular should be registered from birth with a dentist and have continuing good preventative care. She said dentists should be paid to do preventative work rather than pulling out teeth.

Mr McGonigle said younger dentists in particular are trained in prevention rather than treatment and they are keen to do that. He said one of the issues again is the backlog of disease that needs to be cleared up.

Mr McKeever asked if a dentist works from 9.00am to 5.00pm is there any reason for not having another dentist open later hours using the same facility?

Mr McGonigle said a shortage of dental nurses is also a major issue. He said the Further Education Colleges or the Board who previously ran training courses are no longer doing them. He said the dentists now train their own nurses.

Mr McGrade said he works part-time in a local College and he sees this as something that could be looked at to meet the needs of the dentists.

### **ASD Services:**

Mrs Gormley said Ms Reilly and she had met with Mr Kieran Downey on the 14<sup>th</sup> May 2008 to discuss the disparity that exists between the Northern and Southern sectors of the WHSC Trust in relation to the waiting times for children with ASD. She said they were particularly concerned about the 6 children who fell into the category of what is reported as 48+ months. She said when they investigated further they found some children in this category were actually waiting in excess of 5 years.

She said she was pleased to be able to report that Mr Downey had given an assurance that all 6 children have been given appointments for June.

However she said there are still significant waiting times. The Southern sector has been sitting static for quite a while because the Trust has not had a team in place to deal with the waiting list. Mrs Gormley said Mr Downey reported that the Trust has now appointed a Clinical Psychologist and a Social Worker who is commencing on 2<sup>nd</sup> June 2008. The Trust is planning to blitz the current waiting list over the next couple of months. However they are having difficulty in recruiting OTs and Speech and Language Therapists to work in the multi disciplinary teams.

Mrs Gormley said Ms Reilly and she are monitoring the waiting times and will be meeting with Mr Downey again.

**Action Point: AP b/06/08**

WHSS Council to continue to monitor waiting times for ASD.
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**Minister's 'Vision for Health and Social Care':**

Mrs Robson referred to a meeting to be held in Dungiven by the Minister to give his vision for Health and Social Care. She asked Mr Mclvor or Mrs Hamilton who had indicated at the previous meeting they would be attending to give a report.

Mr Mclvor said the meeting had not taken place as the Minister did not turn up. Mrs Hamilton said the Minister had sent two representatives who had answered questions and she said another date is to be arranged.

**Members' Issues:**

***Ms Lynch***

Ms Reilly said Ms Lynch had previously raised some issues about care of the elderly and a letter had been sent to the WHSC Trust on 13<sup>th</sup> January 2008. A copy of the Trust's response received on 16<sup>th</sup> May 2008 is included in member's packs.

She said some of the questions had only been partly answered. She said Mrs Gormley and she are to meet with Mr Corry Finn about AHP services and they will take the opportunity to go through the letter in more detail and report back to members.

Ms McKeague said there were a number of issues in the Trust's response which actually contravene the RQIA regulations. She said she would talk to the Chief Officer regarding these.

## Action Point: AP c/06/08

Chief Officer to report back to members on the issue of care for the elderly following meeting with Mr Corry Finn.

### **Any Other Business:**

#### ***Altnagelvin Consultants leaving post:***

Mr McKelvey referred to the Press Release on this matter and said he was disappointed to learn that three Consultants were leaving their posts at Altnagelvin Hospital. He said the WHSS Council has got to be very concerned about it as it is a major blow to the area. Speaking from personal experience as an ex-patient of one of the Consultants, Mr McKelvey said it is a sad blow for the Western area to lose three highly experienced Consultants at the one time. He said the reasons would be important but they are not in the public domain and all the Council can do is raise an expression of concern and regret that this should happen.

Ms Reilly said Mrs Elaine Way, Chief Executive with the WHSC Trust had confirmed at a meeting with Derry City Council that the three Consultants involved were two Colorectal surgeons and one Haematologist. Ms Reilly said she had been asked to do a radio interview the next morning and raised as Mr McKelvey had said the Council's concerns and in particular about the Haematologist leaving. She said most of the members would remember that the lack of Haematologists in Altnagelvin has been a long-standing problem.

Ms Reilly said she has since spoken to Mrs Way and reported she is very anxious to reassure the members and that obviously the Trust was also disappointed. Ms Reilly asked Mrs Way if there was an underlying issue within Altnagelvin that would have caused three Consultants to leave at the one time? Mrs Way was quite adamant that there was no underlying issue and that the reasons given were both personal and professional reasons. Mrs Way said that the Trust would immediately start the recruitment process.

Mr McIvor said he became aware of the story about two weeks ago through the Mark Patterson show on Radio Foyle. He said the radio station was inundated with calls from concerned patients and the Council should be fighting very hard for not only a Locum but for the replacement of all three Consultants.

Mr McKelvey referred to Mrs Way's attendance at Derry City Council and her interview with the media. He said that the WHSS Council should be informed about these matters before the Trust speaks to the media.

Mrs Hamilton said the meeting of Derry City Council at which Mrs Way was

present was a regional service meeting. These meetings are held once a month and on this occasion the topic was Health.

Ms Reilly said she would update members as and when she gets further information about appointments.

**Action Point: AP d/06/08**

Chief Officer to update Members when further information on the appointments of Consultants at Altnagelvin has been received from the Trust.
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**Joint HSSC Event.**

Ms Reilly said that she and Mr Noel Graham, Chief Officer NHSS Council were working on the Joint HSSC member event with the NHSSC leading on it. She said the Joint event will be a visit by members to the Assembly in October. She said Mr Page had offered to make contact with Ms Michelle O'Neill, Vice-chair of the Health Committee regarding this. However protocol requires a formal request and Mr Graham will arrange to do this on behalf of the four Councils.

***Declaration of Interests:***

Ms Reilly said members' declaration of interests were now published on the Council's Website ([www.whssc.org](http://www.whssc.org)).

***Pharmacy:***

Ms Reilly said Mr Joe Brogan, Director of Pharmacy, WHSSB had requested to meet with a sub-group of the Council to provide a briefing on issues relating to the Community Pharmacy including collection and delivery of medicines, dispensing and repeat prescriptions. There are governance issues within these that are very important in terms of patient care.

Ms Reilly said two dates are being held for the briefing - Monday 16<sup>th</sup> or Friday 20<sup>th</sup> June 2008 at WHSSC offices, Hilltop. She said members will be contacted with further details of the meeting and to check their availability to attend.

**Action Point: AP e/06/08**

Chief Officer to contact members re meeting of sub-group to receive briefing from Mr Joe Brogan.
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***Hospital Visiting Policy:***

Ms Reilly said a copy of the Western Trust's Hospital Visiting Policy is included in members' packs.

***Personal and Public Involvement (PPI):***

Ms Reilly referred members to the Council's previous participation in developing the Department's standards for personal and public involvement. She said she has been in contact with Mr Brendan McKeever who is involved in the Family Information Group and Mr Joe Duffy who works in the Social Policy Unit, Queen's University Belfast. Mr McKeever and Mr Duffy have worked together quite often on user involvement and Mr McKeever had suggested that she meet with them to discuss personal and public involvement issues.

As a result of this meeting Ms Reilly suggested it might be useful for the Council to monitor how well PPI is happening in the Western Trust.

Ms Reilly asked for members' agreement that the WHSS Council could explore commissioning a small piece of work that would seek to find out what the level of personal and public involvement is within the Western Trust area. Given that by March 2009 the Trust is obliged to have a policy, a strategy and an action plan in place she said it would be very timely to carry out a scoping exercise to find out:

- what is the current state of personal and public involvement?
- how does the Trust intend to ensure that their communities and the public are involved around decision making?
- what is the experience of front line staff and their understanding of how PPI happens?
- and through using a focus group technique to reach out to communities and ask how they are invited to be involved by the Western Trust in their decision making, either on a personal or a community level?

Ms Reilly said the scoping exercise would perhaps inform another piece of work that the new PCC could take forward. For example how better is patient and public involvement one year on from the scoping exercise? PPI is one of the areas that a Chief Executive and the Corporate Trust has a responsibility and a duty to ensure is happening. Ms Reilly said she would see it as a legacy piece of work that could be handed on to the new PCC.

Members agreed with Ms Reilly's proposal to explore commissioning this piece of work.

Ms Reilly said in the course of her conversation with Mr McKeever it was

suggested that when trying to make savings under the Comprehensive Spending Review the Trust is cutting back on funding to community groups. Ms Reilly said Mr McKeever who has worked almost single handed (working to a voluntary committee of management) and funded by primarily the Board and the Trust is now out of business as of last Friday. After 12 years of providing a service to a very disadvantaged group of families with children with very severe and complex disabilities the Family Information Group has had to cease its work due to lack of funding. Ms Reilly said the WHSS Council was not informed where the Trust was going to make savings in communities which they had grant aided and funded.

Ms Reilly said the Council needed some kind of feedback on this and asked if members were in agreement with her asking the Board and Trust to provide the Council with information about how many groups they have cut back on this year and by what amount and the overall savings they have made by doing this.

Mrs McKeague said it would be useful to go back 2 years because some of the cuts have been made on a sliding scale.

Ms Reilly said she would speak with Mrs McKeague about the key questions that need to be asked as she has had experience with groups which received funding. Ms Reilly said she will contact the Trust and Board to get the information.

Mr Maguire said it would not be any surprise to find such cuts were in some way connected with the Comprehensive Spending Review.

Ms Reilly said community groups are providing valuable front line services and are highly responsive to the needs of the vulnerable in our community.

Ms McKeague said community groups did not just sit back and let the cuts happen. She said for example the former Sperrin Lakeland Trust said that they were in financial difficulties and were not able to provide funding in a particular year but asked the community groups to try and keep going which they did in the hope that they would get funding in the next financial year. She said that is why she suggested going back a few years for information.

Ms Reilly said she will ask about funding they provided for the last 2 years.

**Action Point: AP f/06/08**

Chief Officer to contact the WHSS Board and WHSC Trust to get information on funding to community groups.
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***Waiting List Monitoring Group***

As mentioned earlier, Ms Reilly said Mrs Gormley and she will be meeting with Mr Corry Finn around the re-establishment of the waiting list monitoring group. Mrs Robson indicated she would like to attend that meeting also.

### ***Any Other Business***

*Mr Campbell:*

Mr Campbell said he would like to express his appreciation for the work that Paddy McGowan had done as Chairman and for his kindness and understanding as Council Chair.

Mr Johnston said he wished to second Mr Campbell's comments.

*Mr Mclvor:*

Mr Mclvor said he wished to raise an issue, which he has raised before, with regard to media interviews and statements to the Press given by the Chief Officer on behalf of the Council. He said he would like members to be informed when an interview or statement has been given so that they are aware of it.

The Chief Officer reminded members that this issue had been discussed some months previously and it was noted then that members would receive updates on any Press/radio interviews through the monthly activity report as it was impractical for the Chief Officer to notify members prior to interviews going out.

Following discussion members agreed that the Chief Officer would inform the Chairperson or Vice-Chairperson by e-mail as soon as possible after she has given a radio interview or given a statement to the Press. Mrs Robson, currently acting Chairperson, said she would take responsibility for informing the rest of the members. Ms Reilly informed members that she would always discuss unusual or potentially difficult subjects with the Chairperson and/or other Chief Officer colleagues before giving an interview in order to agree the Council's position on such matters.

### ***Date of Next meeting***

Following a discussion regarding future meetings, members agreed not to hold meetings on a Friday evening but to continue with meetings on the first Friday of each month preferably in the morning.

The next meeting will be on Friday 5<sup>th</sup> September 2008 – venue to be confirmed.

Mrs Robson thanked members for their attendance and drew the meeting to a close.

**The meeting ended at 8.50pm**