

MEDICO-LEGAL SOCIETY OF NSW INC.

SCIENTIFIC MEETING

WEDNESDAY, 16 NOVEMBER 2016 AT 6.15 P.M.

THE TOPIC:
PATIENT CENTRED CARE AND PATIENT ADVOCACY -
STRENGTHS AND WEAKNESSES

SPEAKERS: MR PHILIP GREENWOOD SC
DR KAREN LUXFORD

MS KEELY GRAHAM: Phil Greenwood SC is speaking next. Most people here would know Phil. He has been a long term member and supporter of the Medico-Legal Society and is often at these meetings and dinners. Phil was admitted as a barrister in 1982. He was appointed Senior Counsel in 1997 and is a member of Eleven Wentworth Chambers. He has a varied commercial and professional negligence practice, which has included extensive dealings with members of the medical and nursing professions and hospital administrators. This has occurred in various capacities - representing them as clients, and examining or cross-examining them as witnesses or experts - in inquests, Royal Commissions, disciplinary proceedings, medical negligence cases, personal injury cases, product liability cases, commercial cases, and even building and construction cases.

Phil has also had considerable personal involvement with the profession, which has sparked his interest in patient advocacy and the need for patient support. Over the last few years he has served on the Sydney Local Health District Patient and Family Centred Care Steering Committee and the Services Working Group that reports to that Committee. Please welcome Phil.

MR PHIL GREENWOOD: Thanks Keeley. May I say at the outset that my time working with the medical and nursing profession has led me to hold them both in the highest regard. The opportunity to speak and meet in this kind of situation, where we can share our different perspectives on matters of common interest, is something that I think is very valuable. Accordingly I thank the Society for the opportunity to participate in this meeting tonight.

The areas that I want to discuss are a couple where there are differences between the medical profession and the legal profession. Let me state from the outset my view that there are many things that the medical profession does far better than the legal profession. One of them is continuing professional development. Another is the preparation of the slides for these presentations, like Karen's you have just viewed. You will see what I mean in just a moment when I show my first slide.

I have had the privilege of supporting a number of people with serious health difficulties who have been navigating their way through the health system. Tonight I will roll all those people up into a notional person whom I will call "Mum". I have done this because just about everybody has had an experience with a mum. [slide] This is my Mum. She was a competent, intelligent, capable person. It was only

when I had the opportunity to go with her to medical consultations that I saw a totally different person.

When I was with her in consultations, I noticed several things to my surprise. First, Mum was *extremely* deferential. We know deferential is appealing sometimes, but she was *extremely* deferential. Secondly she was also an extremely poor medical historian. When it came to providing answers to questions that she was asked about, even basic ones, she was consistently unable to provide an accurate response. Thirdly, she very rarely asked any questions of the doctors. She received the information from the doctors and never questioned it at all. Fourthly she would commonly say that she understood what was being said, when clearly she did not.

This was not a one-off experience. It was the usual *modus operandi* for her and many others.

Let me move on to what I noticed about the doctors. [slide] You will see I have selected a bald man for my slide, because most of them were bald men. Indeed, all of the ones who were bald were men. However, my comments tonight apply to both the male and the female doctors at the consultations I attended.

The first thing that I noticed was that the doctors had no detailed knowledge of what we were there to talk about, apart from what was contained in a very brief referral note. Accordingly, the doctors were starting from an almost blank slate. The doctors asked questions that Mum had not prepared herself for, and had given no thought to what the answers should be. Hence her answers were, often, relatively incoherent or confused. But her answers were received and accepted by the doctors. Of course, the doctors had very little choice - after all, the doctors were gaining this information for the first time directly from the patient, and were dependent upon the quality of the history that they were given.

Another thing that I observed was that the doctors very often provided a lot of information that was quite unnecessary. They would say things like: "Now you do not have [a condition], but if you did, then this would be what would happen [explanation], but fortunately you do not have that".

Lastly, sometimes the doctors were not very keen on me being at the consultation, initially at least.

After the consultations we would go home and my brother (or another family member) would often come over. We would have a discussion where Mum would say what had occurred during the consultation. I was startled to hear her account. I was startled because this was immediately after the consultation, and Mum's recall was *extremely* poor. She was clearly very confused about what had been said and, very often, what she did remember was completely, 100% wrong. For example, if the doctor had said Mum *must* do X, she would recount it as the doctor saying that she *must not* do X.

This led me to think that this was not a great outcome from anybody's point of view. It was not a great outcome for Mum. She was confused and unlikely therefore to follow the advice that was given. It was probably not great from the doctors' point of view - operating on less than adequate information and having a sense that the patient did not really understand their advice.

This caused me to think about the difference between what the medical profession does and what the legal profession does.

The practice within law is that if a member of the public has a problem, they go to see the equivalent of the general practitioner - their solicitor. The solicitor then looks at the problem, like the GP, and decides whether or not it needs to be referred to a specialist. If it does, then the solicitor prepares a brief for a barrister that contains an explanation of the problem and all the relevant documents. The barrister is asked to provide specific or general advice. When the barrister receives the brief, the barrister reads the relevant material *before* the consultation with the client. That way the barrister can request any additional material considered relevant or undertake research. The solicitor and the client then go to the conference *together* to discuss the matter with the barrister. The barrister provides the advice to them both. The solicitor is there to support the client, prompt the client if need be, ask questions or raise matters that are of significance and take notes of what is said. Afterwards the solicitor and the client go away and talk about the advice and decide on what to do next.

This is quite different to the medical approach. I think that is for cost and billing reasons. However, not having the information available to the specialist in advance, and not having a third person present at the consultation creates problems for patients.

My experience of seeing the extremely poor recall of patients led me to do some research about retention rates of patients after they receive medical advice. What I found out was surprising.

The research on retention rates, and there is quite a body of it, some quite specific and some quite general, comes up with this first statistic:

40% to 80% of the information provided by healthcare providers is *immediately* forgotten.

The amount forgotten depends on certain factors that I will discuss shortly.

A second statistic, which has also proved to be true in my experiences, is that:

About half of what is remembered, is wrong.

These are worrying statistics for every doctor who is giving advice - knowing that the patients are going away having retained only a small amount of what has been said, and of that, about half of it may be wrong. And, of course, the doctor doesn't know what information is going to be retained by the patients, and what information is going to be retained *incorrectly*.

What are the factors that effect the retention rate? There are many and I will discuss only a few of the more important ones. Firstly, there is the amount of information given - the more you give, the less is retained. This is a problem when you are talking about something that is complicated and that you need to explain in full. However, at the same time you realise that the more you try to explain it, the less of that explanation they will retain.

Secondly, there is the emotional state of the patient. A very anxious patient recalls very little. At the other end of the anxiety scale, if a patient doesn't care at all, they will not retain much either.

Thirdly, there is the order in which the information is given. That is, the primacy and the recency effect - what you say at the beginning and what you say at the end - are remembered best.

Fourthly, there is the way the information is presented, especially with older people. The evidence is that if the

information is structured, there is a much greater likelihood that the patient will recall the information. However, if the information is given in an unstructured way, it is not retained as well. Written information is better retained than oral information but cannot be done particularly well in a consultation. The way in which information is explained with diagrams is helpful if it is a simple diagram with a simple explanation. However as soon as the explanation becomes complicated, less is retained. Also important is the manner and tone of voice in which the information is delivered.

Fifthly, the patient's education and language skills are relevant. This may seem self-evident. My observations have mostly been with patients who have high levels of education and good reading skills. Yet they have poor retention. For those people who have poorer language skills and a poor education, the situation will be much worse.

There were some specific findings from all this research that I found noteworthy.

Firstly, patients recall better what they are expecting or wanting to hear. That was interesting to me because I had thought hearing something entirely different from what you were expecting might be something that you would recall better.

Secondly, new information that is inconsistent with the patient's expectations tends to be misinterpreted or forgotten.

Thirdly, recall is worse when you are talking about the patient's own particular condition. If you are talking about somebody else's condition, patients are more inclined to remember that information than information about themselves. You might think, as I did, that this is bizarre. What could be more important and what am I more likely to remember, than information about myself? However when you think about it more, you realise we all have our natural defence mechanisms. None of us want to hear bad news. We often don't really want to know what is wrong with ourselves. We are brought up to focus on the positives and not the negatives. Hence we tend to immediately close off mentally when information is being given to us that we don't want to hear.

All of this leads me to two propositions that I want to place before you tonight for your consideration.

Proposition 1: Patients are cognitively compromised.

The very fact of being a patient means that we are not functioning as well as we would normally. There are a whole lot of reasons for this, which will vary depending on the patient's medical condition. However, the basic starting point is that, as a patient, you are unwell and not operating at your full capacity.

In addition there are many other overlays - being scared, feeling powerless, feeling uncomfortable in unfamiliar surroundings and the use of unfamiliar language.

It is not just lay people who are affected in this way - it affects doctors as well. Oliver Sacks is a well-known American neurologist who has written about his own personal experience when he had a problem with his vision and consulted an ophthalmologist. He says this:

"The ophthalmologist took his ophthalmoscope and peered into the eye. Then he put down the instrument, leaned back and gazed at me, I thought, with different eyes. There had been a certain lightness or casualness in him before. We were not exactly friends, but we were colleagues, both medical men. Now suddenly I was in a quite different category. He spoke carefully, picking his words. His demeanour was one of seriousness and concern.

'I see pigmentation,' he said, 'something behind the retina. It could be a haematoma or it could be a tumour. If it's a tumour, it could be benign or it could be malignant.' He seemed to take a deep breath. I cannot be sure what he said next, for a voice had started up in my head shouting 'Cancer. Cancer. Cancer.' and I could no longer hear him."

I do not think that is an unusual experience for anybody in that situation. Your brain gets caught on the item that has been said, you are distracted and from then on you are in another place.

Then there is the use of unfamiliar language. I do not mean the use of acronyms and very complicated language. I am talking about the most basic language about the anatomy. The figures in relation to "health literacy", an expression commonly used by the medical profession, demonstrate how poor our general knowledge is about such matters. I think it is grossly under-estimated. My guess is that 90 per cent of the general public would not know the difference

between a liver and a kidney and what it is they do, except in terms of cooking. You do not cook steak and liver pie. But beyond that, I do not believe the vast majority of people are able to differentiate between the two.

My own personal experience of this relates to my Dad. Dad rang one day to inform us that he had been told by his doctor that he had kidney cancer. We sought some advice from a friend about kidney cancer and learned that you have two kidneys, so you can have one removed and be alright. We were relieved. But it was not kidney cancer - Dad had been told that he had liver cancer. He had retained "cancer" but not the location. My Dad was an intelligent man and he had not differentiated between the two organs.

This leads me to my second proposition.

Proposition 2: Every patient needs a support person.

Because patients are cognitively compromised, they need someone else to be there in consultations - another set of eyes and ears.

Not everybody has a person who is prepared to do that. Realising that has led me into the world of patient advocacy, which is more developed in the United States than it is in Australia. In the United States they have professional patient advocates and a professional Patient Advocates Institute which runs courses for patient advocates. I can tell you the course that they run is a measured, appropriate course.

What is a patient advocate? It is an expression I do not like for a couple of reasons. The first one is that there is a contradiction in terms - who knows an advocate that is patient? It just does not happen usually. The second one is it suggests the role for the person is to speak out and speak on behalf of the patient, rather than the patient speaking for themselves. Further, it also suggests an adversarial role. Hence I prefer the expression "patient associate". However we can use the general expression "support person", someone who is there to help if required. They may be a member of the family, a friend, a volunteer or a service provider.

The main roles that support people have are as follows. Firstly, to provide moral support through their physical presence. The value of having somebody physically there; to sit with in the waiting room, to chat to the patient, to distract them from what is about to occur, rather than the

patients becoming more and more anxious before going into a consultation. The value of these things should not be under-estimated.

The other roles are to listen to what is said; to write down important things; to prompt the patients with information or questions that they may have indicated they wanted to ask; to be available to discuss options afterwards; to help organise next steps; and sometimes when the patients are very unwell, to be the voice for the patients speaking on their behalf.

The advantages to patients seem obvious and are as follows. Firstly, the patient feels supported and is, as a result, more comfortable. Secondly, the support person can provide a backup to prompt additional information, if needed. Thirdly, and probably most importantly, they are the extra pair of ears to listen and hear the advice that the patient may not be receiving. Fourthly, they can record the important information for the patient for later use. That of itself leads to a fifth advantage, - a greater likelihood of understanding the advice that is given, and a greater likelihood that it will be understood correctly. Sixthly, once you have a better understanding of the advice that is being given, that leads to a likelihood of greater compliance, and with that to the likelihood of a better outcome. Finally, and particularly importantly, it provides the patient with a sense of being much more involved and connected with their care to a point where they have a feeling of being a little in control.

The possible disadvantages for patients include the embarrassment of something said during the consultation; the loss of confidentiality in terms of the person passing on the information that they hear; the cost if they are using a service provider, which is an additional cost they have to incur on top of the medical expenses; and that the advice that is written down may not be accurately recorded. However, each of these possible disadvantages is controllable and unable to be mitigated.

From the doctor's point of view, the advantages of having a support person present are significant. First, the fact that the patient *feels* supported is invaluable. The doctor may not sense it, but the patient does, and that provides a big change in terms of the dynamics in the room. The support person also provides an additional potential source of information for the doctor which may aid them in achieving the correct diagnosis. There is someone else there to listen; to hear the advice when the patient is not

hearing it; and to take notes and to record what is being said for later use. As noted previously this increases the likelihood of greater understanding, which in turn increases the likelihood of a better outcome with a happier patient who will then recommend the doctor to others.

Another advantage (that may be contentious) is that it can save everybody's time. Without the support person, there is a need to repeat things over and over again, trying to ensure that the patient understands. The doctor says to the patient, "Do you understand?" and they say "Yes". The doctor then says, "Repeat back to me what I have told you so that I can hear it from your own mouth". Then, when the patient is unable to do so correctly, the doctor has to re-explain everything and then ask the patient again to repeat it back. The alternative is for the doctor to say to the patient advocate or the support person, "Just read back to me what you have noted down so that I can ensure that you have got it right to take away for the patient to review later."

There are three possible disadvantages for the doctor. Firstly, if the support person interferes, that can increase the time taken for the consultation. Secondly, the advice may be recorded incorrectly. Thirdly, some doctors may find it uncomfortable to have somebody else there.

Again, those possible disadvantages are all controllable. For example, a doctor can easily ensure the advice is recorded correctly by saying, "Tell me what you have noted down so I can reassure you that you have recorded it correctly", is a very easy way to proceed.

There are some real legal issues for support people. They have an important role to fulfil and must have a clear arrangement with the patient. It is important that everybody knows who is doing what and what the limits of their involvement are. Issues for the support person include, but are not limited to, the capacity of the patient to make decisions, acting in the best interests of the patient, respecting confidentiality, not interfering with medical advice or care, the ownership of notes and not providing legal or medical advice.

In summary, the strengths of patient advocacy are:

1. it is good for the patient with improved outcomes at all those different levels;

2. it is good for the doctor whose effectiveness is improved.

It is easy and important for doctors to encourage patients to have a support person present at consultations. Patients do not appreciate that they are "cognitively compromised" until someone else tells them (and perhaps not even then - that is why it is best coming from a doctor). People who have consumed too much alcohol often do not think that they are compromised. Patients are the same. That is why they need to be told of the benefits of having a support person present. Doctors are in the position to be able to do that, and it is a very simple and effective way that they can make a major change for the benefit of their patients and the whole health system. And there is no additional cost to the health system. If there is any cost at all, it is borne by the patient.

In my view, the weaknesses of patient advocacy presently are any additional cost for the patient and the variable quality of the support person.

As I mentioned earlier, the support person must understand their role and be able to fulfil it. Doctors have an important role in encouraging support people to take notes and be engaged.

If professional patient advocacy increases in this country, as I expect it will, there may be a need for training requirements to ensure proper standards and ethics are taught.

In conclusion, the previously quoted statistic about the amount of information correctly retained by patients being strikingly small is something that cannot be ignored and must be a catalyst for looking at the way in which we currently do things. One simple solution is to encourage patients to have a support person present. This applies not only to consultations in the doctor's rooms but also in hospitals, and wherever a patient is going to be needing and receiving medical care. It should be on hospital admission forms so that patients are aware of it. It is certainly something that doctors' receptionists can tell people when appointments are made: "We recommend that you bring someone with you. It is not compulsory, but we do recommend that you do." It is a statement of respect for the patient. It also shows a willingness to embrace the patient, and whomever they wish to bring with them, in the process. It is a very significant and easy step in providing patient-centred care.

Thank you.