

**Guest Presentation to Painaustralia Annual General Meeting
23 May 2017**

Ms. Leanne Wells, CEO Consumers Health Forum of Australia

I would like to start by making a personal declaration.

As someone whose hip is becoming a nuisance, is it too trite to say to this audience “I share your pain”?...

That’s physical and financial pain I might add as I hobble around, assessing the cost of forthcoming hip replacement surgery.

So... I have just shared a health experience with you. Your sympathy is accepted.

But that personal disclosure also helps to make the point that consumer advocacy in health crucially depends on conveying the consumer’s experience.

When you hear about an individual’s health journey, your thoughts are likely to turn to similar experiences encountered or suffered by yourself or others you know.

Health and illness is a personal thing whose impact on others is likely to be sharpest when they can identify with it.

And of course one of the achievements of Painaustralia has been to present the issues confronting its supporters by getting the message across through the telling of personal experience.

For a variety of reasons the consumer voice can play a stronger role in health decision-making these days.

When costs and complexity of health decisions are balanced between provider interests and economic benefit, consumer advocacy can help set a middle course.

The compacts the Health Minister announced in the Budget indicate the influence of provider organisations is strong. But electorally those compacts will be of little

worth if they don't lead to more satisfaction or at least less discontent among the population at large.

The Government's Budget decision to roll back, very gradually, the freeze on Medibank payments is welcome and comes with some support for the Health Care Homes reform we have been urging.

The Pharmacy Guild which is easily the biggest health provider group winner out of the budget, not only receiving hundreds of millions more for its members but also securing a government pledge of maintaining the protection of community pharmacies, a review of the \$1 prescription discount AND solid support for pharmacist involvement in Health Care Homes.

Consumers organisations have fewer resources and less clout than practitioner organisations and particularly the Guild.

That makes our advocacy efforts important, choosing the right issues, generating the interest and energy of our supporters and of course being able to champion our case through affected consumers.

These days it may seem reasonable to think that any effective media/lobbying campaign is likely to involve substantial costs.

But that need not be.

Powerful campaigns depend on powerful ideas that, particularly these days with social media, can carry your message far and wide at modest cost.

Even getting an initiative carried in the mass media need not require significant cost to get wide coverage so long as the idea and content are credible and attention-generating.

The ideas that drive the campaign must be of vital interest, or reveal and highlight a pressing issue, and be conveyed through the words and experiences of those at the touching point --- the consumers.

Credibility is central to consumer organisations and again that will often rely on communicating the experiences of health consumers to the world at large.

There is something of a paradox that challenges an organisation like ours.

That is that most of us keep relatively good health, or at least do not face the substantial physical and financial difficulties that confront people living with chronic illness.

So, many Australians, even though in the opinion polls they place a good health system at the top of their concerns, remain fairly complacent about health care because they do not require routine and potentially expensive care and medication.

Our job has been to remind governments of realities like the relatively high impact of out of pocket health costs and supporting changes to end the inadequacies of our primary health care arrangements.

Any effective health consumer organisation obviously needs to be in touch with the real world of their supporters and members.

We rely on credibility to advance our cause. Having strong consumer voices talking about real world issues enhances that credibility of course.

But we importantly also need the data, the facts and figures, to make our case. CHF strongly supports the authoritative sources that provide data that we can use to ascertain the performance of our health system, like the AIHW.

We need even more transparency about the workings of our health system, like the provision in a secure and de-identified way of Medicare, PBS and hospital data, and public access to costs and performance of providers, like surgeons..

Such information equips us to argue for the best interests of consumers.

On every front of major change or hoped-for reform we can recognise the need for strong consumer input. Our challenge is to ensure that we are not just at the

table, as we normally are, but that we can have a decisive influence....which is a lot harder.

An encouraging trend we have noticed is that increasingly institutions like companies in the health sector and universities want to hear more about the perspective of health consumer organisations.

A recent example was when health consumer advocate Diana Aspinall spoke to an academic audience about the experience of somebody like her.

She lives with several chronic conditions, complicating her dealing with the health system, whether it be gaps in care, cost or related issues like inadequate transport or communications.

Diana recently spoke to a *Can We Bridge the Gaps in Healthcare?* session at Sydney University's Faculty of Health Science as part of the Dean's Future Health Forum.

She can speak from deep experience as she chairs the Nepean Blue Mountains Joint Primary Health Network and Local Health District Community Advisory Committee and has played a pivotal role in organising a vigorous consumer health movement in the region.

So much of successful health care particularly for those with chronic and complex conditions has to do with bridging gaps so that patients receive integrated care and continuity of service from a range of practitioners.

As somebody with five chronic medical conditions, Diana spoke of the importance of bridges in care.

As she says while doctors might talk to other doctors, they don't necessarily talk to other allied health providers like podiatrists and physiotherapists about the individual needs of a patient.

It is circumstances like that, where there is possibly meagre interest from practitioners, that the role of the seasoned consumer advocate takes on such value.

Every advocacy body, government agency and business uses ordinary people talking about their experience to promote their particular cause.

We at CHF are frequently called by media wanting to interview an individual affected by the health issue, or health-cost issue at hand. The interview request will often be to do with health insurance and the media comes to us because of the realisation of the central place of the consumer in health insurance choice...and the conflicting views they are likely to get from the other players in the health insurance merry go round.

That central role of the consumer/patient is of course true of most health issues but with health insurance there are the additional aspects of personal choice and personal cost playing a more significant role than in other health settings.

The current review of health insurance, which Minister Greg Hunt has indicated will be a major focus for the coming 12 months, presents the opportunity for the consumer voice to be heard, given the increasingly problematic position of health insurance.

Our place in the health insurance review, to present a strong and well-thought through position in consumers interest is backed up by our own surveys of consumer opinion and the recent edition of our journal Health Voices which presented the thoughts of 20 health leaders on the topic.

Increasingly, the informed views of consumers are being sought in a wide variety of areas including primary health care reform, the MBS review, medication labelling and Choosing Wisely, to name just a few areas of our active involvement.

And the challenge of choosing where a small organisation like ours should focus its efforts is virtually a daily consideration. Every health organisation wants to be able to show it has at least the appearance of consumer involvement and so they come to us, inviting our involvement in their project.

For many organisations the “consumer friendly” image may not go much past appearance. For instance a survey we undertook last year showed that health workforce organisations include consumer awareness in their guiding literature but many do little to actually involve consumers in practice and governance.

Lived experience powers health consumer advocacy. There may be great data, powerful politics and persuasive economic arguments but it will often be the personal story about suffering or success that will clinch a policy decision or a change in clinical practice.

Capturing patient stories on video is now more important than ever. We have a video on our website, featuring one of our longtime supporters and former office-holder, Janne Graham, describing how consumers can play an effective role in their treatment.

Janne makes the point that practitioners can see themselves as the “only experts” of a given set of conditions when in fact better outcomes are more likely when clinician and patient work to maximise therapy.

Janne recounts how in overcoming an unusual medical condition she learnt to work proactively with clinicians and as a result spent less time in ICU, and less time in hospital than expected and did not need the rehab that had been expected.

Consumers have to learn “to take charge” and learn what to know and what to ask about, she says.

Janne’s message is one that should underscore the message from health consumers: we should not accept that we are the passive recipients of health care or the bystanders in the design and development of health policy.

We health consumers must recognise that an important part of achievement in health care lies with the recognition by health providers that an engaged consumer will deliver better results, more staff satisfaction and often at lower cost.

When we talk about consumer power I would guess many of you will be thinking particularly of an individual whose impact as a consumer leader has been transforming and who more than any of us has had a long and challenging experience as a consumer of health care.

That is but a bland description for what Lesley Brydon has endured and still does in her trials with health care.

Lesley has turned her physical trials into ammunition for use in her advocacy.

She and Michael Cousins have been instrumental in elevating the recognition of pain as a condition demanding a status and standing requiring the active and committed attention of the health establishment. From being an affliction that so many Australians have previously endured with minimal attention from clinicians, pain now receives much more attention and recognition as a state demanding focused attention and targeted therapy.

Pain has been always with us.

But until the campaigns by people like Lesley and Michael, it was seen as a symptom of something else. The first International Pain Summit, chaired by Michael, led to the National Pain Strategy.

But there is still unfinished business particularly with respect to Commonwealth leadership and action in primary care – Lesley says the states and hospital clinics all quite good but as she says the trouble is big gaps remain in the community.

So Lesley is stepping down but we hope not stepping away in providing her guidance and indefatigable leadership.