

Submission

No 98

INQUIRY INTO THE ROYAL NORTH SHORE HOSPITAL

Name: Mr Allan Quirk

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Submission to the Royal North Shore Hospital Inquiry

Re:RNSH Treatment of Patients with Pre-existing Physical Disabilities, not caused by spinal injuries.

Such Patients with Pre-existing Physical Disabilities (PPPD) have often worked very hard at their original rehabilitation and still have the drive to maintain their continuing level of independence, despite arbitrary barriers being put in their way to receiving adequate medical care.

The Health Department's & RNSH's systemic management, culture, excessively narrow accounting practices and the misuse of "case management" techniques to cases it was never designed to be used for; appear to be at the heart of a most of the problems faced in this area of care. PPPDs often experience serious anxiety, because the reason for their admission may collaterally cause temporary serious loss of independence, and the fear that if the whole patient is not treated correctly, it could become more permanent..

I find it amazing that RNSH was designed for 750 beds, but was reduced down to a minimum of about 400 in the last 2 decades, for cost reasons regardless of the catchment population increasing, and while also closing or diminishing many other hospitals!

All of the following have happened to me, over in the last two decades, and up to last year at RNSH, and I am sure would have happened to other PPPDs. Polio caused me extensive paralysis. Further details appear in the appendix below.

1) **No bed allowances are made for patients with complex issues additional, to requiring treatment in Emergency.**

Doctors are generally under considerable pressure to send patients home rather than admit them.

For example, I was admitted to Royal North Shore Hospital Emergency with a broken arm (humerus) and dislocated shoulder. After this was treated correctly, I was told that I could go home!! This is the usual procedure.

[No account was taken of the fact that the injury left me unable to use *both* arms to sit up by myself, or the complete loss of independence I would experience until the arm was X-Ray healed.]

When I protested, I was told firmly that there were no beds! . My teen age sons both agreed that *they* could not manage me at home [which I had realised], so I had no choice but to insist on staying; for as long as it took for a bed to be found!.

2) **Families cannot be expected to cope at home with a PPPD being sent home prematurely, before rehabilitation & assessment for loss of the limited independence the PPPD had after the injury/treatment.**

This issue is related to point 1, above. I regard this issue, 2, of sufficient importance to be included in a point of its own. The issue that RNSH conveniently seems to fail to comprehend, is that:
the families of PPPD have often been helping out the PPPD for a long time at the pre-injury/operation level of disability and cannot be expected to cope, at the drop of the hat, with their relative who was sort of independent, further losing the limited independence they had, and still provide rehabilitation. These days, most members of families are either working, learning & studying, or have time commitments elsewhere.

3) **Patients with weak limbs and torso find it very difficult to obtain patient-adjustable beds.**

A patient adjustable bed greatly assists staff workloads, safety, and saves the patient injuring themselves, like I did, when trying to sit up or change my bed position, without such a bed. I can barely lift my neck, and my arms are weak and/or are carrying injuries.

Oedema and cellulitis can also be kept at bay by raising the bed, and hence the legs

The injury further tore my already significantly torn shoulder rotator cuff [of tendons, which hold the socketless shoulder together]. A repair was out of the question because of the heavy loads I need to put through my arms as they are used so heavily for *everything* I do. The supraspinatus tendons were debrided [torn ends cut off so they did not snag the acromion bone, they had to pass under] to reduce the severe pain and the limitations it placed on the movement of the shoulder joint..

4) **Physiotherapy is usually not available for loss-prevention physiotherapy to maintain muscle fitness for vital high performing muscle groups,** not part of an injury or surgery, while the patient needs to stay at RNSH.

For example, Physiotherapy is **only** allocated to orthopaedic, burns patients or those with breathing problems. The PPPD may be on different ward, but may still need physiotherapy to maintain the *peak* performance of the few small muscle groups the patient has left. These need to be kept functioning at the loads that are necessary for the patient's future independence. Like a highly tuned athlete, these muscles detune very quickly, and are hard to get back to their high performing levels if not kept in training or physiotherapy.

Therefore Nursing Homes are definitely NOT appropriate for patients with the drive to undertake rehabilitation and want to continue to live in the community

5) **No extra staff are available for patients with high level needs.** Nurses are overloaded, which can cause injuries due to time constraints, and can cause Staff to be judgemental towards their PPPD.

Telling the patient, "You're not even *trying* to help me!" in whatever task, is positively insulting to a person who knows how much they have achieved and still intends to, regardless of age: or regarding their patient as an unnecessary bed-blocker (not helpful to a patient already facing substantial frustration and anxiety!)

Too often the patient faces excessive delays in their needs being met. This leads to the patient taking risks of injuring themselves, that they might not otherwise take.

6) Day Surgery Categories do not make adequate provision for PPPDs needing to stay in hospital instead of going home, after the operation.

Case Management techniques are being misused where they were never designed to be used.. The patient feels the constant frustration of the staff not having another hospital or Rehabilitation Hospital to send them to, *instantly*.

Then all the PPPD problems start all over again when the patient is transferred!!

7) Staff often don't recognise that such a patient, who has lived with their disability for a long time, may have developed some considerable knowledge of their case, that nurses or young doctors would be well advised to consider *before* going all "authoritarian" on a case they may have little wisdom about.

I badly tore my leg midway up and beside the shin. From my experience of other grafts I have had to have, I was fairly sure that it would need a graft, because of my poor circulation, the size of it, and that it would be best done within 12 hours.

Three doctors in Emergency came to me separately, after the the first doctor referred them to me. Each time I strongly suggested to them that a plastics doctor needed to see it first. I felt that I was being fobbed off with 2 other doctors suggesting dressings I believed to be inadequate for the extent of the injury.

Eventually, I told the first doctor firmly, that I would be complaining to the management if a plastics doctor did not get to see wound before I was sent home.

When he eventually arrived, he got within 10 feet of the bed, and said that that wound is going to need a graft!

8) Allowances are not made for the affect of pre-existing disabilities on the patient's injuries/surgery.

Eg Patients suffering frustrations due to their high drive for independence, or may suffer high cold-sensitivity, aches and pains, sensitivity to anaesthetics, slower healing due to poor blood circulation, anxiety or depression etc.

9) Pressure on Hospital Registrars to Prematurely Discharge Patients

When I was admitted for an infected anal gland, it required a deep cut to my buttock for draining. No disrespect is meant to the mid-case change-over Registrars, as they were following "normal" hospital procedures.

They arrived for the first time, the day after the Specialist had agreed with me, that if I was sent home prematurely, I would have to come back to the hospital in a worse state, if I was discharged before the wound was healed. In that case he

agreed to keep me in hospital, until the wound could handle, the twisting, dragging, and turning [all excessive pressure on the wound reducing its healing capacity] it would have to cope with while in bed, because I did not have use of my legs!

When these registrars conferred with themselves they told me that I would be going home tomorrow, I became so *extremely* anxious that my blood pressure shot up, because I wanted the wound cleared up as quickly as possible, to reduce muscle weakness/loss, so that I could get back on my crutches and callipers ASAP. This high anxiety lasted until the next day when I had the matter cleared up by the Specialist!

10) Could such a rundown Hospital System seriously be expected to cope with a major terrorist attack, or infectious diseases such as Asian Bird Flu?

11) I have not complained before because of the fear of even more *Negative* discrimination than I have already found.

But it has got to the stage where I feel the need to speak out for myself and others in a similar situation, who do not have adequate communication skills.

My comments are not directed so much against the staff, but the system which causes such behaviour changes.

Brief Biography

I am one of such people who fits in this PPPD category. In January 1956, I contracted paralytic polio, very severely, in Perth, aged 13.7yo. Fortunately this allowed me to be treated as an adult, which suited my personality, as I had wanted to be a doctor since 8yo, and being treated like a child was not appropriate for me and my need to learn about my case and to be involved in decisions about it..

. I spent time in an Iron lung, have been totally paralysed in both legs, with my left arm very severely, permanently weakened, and for the last 20yrs have had an irreparably, severely torn right rotator cuff. I am still capable of only lifting my head off a pillow, unless I use both arms with a something attached to the bottom of my bed, *even* with the help of an adjustable electric bed, to sit up or change my body position.. There was no semblance of "access" in the community in those days, and I still knew I wanted to go back to school and on to University. Consequently, I had to be able to manage getting up steps, which could not be done in a wheelchair..

The only way this could be done was using lock-knee callipers and crutches. So in consultation with my doctor, and physiotherapist, Thea Stein, I decided to go hard at it, and undertake a year of physiotherapy with Thea (for whom I am eternally grateful) for a packed 4.5 days/week.

I knew it would be amazing, if I could only build up my strength sufficiently to be able use crutches and callipers.. For 46 years. I managed on crutches and lock-knee callipers, then went straight to an electric wheelchair when it was necessary, about 5 years ago.

I still continue to be amazed that I had the God-given gifts to be able to join a school.(Christ Church Grammar School in Perth), whose staff accepted and facilitated my growth, and then on to University, twice to obtain 2 degrees, and work for twenty years.

I continue to have a stimulating life, living alone in my house, with my assistant dog, and home care twice a day

When I was getting my bathroom modified for wheelchair access, I found the experience in a respite nursing home was horrible and very restricting and unsafe for my care because of a "rush rush" culture due to severe staff shortages. Staff helping me, often worked at the limit of my balance and muscles, which could barely keep up. I am just not suited to so many restrictions, even though I was able to go out and walk my assistance dog.. My active mind and personality just did not fit in with nursing home regimens.

Consequently I will only go to a nursing home, if necessary, to die: and while I am able to live at home I will not be ready to do that yet!.

Thank you for considering these matters.

Yours faithfully

Allan Quirk

NOTES:

1. ADMISSION

1. **Emergency have treated the presenting injury professionally, BUT may be inclined to overlook complications of injury + pre-existing disability..**
Not the corresponding independence impairment, or insufficient or unsafe existing services at home (e.g. family or home care) to care for patient..
Nursing homes are unable to give adequate care to return to level of independence.

2.

2. Prevention Of COLLATERAL DAMAGE

Need to assess equipment, level of nursing and physiotherapy which might be required. .e.g.

1. **The use of a patient controlled electronic bed, and bed rope/ladder, monkey grip (as appropriate), in order to be able to sit up with if unable to sit up with,** in order to reduce the high load on nurses if patient needs to change position, to alleviate pressure areas. *I ended up further injuring my torn rotator cuff, because I am only able to lift my head a little without using my arms to wrestle my way up, and no such bed was available.*

1. The patient may suffer oedema in the legs, normally, and if they have an injury in the legs it is important that the patient can adjust the bed raise their leg their leg height to aid reduction in swelling, and possible cellulitis or infection.

2. **Adequate levels of nursing care and response times,** to ensure that the usually over-independent disabled person, does NOT feel forced to attempt to do things which *may* cause further injury, hoping they may get away with it.

1. The high workload on Staff makes it much harder to give adequate high Needs treatment to those patients who need it to return

3.