From:
To: Community Affairs, Committee (SEN)
Subject: Dementia Care Re Kenneth Patrick Drury
Date: Monday, 11 March 2013 6:29:36 AM

Good morning!
I understand you are interested in experiences concerning the care of Dementia patients with the view of using this information for better future provision of services & care facilities.

My husband, Ken, was diagnosed in August 2009, after an extended 2 1/2 week stay at the Royal Melbourne Hospital Neuropsychiatry Unit where intense physical & neuro tests were conducted. The resulting diagnosis was Cortigo Basal Ganglionic Degeneration.
We, as a family (that is, myself & our 4 children) were requested to attend the diagnosis with Consultant Neuropsychiatrist Dr Ramon Mocellin, Consultant Specialist Dr Andrew Evans, Registrar, Occupational Therapist, Senior Social Worker & other staff.
We were advised my husband was also suffering Palsy, and there would be many ramifications of this illness & other conditions he was found to have on the more debilitating, aggressive & rare CBGD.
Our children, at the time, were 22, 20, 18 & our youngest daughter having just turned 15 whilst Ken was in hospital. Needless to say this news was devastating, especially, as we found out, the life expectancy would be between 4-7 years. The younger the patient at diagnosis seemed to be of concern & Ken's was a late diagnosis. Whilst we would all have liked to know at that point at what stage Ken was, we were advised there was no way of knowing but tests at a later date could be performed as to estimate the progress of the illness, the main reason is there were so few case studies & they would need compare test results.
It is our understanding that anyone under 65 with dementia is of concern & the younger the person, the more aggressive the illness.
Ken was 54.
After we found out he would constantly fall, would be unable to feed, dress, shower, speak, walk without assistance, Ken was brought into the room & things were simply explained whilst we watched helplessly as we knew he did not fully understand.
The heartbreak, when we were alone at home, of having to explain he was dying & asking if he understood there was a time line was enormous. I explained the problems he would face & we would all look after him at home for as long as we could.
Although Ken found it difficult to make decisions, we had months before discovered a choice of even 2 things was too difficult, he was that night able to tell me he did not want to live longer than the unlikely 7 years if that's what it was to be for him.
I would like to point out, at no time did he become morose or violent - in fact we were told Ken's good nature & sense of humour would get him, and ultimately the family, through.
We used this knowledge many times to diffuse situations, often due to lack of sleep, aching bodies & pure emotional roller coasters due to financial pressures in addition to all the changes at home.
Ken's life at home became the lounge room & toilet with an occasional peep into a bedroom because he couldn't work out how to turn to come out.
With the Aged Care Assessment Team organised by the hospital 10 months later, we were given some assistance which gradually increased to full on hospital equipment which included bed, wheelchair, commode, lifting machine & carers 2 days a week to allow me to work, weekly Physio & district nurses 2 mornings a week to assist with washing.
When we realised we could no longer keep Ken at home safely, the difficult but necessary decision was made that permanent care was needed. So, as a family, it was Christmas every day for the last week in Dec 2011.
Ken went into care on New Year's Eve.
Prior to this we had used respite stays in 3 different nursing homes on 4 occasions for a maximum of up to 2 weeks duration.

What we found was there is no standard of care across the board. Whilst we have no medical knowledge our being thrown in the deep end, as it were, and knowing intimately the nature of the person, we were able to learn very quickly how to get around issues as they arose at home, eventually this was everyday rather than weeks at a time. I learnt thru behaviour when there was an infection & blood tests were needed or when an excess of iron in the blood was causing a lack of clarity.
Relaying this information was difficult to explain as it was second nature to us.
Not all nursing staff know how to 'ask' the questions for the info they need to know.
Not all nursing homes even have any questions other than what is the favourite colour or do they

like music & medical type info is not high on the agenda.
Not all nursing homes provide safe sleeping arrangements, even when they have been told there will be falls.

To be brief here.... and I have tried to block a lot of the heartbreaking issues - my concern was the care I needed to provide when my husband came home again, I did not have the physical & more importantly the emotional energy to be forever angry without it effecting Ken.

These are things which we came across & I hope that by you being aware of them & in speaking to many others this behaviour will be addressed.

Providing drugs without consent after the specific request they do NOT be administered due to the effect on Ken.
Administering those same drugs without the appointed or a locum Doctor attending/visiting/examining Ken.
The pharmacist providing the drugs without a prescription being written up.
Nursing staff/management contacting the local pharmacy to request drugs be provided without having a doctor see Ken or prescribe them.
SO, no doctor, no prescription, (the pharmacist had confirmed to me the doctor had been in earlier in the day to drop off a script - however I did not know at the time it had been filled at least a week before for the exact drug that was detrimental - I thought it was for antibiotics which were started about 5 days after admittance)
My question is----how can a nursing home give drugs without the doctor EVER meeting the patient?
How can a nursing home not inform the family when the family have informed them it is a dangerous drug.
Staff checked & said he was not having sleeping tablets after my husband told me they were giving them to him!
How can the same nursing home not act on safety issues with beds on the very first night?
How can the same nursing home leave a patient lying on a mattress, facing the door, on the floor with no underwear, fully exposed to every visitor & staff member who walks past - including a 15 year old daughter to walk in the room on day 2 of the first respite visit?
How can the very same nursing home not inform the family of falls, but the administrator(owner) start to say but stop when another manager is present? I was informed of a fall by one of the local shop keepers over a year later after a conversation one of the senior nurses had with him. This explained why his shoulder was sore when we moved him in & out of bed, all of a sudden & only after he returned home.
The same nursing home had tiny portions of food & the time not spent making sure he was eating.
Unopened bottles of water on the table & out of reach with seemingly no record of daily consumption & staff not knowing.
Inappropriate clothing to wear for specific medical procedures.
Resident being left in the car upon return to the nursing home because there was an audit being performed & they did not want to be seen lifting the patient out - they had no equipment to transfer from car to chair. At initial arrival we were assisted by the owner & also assisted the morning of the medical procedure by the owner's son (?) or nursing staff, but when we returned I was advised the staff would not help.
I advised staff my husband needed to be changed as he was wet, but they left him in urine soaked clothes for an hour, despite being by the bed when told & talking with residents when I returned after a discussion with the owner.
The reason he was there is because he could not walk all of a sudden - which, after antibiotics for a bladder infection he could walk - but he was not being cared for at all.
Nurses yelled at him, I needed to point out he was not deaf & they could speak with him normally, he was not an infant.
Also telling my family repeatedly there was no way he was walking before we brought him in showed a total disregard for what we had tried to tell them.

No way for the staff to deal with the family.

Lucky for us we were able to find a different home for the next respite visit & it was a little better, however, the issue of meals was totally disregarded & Ken again was not fed, which was apparent with food stained clothing. 80% was worn & weight loss was very evident. Approx 5 kgs in a week with no shaving & several discussions with nurses. We were driving approx 75kms return to feed Ken, arriving just before the food should be given to the residents, only to find the plates had been removed - they were only on the tables for 5 mins & there was no food to give Ken. We ended up taking food in which we should not have had to do.
Eventually Ken was weighed again & then things changed, but again, if we were not there to

physically give him a drink he did not have one.

The third nursing home was an emergency visit due to an injury I had & I could not lift more than 5 kgs. He was well cared for & the family were very happy, however, a second visit in December 2011 proved too much with him being drugged heavily because of the noises he was making. The doctor advised the nursing staff were concerned he may upset other residents with his moans. I spoke at length with him on the phone in order to stop the medication, as again it was detrimental to his health.
These moans was him telling them he needed the toilet & he was in a single room. He was left in there all day, unlike the first visit when he was socialised daily. Every visit, no matter what time of the day he was totally off his face. He did not know us. He did not eat. He could not sit up. He could not walk.
Again, he lost weight as he was not eating or drinking. The staff said it was because he was sleeping.... It was also difficult to weigh him because they couldn't get him to sit up, so hygiene was also an issue.
I had to remind them I held medical power of attorney & demanded they stop the drug & I wished to speak with the doctor. It was at that point he advised it was the nurses requested the meds. They had been previously advised not to administer any mind altering medication.
Even at the time we went to collect Ken before Christmas at the end of his stay, he was not ready & the staff were unaware he was leaving & did not assist us, even though they could see we were struggling to dress him.
After speaking with the Physio who came weekly about the rapid loss of weight on his legs, I was advised no movement due to heavy drugs he had lost all muscle tone.
He could no longer stand.

This stay was because I was exhausted but Ken was able to walk with assistance before the respite. Once he was home we realised the week before Christmas & the following week would be his last at home.
The drugs administered without notification - which the nursing home acknowledged was wrong on their part - and then continued after they said they would stop - which some staff said they had & then others said they had not- directly resulted in an early entry into permanent care.
This same drug should have been, according to the doctor, administered as a daily total - however some staff were administering the daily amount every few hours, as confirmed by nurses & the doctor. I was also advised the drug's effect should only be in the system for a few hours - it took 8 days.

So, for my family, we were robbed of valuable months which we could have cared for "dad" & "husband" at home.
I have been told we cared for him at home far longer than the nurses, the GP, the Physio thought possible.
Simply out of frustration of bad care we did what we saw as right, as he would have done for us, without a second thought.
I retaught him to hug us, he wanted to kiss us & he knew us, we would hold his arms around us and rock gently to dance, although he could not move his feet, to the music he loved so much & craved for.

When it was time, the small, old nursing home was staffed by wonderful people who asked questions & were interested in Ken as a person. He was taken to the day centre, was taken outside, and the staff were greatfull for any help given. Every effort was made to make him comfortable from the minute he was there.

I find it very hard to understand why there are such huge differences in care but am glad they are not all like the first one!

It seemed eventually his will to live stopped. Eventually he could no longer eat, no matter what we did, and the doctor explained almost 3 months before he died what would happen. The decision was made not to take him to a hospital when he would get pneumonia but allow him to be comfortable in surroundings he had become familiar with.
If all families were allowed this final luxury of compassionate care for loved ones, we would all be in a better place.
And people making these decisions need to be aware of what does go on - I am sure I have blocked a lot out in trying to move on.
More & more of us are likely to need specific care in the future & it does not appear Australia is prepared for it.

Especially for younger aged people.
Activities, celebrations & music - just to mention 3 things - need to be age related. Put a 50 year old in with 80 year olds & play Bing Crosby...it just doesn't work.

Ken passed away, May 21 2012, less than 5 months after he went into care.
3 weeks before his son turned 21.
5 weeks before his daughter made her Deb.
11 weeks before his youngest daughter turned 18.
He was aged 56 years & 52 days.
He didn't even have 3 of the expected 4-7 years......

Thank you for taking the time to read this, I truly hope some good for another family will come from what we learnt along the way.

Yours sincerely,

Julie Drury

Sent from my iPhone