

Princess Royal University Hospital

A PATIENT'S VIEW

OF

AN UNPLANNED ADMISSION
(via outpatients and A&E)

January/February 2013

INTRODUCTION

I am just a patient with no medical training or background.

I am 58yrs old and have lived, been educated and worked in the UK all my life. My health has, overall, been good so my experience of emergency admissions and hospital stays has been minimal. Over the years, when I was working, I had a few tests and brief inpatient stays in the private sector but now, since stopping work in 2006 due to problems with health and disability, I rely on the NHS to help me manage chronic as well as acute medical problems.

While what I write is often critical, bear in mind it is coloured by the fact that it was first drafted very soon after the events occurred.

I now wish to add that there are also stars among the PRUH staff, especially my consultant gastroenterologist and his secretary, whose courtesy, ability, compassion and humanity shine very brightly and very obviously. To them I now and always will say a big "thank you" and express my appreciation of them.

When I mention experiences of other patients, although I don't mention them by name, I do have their permission to report the event – all were very happy that I was going to submit this note and many went out of their way to point issues out to me.

History

Attending a gastroenterology outpatients appointment at the PRUH in January 2013, I had been doing my best to cope with another ?partial small bowel obstruction crisis which had started on Christmas Eve but which was barely improving. My GP had written to the specialist as he was concerned that an additional left-sided abdominal pain had not responded to two courses of oral antibiotics. I was feeling so acutely unwell that, parking my car on arrival at hospital, I had been wondering how I would get myself home again, so when my consultant expressed concern at my condition after examining me, and said it would be possible for me to be admitted immediately for bowel rest, tests and treatment I agreed with a huge sense of relief.

My expectation, then, was to receive prompt and immediate care and treatment for the not inconsiderable pain and discomfort I was experiencing. My consultant told me that I would not necessarily be admitted to a gastro ward, due to pressure on beds, but as the nurse from outpatients escorted me from the clinic I thought I would at least be heading to a bed somewhere. Instead I found myself sat/semi-propped in A&E for several hours, as if I had just walked in off the street. What follows below are a series of observations of an almost three-week stay at the PRUH – bullet points supported by background and personal anecdote. This, my first experience of an NHS admission, and of A&E, in 30yrs turned out to be a worrying and in parts terrifying time for me as I had no one with me to intercede for me. The process is not designed for people on their own.

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1. My Admission Process

No information – no sense of how long to wait

Background/anecdote

Attending an outpatient appointment on 29 January and feeling utterly wretched, I was very relieved when, after examining me, my consultant indicated he could arrange immediate admission for bowel rest, tests and treatment. He said that his clinic nurse would take care of things for me.

Having not been admitted into an NHS hospital for more than 30yrs and only experiencing brief stays in private ones I, naively, thought this would mean my having to sit in his clinic waiting area for a while and then be taken to a bed somewhere. The reality was that I was escorted not to a bed but to a long wait in A&E. My file was handed over to A&E reception, the clinic nurse said I would be attended to soon, and she left me.

The small A&E (minors) waiting area was completely full with every kind of humanity – from half-dressed seemingly demented elderly people in wheelchairs, to toddlers running around with worried parents and pale adults stifling groans of pain. It was a noisy, cramped and chaotic environment and, feeling as unwell and as in pain as I did, I just wanted somewhere to lie down, but that was not an option. There was no clock, no “patients seen” ticker, no health information screen to watch, just a reception desk with two staff very busy at their computers who occasionally glanced at the mass of bodies in front of them. It felt like being caged in a group of unwanted/undesirable creatures. At one point, I just had to make my way outside for fresh air - the temptation to just go and lie down in my car in the carpark was very strong, but common-sense and a realisation that I was very unwell and needed to be seen/treated prevailed.

After about three/four hours I was seen by a triage nurse who verified who I was on the computer, and then said I would have to wait again to see a doctor. When I queried this, as it was my consultant gastroenterologist here at the PRUH just a few hours earlier who had recommended my admission from the outpatients clinic, he said that the outpatient specialist's opinion did not count and that to be admitted to the hospital I now had to be seen by an A&E doctor who would decide whether or not I should be admitted.

Returning to find another seat in the ever more crowded A&E waiting area, it was about an hour before I finally heard my name being called by someone in scrubs. Everyone wears scrubs of various hues so there is no way of knowing who it is that is dealing with you, especially if they don't introduce themselves.

I move and walk slowly with a stick anyway, but now was in so much abdominal pain I felt I was about to collapse, so had to walk even more carefully. As I approached the person who had called my name, they turned and marched briskly away. I presumed I was meant to follow, although I had been given no sign to do so. Looking through a doorway I could see the person I was trying to follow, partway down a curtained area. She seemed impatient with my slowness. I did my best to apologise as I was shown into an A&E bay where a paramedic (“just helping out”) welcomed me as “the lady with heart problems” and, together with an anorexically slender and exhausted-looking lady doctor, proceeded to get me to put on a gown and conducted an ECG. They both commented

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on the abnormalities found on my heart tracing although, rather worryingly, this was never followed up or discussed at any point subsequently.

The doctor took a brief history from me in relation to my heart, while I repeated that I wasn't being admitted for heart problems, to the best of my knowledge, but for abdominal symptoms. She then asked me to tell her why I thought I was there so I once more went over what had happened that day. As I was speaking, her bleep went, and she excused herself. I lay back on the A&E couch really feeling as if, like Alice in Wonderland, I had just fallen down some curious rabbit hole into surreality.

At this point, in addition to pain and discomfort, I was also rather worried because I appeared to have been misidentified as having a heart problem and my heart had just produced anomalies on the ECG. BUT... at least I was lying down. I have no recall of anyone coming back to tell me what was going to happen next, so I just waited.

After a while, a nurse then came to take me to a "more comfortable bed on the ward" and while I don't remember the details as I was in too much distress, I was wheeled in a chair from the A&E bay to "the ward". I thought this would be the ward where I would undergo tests and receive treatment as my gastroenterologist had indicated.

I was pushed into what can only be considered an extremely chaotic (to the outsider) area and thence into a single room where I was left alone. The bed wasn't properly made so I unfolded the sheets and blanket and feeling even more wretched and in pain than before, lay down and hoped that someone would be along to tell me what was happening. I have no relatives and no friend was with me to go and find out for me, I was in considerable pain and very scared about what might occur.

It turns out I am in the EAU (see 2. below) and I only reach a medical ward, via a surgical overflow ward, some 10 days later.

2. EAU

"a kind of hell"

Background

The Emergency Assessment Unit (EAU) is the first port of call for patients admitted to the hospital from A&E. A&E is where you are first admitted to the hospital for all non-planned treatment and procedures. EAU appears very understaffed, and consequently provides no welcome or introduction to either the ward or the hospital. The bed I was shown to in the single room was unmade, the bathroom looked as if it had been used recently and there was a broken monitor being stored there. Nothing was explained and what interactions I had with nursing staff were perfunctory and impersonal – it was as if I were some object on a conveyor belt. The only doctor I saw here did his best to be reassuring in the very brief time allowed and conducted his examination of me rapidly and professionally.

Anecdote

The EAU admits patients from A&E. Many patients are accompanied by their friends/family. The staff on EAU is, as everywhere, low in numbers and they seem

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stretched beyond limits. There is little attempt at normal courtesies or, in some cases, even basic politeness. I felt that patients are not treated as individuals but as objects to conform to a system.

It is a very loud environment, with shouting not only from patients (drunk? angry? in pain?) but also from patient's relatives, mostly demanding to know what is happening or going to happen, and even from some of the staff present, who have loud and sometimes inappropriate conversations easily within earshot. Porters are good guys (as I found out later) and they would probably be shocked to realise just how their words and behaviour are held up to judgement. At one point, it felt as if the porters and the nursing staff of EAU were putting on some kind of ribald and appalling show, with patients as the captive audience. I know this is not the case and staff are probably just trying to cope as best they can with an appalling set of working conditions, but to an outsider, alone and unaccompanied, with no knowledge or experience of this environment and in pain and distress, it is a frightening and hostile place.

One just has to cling to the hope that the maxim "first do no harm" still applies.

I had received no briefing as to what I should expect from this admission from a process perspective and having not been in an NHS hospital for more than 30 years I had no idea what would happen. Feeling as unwell as I did, all I wanted was to feel safe and to feel confident that my consultant and his team were "on the case" and have someone help me with the pain and discomfort I was experiencing.

The first staff member who came to see me did not introduce herself or what she needed to do but, standing halfway between me and the door, simply started asking a curious set of questions. Perhaps due to my unwellness and the stress of the situation, it seemed to me that her grasp of the English language was so poor that she could barely pronounce/read the questions in what was apparently a "new patient questionnaire", and she completely ignored the few simple questions I posed. She attempted to write on the paper without support and folded the paper as she went. Most odd.

I was not told at the time why this curious range of questions was being asked and afterwards was left stranded, my queries unanswered and with my belongings in a green plastic bag on the end of the bed – I had no idea what would happen next or when.

Moments later the same ?nurse (NOTE: *probably an HCA as I later came to understand that only one qualified nurse is usually on duty, assisted by HCAs of varying skill levels and competences*) came back and announced she had to "swab" me – again no explanation of the process. I have never been swabbed before so had no clue what to do, and when I asked what had to be done, the swab was snatched from me and the process completed for me with accompanying noises of annoyance. It felt more like an assault than a procedure – conducted entirely in silence and once complete, this person left without any further word. I felt close to tears, the whole situation made all the worse by the extreme pain I was experiencing.

Some time later, a very pleasant doctor in scrubs appeared and introduced himself. He examined me quickly and said he wanted me to have a CT scan. Although his manner was reassuring, his rapid arrival/departure left me even more bewildered than before as no-one had said anything about my consultant's original intentions or even mentioned his name in connection with the test (scan) to be conducted. I felt as if I was meant to be fitting in with some kind of process but no-one was telling me what that process was.

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The stark contrast with a private hospital where everything is explained and the patient is treated with courtesy and good manners was just awful for me. I dry-swallowed a Stalevo (parkinson's medication) tablet – there was no water available – and hoped for the best.

At 9pm I was taken down to CT by porters, scanned immediately, and returned afterwards.

I don't recall seeing any nursing staff again until I was roused by my bed being moved (my watch showed it was 2am). Upon enquiry porters told me I was being taken to "the ward" (again I foolishly thought it would be a Medical ward as I am a gastro patient) and I and my bed were halfway out of the room before I realised they hadn't picked up my green plastic "patients belongings" bag, my walking stick or my glasses!! And thus it was I escaped from EAU.

3. Surgical 4 - an overflow ward

NO permanent staff – chaos - no continuity of care

Background

An overflow ward, I was subsequently told, is a ward that is not meant to be in everyday use but is opened as and when there is an excess of patients vs beds normally available. Surgical 4 is one such ward at the PRUH, but I was told it is almost always open, despite its alleged temporary nature.

As a consequence of this not being a permanent and fully-staffed ward, I was told, this means that there are NO permanent nursing staff at all and thus no permanent management and thus no continuity of process.

Each shift, every day, has at least (?most) one qualified nurse in charge (either PRUH staff or bank/agency) and a crew of mostly bank/agency HCAs. Bank nurses are agency nurses whose employer is the NHS Trust rather than a private company.

The vast majority of the staff I encountered on this ward were from the Philippines, and while their interactions are efficient and pleasant there seemed very little sense of depth of understanding or caring, possibly born out of pressure of duties to be undertaken. Tasks and duties are carried out but the staff constantly re-prioritise thus leaving many patients half-attended to, drug rounds part-way completed, IVs half set up etc, rather than adopting a methodical approach.

The desire to tackle all tasks is commendable, but just doesn't work. Duties are carried out seemingly without any plan or sense of organisation. There is often only lip service paid to patients e.g., an elderly patient being pleasantly told that a bedpan will be fetched, so the call-bell is cancelled but... the bedpan arrives perhaps an hour or so later because the individual has been distracted by other patients and other issues and failed to return, and the patient is nervous about pressing the call-bell again. The staff will change a soiled bed without comment, but fail to appreciate a patient's sense of humiliation, stress and hopelessness at having to soil the bed when it wasn't necessary.

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Everything is answered in a positive manner but when nothing gets done, repeatedly, then any initial feeling of confidence is completely eroded and patients end up helping each other and feeling they need to look out for each other's needs. It is not good – in fact it feels like survival.

This ward may be called Surgical 4 but the reality is its patients are suffering from a wide range of conditions – from terminal cancer to alcohol related problems, bowel problems to broken limbs!

Anecdote

My arrival at the ward was in the early hours of Wednesday, 30 January, as I was moved from the EAU without notice or any kind of preparation at 2am. In fact I only became aware of the move as my bed was being moved – I had to ask the porters to gather up my belongings (including my walking stick and my glasses) which would otherwise have all been left behind. Local newspapers have reported patients suffering loss of belongings and this is probably one of the ways in which it occurs.

I suffer from Parkinson's Disease/parkinsonism and this means that stress of any kind can trigger tremor, can cause extreme upset through lack of awareness about what is happening and can have a bad effect overall on my ability to cope. At no time, as is repeated elsewhere in this paper, did anyone manage my expectations and explain that, as happened, I might end up being moved at any time from one part of the hospital to the other without notice, or that in fact even the nursing or medical staff would not necessarily have any idea that it is going to happen in advance of it happening.

Something is very wrong here – it should be the medical staff dictating where their patients should go, and the administration making it happen – instead at the PRUH, medical staff have to hunt down their patients and skip from ward to ward to find them and often the first that nurses know about a patient being moved is when the porters arrive to push the bed. I am sure this is partly the reason that I did not get to see a doctor while I was on this ward.

On arrival at Surgical 4 I was spoken to very quickly and quietly (not helpful for someone with parkinsonism who is trying to figure out what is happening at 2a.m. and who is experiencing their first ever unplanned admission to an NHS hospital) and then, pretty much, left alone.

At the best of times I am claustrophobic these days, so being left with curtains pulled round 90% of my bedspace, with no idea of how big an area I was in, how near a doorway was, how close a window might be, no idea where the closest loo might be, all without my glasses on (I am very short-sighted) was very distressing. Not a good introduction to a ward.

Over the coming days I was to find that on Surgical 4 you don't see a doctor every day (although you are apparently supposed to) and your consultant might only come by with his team in tow, at best, twice a week. On the first "grand round" on Friday, 1 March, which was the first time I had spoken with a doctor since admission to Surgical 4, my consultant told me that the CT scan had revealed diverticulitis. He then said how I would be managed, with antibiotics, bowel rest initially and then as I began to feel improved I should begin eating low residue as we had planned.

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The process by which this is put into operation is that at the bedside, the consultant semi-dictates to his team what is meant to happen with the patient, after the round a junior doctor writes up the instructions (including any medication that is required) in the patient notes, and the nursing staff then carry out the instructions that have been written down. In this "chinese whispers" way, then, it is not surprising that what the consultant/patient have agreed is to happen is often not what the nurses find written down. This was carried to such an extreme that both medication and the nature of my eating plan was misunderstood. I am a coeliac and have been since my 20s so I should apparently have had a dietician visit me to write up the gluten-free diet AND discuss the low residue diet to follow the agreed period of bowel rest - special meals can only be written up by the dietician. At no time until discharge did this happen and instead, on Day 1 on Surgical 4 I was repeatedly, impatiently and even angrily being told by HCAs that I was to eat. When I told them that the consultant had said that I would be started on antibiotics, should have a couple of days of bowel rest on IV fluids and then start a low residue diet, I was told that "doctor has not written that". So stressful to be thought uncooperative and be treated harshly as a consequence when it was unnecessary.

On Surgical 4 there was often a sense of hostility between staff and many of the ambulatory/alert patients - probably because staffing levels seemed dangerously low - a member of staff even dismissed a patient with the comment that she had "no time to waste speaking with patients". Patients who ask questions are clearly an irritant here, while drugged/out-of-it patients who can be treated as mere objects are preferred. There was little or no sense of care from the majority of staff here. Mostly due to poor communication and lack of expectation management, it was simple things that caused problems.

One patient, now diagnosed with terminal cancer with only a few months to live, was at the time only comfortable sitting out of bed on a visitor chair. The large "nursing-home" armchairs are very uncomfortable to sit on - putting a lot of pressure on the backs of legs - so this cancer patient really did need the other chair. For two days all was fine, but on the third, the chair was repeatedly removed and despite this lovely patient explaining why she needed the chair, the staff removed it yet again while the patient was in the bathroom. The patient was reduced to tears and went back to bed. Her family were very angry. The patient was in an inner bed in the bay and the visitor chair positioned by the window so absolutely not in anyone's way - the patient even offered to let the nurses choose where to put the chair. To hear this patient being shouted at by a nurse was not pleasant for anyone - what was said was unintelligible as anger made the nurse's accent stronger and her choice of words was puzzling, although her meaning was clear as the offending chair was snatched away. We were all so aware of how reliant we were on this very nurse for our drugs and our safety that this incident completely eroded any confidence we might otherwise have had.

Because of there being new staff every day, it was immensely tiring and worrying for patients to have to highlight discrepancies or explain things over and over again to new staff, shift after shift, because of inadequate paperwork or handover. There was absolutely no sense that any of the nursing staff had any real awareness of individual patients or their medical condition. I actually asked one member of staff if they knew anything about my medical history - the reply I got was "you must speak with doctor"!

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There were of course a few very good examples among the nursing staff here, especially among the qualified night staff, but they were few and far between. No sense of coordination or leadership though and absolutely no sense of teamwork.

I was told that these problems are all due to the impermanence of this ward but management should be able to create a working environment that does not impact on the way in which patients are treated there. For many it is the only ward they will ever experience.

4. Confusion with treatment / scans

nurses say drugs are not accurately written up – conflicting notes

Background

I was told in outpatients by my consultant that I would be admitted for some days while tests were done to assess my condition, that initially I would be on bowel rest with IV fluids and once test results were known, we would agree a plan for future management (including diet). In addition to the known gastro problems of coeliac disease+ parkinson's gut dysmotility + small bowel adhesions causing recurrent partial bowel obstructions, tests revealed that I was experiencing a bout of diverticulitis (my first) and on 1 February my consultant ordered up a course of IV antibiotics as well as fluids.

Anecdote

When the IV antibiotics were being put up, I asked what drugs they were as I am unfamiliar with the world of antibiotics, having taken them rarely throughout my life. To be told impatiently "antibiotics" as an answer is not helpful. I have always had strong and/or unusual reactions to many medications and so take an interest in what I am given. e.g., during 2012 I had been prescribed Ciprofloxacin - a gut antibiotic to help resolve the bacterial overgrowth aspect of my partial bowel obstructions - and this had caused raging hallucinations within an hour of the first dose. I therefore need to know what drugs/doses I am being given to avoid known problems as well as to learn which drugs are OK for me to take in future. Unfortunately, the overworked/overstretched nurse did not have my drug chart to hand as she administered these IV drugs, although it would have been reassuring for there to have been a final bedside check that the drugs being administered were those written up, but I had to be satisfied with being told curtly that I was getting "antibiotics" (no specifics). IV drugs are checked, I understand, by two staff at the time they are collected from wherever they are stored, but I have no evidence of that – at no time did I see more than one member of staff administer drugs either orally or IV.

Other patients had similar experiences – one, told by a consultant that they would be switched from one medication to another (for a pre-existing condition) found herself in an argument at the drug round when she queried an extra tablet among those she was being asked to take. It transpired that the drug chart had not been amended to discontinue the first drug, so the patient would have been doubly-dosed had she not queried the situation. On another occasion a patient had been told by her consultant that she would be started on Drug X, when this was not forthcoming at drug round, she asked the nurse about Drug X – the nurse shrugged her shoulders and said that if the drug wasn't written up then it can't be given. No suggestion of trying to rectify the omission which was only resolved the next time the patient saw the consultant several

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days' later. A third example was of a patient being told by her consultant that she would be started on an excellent new drug but by the time she was discharged some days later she had not received a single dose - apparently the hospital pharmacy did not stock this new drug. I wonder if the consultant ever found out.

No-one ever seemed to know when a patient would be taken for a scan or tests - some requiring fasting or preparation - and it wasn't unusual for someone to be left nil-by-mouth all day, after being told their scan would be in the morning, but they weren't taken for it until evening. Even if there had been mention of a scan during a round, no-one came back to patients to explain when it would happen, how it would happen, what it would be like, who would take them there, if they needed to remain in bed or a chair, if they needed to wear a gown, etc.

The comrades-in-arms spirit again prevailed among patients and we would share information in the hope that our experiences might help others who, newly arrived, were very anxious and unsure of what was happening and worried by the chaos around them.

5. Drug Trolley

medications missed - hygiene

Background

There is only ONE nurse at the drug trolley, so no double checks on the oral medications actually being given to patients, many of whom are totally reliant on the system. IV medications are brought separately and frequently run out. Patients worry that medications are being missed or wrong ones given. Patient drug charts appear inaccurate and even misleading. Nurses frequently ask patients which drugs they are due to take.

Anecdote

Patient drugs are either on the trolley (if issued by the hospital) in a lock-box above a patient's bed (if brought from home) or in a bedside locker (if self-medicating and unable to get to the lockbox). Night after night/day after day nurses would go to the lock boxes for medication that wasn't there - notes clearly didn't show which drugs were to be issued from the trolley or which from the patient's own supply. Endless toing and froing by the nurse trying to complete the drug round as quickly as possible, while completely ignoring/overruling attempts by patients to explain their particular drug regime.

IVs are left run-out for many hours despite staff being reminded that the next one is due. IVs, including IV antibiotics are managed separately from the drug trolley and it is not uncommon, especially when nurses aren't methodical, for antibiotics to be given long after they are due.

On more than one occasion the nurse giving out the oral medications wasn't wearing gloves and didn't wash her hands before fingering the tablets/capsules into the plastic drug pots as she went round the ward from patient to patient (some of whom she had to help take their meds and did so by putting the tablets by hand into their mouths). Not something one could criticise on the spot as, again, one is completely reliant on the staff

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for any kind of intervention/support and alienating them is not a good idea, especially when confined to bed.

To be effective, medication has to be correct as to dose and generic type and given regularly/on time. Luckily for me I had permission to self-medicate most of my regular drugs and this I did. I was however reliant on staff for all IV fluids/drugs, and oral medications for osteoporosis and heart rhythm (ectopic storming). To miss a dose of either of these oral drugs is, probably, not a major problem although Bisoprolol also eases my parkinson's internal tremor, thus reducing the nausea it otherwise causes. The IV fluids, IV paracetamol and IV antibiotics were, however, vital.

Drips were allowed to run dry for hours on end (I would remind someone but after doing so a couple of times I just felt I was being a nuisance). IV paracetamol was forgotten about on several occasions, nurses offered me tablets instead and were clearly irritated when my system regurgitated them, so they had to continue finding IV paracetamol from around the hospital for me.

As for the antibiotics, I could perceive of no precise schedule with respect to their administration. Because only a qualified nurse is permitted to administer IV drugs and because, especially at night, there is only one qualified nurse for the entire ward, he/she clearly has to pick priorities. In their world, then, my antibiotics perhaps weren't a priority. For me, my priority is always to ensure that I am medicated correctly and on time so that my doctor's plan has the best chance of working and I can be out of hospital and feeling well again as soon as possible. I think I should be entitled to get my medicine when it is due. I was lucky in that after a few days I was feeling well enough to press a call button or remind staff that my medications were still pending.

Many other patients who were elderly, very unwell indeed, and/or perhaps even confused, were not able to be so interactive and were totally reliant on their drug regime being managed well on their behalf. If mine wasn't, despite my vigilance, then I am sure theirs weren't. If I hadn't had my own parkinson's medication I can only fear what might have happened to me.

A patient's drug chart must be kept up to date and must be accurate. At least that is what I thought. I was, then, very surprised when after a week I was asked by one of the qualified nurses when it was I had been started on antibiotics. When I said that it was after the grand round on Friday 1 February, the nurse nodded and said "I thought so". I queried what the confusion was and she showed me my drug chart which showed that the antibiotics were first given on the afternoon of Tuesday 29 January... BEFORE I WAS EVEN ADMITTED!!! I have no idea why someone would have backdated these drugs. As my consultant prescribed an 8-day course of antibiotics on 1 February I just have to hope that I did receive the full course. I have no way of knowing if I did.

6. Anti-thrombosis prevention

patients randomly treated

Background

Clexane is a drug to be administered by injection to all those who have undergone surgery or who spend their days in bed – whether through age or disability. Anti-thrombosis stockings are to be worn by all surgical patients and those who spend their days in bed.

Anecdote

There is a high degree of randomness over who is injected daily with Clexane and, for that matter, who gets to wear anti-thrombosis stockings. On Surgical 4, I never received this injection, despite being in/on my bed all day with permanent IVs and spending some days completely immobile and catheterised, but I was required to wear the stockings.

Other patients who were completely ambulatory and who were not undergoing surgery received the injection and wore the stockings, while several other patients who were bed-bound received neither injection nor benefit of stockings.

After transfer to Medical 6 the injection did put in an appearance but only for the last days of my stay, by which time I was more mobile than I had been. I continued to wear the stockings as I remained mostly on my bed – no other patients in my bay, some of whom were equally as immobile, were given either the injection or stockings to wear.

7. Paperwork

missing - inaccurate

Background

My drug chart contained inaccuracies, other patient charts contained inaccuracies, "vitals" were misrecorded and no individual variations noted. Labels for lab work were inaccurate. Patient records were found in a chair that had been left at a collection point. Wristbands missing or wrong.

Anecdote

Accurate hospital paperwork, even in this technological 21st century, remains fundamental - unlike computer records which can be altered very easily, any corrections or amendments to paper records are readily visible, which is why paper records are vital as evidence of what has occurred. It is concerning when the paperwork is evidently out of step with reality. Such was the case when a nurse asked me when I had been started on IV antibiotics. It had been on Friday, 1 February after the grand round and I had seen my gastroenterologist for the first time as an inpatient, after initial blood tests and CT had revealed diverticulitis. She then showed me my drug chart which had the drugs written up as from 29 January. As I was admitted to hospital via A&E on the afternoon/evening of 29 January and only arrived on a ward, with my first drug chart, in

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the early hours of 30 January, this was clearly a completely incorrect record. If this was incorrect, what else is? Why is there no document tracking or management system from which basic accurate paperwork could be printed to form ward records and which would have data entry timelocked/encoded?

On another occasion one of the visitors to the bay I was in, went to fetch a wheelchair so that their relative, the patient, could be wheeled outside with the family to get some fresh air (or maybe to the restaurant to get something to eat). When the family member returned with a chair, it was realised that there were three sets of patient notes tucked into the slot in the back of the chair. It then took the family of this patient nearly 15 minutes to get the attention of a member of staff and to hand over the notes.

A patient's date of birth is a double-check (as well as the name) that the right person is being treated. One patient was having regular blood tests. Each day for nearly a week the phlebotomist would look at the paperwork, check the patient's name and check her date of birth on the labels that would be used for the bloodwork. Each day the date of birth was different - the patient, in her 40s, was, variously, a newborn, in her 50s and in her 80s! It became a standing joke to see how old she was each day. The patient did not have a common name so quite why there was this birth date discrepancy is a mystery.

Wristbands are handwritten at some point - precisely when seems to vary from patient to patient - and many are unreadable with dates of birth, names and, in my case, drug sensitivities mis-stated.

Blood pressure and temperature charts are very random. It would seem that unless one is extremely unwell with temperatures or BP far exceeding normal parameters, no-one is bothered. It was very worrying to be told that everything is normal when a temperature reading is regularly more than 2 degrees above a personal "normal" - especially as I knew I was running a fever, looked permanently flushed, had a headache (rare for me) and spent my time desperately trying to cool down by lying in the cold blast of a fan 24hrs a day, none of which happens when I am well. Other patients, familiar with their normal-for-them blood pressure readings, were very concerned when readings far in excess (or far below) their "normal" were taken. The worry was compounded when one patient read her chart and could see that the nurses were not putting the readings anywhere close to the numbers on the equipment. The charts were, essentially, being made up.

Also being fabricated were the "comfort scores" and patient reports - from time to time HCAs would wander past, pick up the bed-folder and write in it. We all wondered what was being written, so one young, ambulatory, patient decided to read her folder and was surprised to find that she had been incontinent several times already that day and had had to have her bed changed each time! Who knows what other fictions were being written to complete this paperwork, just for the sake of completing it and without any questions being asked of the patient.

8. Cleaning and hygiene

very random standards esp. on Surgical 4

Background

Lackadaisical cleaning. Tables being wiped with cloth rinsed in floor-mop bucket immediately after floor-mop had been rinsed in it. Fluff and hairs from other patients in showers. Lavatories smelling bad with no means of freshening the air. Staff rarely using the hand-hygiene products attached to each bed. Fluff and dust on and under beds. Patient bedside cupboards containing leftover tissues and other items.

Anecdote

Cleanliness and hygiene are, one would imagine, absolutely top priority in all parts of a hospital. Surprising then to find that staff employed for cleaning also double-up as food hostesses (although you can tell the role-change by the hairnet donned by some when serving food) and that for some, cleaning involved randomly sweeping a mop or duster over a surface/floor without ever moving any object. The quality of staff is wide-ranging. From the worst, a cleaner who by her manner and physical movement should probably not be working (sniffing and limping as she moved incredibly slowly round a room, dipping the bed-table cleaning cloth in the bucket in which she had just rinsed the floor mop) to an energetic young woman who lifted/moved/dusted/wiped/cleaned everything to a good standard while being pleasant and polite and efficient as she worked.

Some of the guys employed in this service don't appear to speak or understand English and have a curious manner about them - perhaps they are not used to being around women, particularly women of all ages in various stages of dress/undress. Several patients commented on being watched by these guys - it was unnerving to say the least. The wards and how they are run clearly have a direct impact on the auxiliary staff members associated with them. Sadly the overflow surgical ward where I found myself for the first week, by its temporary nature, had the poorest quality cleaners/auxiliary staff - shocking if one actually had had to have surgery and recover there.

Each bed has a bottle of hand-steriliser hanging from it but they were rarely used. A few staff do clearly take hygiene seriously, the majority however, including nursing staff, appear not to be diligent at all in this respect.

9. Food/dietician/special meals

no menus - no gluten free - no balanced nutrition

Background

Scant attention paid to the needs of special diets or to adequate diet or food consumption. No patient menus. Available food choice poor. Hot breakfast unavailable. Hot (rather than tepid) drinks unheard of. Water jugs rinsed and refilled without being cleaned. Water glasses (plastic) never looking clean.

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Anecdote

I have been a coeliac since diagnosis in my 20s and this fact is in my medical notes. One of the rules of being admitted to the PRUH, so I was told, is that if you require a special diet then a dietician must see you before special meals can be ordered. My admission was due to recurrent partial bowel obstruction so, in addition to a gluten free diet, once I was permitted to try eating again, my diet was to be low residue/light. As soon as I wanted to start trying to eat, I asked someone if it was possible to get a gluten free meal and was categorically told that it wasn't, unless a dietician had written it up. I was offered a yoghurt. I was offered yoghurt for the next three meals. My system wasn't particularly well and I wasn't particularly hungry, but food is as important as medicine for a good return to health and when I persisted in asking for gluten free options I was then completely ignored and found myself without even yoghurt for several mealtimes. As luck would have it, a woman came into the bay where I was and was clearly looking for something. Being a helpful sort, I asked her what she was looking for. She turned out to be a supervisor of Food Hostesses and was looking for patient menus. The two other alert patients in our four-bed bay looked at me and I at them and, with one voice, said "what patient menus". Apparently each patient is meant to be provided with a menu from which their daily selections can be made. There were no such menus visible anywhere. Seizing on this serendipity I asked if there was such a thing as a gluten free menu and was delighted to be brought one within a matter of moments. BUT to find gluten free options that were also low residue/light then meant that there were precisely two items on the menu that would work for me, both fish. No sooner had I found a solution to ordering food my time in the Surgical ward was over and I was moved to Medical 6 – taking my precious GF menu with me. The Hostesses on the new ward were fantastic, nothing was too much trouble, and I soon found myself with scrambled egg for breakfast and each of the two appropriate GF meals being ordered for me for lunch and for dinner. The stark contrast between sarcastic comments like "I'd like to lie in bed all day and be waited on like some people" with no food on offer from a Food Hostess on Surgical 4 vs pleasant and competent staff going out of their way to make sure the right food was hot and on time on Medical 6 was simply staggering. Feeling as rotten as I did, I was very relieved to finally be able to try and eat and get my system working again.

I never did get to see a dietician.

10. Staffing

levels are way too low for safety - patients are/feel vulnerable

Background

At night, a fully occupied ward, with 18 of its patients doubly incontinent and bedridden, had only one qualified nurse and one HCA on duty. Call bells were frequently ignored, or cancelled and patient requests not attended to. Many patients appeared distressed and in pain. During the day, despite a few more staff, the volume of work to be done clearly exceeds the numbers of hands available to do it.

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Anecdote

Nurses and the majority of HCAs seemed to be trying to juggle half a dozen patients/requests/issues at once. As a consequence it was not uncommon for call-bells to be ignored or to be acknowledged but the staff member returning to whatever it was they were doing before being summoned, without actually attending to the patient.

During the day, no-one doubts that there is a constant barrage of "summoning" and at every stage priorities have to be picked. As a direct consequence of this failure to respond, though, many patients who are bedridden and completely reliant on the nursing staff can end up having accidents in bed when bedpans are not forthcoming in time. The staff are very good at accepting incontinence and beds are usually changed without much complaint, but no-one appears to recognise that having an accident is horribly humiliating. Being left on a soiled inco-pad is disgusting, unhygienic and again .. humiliating. If patients are so old, infirm and unable to communicate and don't have family members or friends to look out for their needs, then they are frequently overlooked. For them, like many others, their only hope is that the doctors on their rounds can work out that something is amiss and care enough to try and manage the situation, in spite of the low numbers of nursing staff available.

For patients who are ambulatory it remains problematic if you need help. Do you ring the call-bell and hope that whoever arrives isn't impatient or dismissive of your needs. How often should you remind the staff of medication still waiting after a drugs round or drips that need to be changed? It is all very difficult and it shouldn't be. You are very much on your own trying to make sure that diet/drugs/treatment is carried out in line with what your doctor has told you will happen. This is very wrong.

One night nurse on Medical 6 was light years better, nicer, more efficient and coping than all the others. She trained many years ago, was unfailingly pleasant and polite to all patients (some of whom, being treated for alcohol-related conditions were aggressive and rude), worked her way round the ward methodically ensuring that each patient had their "moment" of her full attention, were comfortable and needed nothing more from her. If she was called away to answer a call-bell then she would take care of that issue and then return to where she had been to complete dealing with patients in turn. She coped with an incredibly difficult and combative patient in a remarkably smooth way and ensured that they were moved from the bay they were in so that the other patients could feel less vulnerable. It was a blessed relief when we saw that XXX was on duty! It was she who ensured that drips were swapped out, even at 2am, who was the only one to consistently practice good hand hygiene and generally gave patients confidence and a sense of genuine caring. Just knowing that she was on duty overnight brought a huge sense of relief that all would be well.

This nurse was the only one I recall genuinely asking patients how they were feeling (as she did their blood pressure/temperature) and actually listening and discussing their replies with them.

Otherwise it just seemed that levels of nursing staff were dangerously low with those on duty having to rush hither and thither, immensely stressed and never having a moment to catch their thoughts. By stark contrast, however, there were a few HCAs who had perfected the art of wandering languidly from bay to bay, randomly picking up paperwork and looking at it, idly straightening a blanket and doing as little as possible

while their co-workers were rushing from pillar to post trying to get everything done. Without supervision some people are just lazy and without good staffing levels the lazy can get away with doing very little, because those who are in charge and take their duties seriously are running flat out just to get tasks done and have little to no time left to manage or supervise.

Being taken for a scan is a scary process if you are bed-bound. There is no staff available to act as a chaperone so you are just left by the porters in a corridor or waiting area that is not just for inpatients but where members of the public and their relatives are also waiting. Being observed by strangers when feeling very ill and in bed, covered only with a sheet or blanket, makes one feel very vulnerable indeed when there is no one to help or supervise the situation. Relying on the public's good nature/behaviour is risky at best.

11. Conflicting Diagnosis/Information

contradictions - uncertainty

Background

A patient being told they had cancer when no diagnosis had been arrived at. Another patient being told that a scan revealed nothing when in fact a blockage was clearly visible. Relatives being told different information (in front of patients) than patients themselves had been told previously.

Anecdote

Patients being given conflicting information seemed to occur with quite some frequency. Patients rely on what they are told by a doctor as being gospel. Patients don't differentiate between a junior doctor, a medical student or the consultant. Anyone who announces themselves at a patient's bedside as "I am one of the medical doctors" or "I am one of the surgical doctors" is believed to be in full possession of all facts and to be bringing the latest news about diagnosis, treatment and prognosis. Many patients don't even seem to know which consultant is responsible for them or any of the doctor's names.

If, for example, a helpful junior doctor doing a daily round by him/herself, wishes to cover all bases and in the course of describing what has been discovered thus far, tells a patient that they shouldn't rule out a cancer diagnosis, then all that patient hears is "cancer". That the junior doctor has continued on to explain the various other possibilities often doesn't register. As soon as the doctor, of whatever seniority, leaves the bedside, the patient is on their mobile phone to relay the news to their nearest and dearest. The same news, however inaccurately, is repeated to family/friends/visitors. If a second doctor appears and is questioned about the cancer diagnosis or treatment, perhaps by a very concerned member of the family, it may come as a surprise to them to hear that second doctor say that there has been no such diagnosis made but that there is clearly something to be investigated further. It all can get completely out of hand if a third doctor arrives, pooh-poohs what the previous two have said with a "we don't even have the radiologist's report yet... who told you you had cancer" statement. At this point no medical professional seems to know what is happening, the patient and

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their friends/family are completely confused and all because no-one has stopped to consider when and how and by whom it is best to tell a patient about what may or may not be a grave cause of symptoms that have brought them in to hospital. When it all goes to worms (or Chinese Whispers) then confidence in the system is lost. With this very real example I am using, it appeared that neither Doctor 1 nor Doctor 2 made any note of what they had said, so that Doctor 3 ended up looking foolish, despite their seniority and had to hear about the comedy of errors from the patient and her family.

There were several instances of patients being told conflicting information - some, a fault of the way in which the information was relayed to them by junior doctors, others by doctors not ensuring that patients really understand what they have been told. There does need to be a greater care taken when bad or potentially grave news is conveyed.

As for me, after not seeing a doctor after EAU (Tuesday overnight) until my consultant's round on the Friday, once I finally arrived on the Medical ward I was lucky enough to have an excellent team of doctors attending to me who all spoke with me at the appropriate level and were happy enough to translate from jargon to plain English when I said I didn't understand something. It probably also helps that because of my parkinson's, I regard doctors as a vital part of my "home team" who are there to help me maintain optimum health and mobility for as long as possible. I am used to being kept informed and completely in the loop as to what is happening. Fortunately for me, the doctors I encountered on Medical 6, all part of my consultant's firm, were prepared to keep me fully updated at all times.

12. Pharmacist

an unnecessarily complicated process

Background

Lack of availability of (some) medication is not communicated well between pharmacy-doctors-patient. Nurses shrugging shoulders when there appear to be medication discrepancies causes major concern/worry. Patients don't understand the role of pharmacist.

Anecdote

I didn't encounter a pharmacist until I arrived on the Medical ward. The pharmacist in question was pleasant, competent and efficient and I was lucky in that my needs were fully met on that ward.

Not everyone was so lucky.

Not all medications prescribed by doctors are always available on a ward and sometimes not even in the hospital. When new meds are not available and there is going to be a delay, there were instances of great anxiety for some patients who were expecting the new medication for a particular symptom/condition, but when it wasn't available didn't understand why the previous medication for the same symptom/condition couldn't be continued until such time as the new one was available and no-one explained this to them.

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Most patients, if they have been taking medication to counter, let's say, high blood pressure will be extremely anxious if they find themselves without any medication to counter high blood pressure if a new drug is not available and the old one no longer "written up". It may actually be a problem that the doctors need to address or it may be medically fine for someone not to have any medication for those symptoms. This needs to be explained to the patient. Having a nurse shrug shoulders and say "its not written so you don't have" is unhelpful and leaves people genuinely worried that their condition might worsen suddenly. Pharmacists have an easy familiarity with drugs and perhaps should be involved more in helping patients understand the regimes they are put on in hospital.

Explanations about changing a drug regime need to be made by doctors, for it is only doctors that most patients completely trust and rely on. If a junior doctor comes to write up a new medication following a ward round and finds out that the drug is not available either to the ward or in the hospital, then that doctor should come and let the patient know what is happening, which will be one of three things (a) it is OK to go without any medication for the symptom/condition until the new drug is available (b) their old drug will be continued until they start the new medication in hospital or (c) the new drug won't be available at all while they are an in-patient so they will be continuing on their old medication until they return home and their GP can prescribe the new drug.

Without this reassurance, someone who has been taking their "tiny white pill" every night for years is going to suffer unnecessary stress not only from not being given their regular medication but also from having to have a difficult conversation with an over-stretched/over-stressed single nurse attempting to complete a drug round when he/she really hasn't the time or the desire to enter into discussions about what should or should not be written in a drug chart.

Many patients do not understand the role/qualifications of a pharmacist or how important a function they fulfil. As I was admitted from outpatients I had only my handbag-supply of parkinson's medication with me, so was reliant on the pharmacist supplying what drugs I routinely take and this all worked well.

13. Meals - Food is also medicine

failure to eat unreported/unnoticed

Background

No patient menus. No supervision of food choices or a sense that people unable to make good food choices through age, infirmity or disability, are helped to do so. No overview of patient nutrition. An elderly patient was never fed more than a few spoons due to time pressure and became very undernourished.

Anecdote

I am sure that wards differ in their day to day process according to the medical conditions they treat, but fundamentals of cleanliness, hygiene, nutrition and care should be uniform throughout . All patients who are supposed to be eating should eat and

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should be encouraged to eat and even helped to eat if that is what it takes to ensure good nutrition.

I can only comment on the two wards I was in, one Surgical, the other Medical. Forget for a moment that I didn't get any proper food on the Surgical Ward (well, probably shouldn't forget really - but my system was so below par that it didn't want food at the time!) and think of those who through a combination of ill health and/or age were no longer in a position to eat by themselves or choose their food. Think also of those who don't normally eat a balanced diet but who need to be encouraged to eat well to regain health and strength.

There are no patient menus so the food-ordering process, on both wards I was on, was done by an HCA coming to each patient in turn and, like a waiter in a bistro, rattling off the daily offerings. Many times the older or deaf patient had no real understanding of what was occurring and the HCA would then make choices for them, sometimes still trying to get their input, other times not bothering. If a main chosen is pasta the sides might be boiled potatoes, mashed potatoes, mixed vegetables (virtually all carbs and no protein). No cooked food at breakfast - no toast - just bread and jam/marmalade or cold cereals (more carbs). Sandwiches and salads are available for lunch and dinner. Hot drinks are lukewarm drinks.

If someone were to choose/have chosen for them, cornflakes for breakfast, pasta and mashed potato for lunch and dinner, with a yoghurt as "dessert", no one raises an eyebrow. If that person isn't fed more than a couple of spoons of any meal (staff have no time to feed an entire meal to a patient, especially one eating slowly) again there is no one to raise concern. One elderly patient I saw this happen to was also put down as "vomiting" when in fact she was simply regurgitating food which had been fed to her too quickly in a few giant mouthfuls that would make anyone feel nauseous. This same lady was also seen to be obstructive and unwilling to eat when all she needed was time to try and eat. Full plates were regularly removed by hostesses at the end of meal service and no note of the fact that a patient hadn't eaten was recorded anywhere. No one seems to realise that a good diet is fundamental to maintaining and regaining health.

I have spoken elsewhere of how I managed to get appropriate-for-me food. I was lucky maybe but I was also prepared to risk being considered "difficult", so long as it meant I could start to eat appropriately and get home as soon as possible!

There were many elderly patients who had their food left in front of them. It wasn't food that they had necessarily ordered, it wasn't food that they necessarily wanted or liked, it wasn't food that they ate. Some occasionally were spoon-fed, but the horribly loaded spoonfuls would be enough to make a healthy person gag so it wasn't surprising that many regurgitated food or objected to eating. At present I eat very slowly because I feel nauseous and want to avoid regurgitation. I know that a small amount, taken slowly, will stay down. I am sure this is the same for anyone feeling nauseous who knows they have to eat. An elderly lady in my bay was regularly regurgitating her food because (a) she was being given too much too quickly (b) she wasn't sat at the optimum angle for food go to down (c) the food being fed to her was not low residue. Once she had regurgitated her meal, which was loudly reported as "vomiting", she wasn't given an opportunity to drink Ensure, wasn't put on even a basic IV for fluids (she didn't drink much either) and after a week, when she was visibly weaker and less able to move or coordinate her movements her doctors expressed puzzlement. No-one said anything

about her not getting enough to eat. She had no relatives visiting and the couple of friends who came were themselves puzzled at her decline as, prior to admission following a fall, she had been teaching piano lessons, feeding herself and had a very healthy appetite.

It was very sad to see this lady decline and although the other three of us in the bay with her tried to tell nurses or visitors that she needed more help with eating, it was clear that our comments weren't welcomed and we were seen as interfering. It didn't help that this lady was deaf and needed two hearing aids (which only appeared after a few days) but it was curious that she was able to have lucid and good conversations with the visiting padre and her visitors, but as soon as the nurses or physios appeared, she seemed to completely withdraw from them.

14. Equipment/supplies

only one bp machine for entire ward - equipment cannibalised/out of order - tape that doesn't stick

Background

Monitoring a patient's vital signs (BP, temperature, O2 saturation) is a routine but essential way of spotting alterations/variations in health. I have already spoken of the lackadaisical way in which this was attended to in some instances, but couple that approach to equipment not working and a simple process becomes a comedy of errors.

Anecdote

One ward appeared to have two BP machines. The first had a cuff that no longer Velcro-ed shut so it was either left to pop open OR the person taking the reading attempted to hold it shut. The second kept switching off/making random readings (or at least that is what we were told was happening) – that the patient in question had a very irregular pulse never seemed to bother anyone, so long as the machine generated a result. A manual process, adopted by some, particularly at night, often produced very different readings.

The O2 saturation readers were both broken – one did not generate any readings, the other had to be held on a patient's finger as the spring would not close any more.

Thermometers used are electronic oral probes and are held in a patient's mouth by the person taking the temperature. The probe is often not under the tongue or moves from under the tongue during reading because the attention of the temperature-taker has wandered and their hand is moving. Patients have two choices, try to stay attached to the thermometer (and risk being reprimanded for moving) or just let the thermometer misread.

Any suggestion that the readings from BP/SAT/Thermometer might be unreliable is dismissed. Rarely was anyone actually asked how they were feeling – a casual and general "so how are we today" when a nurse first enters a bay is not the same as someone asking "how are you feeling now" when their observations are being taken. Swap out many of the nursing staff for supermarket workers and there would be scant difference between many patient/nurse interactions.

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IV access needles are stuck to hand/arm but come unstuck. To remedy this, tape is applied but the plastic 3M tape that is used does not stick to skin for more than a few minutes and has to be retaped over - apparently 3m plastic tape is cheaper but, probably in the final analysis, so much of it is used to do the job of a small piece of micropore or other good quality tape, that any cost savings are completely lost. It also looks and feels disgusting to have layers of curling and unsticking tape attached to one's hand or arm.

I need to wear light pads due to mild parkinson's bladder incontinence. These are worn inside regular underwear. Surgical 4 had small pads and one of the nurses obtained a pair of paper pants for me. Medical 6 had no small pads, only giant ones, and no disposable underwear that would fit me. Each ward, it seems, has its own limited range of supplies needed for what is considered its core group of conditions - anything else is unavailable unless someone is prepared to go and get it from another ward. There is no common range of basics (underwear, pads) available in all areas of the hospital.

15. Language Problems

ignorance of colloquial English - accent barriers - tone - volume - technical language

Background

While the mostly Filipino HCAs and some nursing staff (esp on the Surgical ward) are speedy and without question unfailingly polite, their inability to communicate clearly with many patients, who have difficulty understanding accents dissimilar to their own, leads to completely unnecessary feelings among nurses that patients are refusing to "cooperate" when the patient in question has either not heard (being old and deaf and the staff member being unwilling or unable to raise their voice or pitch it clearly), misunderstood (the language used is not familiar or customary) or what has been said was couched in technical language and just not understood. Many of the non-British staff are, by their upbringing, quietly spoken and have probably never been told that they are hard to understand because they speak quietly. I have been lucky enough to work with people all over the world for most of my working life and have dabbled in learning several languages, but when I was feeling particularly unwell (and perhaps because my Parkinson's auditory dysfunction was sneaking in when my medication levels were lowering) even I found some people difficult to understand.

Speaking very fast and in a quiet voice to patients who are, for the most part, in a very unfamiliar and scary environment, ignoring their requests for something to be said again and not replying to questions asked, really does not create a pleasant environment. It is also very unhelpful when someone plucks up the nerve to ring the call bell, has it answered after maybe 20mins in a polite manner, but then does not have their request followed up on, sometimes for hours on end.

Anecdote

One example was my IV fluids drip, it ran out soon after the nightshift came on. I notified a member of staff who was in the bay at the time and was told it would be attended to. Two hours later later the drug round was under way and I again mentioned my empty drip and again was told that the replacement bag would be brought shortly

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with the antibiotic drip I also needed. Another two hours passed and at lights out I again mentioned that the drip hadn't been replaced and was told that someone had just gone to get the antibiotic IV from another ward and it and the fluids bag would be put up at the same time. I went to sleep and due to pain/discomfort, woke several times during the night and each time could see the IV fluids bag had still not been replaced. There was no sign of an antibiotic drip. Blood had flowed back into the tubing and seemed to be coagulating (OK so it is in a vacuum and not exposed to air but it still appeared horrible). At one point I got up and went to the bathroom and fortunately for me, as I returned to my bay, the two members of staff on duty (one nurse, one HCA) appeared and when I reminded them about needing the IV and antibiotics, they admitted they had forgotten as they had been busy elsewhere. I finally I did get my antibiotics (7hrs late) and new IV fluids, also hours late but only because I had persisted.

I mentioned this delay to one of the junior doctors the next day. He looked at my chart and, according to the chart, all drugs had been administered on time over the previous 24hrs when I, and those in my bay who corroborated my story, knew very well that they hadn't. Yet another example of fictional record-keeping.

Another example where lack of fluency in English caused problems occurred when I experienced a curious episode of immobility and somnolence.

I am known to be unable to metabolise anaesthetics and sedation very well. Throughout my life when I have been sedated or anaesthetised I have had a more than normally somnolent response. In Spring 2006 my parkinsonism appeared after/was triggered by a general anaesthetic and initially manifested in an odd form of extended sleep paralysis and somnolence with inability to initiate movement. This happened again in December 2006 when my gallbladder was removed, resulting in a worsening of my parkinsonian symptoms.

While an inpatient at the PRUH, completely unexpectedly, a similar episode of immobility+somnolence occurred without any sedative or anaesthetic trigger, but just after I became totally exhausted from taking a shower (with drip stand, surgical stockings etc etc). Returning to my bed, I passed out from the extreme exertion and when I woke several hours later I couldn't remember how to move...my limbs felt encased in foam and there was a complete disconnect between my brain and my body.

Luckily for me, the relatives of one of the other patients in the bay heard me trying to call out for help. I told her that, however odd it might sound, I couldn't remember how to move and was terrified of what had happened as such a thing had only ever previously happened after sedation or anaesthesia. The stranger went to tell nursing staff of my problem. The response was shocking to say the least. Someone came and looked at me, said "so what is wrong" and when, almost in tears, I said I couldn't remember how to move just said "oh" and walked away without another word.

Some time later they reappeared and said "so you move now" and I replied that I couldn't remember how to. My head remained turned to one side and my limbs just wouldn't move however much I tried to convince them to.

After a few more hours I knew I needed to urinate, so when one of my "bay-mates" came over to see how I was I asked if they would get help. At this point they were as

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shocked and surprised as I was that no-one seemed to care that I had been lying in one position, immobile, for nearly 8hrs.

My bladder was scanned to see if it was full, it was, so I was catheterised and immediately filled nearly two bags! The nightmare of being immobile/frozen without any sense of anyone caring about me continued for many hours. As I am claustrophobic, the feeling of being trapped inside my body, with no-one even briefly stopping by to check on me, was just terrifying. From the position I was in I could not see anything other than a curtain.

The foam encasing effect takes days to wear off after anaesthetic, but fortunately the non-drug-induced episode at the PRUH this time saw my system begin to remember how to make some tiny movements after several more hours. From the outset I wanted a neurologist to see me as none had ever been present at the onset of one of these episodes – a couple of on-call doctors did visit me at different times, one even tried and failed to get any reflex reactions, but no-one seemed to be at all concerned and no neurologist appeared. I suppose as I was breathing and could talk, it did not matter to anyone else that I was unable to remember how to move and in considerable limb pain in addition to the pains of partial bowel obstructions and diverticulitis for which I had been admitted. From being immobile and "foamy" my body goes through a phase where the foam seems to creep back down my limbs as some sensation returns, then I feel extremely heavy – as if the weight of the world is on me – and finally major limb pains and stiffness. It is like an extreme and sudden attack of late-stage parkinson's and very scary to experience as I never know if I will recover, I just have to hope I will.

It took, in total, about three days for my body to fully recover former mobility and it was at this point that a neurologist came to see me. Naturally he found nothing noteworthy as by then all but my left thigh muscle had returned to previous levels of functionality. The relief on seeing this specialist, though, was overwhelming and I am sure if he is asked, he will remember how unusually effusively I welcomed his arrival.

16. Lack of Information

failure to manage expectations

Background

Patients admitted other than as a planned admission are left completely uninformed about the process and what to expect. In Outpatients I was told by the consultant that I would be admitted to a Medical ward after, perhaps, a few hours on an interim ward. I waited 4hrs in A&E, then spent several hours in EAU (aka "the hellhole") then was moved to Surgical 4 and more than a week after admission finally moved to a Medical ward.

I haven't had a planned admission to an NHS hospital for more than 30years so I have no knowledge of how it is managed these days. I would, however, hope that there are leaflets explaining what to expect not only in relation to a specific procedure but also in relation to how wards are managed, when you can expect to see your doctor, what the daily routine is, what you should bring in with you etc etc. All designed to reassure and help someone, unfamiliar with hospitals and their process, to understand how things will

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happen. None of the patients I shared bays with had been planned admissions so I have no idea if this is the case or not.

What I can say for certain is that there is absolutely no expectation management for patients admitted through A&E, i.e. unplanned admissions. There is no information about the hospital, its wards, how wards are run, when you will see a doctor, how food is ordered, what can be expected day-to-day, where you can purchase necessary toiletries, how you can contact friends/family (if you don't have a mobile phone).

It is a scary and unfamiliar situation. Not only are you unwell but you are completely alone with no-one letting you know what is happening to you or what is happening around you. Mostly you don't care because you do feel so unwell but when alert you are, in the back of your mind, wondering what is happening, going to happen, when it will happen and there is just no-one to reassure you or explain.

No process, no procedure is evident. The system is happily running itself (or rather not so happily, judging by many of the conversations I had with staff during my stay) but the individuals for whom this system is designed, the patients, are often left stranded and uninformed. It is not at all pleasant and makes one feel extremely vulnerable to find oneself and one's bed being pushed out of the ward by two porters "for a scan" with no-one telling you what kind of scan or why it is being done, then being left flat on one's back in bed, catheterised and on a drip, in a public corridor, with no chaperone and completely relying on a rapidly disappearing porter who, as he leaves calls over his shoulder "we'll let them know you are here".

17. Discharge

Confusing process – Discharge Suite - Followup

Background

When a patient is ready to go home the consultant or doctor will tell them so during a round, will usually say when, by whom and how they will be followed up and then the doctor moves on to the next patient. No-one actually then lets the patient know how soon they can leave the building or what the discharge process will be or how long it might take. No management of expectations again.

Anecdote

As soon as a patient is told they can go home and if they are not bed-ridden, so not reliant on an ambulance transfer, they usually want to phone a friend or relative who then wants to know what time to come and collect them. No-one can answer this.

A patient in my bay was diagnosed with terminal cancer and not long to live, so when she was told she could leave by her doctors, just wanted to get home to her family, but ended up in tears because no-one would tell her what time she should tell her family to come and get her. When she asked, more than once, she was simply told that she would have to wait for her take-home drugs to be available. She lived close to the hospital so asked if she might leave and have a relative come in later to collect the drugs. The answer was no. In the end, she called her family who all came at visiting time and finally, when her drugs appeared, they left together – hours after she had

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initially been told she could go home. For a family with a loved one given only a couple of months to live, this was an unnecessarily negative and uncaring experience.

When it was my turn to be discharged, I didn't expect any drugs to take home as I have full supplies at home and, as my car was still in the car park, I planned on driving myself home. I therefore thought it would be simple. All I needed help with was getting my bag to the car. Instead I was told that I had to go to the "Discharge Suite" to wait for my drugs to take home – when I said I did not need any drugs to take home, I was told that they had been ordered from the pharmacy and I had to wait for them and then be discharged from the hospital. When I asked about the date of my followup appointment with my consultant, which he had said was to be within two weeks, I was told that "doctors do that" but no mention of how or when this would be done or how the information would be relayed to me. I was then taken to the Discharge Lounge.

The **Discharge Lounge** is an oddly-shaped room reminiscent of a nursing home lounge – chairs lining the walls, with no gaps between them, occupied mostly by people sitting vacant and staring, many looking as if they should be on their way in to hospital, rather than leaving it. The room echoes to the sounds of coughing and spitting and smells awful.

By contrast, the staff and the escorts belonging to the lounge that I met that day, however, had a cheery, positive and upbeat attitude and dealt with me efficiently and helpfully. After about an hour's wait I was brought my drugs and "checked out" (another patient from my bay leaving at the same time and her partner helped me with my bag).

When I got home, among my answerphone messages was one from the ward telling me that some of my take-home drugs had been brought to the ward so would I please come back and collect them. I called back and confirmed that it was OK for me to collect them in a day or two when I felt better. When I did return to the ward, I was told that take-home drugs are never brought to the ward, I insisted that I had been asked to come and collect them so an initial search was made but nothing was found. I was just being told again that I was wrong and there were no drugs when the sister on duty came past the desk to see why I was standing there. The staff explained that I was insisting that there were drugs to be collected when there clearly weren't. The sister, however, immediately confirmed that she had seen a bag with my name on it exactly where I had been told my drugs would be stored, and sent the staff member off to look again. They were there alright.

So... confusion and muddle on the ward right to the end – if the sister had not been aware of my medication on the ward, I would have ended up majorly trembling and upset from the stress of a negative encounter, the staff member I dealt with would have persisted in believing I was being difficult and making things up (such was their attitude) and who knows what would have happened to my medication.

18. Conclusion

Desire for improvements - Understaffing – lack of coherent organisation – papertrail/record keeping inadequate and even false – patient vulnerabilities

The above notes will make each reader draw their own conclusions. What is inescapable, though, is that not only are wards understaffed with respect to nurses but also with respect to clerking and routine administration. With a hospital computerised record in place, either set up in A&E or verified with the patient by the triage nurse in A&E, there should be no need for a patient to undergo a further paper admission process on a ward. All basic/essential data should be stored centrally and a document management/tracking system in place to duplicate, as required, those elements of information needed to be printed off to make paper ward records or accurate labels.

I was not aware of the existence of a ward clerk or anyone other than nurses or even junior doctors handling the paperwork, booking scans, or otherwise ensuring that an individual patient's plan was being implemented. There was a lot of confusion as to timing of tests and scans and sometimes even which scans had been ordered (CT or MRI, ERCP or "just" endoscopy). Just worrying.

There is no colour coding or system of identifying that a patient has a particular problem with mobility or hearing (both of which can make a big difference in how a patient responds or is seen to be cooperating) – even the patient name notices above beds, which also show which consultant is responsible for them, can be incorrect and being handwritten in a hurry often means they are illegible or misspelled. Nil by mouth and other signs seem to be hard to find and rarely in place.

On the other hand, it is lack of hands-on-staff that means vulnerable, bed-bound, patients are left in corridors where the general public walk to and fro past them – where anything can happen to them (and sometimes probably does). Lack of staff means patient care suffers, medications are missed, food is left uneaten, exercise and nutrition given scant attention, patients feel ignored because they are and nurses/staff feel frustrated and stressed because the one element of their role that brings joy, the caring and nurturing of patients, is overwhelmed by the volume of paper admin and numbers of patients each has to deal with. Patients are vulnerable when the few staff on duty are bus at one end of a ward, while a problem erupts at the other, and patients in bed have no way of escaping and can only hope that a call-bell will be answered.

There does seem to be a giant computer game in play however with respect to beds, whereby a "win" is achieved only when the ultimate, correct, bed-space is reached. Until then, patients and their beds are bounced around from bay to bay, ward to ward without notice or explanation. Each move means that patients have no sense of being looked after or cared for by anyone, nursing staff just have to immediately forget anything they've learned about a patient as they won't be in one place for long (it is probably for this reason that so many nurses appear uncaring). It seems bizarre that doctors and medical professionals, whose time and expertise is most valuable, are required to clocking up endless foot-miles to see patients randomly scattered throughout the wards. It was not unheard of for doctors to arrive hurriedly at a bedside, start talking to a patient who they have never met before, and only when they reach for the notes find that the body in the bedspace is not someone they are meant to be seeing – their patient has been moved but no-one has told them!

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Most staff are adequate. There are a few wonderful people whose compassion, competence and all-round good nature just light up a ward and whose presence makes patients feel safe. There are, however, several who, day after day, skimp and shirk their duties, finding ways to do little more than the absolute minimum. That the majority of staff appear to be "bank", i.e., not employees with a sense of pride in where they work, is a major problem. Not only do some bank staff seem to have no sense of loyalty, there is also little sense of needing to do more than the minimum to get their hourly rate, and once they have left the ward they feel no responsibility for what follows. Again there are exceptions.

The inability of the hospital to organise take-home drugs in a timely fashion, and to book follow-up outpatient appointments before discharge is poor.

When a patient leaves hospital it really should not be with a sense of relief at having escaped alive from a very dangerous environment!

All of what I have written here is my personal opinion, backed up by observations and supporting comments from patients who shared bays with me and from several staff members who not only seemed pleased that a patient was genuinely taking an interest in their working conditions but also hopeful that someone might actually write in to management.

I have deliberately not named names and truly hope that what I have written will be useful in some way.

jsbc/April 2013

Note: due to continuing bowel problems I have felt too unwell until very recently to complete the formatting of this paper. I am sorry it is no longer timely but hope that despite the changes at Trust administration level, my comments retain relevancy.

jsbc/June 2013