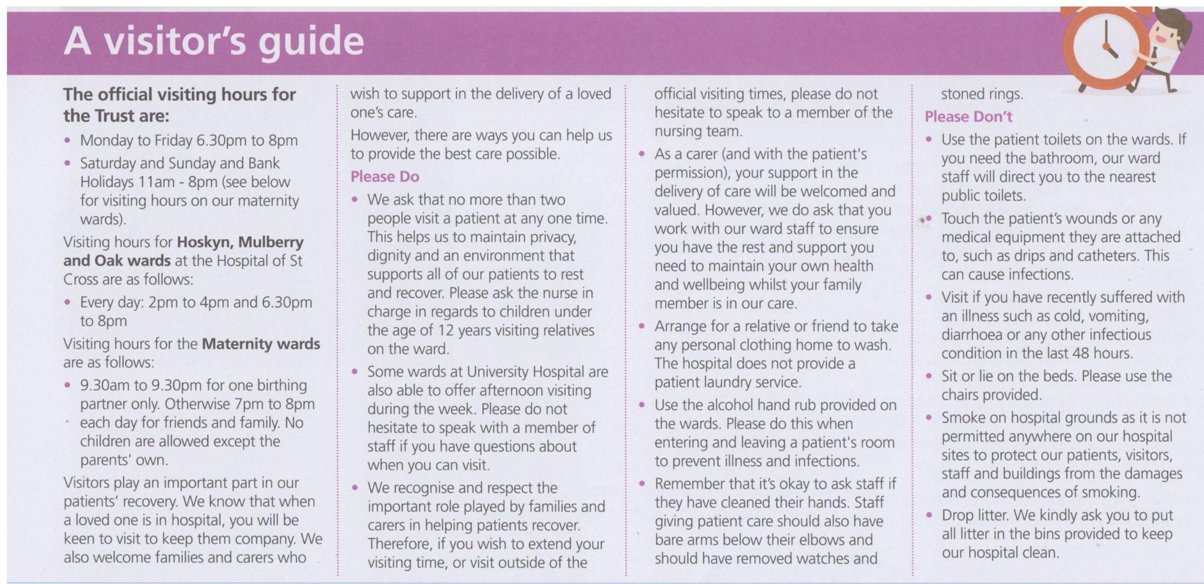
Something slightly interesting, arising from a UHCW information leaflet

I recently stumbled across something about the visiting hours for University Hospitals Coventry and Warwickshire, in 'We Care [issue 3]', and from my end-of-life perspective I wasn't entirely happy with it. I tweeted about it, and an interesting discussion with Dr Kathryn Mannix followed on Twitter. It is not easy to describe exactly what we were 'disagreeing about', but it is something to do with 'perception' and 'power/authority'.

I'll show you the section of the leaflet, which attracted my attention:



A visitor's guide

The official visiting hours for the Trust are:

- Monday to Friday 6.30pm to 8pm
- Saturday and Sunday and Bank Holidays 11am - 8pm (see below for visiting hours on our maternity wards).

Visiting hours for **Hoskyn, Mulberry and Oak wards** at the Hospital of St Cross are as follows:

- Every day: 2pm to 4pm and 6.30pm to 8pm

Visiting hours for the **Maternity wards** are as follows:

- 9.30am to 9.30pm for one birthing partner only. Otherwise 7pm to 8pm each day for friends and family. No children are allowed except the parents' own.

Visitors play an important part in our patients' recovery. We know that when a loved one is in hospital, you will be keen to visit to keep them company. We also welcome families and carers who wish to support in the delivery of a loved one's care.

However, there are ways you can help us to provide the best care possible.

Please Do

- We ask that no more than two people visit a patient at any one time. This helps us to maintain privacy, dignity and an environment that supports all of our patients to rest and recover. Please ask the nurse in charge in regards to children under the age of 12 years visiting relatives on the ward.
- Some wards at University Hospital are also able to offer afternoon visiting during the week. Please do not hesitate to speak with a member of staff if you have questions about when you can visit.
- We recognise and respect the important role played by families and carers in helping patients recover. Therefore, if you wish to extend your visiting time, or visit outside of the official visiting times, please do not hesitate to speak to a member of the nursing team.
- As a carer (and with the patient's permission), your support in the delivery of care will be welcomed and valued. However, we do ask that you work with our ward staff to ensure you have the rest and support you need to maintain your own health and wellbeing whilst your family member is in our care.
- Arrange for a relative or friend to take any personal clothing home to wash. The hospital does not provide a patient laundry service.
- Use the alcohol hand rub provided on the wards. Please do this when entering and leaving a patient's room to prevent illness and infections.
- Remember that it's okay to ask staff if they have cleaned their hands. Staff giving patient care should also have bare arms below their elbows and should have removed watches and stoned rings.

Please Don't

- Use the patient toilets on the wards. If you need the bathroom, our ward staff will direct you to the nearest public toilets.
- Touch the patient's wounds or any medical equipment they are attached to, such as drips and catheters. This can cause infections.
- Visit if you have recently suffered with an illness such as cold, vomiting, diarrhoea or any other infectious condition in the last 48 hours.
- Sit or lie on the beds. Please use the chairs provided.
- Smoke on hospital grounds as it is not permitted anywhere on our hospital sites to protect our patients, visitors, staff and buildings from the damages and consequences of smoking.
- Drop litter. We kindly ask you to put all litter in the bins provided to keep our hospital clean.

The tweeting with Kathryn, starts at:

https://twitter.com/MikeStone2_EoL/status/1122778360571146251

1. **Mike Stone** @MikeStone2_EoL Apr 29

@nhsuhcw @DrMarkTaubert @learnhospice @drkathrynmannix @drol007 @EndofLifeStudy This is on the back page of issue 3 of 'We Care'. It implies that 'officially' if I've got a 'known-to-be-dying' elderly parent, or partner, or child on a UHCW ward, 'visiting outside of 6.30pm to

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2. **Mike Stone** @MikeStone2_EoL Apr 29

8.00pm 'would be by negotiation'. There is only an explicit exemption mentioned re maternity - in my opinion those official visiting hours are totally unacceptable for 'known end-of-life' [as indeed is the 2 visitors at a time 'request']. I'm not sure if there is 'an exemption'

3. **Mike Stone** @MikeStone2_EoL Apr 29

re EoL, and the visiting arrangements for EoL are not as implied, but that is 'due to brevity'? Will UHCW please clarify (that might save me some e-mails to people at UHCW) and what does 'the EoL community' think, if that '6.30pm to 8.00pm is indeed UHCW's 'official EoL visiting

4. **Mike Stone** @MikeStone2_EoL Apr 29

hours'?

5. **#hellomynameis Jess** @Jess_STN Apr 29

People don't die on a timescale... fitting neatly into a 1.5 hour slot... I wonder if there is actually 'unofficial' open visiting for those in that position? It would surely lessen anxiety of the family to have it written down like it does for those using maternity services.

6. **Mike Stone** @MikeStone2_EoL Apr 29

I wondered that - but, I don't want the relatives and friends of dying patients (as in 'final days of life') to be required to 'negotiate for something better than 'the official hours': I want 'the official visiting rules' to be more sensible.

7. **#hellomynameis Jess** @Jess_STN Apr 29

Definitely, it's even a little odd that birthing partners can only stay until 9.30pm, if you give birth after that you have to do it alone? Very draconian.

8. **Mike Stone** @MikeStone2_EoL Apr 29

If @nhsuhcw doesn't get back to me on Twitter, I'll almost certainly follow this one up: either e-mails to UHCW Chair and CE, or a visit to the hospital to enquire, or both. I like 'very draconian' - it is 'messing with the memories of the bereaved'. @drkathrynmannix

9. **Kathryn Mannix** @drkathrynmannix Apr 29

The wording may be unfortunate, but the fact is that sick people need rest times, and the least well who are in shared rooms need protected peace. Birth partners are not expected to leave - 'maternity' refers to the wards where Mums & babies are resting. Here's our local wording

Visiting times

All wards Monday to Friday between **2.00pm - 4.00pm** and **6.00pm - 8.00pm**

Saturday and Sunday between **2:00pm - 8:00pm**

Wards with special visiting times are:

Children's Wards

One parent or carer can stay with their child all the time. With parents' permission other family and friends, including brothers and sisters, can visit throughout the day.

Maternity Unit

Partners may visit between **8.00am - 12midday** then **2.00pm - 8:30pm**.

Other visitors are welcome between **2.00pm - 3:30pm** and **6.00pm - 7:30pm**.

Critical Care and Coronary Care Units

Visiting is by arrangement with the Sister/Charge Nurse of the Unit.

Patients have a sleep period in the afternoon where visitors are requested not to visit.

Children under the age of 16 years need special permission to visit from the Ward Sister/Charge Nurse.

In all areas we will try to be flexible in difficult or unusual circumstances. Please speak to the Ward Sister/Charge Nurse.

10. **Mike Stone** @MikeStone2_EoL Apr 29

It seems to be 'rule' not 'wording' - and we are talking about dying people, not 'sick people': I do NOT like 'that rule'.

11. **Kathryn Mannix** @drkathrynmannix Apr 29

In both our examples, I read perfectly acceptable 'general principles' & an invitation to talk to staff in circumstances when varying the principles is appropriate. In fact, nurses are likely to tell families that extended visiting is welcome for dying people.

12. **Mike Stone** @MikeStone2_EoL Apr 29

I think that during EoL, visiting should be as unrestricted as possible by default - and the nurses should explain if/when/why visiting might be problematic: the 'opposite way round' to that UHCW 'information' publication. 'Perception &'the starting assumptions'.

13. **Kathryn Mannix** @drkathrynmannix Apr 29

Could you be making an assumption here? Most people in hospital aren't dying. The principles are general and will be relaxed to make the dying person as accompanied as they wish. If they wish: not all do!

14. **Mike Stone** @MikeStone2_EoL Apr 30

My issue is that for dying patients, relatively unrestricted visiting hours should be the expectation, or 'right' - NOT 'a privilege to be negotiated'. The information leaflet implies the opposite - that runs counter to most EoL 'guidance' from memory.

15. **Kathryn Mannix** @drkathrynmannix Apr 30

I think in practice it is a right, but info wording prevents all other visitors from assuming it's a free-for-all. In real life, staff will always make this clear to the families to whom it applies.

16. **Mike Stone** @MikeStone2_EoL May 1

Not sure if I've already posted this (misplaced click and it disappeared). I've just sent an e-mail to UHCW, and if I get a reply I'll be interested to see what they say.

Dear All,

I am e-mailing because I am less-than-happy, with something in 'We Care' issue 3.

I have been discussing this with Kathryn Mannix on Twitter, and it seems to partly be 'a matter of perception or implication': she thinks what I read is 'fine' but I don't.

On the final page, there is a section 'A visitor's guide' and we can read:

The official visiting hours for the Trust are: Monday to Friday 6.30pm to 8.00pm.

This is my issue – I write about end-of-life, and for the purposes of this e-mail I will be using 'dying' to mean 'in the final few days of life': **and for dying patients those visiting hours are not appropriate**.

Kathryn pointed out on Twitter 'I'm sure those hours would be relaxed if the patient is dying' ***and I imagine she is correct – but that isn't my point***.

My point, hinges on the word 'official' - although your publication makes it clear that wider visiting hours are open to negotiation, and Kathryn sees that as perfectly fine, my position is that dying patients and the relatives/friends of dying patients, should have an expectation that visiting will be subject to as few restrictions as possible: in essence I consider that the 'official visiting hours' for dying patients should be 'all day' and then if necessary, the staff should 'negotiate' any necessary restrictions.

Even if very similar visiting arrangements might eventually emerge, as a former family-carer during EoL, ***I see it as significantly conceptually different to have very limited official visiting hours which visitors extend by negotiation, compared to as-relaxed-as-possible visiting hours which staff negotiate restrictions to***.

Personally, if a dying wife is in a single room, and her husband wishes to visit at 4am, I have no problem with that at all – clearly it would be different if a shared ward was involved – but, I'm not going to 'debate' the specifics here, I am simply stating that your 'official hours' as stated in We Care look rather like 'fitting the patient and visitors into what works best for the hospital', and my position is that when patients are dying it should instead be [and look like] 'the hospital's behaviour being fitted to the requirements of the patient and the visitors'.

You do seem to understand that dying is different to being cured: you have a Bereavement Suite, but personally I do not see those 'official visiting hours' as being 'from the same song sheet' as compassionate treatment of the bereaved.

I would be interested in your comments, so I hope you send me some (please do not suggest a phone call – I've never found phone calls helpful for EoL discussion: however, I would be willing to visit Walsgrave for a conversation, if you really dislike discussion by e-mail),

Regards,

Mike Stone

17. **Kathryn Mannix @drkathrynmannix**

Nicely put, Mike: I do rather like your 'open visiting with restrictions as necessary' suggestion. I note @RDEhospitals have just declared all-day visiting across all sites.

Why does this ‘matter’?

There is an awful lot of ‘backstory’ – of ‘where I’m coming from’ – behind this.

There is a recognition in the visiting hours, ‘that maternity is ‘different’’. And the hospital will have separate wards for maternity. There is, as it happens, a hospice on the same ‘campus’ as the main hospital, but in general we do know that many patients do die in hospitals.

We also know, that identification of ‘the final days of life’ and any associated advance planning, is quite well-developed for some illnesses, such as cancer, but much less established for other situations: in particular, it seems to still be very problematic for ‘the frail elderly’ who are admitted to hospital ‘suddenly’:

https://www.bmj.com/content/358/bmj.j3954/rr-0

As it happens, since last Christmas I have been regularly having chats with the daughter of a until-recently near-neighbour (her mother) who died in hospital last autumn: the lady moved to be closer to her daughter about a year ago, and she died in a hospital which isn’t in Coventry. The communication with the daughter, was somewhere between very poor and totally unacceptable – and it is clear to me, that it was not made clear to the daughter when her mum’s treatment changed from ‘investigation and possibly treatment of a medical problem’ to ‘this lady is almost certainly dying, we cannot offer any useful ‘active treatment’’.

Those stories from relatives seem to be far too common – basically ‘I thought they were trying to cure my dad, but without making it clear to me they had stopped trying to cure him!’.

This leaves bereaved relatives confused at best, thinking ‘the NHS doesn’t really care about old people’ very commonly, and at its worst believing that ‘the NHS wants old people to die’.

Probably most of these situations, arise from a combination of issues: doctors and nurses under time pressure, rapidly changing clinical situations, an attitude [and in some cases Trust Guidance] that ‘bad news should be ‘broken by the consultant’’ (fine if the consultant is always available to do that, not so good if it leads to a nurse saying ‘the consultant will talk to you tomorrow’ if your dad dies before tomorrow comes), a reasonably general ‘unease’ about ‘talking about dying’ as described in a recent RCP report

https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead

and other factors, including the difficulty of predicting an imminent death (which I will discuss later, because it deserves a section to itself).

Maternity compared to Dying

It is in my opinion, definitely easier to talk around maternity than around dying, but in the context of those publicised 'official hours' - surely most people who are not very close family, would visit the mum-to-be at home **before** she entered hospital for the birth, or **after** mum and baby have returned home. 'Dying' is entirely different: some friends will visit in the hope of 'saying their goodbyes' and ideally the dying person will be 'awake/alert' for that to happen, which is largely a matter of chance (I think the idea that a sleeping dying patient, should be deliberately woken up during restricted visiting hours would be considered unacceptable by most people – see tweet no 5). Of course, there are similarities: a partner might want to be present during maternity to offer support, and a family-carer during 'dying' might feel a strong need to 'carry that through to the end' and to be present when their loved-one finally dies.

But, overall, it seems logical that visiting should be less restrictive during 'dying', than for maternity.

Gosport

The events which occurred at Gosport, and which have hugely distressed so many bereaved relatives, are very difficult to clearly analyse: personally, I think that the relatives will be frustrated and disappointed by the new investigation – it seems clear to me that there was practice (both 'system' and also 'individual clinician') which would have been considered poor, and perhaps even bad professional practice to the point of sanctionable, but at the time (before the MCA, before Montgomery, before Tracey etc) the legal situation was in my opinion very unclear, and I suspect the difference between 'bad practice' and 'prosecutable' will prove significant. I have little doubt, that if similar behaviour occurred now, that prosecutions would result.

However – surely the **more** family and friends are present during end-of-life (which here means 'the dying phase of end-of-life') then the **less** scope there is, for poor practice to take place: **so we should be encouraging visiting while patients are dying in hospital**.

Uncertainty of Prognosis

I pointed out, as an aside during an e-mail discussion with a doctor, that one thing which would follow if the 'official' visiting hours were limited while patients 'might be cured' but were 'open' once patients were considered 'dying phase', is that at least this would mean that the doctors and nurses would 'have to tell the relatives' when the patient was actually dying. Quite correctly – but in a 'private' e-mail, and one which also contained a correct but quite sophisticated description of the ideal approach to treatment during **the suspected** dying phase – the doctor said 'the doctors and nurses don't know how soon the person will die'.

Curiously that did not stop people from writing things such as 'the Liverpool Care Pathway is intended for the final 72 hours of life', or the creation of 'registers of patients predicted to die within a year' and the like.

It isn't acceptable, to justify not telling relatives that their loved one will probably die within a few days, just because that word 'probably' is a truth: if clinicians argue 'many lay people think we deal with certainties, and they can't handle the inevitable uncertainties' then switched around, the thinking of such relatives who are not told, would surely be 'they knew mum was dying, but they deliberately hid that from me'.

And 'they knew mum was dying, but they deliberately hid that from me' **is very bad!**

A bereaved husband on Twitter, who isn't very happy with events when his wife was dying, has several issues around what happened: he has explained on Twitter, that one thing he thinks is very wrong, is that when his wife was being discharged home and he was asking the doctors and nurses 'is my wife coming home to die, now?' he found it almost impossible to get an answer (the answer should have been 'yes' - I think he tweeted that his wife died on the second day at home).

My e-mails '[and look like]'

In my e-mail, I wrote:

I'm not going to 'debate' the specifics here, I am simply stating that your 'official hours' as stated in We Care look rather like 'fitting the patient and visitors into what works best for the hospital', and my position is that when patients are dying it should instead be [and look like] 'the hospital's behaviour being fitted to the requirements of the patient and the visitors'.

To be frank, I am tired of reading about 'shared decision making' and an inclusive attitude towards relatives on the one hand, while at the same time reading assertions about decision-making, published by bodies such as RC(UK) and the Royal Colleges, which are between 'misleading' and legally incorrect. While many doctors dispute this, it definitely seems to me, that a lot of this **does** stem from doctors being

unable to come to terms with the MCA's description of decision-making, especially when combined with the 'safeguarding' which is thrust at doctors and nurses. '... *look rather like 'fitting the patient and visitors into what works best for the hospital''* seems to be a major problem – I keep coming across things which look fine from the postion of a doctor, but look problematic and not 'perspective-balanced' from the perspective of relatives in particular.

That statement of UHCW's 'official visiting hours' just 'looks wrong' from my perspective, and it is interesting that Kathryn [a doctor] did not see it as wrong.

However, Jess (see tweets 5 and 7) is a third-year student nurse, and Jess does seem to see an issue with the wording.

'Power'

As I said at the start, it isn't easy to explain precisely why that wording about 'official' visiting hours seems wrong to me: one possibility is that it seems to reflect an attitude about 'power' - the attitude 'your loved-one is now in our hospital, so we make the rules'.

I posted a 'bit-of-fun' poll on Twitter recently, asking if people thought a comment sent to me was from a clinician or a lay person:

https://twitter.com/MikeStone2_EoL/status/1126457803462279174

This comment was sent to me: 'I just love your continuous challenge to the 'power structures' and the rhetoric of shared decision making !'. A curiosity or 'Bit of Fun' poll - do you think it was written by a clinician, or by a lay person? I'll say which after the poll closes.

After the poll closed (10 votes – 8 people said 'by a clinician' and it was indeed sent to me by a clinician) Dr Mark Taubert, a consultant palliative care doctor, picked up on my subsequent tweet 'what gave away that the comment came from a clinician?' and Mark commented on the 'power structures' in two tweets he posted:

mmmmh, lay person? Although when I am ill and go to seek help, I feel like a lay person myself! And I don't see myself as a power structure. I wonder if these divides are just a natural human product wherever there is disagreement?

..and reflecting further on that, if you read tweets on controversial topcs like Assisted Suicide, within moments you find a "Us versus Them" narrative. But I don't feel like I'm part of 'them' or 'us', and my views are quite idiosyncratic. Herd instincts.

Then I tweeted:

I definitely feel like a 'them' at times! I agree - we need more 'we' and less 'us & them' if we are to improve EoL. I've written that, somewhere.

And Sarah Russell, a nurse, chipped in with:

Maybe us and them should have fluid boundaries- i certainly agree with Mark...but now I am curious..

I've currently got another poll running on Twitter, asking if people do think there are power structures in the NHS – I think most people will answer 'yes', so it intrigues me that a consultant doctor writes ' *And I don't see myself as a power structure'.*

Closing

The reason I wrote this, is that I would like to further discuss that wording about visiting hours with UHCW, and as it happens I would also like to discuss the ReSPECT form which UHCW is also using (and I object to the ReSPECT Form – which, to be clear, needs either fundamental redesign or else throwing away completely - much more forcefully than I take issue with the visiting hours in We Care) : I don't yet know if UHCW will discuss one or both things with me, but I have indicated to UHCW that I would like to copy-in three doctors on our discussions, if discussions take place. So, I needed to write something for the benefit of those three doctors, so that they could understand my issues with what was written in 'We Care' - and, it occurred to me that if I explained that in a piece and posted it online, I could point both those three doctors and also anyone UHCW puts up for discussion at the piece.

This is the piece, and I hope it is a reasonably clear starting point for a discussion of my 'problem with' those official visiting hours in the information leaflet.

Written by Mike Stone 11 April 2019

Twitter: @MikeStone2_EoL

PS Readers might notice a few faint horizontal lines in the PDF: I don't want them to be there, I can't understand why they sometimes appear, and I cannot work out how to get rid of them!

Such as the faint line here: I don't want it, but I can't work out how to get rid of it!