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TREATMENT FOR BLINDNESS:

Moorfields and UCL research trust tells us that "Diseases of the retina are the commonest cause of blindness across all age groups. Age-related macular degeneration (AMD) is the leading cause of severe visual loss in Europe and North America and, with an ageing population, the burden of this disease is projected to increase dramatically.

As its name suggests AMD predominantly affects the macula, the centre of the retina that is important for reading and detailed vision. It can be classified into early and late stages based on specific clinical features. Early AMD is characterised by the presence of drusen (tiny yellowish deposits under the retina) and is compatible with reasonable vision. However, many patients with early AMD progress to the vision-threatening late forms of AMD.

The late 'wet' or neovascular form is characterised by the growth and leaking of abnormal blood vessels beneath the macula causing severe loss of vision.

Currently, we have treatments for late neovascular AMD but these involve intensive intervention with frequent injections into the eye and long-term monthly follow-up of the patient. Such treatments can be problematic to deliver, and only a third of patients recover some of their lost vision. We have no effective treatments for early AMD or for the late dry atrophic form of AMD."

So, what's the way forward? The use of embryonic stem cells has exciting potential - but this potential is not always realised in practice. It's easy to see the attraction, though, of this form of treatment for patients with age related macular degeneration. Fergus Walsh, the BBC's medical correspondent, reports: "Surgeons in London have carried out a pioneering human embryonic stem cell operation in an ongoing trial to find a cure for blindness for many patients. The procedure was performed on a woman aged 60 at Moorfields Eye Hospital. It involved "seeding" a tiny patch with specialised eye cells and implanting it at the back of the retina."

The fact that similar treatments have proved successful in the past gives grounds for hope that this treatment will greatly improve the prospects for those with this sight threatening condition.

RIGHTING WRONGS

Patients and clinicians are often in the best position to see what is wrong with the NHS at first hand and to report back to the people running the service. The problem is that the system is in chaos and, for all the pretence of improvement, nothing ever changes. Here's the gist of a letter I'm about to send to the Chief Exec of the NHS:

Dear Simon Stevens

I enclose correspondence that relates to a letter sent to you by a patient at this practice.

You should get a senior member of staff to glance through it as my patients have been uniquely short-changed by the NHS for over a decade now. You won't do that, of course, because that's not the way the NHS works.

There are currently a number of ways of dealing with these matters – but they all share the same end result. Let's say a patient runs out of options (having exhausted the local 'mechanisms' for seeking redress) and so writes to a more senior figure/body. If they are lucky they get a brief letter from a minion saying the matter is being looked into. The minion may, on a good day, then pass it over to the body about which the complaint has been made (leaving it to respond). On a bad day s/he will simply tell the patient to write their own letter to whoever they are complaining about – which is fairly pointless exercise as, by this time, people have done all that already.

Once in a blue moon a more senior member of staff will deal with the problem – very occasionally even the person to whom the letter was addressed will get involved. S/he then asks the body in question – the one about which the complaint has been made – to provide him/her with a suitable reply and this is then copied word for word to the complainant. There is no attempt to investigate the matter – it's simply a matter of rubber stamping the explanation that is received.

I've enclosed an example given that you are fairly new to the job and may not be fully aware of the protocol – this was a reply from 'Moneybags Mackay' to one of my patients. As you can see the reply to him from the PCT was faithfully copied onto his headed notepaper – which allowed him to avoid the inconvenience of leaving his counting house where he was counting out his money. You wouldn't expect the PCT that was the subject of the complaint to have taken responsibility/admitted blame – so the whole exercise was farcical.

There has never been any attempt whatsoever to improve 'the system.' In May 2004, at a time when literally hundreds of my patients were writing to complain about the high handed behaviour of the Maldon and South Chelmsford PCT (which took no heed whatsoever of their views) I wrote to John Reid , the then Secretary of State for Health, as follows:

"This is very much what I have been hearing from patients – no matter where they write, they are referred back (directly or indirectly) to the very organisation about which they are making a complaint. When the dust has settled on this case, I think you are going to have to think about introducing an effective complaints procedure. Devolving power is all very well when things run smoothly, but there have to be effective mechanisms in place for the times when things go badly wrong." I went on to complain that there was "No structure to a complaints procedure founded on the principle of buck-passing, and no will to introduce effective checks and balances." Nothing has changed for the better from that day to this."

I go on to give a few practical tips to Mr Stevens most junior member of staff in case s/he isn't familiar with the way these matters are dealt with by the NHS.

"Firstly find the standard response to any letter of this nature. It'll probably be on your desktop as it's in frequent use. It will be called 'Stock Reply' or similar. You can make minor changes to the letter as the mood takes you, but make sure these are 'safe' … in other words try to stick to platitudes, and make them as meaningless and as soothing as you can. A standard first paragraph would read as follows: "The Chief Executive is very busy and can't deal with the everyday problems of the NHS. His job is to have a 'vision' for the future. For example he might think it's a good idea to have more consultants in the community.

Ignore the fact that people have been trying to do this for years – from the time of fund-holding onwards – and during the 'commissioning phase' that ran throughout the Primary Care Trust era but didn't get off the ground in most areas as the PCTs were (a) too inept to manage this departure from the norm and (b) didn't want to hand over any powers/funds to people who might just know what they were doing … like GPs, for example. Make it look as if the Chief Exec's brainwave is a brand new idea and everybody should get very excited about it.

Go on to say: “Despite what you may read in the papers, the NHS is getting better/stronger/more efficient. Morale has never been healthier. Say there are x% more nurses in training, and y% more doctors (and that z% of those new doctors have given a firm commitment that they will become GPs.) NOTE – x, y and z are any numbers between 20 and 99 that happen to pop into your head whilst you are ‘customising’ the standard letter.

Do NOT pick a number lower than 20 or you will be told off by your superiors … or greater than 100 or you will be found out.) Under NO circumstances mention the only way the NHS is realistically going to ‘keep the show on the road’ a little longer … in other words DON’T say the plan is to carry on doing what we’ve always done – pinching doctors and nurses from countries that can least afford to lose them.

Whatever else you do, don’t make ANY reference to the fact that, in the case of a Chief Executive, ‘the buck stops here.’ Pretend that somebody else is responsible. You must regard this sort of thing as an elaborate version of ‘pass the parcel’ – one in which the music never stops. The idea is to keep passing the complaint or criticism on until the disgruntled patient or NHS employees gets so worn down that s/he gives up."

For all the talk of a modernised and patient responsive NHS, it continues to be run like an old boys' club ... even when managers go off the rails and cause problems that wouldn't be tolerated in any well run, ethical organisation. The establishment invariably rushes to their rescue – the status quo MUST be maintained at all costs.

As I say, the whole system is a mess. In June 2014 the Health Ombudsman was criticised by Health Secretary Jeremy Hunt over organisation's handling of death of a three-year-old child. Invigia.com reported that the Parliamentary and Health Service Ombudsman (PHSO) – the independent service that investigates patient complaints – has been criticised as ‘wholly ineffective and failing families.’ It came under fire after the Patients Association revealed that it receives weekly calls from patients who feel let down by the service and as a result no longer directs callers to its national helpline to use the service.

To quote verbatim from the article: "Paul Clark, CEO of Charter UK, said it was a matter for serious concern that the effectiveness of a body that serves to act as a final arbitrator for complaints about the NHS had been called into question. “We’ve long said that the public sector is very good at regulating others, yet seems unable to regulate itself,” he stated.

“Furthermore, there is widespread recognition that complaints handling across the NHS needs radical transformation, after numerous tax payer funded enquiries we are left with recommendation after recommendation, but no real drivers for change or a regulatory framework that can enforce it. Now we have the Patients Association publically calling into question the effectiveness of the Parliamentary and Health Service Ombudsman (PHSO). When is enough going to be enough?”

Hear hear!

Dr John Cormack