Medicines and liberty – more than just antipsychotics

About the author: Clive Bowman has been both a consultant physician and geratologist and a medical director concerned with services, particularly care homes for older people. Here he reflects on the risks of prescribed medications and the liberty of older people

Many years ago I was asked to attend an aged lady in a Residential Home because of anxiety. She was a widow who had been living alone well supported by neighbours and her local church. One day she had fallen and been admitted confused to hospital. With no bony injuries she was rapidly dismissed clinically from a trauma perspective but her confusion led to high doses of antipsychotics being prescribed. These rendered her helpless; a junior doctor subsequently considered her to have Parkinsonism and commenced treatment for Parkinson's disease. She was discharged to a nursing home and her friends assisted in the sale of her house and dispersal of most of her possessions. Her condition improved and she transferred to residential care and increasingly spent her days out walking and visiting old friends. Her anxiety returned when she had a further fall. She was fearful that she would be transferred back to nursing care. My review, the first specialist review she had had determined that her original confusional state was almost certainly related to a head injury sustained when she fell (if she had been younger the possibility of head injury would have not been overlooked) and the antipsychotics merely produced further problems including a drug induced Parkinsonism. Needless to say all her medicines were discontinued and her only medical problem really was arthritis of her knees that had led to the falls. No one had sought to deprive this lady of her liberty, indeed the records made clear the real concern for her well being but she was denied expert opinion that could have so easily led to a very different story.

Our present approach to illness is one of diagnosis and treatment with the aim for preventing unpleasant symptoms and complications whilst social care is very much in the business of promoting independence and personal autonomy. Perhaps a third dimension is the increasing medicalisation of death and dying using Palliative Care largely developed in cancer patients with incurable malignancy.

The trajectory to death for older people as a population is evolving. A large American review reported that 20% of people die suddenly from accidents and events such as a fatal myocardial infarction, 20% from cancer and 20% from chronic disease such as renal, chest or heart disease, the remaining 40% die from frailty or long term progressive typically neurological conditions such as Alzheimer's disease. Clearly as progress is made on the prevention and treatment of many traditional causes of death, more people are likely to swell this last group and their course has been termed "progressive dwindling".

"Progressive dwindlers" have usurped the "feckless and reckless" of the Poor Laws as care recipients, their needs neither fitting the capabilities of modern

medicine or the ambitions of progressive social care. We have written elsewhere that this population is distinct from people traditionally receiving palliative care. We have proposed that they should have “Formative care” that is care aimed at providing the best quality of life within the reality of lives reframed by physical and mental impairments mindful of likely progressive deterioration.

Restraint in care takes many forms, at one time well engineered tipping chairs were in common use, they may have been appropriate for a few but clearly tipped back with a table (useless at 45 degress) merely reinforces the completeness of restraint. Adverts for these chairs appeared in specialist medical journals well into the 1980’s. Clearly not acceptable these chairs are largely discarded however history repeats itself with the particularly low arm chairs. Some care homes may have had one or two of these and following feedback the manufacturers added large castors, a foot-board. A Velcro attached table and finally handles added to push the chair around essentially recreate the same capability as a tipping chair. It may well be that this sort of device is really useful on occasion but on a 30 bed dementia unit how many of these are necessary - where is the transition from appropriate to unjustified restraint. We have no guidance but my intuition questions the necessity for more than 2 or 3. The point is I don’t think these physical restraints are commissioned in a malevolent way but over time their increasing adoption becomes an insidious erosion of personal liberty. Similar stories underpin medicines.

I have looked at the use of antispsychotics in care homes both from the perspective of a hospital consultant and a medical director. Simply, in spite of the moral outrage, short term policy initiatives the use of antipsychotics remains unmanaged and a factor in the loss of liberty for a large number of people. The Gosport Memorial Hospital inquiry of 2002 highlighted poor prescribing and poor controls, many would agree with me that for Gosport substitute probably a large proportion of care homes across the UK. I have reported data describing the common diagnoses attached to care home residents from a number of surveys, perhaps the most important point is that the incidence of mental incapacity internationally is high and an indicator, to my mind, of high risk of inappropriate prescribing of antipsychotic medicines and other sedative medicines.

When the UK coalition government started acknowledging dementia as a major health concern focus was brought to bear on antipsychotic prescribing. At that time I had a small team ringing GPs alerting them to their patients who seemed to be over or inappropriately treated suggesting the possibility of antipsychotic medicine reduction or withdrawal. Most prescribers responded professionally in a positive way and this approach worked in the short term. However it echoed painting the Forth Bridge; you’re never finished! No sooner had one cohort of residents been dealt with they were supplanted by another and the home is back to square one.

Last autumn we published a substantive survey of antipsychotic prescribing from before the implementation of the National Dementia Strategy and 4

years post. The findings and brutal reality is there has been no change – not in prescribing rates nor in the type of drugs (old vs new) prescribed. This paper can be found at http://bmjopen.bmj.com/content/6/9/e009882 . What is interesting is that this thoroughly peer reviewed paper though reporting data on a grand scale barely caused a ripple. Essentially it seems that the "it's just too difficult" box may have been ticked and attention has moved on. Most recently I have reviewed the rates of antipsychotic prescribing in a well-run highly regarded care provider and antipsychotic prescribing rates are actually rising. It has been suggested that austerity may be leading commissioners to under commission care, individuals being sedated to compensate. I have no means of substantiating this but it is crucial that the responsibility for prescribing is understood to be the legal responsibility of the prescriber not care provider or for that matter a service commissioner.

The principal regulator CQC has done much to improve safety in medicines management but it simply lacks the capability to systematically provide oversight of medicines prescribed. My observations have been that well over 50% of antipsychotic prescriptions for care home residents are initiated in acute hospitals. As a one time consultant physician I sympathise with this. If on an acute ward with desperately sick people an older person is a danger to themselves and those around them control has to be established and fast. It's a far cry from preferred practice but often the only pragmatic solution. Where things go seriously awry is that what should has been used as an emergency measure only becomes incorporated into long term treatment regimes. It is important to reflect that most of these medicines developed and licensed for psychoses such as Schizophrenia are being used off licence with little or no written guidance to underpin what is a common practice. Doctors in training both for hospital or practice in the community observe their seniors using these drugs in this manner and the "see one do teach one" approach fills the void of evidence for rational practice.

There is profound variation almost certainly unwarranted of prescribing in care homes. The association of high levels of antipsychotic medicines, supplemental feeds and low levels of medicines as required with low levels of simple pain killers suggests to me a one size fits all somewhat institutional approach whereas the converse probably indicates a more personalised practice. The more institutional approach I've described seems to be associated with large care homes where patients may have general medical services from GP's with whom they are unfamiliar whereas the more personalised approach reflects a continuity of care.

So, my view is that medicines and older people in care remain a cause for serious concern. It's not just a matter of simple medicines review that is needed for most people but a clear understanding of why each medicine was prescribed so that reviews can determine whether that is still valid. In the US similar problems led to requirements for prescriptions to be justified and their initiation clearly linked to named prescribers. The effect on prescribing trends was marked.

It's not just antipsychotics, I have observed a home presented as an example of good practice with zero use of antipsychotics only to find high levels of sedating analgesia being used. Really, prescribing in care homes is a bit like the fair ground game of "whack a mole" with new challenges continually popping up.

So, we need much greater guidance and controls on prescribing and I am optimistic that with "e" prescribing and big data from digitally enabled medicines management systems (I declare an interest being chair of a leading company in this endeavour) accountable care organisations should be able to monitor trends actively in real time.

For DoLS assessments vigilance is all. The more medicines prescribed the greater the risk of iatrogenic cognitive or indeed physical deprivation of well-being and possibly liberty. The absence of clear medicines review and poor continuity of medical care should be triggers for concern.

I started with a simple clinical story – I'd like to finish with a cluster of 3 cases, all men with a history of hypertension treated with the Beta-blocker Atenolol for many years. This drug being water not lipid soluable was generally thought not to cross the blood brain barrier. Case one was a man in his early 60's still doing crosswords but the presentation was that he got lost walking familiar streets. I withdrew his treatment for hypertension and he recovered. Case 2 was a builder who my wallet knew well, he could estimate a job reliably by sucking through his teeth and looking around. One day he produced a tape measure I challenged him and subsequently saw him in my clinic where it transpired he had been put on Atenolol for several months, withdrawal saw the tape measure discarded. My third case was the most dramatic a man referred for assessment of dementia his concentration so poor that when undressing he queried what he was doing, following withdrawal of the Atenolol he several months later was able to drive his wife to London confidently. We wrote these cases up and subsequently demonstrated a range of cognitive deficits relating to these generally well-tolerated medicines. The point of these cases is the importance of vigilance. My description of the use of "specialist seating" as a form of restraint has parallels in prescribed medicines and vulnerable people.

In conclusion, medicines are on occasion used inappropriately or continued in such a way that may cause real impairment that could a deprive an individual of their liberty. There is no substitute for a proper, specialist generalist review of medicines to minimise these risks.