Confidentiality and cognitive
impairment: professional and
philosophical ethics

JULIAN C. HUGHES, STEPHEN J. LOUW

Gibside Unit, Centre for the Health of the Elderly, Newcastle General Hospital, Westgate Road,
Newcastle upon Tyne NE4 6BE, UK

¹Care of the Elderly Directorate, Freeman Hospital, Newcastle upon Tyne, UK

Address correspondence to: J. C. Hughes. Fax: (+44) 191 219 5065. Email: jchughes@doctors.org.uk

Abstract

In the UK, the General Medical Council's new guidance on confidentiality restates the professional duty for doctors to regard personal information revealed to them as confidential. Such information can be shared only with the patient's explicit consent—the exceptions to this are narrowly defined. We believe the guidance does not adequately address the reality of confidentiality in modern practice, particularly in relation to patients with dementia. It seems to be naïve or lacking in the subtlety required in complex clinical situations, perhaps because its legalistic, professional ethics have a philosophically limited view of confidentiality. A more sophisticated philosophical picture regards people as embedded in a shared, worldly context, in which relationships and mutual engagement become crucial. Attending to the reality of cognitively impaired people emphasizes this context and suggests that confidentiality cannot be an overriding principle—it is best regarded as a token of trust.

Keywords: cognitive impairment, confidentiality, dementia, driving, ethics

Introduction

In the United Kingdom, the General Medical Council (GMC) has recently issued new guidance on confidentiality [1].

It stresses that doctors must not reveal private information about their patients, unless the patient consents or the doctor can justify the disclosure. It allows that in certain circumstances disclosure is important, either to protect the best interests of the patient, or to safeguard the well-being of others.

There is much in this new guidance that is both useful and relevant to modern practice. For instance, there is acknowledgement of the reality of multidisciplinary working, the need for audit and research, and the risks to confidentiality posed by electronic processing.

The guidance is uncompromising throughout on the right of patients to expect confidential information to be kept confidential; and if it cannot be kept confidential the patient has a prima facie right to know why not. All this seems sensible and proper, but our concern is that the guidance lacks subtlety when it comes to the problem of cognitive impairment. It seems to lack awareness of the realities of dealing with people with dementia. We suggest that this blemish occurs at the point at which professional ethics needs bolstering by philosophical ethics.

Case vignette

Mr Jones was put in an orphanage at a very young age and now, in his seventies, he has developed dementia. Despite an impoverished early life, he has had a remarkably well-adjusted adulthood, having held down a steady job and maintained a secure marriage.

Since they met, over 50 years ago, he and his wife have scarcely been separated. He has developed Parkinson's disease and now has moderately severe dementia. He often loses the thread of a conversation,
but still insists on dressing himself and expresses clear preferences in relation to outings and other activities. Recently, prostatism has led to occasional urinary incontinence. Mrs Jones is finding it increasingly difficult to cope.

**Multidisciplinary working and confidentiality**

Caring for Mr Jones will require a multidisciplinary approach. Not only the general practitioner, but also the geriatrician, the old age psychiatrist, the district nurse, the community psychiatric nurse and occupational therapist might all be involved. The General Medical Council would normally expect that patients should be made aware that ‘personal information about them will be shared within the health care team, unless they object, and of the reasons for this’. Mr Jones also needs a social worker, who in turn must involve the home care organisation and the staff at the day centre. The General Medical Council would normally say it is ‘particularly important to check that patients understand what will be disclosed’ if other agencies such as these are involved. If Mr Jones objects, the General Medical Council would normally expect his wishes to be respected, ‘except where this would put others at risk of death or serious harm’.

Mr Jones, of course, is not a normal patient in the sense that he has cognitive impairment. It might seem reasonable, therefore, to argue that he ‘lacks competence to give consent’ to information about him being shared. This should lead us to paragraph 38 of the guidance and we should bear in mind the need to be able to justify any disclosures. Before discussing paragraph 38, however, let us pause to consider what disclosures we might wish to make and how we might justify them.

Is it relevant for the social worker to know that Mr Jones was in an orphanage? It does seem relevant for some people involved in his care to know, at least, that Mr Jones had a difficult childhood. This will help people to understand his close attachment to Mrs Jones; hence his reluctance to go to the day centre and her reluctance to let him go there. So the day centre staff should, perhaps, know this too. There are quite a few staff at the day centre; it would be difficult to explain to Mr Jones why all these people might need to know something about his childhood. In any case, both the day centre staff and the home carers need to know about his urinary incontinence. Even if they are not told, they will soon find out, partly because Mrs Jones will tell them. It would be difficult to discuss this with Mr Jones, however, who does not recognise that he has any problems. He may not consent to these disclosures. He might not have the capacity to consent and he might also become upset (and even angry) at the suggestion that all of these things need to be discussed so widely. Clearly, Mr Jones cannot be approached as if he were fully competent.

**Confidentiality and incapacity**

In accordance with paragraph 38, if a person with ‘mental incapacity’ asks us not to disclose information to a third party, we should try to persuade him ‘to allow an appropriate person to be involved in the consultation’. But who would such ‘an appropriate person’ be? And how would this help, since the day centre staff need some understanding of Mr Jones’s very close attachment to his wife and the home carers need to know that they will have to deal with his incontinence? Nevertheless, it seems we must have this long and complicated conversation with Mr Jones about medical confidentiality (or we could follow the General Medical Council’s recommendation and give him a leaflet—but it is not clear this would mean much to him) so that, if he refuses, and we are ‘convinced that it is essential’ in his medical interests, we may take the decision to disclose relevant information. Then, having perhaps confused and upset Mr Jones by the discussion which led him to refuse to give his consent, which we did not think he was competent to give in the first place, we have to tell him before we actually disclose the information.

We are encouraged, where appropriate, to ‘seek and carefully consider the views of an advocate or carer’. That seems fine; but who is to give the relevant information to the advocate or carer if they do not have it? Should we go back to Mr Jones to seek his consent to reveal the relevant information to his advocate or carer to allow them to express a view on whether or not we ignore his refusal to allow us to disclose information about him?

The truth is that paragraph 38 is more relevant to a mental illness that might render a person temporarily incapable of giving consent, but which might also pose a threat to others. It refers us, for instance, to the Mental Health Act. Mr Jones, who only needs routine day care and home help, but who also needs understanding (and therefore the sharing of personal information), is an entirely different matter. His problem is that he lacks the judgement to appreciate the need for carers to know his diagnosis, yet has sufficient insight to feel affronted (or at least anxious) during discussions about his predicament. It seems to us that the General Medical Council’s guidance fails to address the subtle ethical conflicts that confront clinicians in their efforts to deal with this fairly common scenario.

Paragraph 39 is also about people who cannot consent, where there is a concern about abuse. It might be important to someone with dementia (if not to Mr Jones); however, it mostly focuses on children.
Confidentiality and dementia

We should state that it is not our intention to suggest that confidentiality should be ignored as an issue in the care of people with dementia. Many people with dementia will have the capacity to understand the need to share information. Most will welcome the fact that others are involved in their care. Some might object to others knowing things about them, and their wishes must be respected. The General Medical Council’s guidance will usually be pertinent in minimal and mild dementia. In any case, confidential information should only be imparted to those who need to know. By the time, however, the demented person needs as much extra help as Mr Jones, it becomes increasingly likely that they will lack enough capacity to decide who needs to know things about them. At some stage of dementia, the required discussions would become farcical and irrelevant; and at some stage before that the discussions are likely to become problematic, not only for the doctor, but (more importantly) for the patient as well.

Driving and confidentiality

The only specific mention of dementia in the General Medical Council’s guidance comes in relation to information being passed to the Driver and Vehicle Licensing Agency (DVLA). Here the guidance is uncompromising. If a person has ‘a condition which may now, or in the future, affect their safety as a driver’ the doctor should make sure he or she understands that the condition might impair their ability to drive and, if the person is incapable of understanding this, ‘for example because of dementia’, the Driver and Vehicle Licensing Agency should be informed immediately. The advice (which is reprinted at the start of the Driver and Vehicle Licensing Agency’s own guide [2]) continues by describing the process which needs to be undertaken if the person refuses to accept the diagnosis and continues to drive. The process is firm on the problem but is considerate to the person, who must be kept informed when disclosures are made.

Many clinicians will take this as no more than a reflection of good practice. Clinicians will be aware, however, that some cases, at the margin, are not accommodated by this guidance. What, for instance, of the person with mild cognitive impairment, where there is some likelihood that the condition will deteriorate into dementia? This would, then, affect the person’s driving in the future. The person might deny this (and they might be correct). Should the doctor initiate the process which ends in a disclosure to the Driver and Vehicle Licensing Agency? Given that there is some evidence that people with mild dementia can still drive relatively safely [3] under certain conditions [4], it does not seem obvious that the Driver and Vehicle Licensing Agency should be informed instantly. A better approach, arguably, might be to monitor the person whilst building up rapport and trust. This is another example of the lack of subtlety in the General Medical Council’s guidance. The upshot is that the individual person with cognitive impairment loses: attention to the person’s individual needs is subsumed by adherence to a coarser legalism.

Professional versus philosophical ethics

We suggest that the lack of subtlety demonstrated in the General Medical Council’s guidance concerning confidentiality with respect to people with cognitive impairment is a reflection of the extent to which professional ethics can be considered precisely as laws or rules. The General Medical Council, after all, lays down the duties which must govern the way doctors behave (and others involved in health and social care will have their own professional standards as well). Failure to comply with these duties leads to censure. The censure occurs (quite appropriately) in a legalistic fashion. This legalism is further emphasized in the opening statement of the General Medical Council’s guidance: ‘Patients have a right to expect that information about them will be held in confidence by their doctors’. The assertion of a right implies enforcibility by an external, lawful authority. Unfortunately, rights tend to be crudely expressed, are subject to exceptions and cannot be equated in a simplistic fashion with ethical principles. Philosophers link rights to correlative duties; but (as the guidance amply demonstrates) if it is the duty of the doctor to respect confidences, this is certainly not the only duty. So the right of the patient to confidentiality is not inalienable. Moreover, doctors are bound not only by professional rules, but also by ‘deeper’ norms which govern their conduct. These deeper norms reflect the doctor’s standing not only as a professional, but also as a person in a worldly context.

It is at this point that a more overtly philosophical ethic becomes apparent and relevant. A philosophically naı̈ve model of confidentiality might be based on the notion that information about me is private and I choose, privately, to pass this information to the doctor, who retains it privately. It is as if the private information is an inner thing over which I and the doctor can have control. This picture of the inner secret being passed from one to another is most obviously manifest when we think of the absolute secrecy associated with the ‘seal’ of the confessional. Even the religious act of confession, however, is public and forms part of a practice which occurs and is understood within a particular social and cultural context.

The naı̈ve picture can hold sway where it is only the doctor who needs to act on the private information imparted by the patient. Nowadays, however, this is scarcely ever the case (except perhaps in psychotherapy, which is akin to confession). More usually, as we have seen, doctors deal with patients and their ills in teams,
involving other professionals and carer groups. The information given to doctors is often, in any case, not private. Mr Jones's Parkinsonism, forgetfulness and incontinence are all too public. Dealing with Mr Jones inevitably involves dealing with Mrs Jones. Indeed the doctor would be remiss if he or she were not to deem Mrs Jones as the key interlocutor, not only in planning her husband's future care, but also in supporting her through her own progressive sense of loss. There is little here that can be kept secret between Mr Jones and his doctor. Dementia, by its nature, involves much of the human, worldly context in which the people who have dementia are embedded. In passing we should note, too, that dementia is not alone as a disease in this regard. In fact, very few diseases do not impinge on the public space inhabited by others.

The more sophisticated philosophical picture, therefore, involves people who are embedded in a shared, human-worldly context [5]. The relationship between the doctor and the patient is—at its best—a matter of mutual engagement within this context. Confidentiality is a token of the trust that should exist as an element of this mutual engagement, but not necessarily as an overriding principle. This trust, therefore, exists within a shared context in which others are likely to become involved as a matter of routine and for the good of the patient.

At the start of the General Medical Council’s guidance a consequentialist argument is put forward for confidentiality: without it 'patients may be reluctant to give doctors the information they need in order to provide good care'. In this era of a highly informed public, this argument seems curiously out of date and naïve. Patients might conceal information precisely because they know that confidentiality is sometimes overridden by the other duties that face the doctor. People with epilepsy or alcohol dependence, for instance, might know that they are in danger of being disqualified from driving. People with certain mental illnesses know that they are in danger of being detained under the Mental Health Act depending on what they say to their doctor.

Since in these sorts of cases confidentiality is a myth, it would be better to regard it as a useful token of trust; not primarily, however, because beneficial consequences flow from such trust, but because trust reflects the dependency inherent to the relationship between a doctor and a vulnerable patient. It is this relationship that is an embedded feature of the human world; and it is a relationship that characteristically involves others.

### Conclusion

The General Medical Council’s guidance on confidentiality remains useful and important. Acting in accordance with the guidance will usually be to act in a way that reflects and fosters the embedded context of good, modern, medical practice. This implies, however, that confidences are not usually private. They are usually shared, but in the doctor-patient relationship this is within a context of trust. Patients will recognise (whatever doctors say) that medical practice involves acting in a broader context still, where others trust doctors to make some confidences public for the broader good. That does not have to negate the importance of the trust between individual doctors and patients.

In the case of cognitive impairment, however, the public and shared nature of modern, medical practice comes to the fore. At this point, acting in accordance with professional rules of conduct becomes less important than acting in accordance with the norms that govern our shared embeddedness in the human world.

In the case of dementia, then, a philosophical analysis of the ethics of confidentiality would emphasize the context in which patients, their families and carers are mutually embedded. In this context the routine sharing of information is not a matter of breaking a sacramental seal, but a matter of the person’s being situated in a shared space of concern and trust. Hence, here and probably elsewhere in medical practice, confidentiality is less important than the respect and trust implicit in the nexus of caring relationships that surround and aim to support the person with dementia.

### Key points

- The General Medical Council’s guidance on confidentiality restates the important professional duty to regard personal information as confidential.
- In relation to patients with dementia, however, the guidance is naïve or lacking in subtlety.
- Professional ethics, which are inevitably legalistic, have a philosophically limited view of confidentiality.
- A more sophisticated philosophical picture regards people as embedded in a shared, worldly context.
- Within this context of caring and vulnerability, confidentiality is best seen as a token of respect and trust.

### References


Received 28 February 2001; accepted in revised form 4 September 2001