FOR DEBATE…

Continuing care – should geriatricians re-engage?

SIMON P. CONROY1*, TONY LUXTON2

1University of Nottingham, Ageing and Disability Research Unit, Medical School, Queen’s Medical Centre,
Nottingham NG7 2UH, UK
2Brookfields Hospital, Davison House, 351 Mill Road, Cambridge CB1 3DF, UK

*To whom correspondence should be addressed. Fax: (44) 115 942 3618. Email: simon.conroy@nottingham.ac.uk

Abstract
Continuing care settings cater for some of the most disabled individuals. Their care can often present major ethical
dilemmas; teams involved in such care require a broad range of skills. We illustrate this with a challenging case history
and discuss specific dilemmas, including investigation and treatment in the absence of specific consent and advance
directives. We suggest that continuing care should be recognised as a valuable component of training in geriatric
medicine.

Keywords: continuing care, ethics, elderly, advance directives, training

Introduction
The duties of geriatricians in the UK have changed, with
growing emphasis on the care of acutely ill people [1].
Continuing care in the National Health Service (NHS) has
diminished and most now takes place in care homes [2]. The
consequence has been that aspiring geriatricians no longer
receive adequate training in continuing care.

The NHS responsibilities for continuing care have
been given attention by the Health Service Ombudsman
[3, 4] and the Court of Appeal [5]. Health authorities now
issue eligibility criteria governing access to free continu-
ing NHS health care, so provision may increase, needing
more involvement by NHS staff including geriatricians.
Continuing care patients can be complex and present eth-
ical problems; some are illustrated in the following case
discussion.

Background
A previously well 57-year-old woman became uncon-
scious following a subarachnoid haemorrhage, complicated
by pulmonary oedema, cardiac arrest, right occipito-parietal
infarction and epilepsy. Initial treatment consisted
of ventilation, phenytoin and an external ventricular
drain (later converted to a ventriculo-peritoneal shunt).
She was subsequently extubated and a percutaneous
endoscopic gastrostomy (PEG) was inserted. It was
thought that she might improve but staff and family
agreed that further cardiopulmonary resuscitation was
not appropriate.

Too young for a geriatrician?
Eight months after admission she had no voluntary limb
movement, was only occasionally able to say ‘yes’ indiscrim-
ately, had left-sided neglect, was sometimes able to track
movement with her eyes and required full nursing care. Her
nutritional needs were met through the PEG. She was
transferred to an NHS continuing care ward accommodat-
ing older people in a community hospital. The lack of spe-
cific facilities for younger adults with chronic disability
means they may be cared for in environments designed for
older people. Whilst current trainees in geriatric medicine
will have dual qualification in general internal medicine, the
curriculum does not incorporate training in caring for
younger adults with chronic disability. Although many skills
of a geriatrician may be transferable to caring for younger
adults, this is not assured.

Empirical management
Over subsequent months, her level of awareness varied but
physical examination and blood tests did not reveal any
cause. Loss of communication prevented normal assess-
ment of depression and empirical therapy was commenced.
This was felt reasonable in the clinical context and also
because depression is common in care homes [6] and hos-
pital residents [7].
The variations in awareness led the family to enquire whether computerised tomography (CT) of the head might be of benefit. Medical Research Council staff, who had already assessed her some months previously (as part of research into coma), also suggested re-imaging. The team holding clinical responsibility felt that transfer for this investigation might not influence her management. Instead, the neurosurgeon who had initially treated her assessed her on the ward and agreed that a repeat scan was unnecessary.

Issues about how far to investigate can arise during the care of chronically ill, dependent patients. The key question to be answered is whether or not investigation is likely to reveal treatable pathology resulting in benefit, considering the co-morbidities. For this to be fulfilled, the individual needs to be fit for the investigation and any anticipated intervention. A CT scan would have involved transfer by ambulance and trolley use, with the inherent risk of pressure sores. Had significant pathology been identified would she have been a candidate for intervention? Making such decisions demands knowledge of the patient’s wishes, constitution and the implications of investigations and treatments available.

Mere prolongation of life?

Lack of improvement implied that eventual recovery might never materialise. Staff tried to ascertain from the family whether an advance directive (living will) was in existence and their views about what could be construed as mere prolongation of life without regard to its quality. The patient’s son and daughter were interviewed and remembered that years earlier their mother had said words to the effect: ‘If ever I am (in this situation), please switch off the machine’. No written advance directive had ever been made. Given her low awareness state and lack of capacity, staff and the family agreed to prepare an application to the Family Division of the High Court to end artificial nutrition.

Advance directives

Advance directives (ADs) can indicate the treatment preferences of persons no longer able to communicate. Whilst relatives and next-of-kin may be able to offer some insight as to a person’s wishes, it can be difficult to be sure if these are contemporaneous, relevant or valid.

The patient had expressed a verbal wish in the past not to receive life-sustaining therapy if unable to communicate and maintained on a machine, presumably. Whilst verbal ADs are recognised in law, it is difficult to rely on them alone when facing such fundamental choices, especially as there may be bias when recalling, second-hand, the situation described. However, the law in England clearly upholds the legitimacy of a statement of advanced refusal. Legitimacy of ADs rests on several key criteria (Table 1).

Table 1. Criteria for a legally binding AD

<table>
<thead>
<tr>
<th>Number</th>
<th>Criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Clearly established and no reason to doubt a recent change in values</td>
</tr>
<tr>
<td>2.</td>
<td>Applicable to the current circumstances</td>
</tr>
<tr>
<td>3.</td>
<td>The maker was competent (had legal capacity) on drafting the directive</td>
</tr>
<tr>
<td>4.</td>
<td>Absence of undue influence</td>
</tr>
<tr>
<td>5.</td>
<td>The present circumstance was contemplated in the directive</td>
</tr>
<tr>
<td>6.</td>
<td>The maker was aware of the consequences of refusing treatment</td>
</tr>
<tr>
<td>7.</td>
<td>No unlawful requests are being made of the health care team</td>
</tr>
<tr>
<td>8.</td>
<td>No clinically inappropriate treatment is being requested</td>
</tr>
</tbody>
</table>

Verbal statements may be made casually or during temporary despondency and may not reflect the individual’s normal views. A written AD made some years before may be doubted because current circumstances might not precisely match those envisaged at the outset. It is therefore preferable to express ADs in general rather than specific terms to guide future treatment decisions. Specific ADs can be useful, but the risk is that a specific directive might not be applicable if the precise conditions are not all fulfilled, thus potentially frustrating the original intention.

Another difficulty with ADs is that views may have changed. As the House of Lords Select Committee noted, ‘Disabled individuals are commonly more satisfied with their life than able-bodied people would expect to be with the same disability. The healthy do not choose in the same way as the sick’ [8]. We would suggest that ADs are reviewed on a regular basis (at least yearly).

Staff may doubt the individual’s knowledge of the circumstances addressed in the AD. The British Medical Association suggests that ADs are discussed fully with a health care professional, although this is not a legal requirement [9]. ADs do not demand that the individual should possess a similar level of knowledge as when giving informed consent, but knowledge of the key issues should be demonstrated.

ADs are often made to refuse treatment but they can also request it; treatment requests should be within the realms of what is deemed reasonable by the health care professionals, who cannot be compelled to provide futile treatment. Futile treatment could disadvantage others who would benefit, an issue if resources are scarce.

PEG feeding: acting in best interests or trespass against the person?

Her level of awareness later improved. She became able to chuckle in response to humour, smile in response to ‘hello’, try and mouth a reply but not produce sound. The nursing staff gained the impression that she might not want the PEG feed to continue and were concerned that they might be imposing treatment against her wishes. This is illegal if a person has capacity and legal if not – the ‘doctrine of acting in best interests’ [10]. She would display agitation and generally seem upset when the feed was assembled. It was impossible to ascertain whether or not there was any consistent and cognate rejection of the feed. When asked about the feed, she would sometimes shrug as if to indicate helpless acquiescence, or apparently decline the feed by shaking her head, even when the necessity of the feed was explained. Asked ‘do you want to live?’ – the apparent answer, conveyed by shaking or nodding of the head, was more often negative than positive, but never consistently one or the other. She would accept the feed when asked again a few hours after refusing. Staff felt that she was probably competent for this fundamental decision and therefore the Court application was abandoned.
Currently, 30 months on, she requires full care and is unable to tolerate chair rest; she has limb contractures but her skin is intact. She has a suprapubic catheter and no bowel control. Her mood appears low, but she seems to enjoy classical music and television. She accepts the PEG feed without dissent.

Conclusion

This tragic case illustrates the need for a range of skills in continuing care settings. Awareness of policy on continuing care and of relevant law governing capacity and ADs is required. Judging how far to intervene and how to involve the family and staff are also important. We suggest that aspiring geriatricians should receive specific training in continuing care to be able to manage these issues.

Key points

• NHS continuing care wards look after severely disabled individuals, who are usually older people.
• Ethical dilemmas in continuing care settings may focus upon feeding, ventilation, advance directives and treatment choices amongst others.
• Continuing care requires a broad range of skills both medical and personal, as well as a willingness to embrace debate and discussion.
• Geriatricians are used to working in a multidisciplinary unit and are well placed to lead in the continuing care setting.
• Continuing care should form part of mainstream teaching in geriatrics.

Acknowledgement

We would like to thank the family for their agreement to describe the case.

References