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# 1 Formative Care: Rethinking the medicine of frailty.

2

## 3 Abstract

4 The care and support of the increasing ill, frail and dependent population, is poorly  
5 served by orthodox health and social care. Policy initiatives such as the integration of  
6 the funding of health and care services, admission avoidance schemes and  
7 improved end of life care are generally reactive to a service problem as opposed to  
8 patient need. What has been lacking generally has been an understanding of the  
9 dependent population and the potential for developing a positive proactive approach  
10 to wellbeing and life quality in lives reframed by frailty and dependency.

11 It is proposed that the term “Formative care”, would bring distinction from traditional  
12 health and care strategies of prevention, diagnosis, treatment, rehabilitation,  
13 palliative and end of life care.

14 The use of life trajectories of older people can help define the population of the frail  
15 for whom new formative approaches to health may be effective and in the absence  
16 of clear clinical markers that define the limits of traditional medical approaches, the  
17 watersheds of social transitions may provide a prompt for the institution of a  
18 formative approach to health and care.

19 Recognising the health and care space for a formative approach to health and care  
20 may facilitate a coherent approach to the development of understanding, policy and  
21 practise and will necessitate new research to inform best practise.

22

23 *Keywords: frailty, well-being, life quality, life trajectories, care homes, clinical*  
24 *purpose, integration, treatment strategy,*

25

## 26 Introduction

27 Modern Medicine generally can be described in terms of prevention, diagnosis and  
28 the evidenced treatment of acute and long term conditions. Additionally and  
29 particularly for older people needs assessment, rehabilitation and good end of life  
30 care are well established. These clinical domains are broadly mirrored in social care  
31 where prevention, personalisation, enablement, empowerment and risk management  
32 are commonly cited.

33 The early days of Geriatric Medicine highlighted the importance of assessment,  
34 treatment and rehabilitation for reducing dependence on care (1) as has the  
35 improvement of living conditions and general support (2). Collectively, these have  
36 successfully limited avoidable dependency. However, ageing populations feature a  
37 growing number of older dependent people who are increasingly unresponsive to  
38 traditional treatment(s) but for whom dying and death is not imminently anticipated.  
39 This emerging population of the frail old is increasingly becoming recognised (3) as  
40 is the complexity of managing multiple morbidities (4). However, there is little

41 coherence to the purpose of medicine for this population in spite of frequent public,  
42 professional and political concerns with common themes of dignity and needs,  
43 quality of life and affordability(5).

44 The continued use of the denominator of age without qualification by clinical and  
45 socio-economic circumstances creates uncertainty for policy makers, should they  
46 plan for a healthy ageing population, a dependent one or a mix and if so what  
47 proportion? Persisting difficulties in achieving a sustainable funding solution for long  
48 term care may be in part rooted in mixed demographic/epidemiological messages  
49 and uncertainties of what is required now and in the future for an increasingly aged  
50 society.

51

## 52 Life trajectories to death and medical responses

53 It is widely recognised that multiple morbidities increasingly complicate health and  
54 the specialist treatment of multiple diseases in specialist silos is increasingly  
55 questioned (4). The analysis by Lynn and Anderson (6) of the trajectories of a large  
56 group of US Medicare (an older population) beneficiaries tracked towards their death  
57 provides a compelling classification of the clinical pathway to death of an ageing  
58 population. Four broad categories were identified,

- 59 • 20 per cent of deaths followed an illness such as cancer that is characterised  
60 by a clear clinical transition from living with to dying from a condition that has  
61 an unrelenting progression. In the UK this group will be recognised as having  
62 benefited from the development and increasing availability of palliative and  
63 hospice care.
- 64 • 20 per cent of deaths were related to progressive long-term conditions  
65 complicated by acute exacerbations during which an increasing likelihood of  
66 death is recognised, for example Chronic Obstructive Pulmonary Disease.  
67 People in this category are likely to be in programmes of chronic disease  
68 management where the limits of treatment and likelihood of dying and its  
69 nature are understood by specialists, primary care and crucially by patients  
70 and their families, enabling their care and support needs to be informed by  
71 this condition.
- 72 • 20 per cent of deaths were classified as “sudden”, for example a fatal  
73 myocardial infarction or an accident. For this group preventative medicine and  
74 continued developments in safety may yield further reductions.
- 75 • The largest group of 40% were poignantly described as dying after a period of  
76 “progressive dwindling”. This group are typified by people with conditions  
77 such as Alzheimer’s disease and other degenerative conditions that are  
78 individually or collectively progressively disabling. It is this population that  
79 forms the greatest collective demand of health and care support over long  
80 periods and the population that is the prime concern of this paper.

81

## 82 The growing importance of progressive frailty

83 As progress continues to be made in the treatment of diseases that have previously  
84 dominated mortality in later life the importance of conditions individually and

85 collectively that lead to dependence and frailty will grow both proportionally and  
86 absolutely.

87 For life trajectories such as cancer or chronic progressive conditions clinical  
88 watersheds are often identified for example, the disease progression that triggers a  
89 clear change in the rationale and expectations of treatment and care exemplified by  
90 cancer that becomes unresponsive to treatment creating a “watershed” to palliative  
91 care and end of life care. The clarity of this “watershed” approach has transformed  
92 care at the end of life in Cancer but it has been extended, somewhat uncritically, to  
93 the progressively frail. Very frail patients may have a life expectancy of several years  
94 and are certainly not “actively” dying.

95

#### 96 Traditional health, care and frailty

97 Evidence based medicine is generally based on “intention to treat” trials where  
98 outcome benefits are sufficient to justify the risks of treatment and costs. Evidence  
99 for sustained treatment of conditions over long periods often into great age often rest  
100 on an extrapolation of evidence which may be tenuous in advanced frailty often  
101 complicated by co-morbidities. Furthermore, the responsiveness of many diseases to  
102 treatment often diminishes with disease progression and proven benefits may  
103 increasingly become blurred or outweighed by adverse effects. The unacceptability  
104 of excluding older people from research is becoming increasingly recognised (7).

105 Often discharge notes from hospital of frail patients, particularly when transferred to  
106 care homes infer that, “nothing more can/could or should be done”, yet patients  
107 typically will be on an extensive list of treatments and subject to varying degrees of  
108 planning for the end of life. This is a bleak and confusing approach and the  
109 uncertainty it creates may contribute both to the application of care pathways for end  
110 of life care when the diagnosis of dying is uncertain (8) and the right to determine  
111 death debate. The majority of these frail patients are entering an emerging “medical  
112 space” where the medical purpose needs both clarification and communication. The  
113 expression “enabling the best possible life quality and experience in the context of a  
114 life reframed by frailty” captures the essence of what many practitioners intuitively  
115 think and often practise. Calling this a “Formative” approach to medical care may  
116 help distinguish it from palliative and end of life care and the more established  
117 diagnosis and treatment of modern medicine.

118

#### 119 Social watersheds and formative medical care

120 Progressive frailty seldom exhibits a clear clinical watershed although one may be  
121 identified in retrospect. However, progressive frailty is often accompanied by social  
122 watersheds of which admission to a care home for long-term care is perhaps the  
123 most readily identifiable. Care Home admission usually follows assessment(s) that  
124 centre on eligibility and the seeking of opportunities through treatment and  
125 rehabilitation to avert admission rather than the on-going health care. An individual

126 with dementia may require the sanctuary and support of a care home for an average  
127 length of stay of some 20 months. Whilst the importance of good end of life care is  
128 acknowledged, active dying will only occupy a small percentage of that stay, so for  
129 the greater part of residence a clinical approach that seeks to optimise quality of life  
130 seems obvious but poorly stated. If Care Home admission were to be established as  
131 a an initial trigger for the “Formative” approach increasing knowledge could develop  
132 understanding of when a transition to a formative approach may be appropriate more  
133 widely in the community.

134 The following case vignettes illustrate a “Formative” approach to medical care  
135 following admission to a care home,

136 • The person with dementia has been treated with sedation in the community to  
137 enable family carers to cope with disordered sleep pattern. A combination of  
138 carer exhaustion and disease progression in spite of maximal support  
139 necessitates care home admission. Sedation is withdrawn and whilst sleep  
140 patterns remain considerably disturbed the twenty four hour care can  
141 accommodate this and the person’s behavioural pattern improves such that  
142 day trips with family become possible. The individual remains dependent on  
143 care but their life quality becomes much improved.

144 *Note: 75% of prescriptions for antipsychotic medication of care home*  
145 *residents are initiated prior to admission to the care home (Personal*  
146 *communication Pharmacy Plus December 2011)*

147 • The person with increasingly poor mobility related to long standing  
148 Parkinsonism whose treatment has been escalated in an attempt to maintain  
149 mobility sufficient for family to support at home develops a treatment related  
150 psychosis and is admitted to a care home. With 24 hour access to 2 carer  
151 enabled transfers treatment is reduced, whilst physically dependent lucidity is  
152 regained to enable meaningful socialisation. Note: overall 5% of care home  
153 residents are diagnosed with Parkinsonism (9)

154 • The malnourished person with advancing frailty, mild confusion and repeated  
155 falls is admitted on long term treatment with beta blockers for hypertension  
156 and Statins for cardiac risk and dietary supplements. The patient exhibits  
157 postural hypotension and so the beta blockers are discontinued as are the  
158 Statins and supplemental feeds. Meal times are supervised and the patient  
159 gains weight and strength to the extent that after several months they are  
160 discharged home lucid and independent with no on-going support. It is  
161 unclear whether the improvement of mental state has been due to improved  
162 cerebral perfusion or a beta blocker related pseudo-dementia.

163 The clinical interventions described are distinct active interventional approaches that  
164 are not easily classifiable in common approaches to medical practise, though  
165 experienced Geriatricians and General Practitioners will recognise them. They all  
166 illustrate an active approach that seeks the “best deal” for the patient in the context  
167 of their circumstances and are about optimising well-being and whilst evidence of

168 inappropriate prescribing is recorded (10) guidance on positive drug withdrawal is  
169 lacking (11). The altered nature of therapeutics in frailty is starting to be recognised  
170 as a dark corner of medicine with calls for trials to clarify the effective and ineffective  
171 use of medicines in older people (12). There is evidence to support systematic  
172 discontinuation of medication in older people who present for geriatric assessment  
173 within the community (13) but such work needs to be undertaken on a larger scale  
174 before robust guidance can be constructed.

### 175 Making formative care evidence based

176 Developing a practice of Formative care for the frail will require systematic  
177 programmes of research into the withdrawal of treatment and the benefits of various  
178 interventions, to develop guidelines. Such trials are unlikely to be funded by  
179 Pharmaceutical companies but as electronic records of prescribing and care become  
180 more accessible and both the relative ease of access to care home residents many  
181 traditional difficulties may be overcome. Furthermore, new treatments targeting  
182 conditions such as established and advanced Alzheimer's data from assessments  
183 could, at scale, provide not only disease registries but a means to investigate new  
184 interventions against a contemporary database.

185 This approach focuses initially on care home residents it is important to recognise  
186 that in the UK the number of care home beds exceed all NHS beds by more than  
187 three times and that some 80% of the adult social care budget is currently committed  
188 to the funding of care home places care homes. Whilst prevention, re-ablement  
189 together with good palliative and end of life care remain crucial an evidenced  
190 "Formative" approach proposed will reduce futile and expensive medical treatments  
191 as well as promote well being and maintain outcomes as proactive managed care  
192 approach has already been proven to deliver (16). Substantial savings will accrue  
193 from the reduction of ineffective prescribed drugs. With over 400000 residents in  
194 care homes presently prescribed an average of 7 items potential savings of £100  
195 million annually to the drug bill and considerable reductions in acute hospitalisations  
196 as a result of iatrogenic disease projected.

197

### 198 Conclusion

199 The lack of systematic approach to the health and care of the frail is a contemporary  
200 demonstration of the inverse care law (17). The use of a social watershed as a  
201 trigger for a developed "Formative" approach the medical care of people resident in a  
202 care home promises a rare combination of improved patient well being, a positive  
203 new medical purpose.

204

205

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