

1 *Review*

# 2 **Treatment, Palliative Care or Euthanasia? Comparing** 3 **End of Life Issues in Human and Veterinary** 4 **Medicine**

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8

9 **Abstract:** Not a lot is known about either death or the dying process. Politicians and many in the  
10 medical profession in the UK tend to shy away from interfering with it by not allowing euthanasia  
11 as an end of life option for the patient. This is the first paper in a series of two, comparing the  
12 situation in human medicine and veterinary medicine, in which euthanasia is well practiced for  
13 relieving suffering at the end of an animal's life. This first part takes the form of a literature review  
14 including best practice around end of life care, its deficiencies and the need for assisted dying.  
15 Veterinary surgeons are well trained in the ethics of euthanasia and put it to good use in the best  
16 interest of their animal patients. In countries which have legalized physician assisted suicide for the  
17 terminally ill reporting indicates that it works well, without increases in involuntary euthanasia and  
18 most importantly without intimidation of the vulnerable. However, there is still an ever increasing  
19 tendency to overuse sedation and opioids at the end of life, which merits further investigation. With  
20 advances in medical science able to significantly prolong the dying process, patient autonomy  
21 demands a review of the law in the UK.

22 **Keywords:** euthanasia; veterinary ethics; medical ethics; end-of-life; assisted suicide; palliative care;  
23 assisted dying.  
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## 25 **1. Introduction**

26 Clinical veterinarians and animal owners have all experienced the relief that euthanasia brings  
27 for a terminal patient which has reached, or is at the point of reaching, a stage of unacceptable  
28 suffering. Conversely, many members of the public have witnessed the prolonged suffering of a  
29 human family member at the end of their life [1]. As medical technology advances, for some  
30 individuals the possibility of extended life in a debilitated condition may not be preferable [2].

31 Death is an emotive and final subject, therefore it is difficult to do controlled studies (without  
32 being intrusive), of people's end of life experiences as to how it could be improved.

33 It may be useful to compare the situation in veterinary medicine and human medicine as  
34 although both aim to prevent and relieve suffering, veterinary medicine has the added option of  
35 euthanasia. The ethics associated with euthanasia are incorporated into every veterinary student's  
36 training. Discussions about euthanasia in the veterinary literature could be helpful in resolving some  
37 of the reservations identified in human medicine as veterinarians have valuable experience of  
38 euthanasia.

39 Since most domestic animals have one-fifth the life span of people, veterinarians see death at a  
40 much higher rate than their physician counterparts [3,4].

41 Humans appear to have an emotional bond to their companion animals that is comparable to  
42 what they experience with family and friends [5]. High rates of family breakdown, rising levels of  
43 loneliness, mental ill health and emotional instability mean pets plug an important gap for many

44 people. Emotional dependence on animals mean they can be over-loved and over-indulged and this,  
 45 according to the RSPCA's chief vet can lead to problems like hoarding, obesity or failure to make  
 46 responsible decisions, including euthanasia, where appropriate [6].

47 Veterinarians are consistently ranked among the most trusted members of society [7]. Today's  
 48 veterinarians are expected to provide ethical and moral guidance in animals' care [4]. The public trust  
 49 veterinarians to reduce animal suffering.

50 This is both relevant and important because the British Medical Association (BMA) argues  
 51 against any form of legal assisted dying as they say the majority of doctors think that it would destroy  
 52 the doctor-patient relationship [8] (p.63). One only needs to read the authoritative studies which have  
 53 come out of the Netherlands to understand that the doctor patient relationship there has not been  
 54 compromised by the legalization of physician assisted suicide. In fact when euthanasia is performed  
 55 it is the family physician who is most frequently involved [9].

56 The argument that legalization would lead to a 'slippery slope' of increased use of involuntary  
 57 euthanasia of the vulnerable just does not hold water [10]. Some people would argue that euthanasia  
 58 in veterinary medicine is totally unregulated. This is why it is necessary to look at regulation in the  
 59 Netherlands, which has been in place since 1991, eleven years before euthanasia was officially  
 60 legalized there. 'There is no evidence from the Netherlands that the legalization of voluntary  
 61 euthanasia caused an increase in the rate of non-voluntary euthanasia' [11] (p.205). Evidence from  
 62 Europe [12], shows that the incidence of involuntary euthanasia has remained the same or decreased  
 63 since legalization of medically assisted suicide in Belgium. In the USA even The Oregon Hospice  
 64 Association's concerns have been allayed [13] (p. 29), studies show that the 'slippery' surface has  
 65 dried out and indeed there is no 'slope' to be found.

66  
 67 **PICO Question.** Would terminally ill patients in the UK benefit from the option of a medically  
 68 assisted death, as in veterinary medicine and some foreign countries and states where voluntary  
 69 suicide/ euthanasia has been legalized?

70  
 71 **Definitions** as used in this article:

- 72  
 73 1. 'Medically assisted dying' (MAD) is an all-encompassing term which includes all measures  
 74 taken, or not taken, by doctors/physicians administering or withholding treatments, or  
 75 prescribing medications to be administered by nurses or technicians or the patient, in  
 76 hastening the dying process. Withholding treatments, ('forgoing life-sustaining treatment')  
 77 can be voluntary, requested at the time or as previously directed in a valid 'advance  
 78 directive', or non-voluntary, decided upon by the doctors, in consultation with the next of  
 79 kin.
- 80 2. 'Physician/doctor/medically assisted suicide' (PAS) is the competent patient voluntarily  
 81 ingesting or starting the infusion of a medication which they have requested, prescribed by  
 82 a doctor/physician with the sole intention of causing death. It is illegal in the UK but  
 83 available in some countries/states under strict regulations.
- 84 3. 'Physician/doctor assisted dying' (PAD).
- 85 • Voluntarily, is at the patient's current or previously validated 'advance decision'  
 86 request, where the medication to end life is administered by the physician/doctor.  
 87 It is illegal in the UK.
  - 88 • Involuntarily, is at the doctor's decision where the medication is administered by  
 89 the doctor. This is illegal so the patient and next of kin are not informed.
- 90 4. 'Euthanasia' is derived from a Greek word meaning a 'good death'. Francis Bacon in 1605  
 91 first coined the term in reference to alleviating suffering of human patients [14].  
 92 It is defined by the European Association of Palliative Care as a physician (or other person)  
 93 intentionally killing a person by the administration of drugs, at that person's voluntary and  
 94 competent request [15] (p. 5).
- 95 • For animals:

- 96 Active euthanasia is the administration of medication to the patient by the vet, with  
 97 the intention to end life.  
 98 Passive euthanasia is forgoing life-sustaining treatments. It may be the best option  
 99 for wild animals if handling and killing them makes them suffer more than leaving  
 100 them to die [16].
- 101 5. Yeates defines euthanasia as killing an animal in its interests [16]:
- 102 • Voluntary euthanasia of an animal as being undertaken with a client's valid full  
 103 and informed consent,
  - 104 • Non-voluntary euthanasia of an animal may be performed during an emergency to  
 105 relieve suffering when the owner is unknown or uncontactable.
  - 106 • Involuntary euthanasia of animals is only legal for veterinarians 'treating' animals  
 107 under the authority of a police officer or Court of Law, being against the expressed  
 108 wishes of the owner [16].
- 109 6. 'Terminally ill' - irreversible fatal illness [17].  
 110

## 111 2. Methods

### 112 2.1. Search strategy

113  
 114 A search of the literature was carried out using CAB Abstracts and PubMed in order to compare end  
 115 of life issues between human and veterinary medicine. Preliminary searches revealed a dearth of  
 116 comparative medicine papers about end of life issues. A broader CAB Abstracts search (Appendix  
 117 A1) revealed 166 papers and a further CAB search (Appendix A2) revealed 25 papers (including only  
 118 a few duplicates). The broader search approach did not work with PubMed in that hundreds of  
 119 irrelevant papers were being included so it was decided to narrow the search terms to find papers  
 120 most closely related to the PICO question. This PubMed search (Appendix A3) revealed 204 papers  
 121 providing a total of 395 papers.

122 Other databases used were Google Scholar and a manual search of the bibliographies of some of the  
 123 electronically identified articles also revealed additional relevant articles.

124 Search terms: (euthanasia OR assisted dying) AND ethics AND (end of life OR palliative care). For  
 125 the full search terms used see Appendix A, 1-3.

126 This review is unique in that it considers end of life issues for both humans and animals from  
 127 the author's veterinary point of view. Due to the lack of comparative medicine papers on the subject  
 128 and the narrowed field of related search terms this review does not qualify as a systematic review.

129 In the end 28 published articles and one veterinary forum on Medically Assisted Dying on  
 130 vetsurgeon.org [1] were chosen as being relevant to the subject matter of this paper and worthy of  
 131 inclusion. They are summarised in the evidence tables. A further 76 resources are referred to in the  
 132 context of this review and the subsequent ethical debate.

133

### 134 2.2. Exclusion/inclusion criteria

135

136 2.2.1. Exclusion: methods of euthanasia; non mammalian species; euthanasia for controlling stray  
 137 animals; euthanasia for controlling notifiable diseases; euthanasia for controlling  
 138 dangerous/aggressive dogs; individual cases; articles about withholding life supporting treatments  
 139 in intensive care; non English language publications; advice about the management of euthanasia of  
 140 dogs and cats.

141 A discussion about the justification for destroying healthy animals to control stray animal  
 142 populations or for Notifiable Disease Control purposes or for aggressive/dangerous dog control,  
 143 does not come under the remit of this study.

144 Ethical dilemmas about turning off life supporting treatments in Intensive Care Units is not  
 145 encountered in veterinary medicine and is already adequately dealt with within the law.

146  
 147 2.2.2. Inclusion: published data relevant to the PICO question and review title.

148  
 149 The studies included as evidence in this review were both quantitative and qualitative in view  
 150 of the subject matter. They were primarily chosen because they surveyed a large or representative  
 151 database. The summary tables of the evidence record the reference details, population studied,  
 152 sample size, intervention details, study design, outcome studied, main findings and limitations.  
 153 Examples of inclusions are:

154 One position statement from the American Association of Feline Practitioners (AAFP) sums up the  
 155 end of life issues succinctly for one species of pet animals in the United States [18].

156 One International collaborative guide, on artificial nutrition and hydration guidelines for those  
 157 attending to patients at the end of their lives, emphasizes that the dying process should not be  
 158 prolonged [19]. On the other hand, one white paper from the European association for palliative care  
 159 (EAPC) states that the provision of euthanasia and PAS should not be included into the practice of  
 160 palliative care [15]. One paper from the USA is a national survey of physicians about receiving  
 161 requests for assisted suicide or euthanasia, and their compliance with the requests [20].

162 There is a dearth of evidence comparing veterinary and human end of life issues so it was decided to  
 163 include a forum by veterinary surgeons on Medically Assisted Dying [1].

164 One published philosophical argument against the comparison of human and animal euthanasia was  
 165 included to add to the debate [21].

166 There is one systematic review, one narrative review and one qualitative study about palliative  
 167 pharmacological sedation [22,23,24].

168 One article summarized the legal status of euthanasia and PAS in the year 2000 in Canada, USA,  
 169 Australia & the Netherlands, with a proposal of practical legislation [25].

170 Three publications were produced by the BMA in 2016 about end of life care and MAD [26,8,27].

171

### 172 **3. The global situation for humans regarding MAD**

173 Following strict guidelines to protect the vulnerable, voluntary, MAD is legal in the Netherlands  
 174 (since 2002), Belgium (2002), Luxembourg (2009), and Switzerland (1942), for mentally competent  
 175 individuals who are terminally ill, severely disabled or very elderly with medical problems.

176 In Canada (2016) and the American States: Oregon (1997), Washington State (2009), Vermont  
 177 (2013), California (2015) and Colorado (2016) PAS is now legally possible for the terminally ill. In  
 178 2009, although not officially legalizing assisted suicide, the Montana Supreme Court's ruling changed  
 179 the legal status of PAS under the state's living will law, 'The Rights of the Terminally Ill Act,'  
 180 permitting physician 'aid in dying,' so if charged with assisting a suicide, a doctor could use the  
 181 patient's request as a defence [28].

182 As far back as 1997, Colombia's High Court ruled that doctors could not be prosecuted for  
 183 helping patients with a terminal illness make the legal decision to end their lives. Conditions which  
 184 must be met include a medical determination that the patient has a terminal illness, and the patient's  
 185 consent [29]. In April 2015 the Constitutional Court ordered the Health Ministry authorities to set  
 186 guideline protocols for medical practitioners to reassure them that they would not be prosecuted for  
 187 PAS of adults in their terminal phase of illness, but excluding patients with degenerative diseases. A  
 188 committee comprised of a medical expert, a lawyer, and mental-health professional then have 10 days  
 189 to reach an agreement that the patient qualifies for euthanasia [30].

190 Currently any practice of euthanasia is illegal in China, and some people argue that euthanasia  
 191 legislation should be considered only when the medical care system, the moral standing of medical  
 192 staff and the social insurance system have been greatly improved [31].

193 On Friday 11<sup>th</sup> September 2015, 330 (v 118) MPs voted in Westminster against the Assisted Dying  
 194 (No 2) Bill which Labour MP Rob Marris had brought before them, (originally Lord Falconer's bill).  
 195 Rob Marris: 'The Bill is not about euthanasia; it is about the self-administration of lethal medication  
 196 at the end of life' [32] (column 659). In 1981 Prince Philip was quoted as saying 'Once a determined  
 197 government begins the process of eroding human rights and liberties – always with the very best  
 198 possible intentions – it is very difficult for individuals or for individual groups to stand against it'  
 199 [33]. Most of the MPs' arguments against the Bill were to 'protect the vulnerable'. Yet people of 80  
 200 years of age or older is the least common age group for euthanasia and assisted suicide in the  
 201 Netherlands [34].

202 The picture is different in the USA according to a review of the epidemiology of suicide in later  
 203 life. In Oregon from 1998-2011, after the Death with Dignity Act was passed, out of the 596 medically  
 204 assisted deaths, 68.6% were people of 65 years or older with serious medical illness that compromised  
 205 their quality of life. Similarly in Washington State from 2009-2011, after their Death with Dignity Act,  
 206 out of 213 of the medically assisted deaths 68.6% were again of the 65 years plus age group, with  
 207 serious medical conditions which compromised their quality of life. This was in marked contrast to  
 208 natural suicides (thought to be pathological, nearly all were clinically depressed, the majority were  
 209 from gunshots to the head or body), for the year 2000 in Los Angeles, only 23% of 713 natural suicides  
 210 were people aged 65 years or older who had debilitating health [35]. It begs the question: Is it 3 times  
 211 more difficult to pull the trigger on your own than have a supportive team around you, respecting  
 212 your autonomy and decision to end your life when you are old and suffering from a debilitating  
 213 medical condition?

214 Patients with advanced neurodegenerative disease also fall into the 'vulnerable' category. In this  
 215 group Low & Ho [36] recommend using Jonsen's 4-Topic approach to resolving ethical dilemmas,  
 216 which takes into consideration: 1 the medical indication for treatment, 2 patient preference, 3 quality  
 217 of life which is complex, unique to each individual and a subjective phenomenon that may not be  
 218 adequately understood even with substitute judgement by family members, 4 contextual features,  
 219 such as social, cultural, religious, ethnic, legal, health economics and organizational practices. These  
 220 factors would be taken into consideration by a hospital ethics committee [37].

221 Arguments that allowing PAS would be detrimental to society's moral values, such as 'It may  
 222 be that legalizing PAS also provides positive role models who help normalize suicide more generally'  
 223 [38], as cited by Jones and Paton, are not substantiated by the latter's study into the effect of  
 224 legalization of PAS on rates of suicide [39]. They found no statistically significant increase in non-  
 225 assisted suicides in States following the legalization of PAS.

226 In The UK the only way doctors can 'assist' the dying process is through the 'double effect'.  
 227 Based on the doctrine of double effect a doctor may do all that is proper and necessary to relieve pain  
 228 and suffering, even if the measures he takes may incidentally shorten life [2].

229 An experienced district nurse interviewed on the BBC radio 4 programme 'We need to talk about  
 230 death', Series 1, on 30th Nov 2016 said, "Sometimes dying takes a very long time" [40].

231 Dignitas near Zurich, set up in 1998, allows foreigners to use its services and according to its  
 232 own figures, up until last year 310 Britons had died there [41]. It is a non-profit members' organisation  
 233 whose motto is 'to live with dignity – to die with dignity'. They believe that 'when someone is  
 234 suffering greatly, the healthy cannot judge what that individual's life is worth' [13] (p. 64). Lifecircle  
 235 near Basle and Ex International in Bern also provide PAS for non-Swiss nationals. This has led to the  
 236 emergence of the term 'death tourism' which is classified as a form of 'dark tourism' [42]. However  
 237 these trips have to be at a time whilst the individuals are physically able to travel abroad and with  
 238 associated costs amounting to over £10,000 [13] (p. 70).

239 In Canada it is claimed that although 'GPs would perhaps be best-suited to aid a patient in dying,  
 240 it has been argued elsewhere that hastening death is beyond the purview of medical professionals  
 241 and should not be part of any physician's practice. In August 2015 the Canadian Medical Association  
 242 weighed in on this debate by polling its members and receiving 1,407 responses to an online survey.  
 243 The survey asked whether the responding physicians would consider providing 'medical aid in  
 244 dying' if requested by a patient, and results indicated that 63% would refuse. This survey points to a

245 much larger issue than can be addressed in this paper; there exists disagreement regarding whether  
 246 physicians should be involved in assisting the death or euthanizing a patient. Assistance in dying  
 247 although best-suited to be performed by a family physician, may be able to be pursued through a  
 248 trained specialist if requirements are met' [43] (p. 1496-1497).

249 In 1997 in a study by the Department of Social and Preventive Medicine at the University of  
 250 Queensland, critical care nurses, more than any other health professional group, supported the right  
 251 of the terminally ill patient to PAS or euthanasia, their responses being very similar to those of  
 252 community members [44].

253 In 1998 when people were dying horribly from AIDS, in a survey of 160 English-speaking  
 254 Canadian nurses working with HIV patients, 73% believed that the law should be changed to allow  
 255 physicians to practice euthanasia and PAS. 53% indicated that nurses would be willing to practice  
 256 euthanasia and PAS. More than one in 5 nurses had received requests from patients to hasten their  
 257 deaths by euthanasia. Nearly 98% believed that the nursing profession should be involved in policy  
 258 development, and nearly 78% believed that nurses should be involved in the decision-making process  
 259 with patients if such acts were legal. Given that nurses are the largest group of care providers for the  
 260 terminally ill [45], it is not surprising that following an extensive and detailed consultation process  
 261 with their members, the Royal College of Nurses moved in 2009 to a neutral stance in relation to  
 262 assisted dying for people who have a terminal illness [46].

263

#### 264 4. The evidence

265

##### 266 4.1. *The Netherlands & Belgium*

267

268 In 1991 The Dutch Government requested the first of a series of comprehensive, nationwide,  
 269 research articles into euthanasia and other medical decisions concerning the end of life (MDEL). The  
 270 guarantee of anonymity of patients and physicians all strengthen the validity and reliability of the  
 271 results. It found that in 17.5% of all deaths, the alleviation of pain and symptoms, with such high  
 272 dosages of opioids that the patient's life might be shortened, was the most important MDEL. In  
 273 another 17.5% a non-treatment decision was the most important MDEL. Euthanasia by administering  
 274 lethal drugs at the patient's request seems to have been done in 1.8% of all deaths [47].

275 In 1991 a new procedure for reporting cases of euthanasia and PAS was introduced [48]. It  
 276 requires doctors to report each case to the coroner, who in turn notifies the public prosecutor.  
 277 Ultimately, the Assembly of Prosecutors General decides whether to prosecute [49].

278 In 1994 a study of the regulation of euthanasia in the Netherlands stated that 'the visibility and  
 279 openness of this part of medical practice will lead to increased awareness, more safeguards, and  
 280 improvement of MDEL' [50] (p.1346).

281 A follow up paper studied the period from 1990-1995. 'In the Netherlands, euthanasia and PAS  
 282 have been practiced with increasing openness, although technically they remain illegal' [48] (p. 1699).  
 283 'In the Dutch health care system virtually all of the population is insured for health care costs so  
 284 economic motives have not yet entered the realm of MDEL' [48] (p. 1705).

285 In 1996 a paper studied The Notification Procedure for PAD in the Netherlands, commissioned  
 286 by the Ministers of Health & Justice. Of the 6,324 cases reported during the period from 1991 through  
 287 1995, only 13 involved prosecution of the physician. The number of reported cases increased over the  
 288 period but there remained a high level of non-reporting, especially of cases in which there was no  
 289 explicit request for euthanasia from the patient [49]. The Notification Procedure was then revised and  
 290 came into effect in 1998 [9].

291 In April 2002 the Euthanasia Act was passed to regulate the ending of life by a physician at the  
 292 request of a patient who was suffering unbearably without hope of relief [34].

293 2003 saw another follow up publication in the Netherlands which found that voluntary  
 294 euthanasia was used 6 times more frequently than assisted suicide in 1990 and 1995 and over 10 times  
 295 more frequently than assisted suicide in 2001 [9] (p. 396 Table 1). 'Euthanasia is frequently preferred  
 296 over assisted suicide because of physical weakness or incapacity of patients' [9] (p.398).

297 In 2003 a paper compared the situation in six European countries. Euthanasia without the  
298 patient's explicit request, happened more frequently than euthanasia at the patient's request, in all  
299 countries apart from the Netherlands [51]. Written living-wills were available for fewer than 5% of  
300 patients in all countries apart from the Netherlands, (13%). Doctors consulted colleagues about their  
301 end-of-life decisions for about 40% of all patients in the Netherlands, Belgium, and Switzerland, and  
302 for fewer than 20% in the other countries. Nursing staff were asked most frequently in Belgium (57%)  
303 and Switzerland (50%).

304 'Despite important advances in pain and symptom management at the end of life, many dying  
305 patients still have pain and other physical and mental problems' [51] (p.349).

306 **2007** Another follow up, to study end of life practices under the Euthanasia Act. They reported  
307 that euthanasia and PAS were to some extent replaced by continuous deep sedation. Physicians were  
308 administering sedatives when they had the explicit intention of hastening death, creating a grey area  
309 between sedation and euthanasia. Subsequently, in the Netherlands, the review committees  
310 disapproved the use of opioids for euthanasia [34].

311 In 2009 Smets et al. compared how the legal notification to a Review Committee, control and  
312 evaluation procedures following euthanasia worked in the Netherlands and Belgium. They found  
313 that the Dutch notification and control procedures are more elaborate and transparent than the  
314 Belgian, and that the Belgian procedures are primarily anonymous. Societal evaluation is made in  
315 both countries through the committees issuing summary reports to Parliament [52].

316 In 2009 Bilsen et al. surveyed end of life practices in Belgium under the Euthanasia Law. The  
317 percentage of involuntary euthanasia use did not increase [12].

318 Trends in end-of-life practices before and after the enactment of the Euthanasia Law in the  
319 Netherlands from 1990 to 2010 showed that the percentage of deaths as a result of voluntary  
320 euthanasia in Holland had not increased since studies before the introduction of the Euthanasia Act.  
321 The percentage of deaths as a result of involuntary euthanasia in Holland had decreased. However,  
322 continuous deep sedation until death occurred more frequently in 2010 (12.3%) than in 2005 (8.2%)  
323 [53].

324 In 2014 a study of international experts on end-of-life sedation suggested that problems were  
325 caused by the use of continuous deep sedation to alleviate psycho-existential suffering. Whilst  
326 withholding artificial nutrition and hydration this has the potential to shorten life. They suggested  
327 that there was a grey area between end of life sedation and euthanasia and that the intentions of end  
328 of life sedation should be clarified [54]. Whereas a previous narrative review from the USA, with a  
329 bias against PAS, suggested that 'expert pain relief and palliative care, including sedation to  
330 unconsciousness when necessary, should be widely available' [55].

331 'The goal of palliative terminal sedation is to provide the dying patient relief of otherwise refractory,  
332 intolerable symptoms, and it is therefore firmly within the realm of good, supportive palliative care  
333 and is not euthanasia,' [56] (p. 407).

334 In 2013 Vanden Berghe et al. described the current situation in Flanders where euthanasia is  
335 embedded in palliative care [57,13]. Palliative care professionals witnessed cases of euthanasia where  
336 the patient was relieved and grateful that their final days did not have to last any longer. This  
337 convinced those professionals that euthanasia could be part of genuinely good care. In Belgium there  
338 have been calls for an extension of the law on euthanasia to cover advanced dementia patients who  
339 had made a written advance directive for euthanasia when they still had full mental capacity [13]  
340 (p.278); as in Belgium an advance directive is only considered valid for an irreversibly unconscious  
341 patient.

342 Countries drafting euthanasia laws for the first time may want to consider allowing previously  
343 validated 'advance directives' for patients with advanced dementia, to come into force at a pre-  
344 requested time of the patient's choosing. This would avoid the requirement for further legislation  
345 'diluting' the law at a later date.

346 It is thought that end of life care in Holland has improved significantly, so this might account  
347 for the lack of increased uptake of the option of PAS. Here are two quotes from the Vetsurgeon.org  
348 forum [1]:

349 “The Dutch approach to end of life care is incomparably better than in the UK - carefully planned  
 350 and co-ordinated care plans implemented by trained staff as opposed to the chaotic interventionist  
 351 NHS treatment which is geared up to deal with accidents and emergencies and not with  
 352 elderly/dying people.

353 I've had 2 elderly relatives die in each country - everyone's experiences were far superior in the  
 354 Netherlands where things were dealt with in a peaceful and caring way, dignified and under control  
 355 of the patient and their regular carers, whereas the UK relative's experiences were a series of forced  
 356 and pointless hospitalisations, hospital acquired infections, invasive treatment that did more harm  
 357 than good, poor treatment in hospital, no communication between home care staff and hospital staff,  
 358 and fear and stress for all concerned. This is without any mention of euthanasia in either of the  
 359 cases” Anon MRCVS [1] (19<sup>th</sup> Dec 2016).

360

361 **Table 1. Summary of the evidence from the Netherlands.**

362

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
van der Maas et al., 1991 [47]	Dutch	9,250 Deaths	End of life issues & euthanasia	Physician questionnaires interviews & prospective survey	Use of opioids, non-treatment decisions, euthanasia by lethal drugs.	MDEL taken in 54% of patients.	Only access to abstract.
van der Maas et al., 1996 [48]	Dutch	6,060 deaths, 405 physician interviews	End of life issues & euthanasia	Physician questionnaires & interviews	Use of opioids, non-treatment decisions, euthanasia.	Involuntary euthanasia rates reduced. Better decision making.	Questionnaires: 77% response rate.
Onwuteaka-Philipsen et al., 2003 [9]	Dutch	6,060 deaths, 410 interviews	End of life issues & euthanasia	Physician questionnaires & interviews	Changes in end of life practices.	Demand for MAD has not risen. PAS & invol. euth. has not changed. Family physicians most frequently involved.	Views of patients, families & other care givers not studied.
van der Heide et al., 2007 [34]	Dutch	5,342 deaths,	End of life issues & euthanasia	Physician questionnaires.	Changes in end of life care. Reporting rates of euth. & MAD.	Increased use of deep sedation near the end. Reporting rates up. euth. & MAD down.	Confusion as to whether opioids hasten death.

<b>Onwuteaka-Philipsen et al., 2012 [53]</b>	Dutch	8,496 deaths.	End of life issues & euthanasia	Physician questionnaires.	%s of euthanasia, reporting, opioids use,	%s: ----- stable----- down3%-- up-----.	Only access to summary.
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365 “I am Dutch. Euthanasia has been legal, well-regulated and organised in Holland for many

366 years now. It is an open, not hidden thing. My grandmother died in terrible pain and my mother had

367 to watch this as a teenager. She was horrified and very scared to die the same way. In the sixties she

368 got the same kind of cancer and died in the same way. My sister got cancer in 2006 when euthanasia

369 was legal. As soon as she knew it was terminal she arranged with her GP. She had a peaceful last 3

370 months, knowing the decision was in her own hands, and she died at home with the dog on the bed

371 and the GP administering the injection. What a difference. If you now read the obituaries of vets in

372 the Dutch Veterinary Journal many of them mention that they went at a time of their own choosing.

373 If I get terminal cancer or become demented, I at least can go back and have my own death decided

374 on by me. I am sure this good practice will spread in the world” Asselbergs, M. [1] (30<sup>th</sup> Nov 2016).

374

375

**Table 2. Summary of the evidence from Europe.**

376

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>Van der Heide et al., 2003 [51]</b>	6 European countries: Belgium, Denmark, Italy, the Netherlands Sweden, Switzerland	20,480 deaths	End of life decision making	Anonymous physician questionnaire.	% of end of life decisions & admin. of drugs to hasten death	Country variation in both. 23-51% & <1- 3.4%	Only 44% response rate in Italy.
<b>Bilsen et al., 2009 [12]</b>	Belgian deaths	6,202	End of life practices under Euth. Law	Physician 5 page questionnaire.	Changes in end of life care since Euth. Law.	% of invol. euth. did not increase.	Published as a correspondence to the editor.
<b>Vanden Berghe et al., 2013 [57]</b>	Dutch-speaking Belgians	Views of all professionals in Belgian palliative care	Embedding euthanasia in palliative care.	Narrative review	Effect of legalization of euthanasia on palliative care	Palliative care & euthanasia, when requested, can work hand in hand in the best interest of the patient	Only one in two non-sudden deaths in Flanders occurs with the support of specialist palliative care professionals
<b>Radbruch et al., 2015 [15]</b>	European association for palliative care (EAPC)	38 European palliative care experts	Ethical framework on euth. & PAS for palliative	Review of 2003 EAPC position statement, online survey, revision of	Concepts, definitions, values & philosophy of palliative care	Complete consensus seems to be unachievable.	Palliative care’s fundamental view that sensitive communication can make the

			care professionals	statement into white paper.	in relation to euth. & PAS.		patient's life worth living is flawed.
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377

378 4.2. *Veterinary Training*

379

380 Three papers discuss the training of veterinary students in the ethics of end of life issues and  
 381 euthanasia, from both the United States and Europe [4,58,59]. Two papers study attitudes to  
 382 euthanasia of practising veterinarians of varied age, gender, work experience and working  
 383 circumstances [60,61].

384

## 385 4.2.1.

386 Herzog et al. [58] delve into the psychology of veterinary students. In 1989 there was a dearth of  
 387 information relating to veterinary students, compared to medical students, dealing with ethical  
 388 issues. One of the subjects which they examined was veterinary students' responses to euthanizing  
 389 animals. This study used qualitative interview techniques to explore the attitudes and perceptions of  
 390 veterinary students who were approaching graduation.

391 'Several students reported that they were distressed when an animal's suffering was prolonged  
 392 because its owner did not want to accept that its disease was incurable and that death was inevitable,  
 393 a situation that occurs frequently in private practice. As one student put it, "Sometimes we take cases  
 394 too far and subject dogs to radiation or chemotherapy or surgery for tumours. At times this is to  
 395 satisfy the client, but I think that we should take more time to explain the situation to the client better.  
 396 Sometimes we take treatment too far just because we can'" [58] (p. 184).

397 One respondent commented, 'Every day, the practicing veterinarian is confronted with  
 398 something dealing with ethics. They have to think and wonder if what they are doing is ethical or  
 399 not.' As part of each interview, they asked the students what they thought would be the most  
 400 significant ethical issues that they would have to face when they began practice. By far the most  
 401 commonly mentioned ethical dilemma related to being asked to euthanize a healthy animal for the  
 402 convenience of the client. This issue was brought up by the majority of the students. Of these, 1/3 said  
 403 that they would refuse to kill an animal in this situation. Only one in six of the students said that they  
 404 would accede to the wishes of the client. The majority said they would try to talk the client out of the  
 405 decision and suggest alternative ways to dispose of the animal (p.186). One student was positive  
 406 about euthanasia of animals, saying, 'I really view euthanasia as one of the marvellous things we  
 407 have over human medicine. We can end animal suffering. When used properly, it is a great, great  
 408 thing' (p.187).

409 One student who had assisted in the euthanasia of about 15 animals said, 'I cried the first and  
 410 fifteenth time. It hasn't gotten any easier over time but I have learned to mask my feelings in front of  
 411 the client to be strong for them' (p.187).

412 Students repeatedly claimed that they were not bothered as much by euthanizing a suffering  
 413 animal, and many mentioned that they were particularly upset at the prospect of euthanizing healthy  
 414 but unwanted animals (p.187).

415 'I don't know what gives us the right to do euthanasia, but it is something we are going to do. I  
 416 really feel that if you allow it to get to you it can drive you crazy' (p. 188).

417 'There is only so much about being ethical that can be taught. It has to come from the heart'  
 418 (p.188).

419 They found that the primary coping strategy used to handle value conflicts was to rationalize  
 420 the necessity of the procedures. That the students used logic and intellect to deal with ethical issues  
 421 is not surprising, given that veterinary students are, on the whole, intelligent and articulate and tend  
 422 to have a scientific orientation (p.188).

423 The merciful killing of an incurably ill animal in pain was considered to be humane [58] (p.188).

424

425 In a comparable study of medical students in 1998 it was found that only 41% thought their education  
 426 regarding end-of-life issues had been adequate, only 27% had ever discussed end-of-life issues with  
 427 a patient themselves, and only 35% thought they had had adequate exposure and education  
 428 regarding advance directives [62].

429 In 2013 junior doctors reported that, although they may have had some form of exposure to palliative  
 430 care at medical school, they felt their training had left them unprepared to care for dying patients [26]  
 431 (p.35).

432

433 4.2.2.

434 In a more recent study in 2016 of practising veterinary surgeons' attitudes to euthanasia [60], coping  
 435 strategy statements (which had been carefully chosen following extensive literature reviews), were  
 436 presented to the vets and there was strong agreement and linkage between the following  
 437 statements:

438 'It is easier for me to deal with euthanasia if I know that the animal would only have lived on  
 439 for a short time'.

440 'The animal's advanced age makes it easier for me to deal with euthanasia'.

441 'Deliberate planning and the right moment make it easier for me to deal with euthanasia'.

442 'It is easier for me to deal with euthanasia if the animal has lived a rich life until its death'.

443 'Treating the owners in an understanding way is a central part of euthanasia'.

444 Younger veterinarians worked more often in a team and working in a team was associated with  
 445 a higher agreement of the statement: 'Knowing that all veterinary medical, social and economic  
 446 options have been considered makes it easier for me to deal with euthanasia'.

447 The willingness of the veterinarian to take the decision for euthanasia instead of the owner was  
 448 linked to the number of other veterinarians working in the same practice, the more veterinarians in  
 449 the same practice the less likely they were to make the decision for the owners.

450 Veterinarians' attitude towards euthanasia is potentially affected by age, gender and working  
 451 experience; this corresponds to previous findings that younger female veterinarians are at a higher  
 452 risk of work-related stress and suicidal thoughts. The presence of experienced colleagues at work –  
 453 not only to discuss the medical point of view but also to provide mutual support for several difficult  
 454 euthanasia cases highlights the role of a 'team' to provide support in stressful situations [60].

455

456

457 4.2.3.

458 In Magalhães-Sant' Ana's study of ethical teaching in 2014, he found that animal welfare related topics  
 459 that were mentioned as part of the teaching of ethics include: the five freedoms (freedom from hunger  
 460 and thirst, freedom from discomfort, freedom from pain injury or disease, freedom to express normal  
 461 behaviour and freedom from fear and distress); quality of life; animal suffering; and animal pain [59].

462 The interviewed ethics' teaching staff contributed to his findings.

463 'One of the main ethical issues is for the vet to be aware of his/her own limits, what I will do and  
 464 what I will not do: Will I accept to kill a healthy animal? Will I do a surgery without anaesthetic?' [59]  
 465 (p.7).

466 Animal euthanasia was a recurring theme across the interviews and an example of the kind of  
 467 ethical challenges faced by practicing veterinarians. Four sub-themes were included within the realm  
 468 of euthanasia: the destruction of a healthy animal by the owners' request, the refusal by the owner to  
 469 ending the life of a severely ill patient, the killing of an ill animal because the price of treatment is not  
 470 covered by the value of the animal, and the culling of a herd for public safety concerns.

471 As part of the teaching, students are introduced to different ethical theories which also helps  
 472 students understand the range of moral values within a pluralistic society: 'Students should gain the  
 473 ability to realize that their choices and opinions are based on moral values and it is very important to  
 474 clarify to them that many of the disagreements we have about animals are based on different moral  
 475 values' [59] (p.8).

476 Decision-making abilities were considered an important aspect in ethics' teaching. The  
 477 principle of autonomy was deemed as a relevant topic for both the veterinarian and the client,  
 478 because students should learn how to guide people through making a decision in a particular  
 479 situation while respecting their autonomy. The process of decision-making seems to be closely  
 480 connected with critical thinking abilities. Educators provide students with the experiences that will  
 481 make them aware of the different ethical issues and reflect upon them. This will help students  
 482 'becoming critical thinkers'. They introduce themes pertaining to the human-animal bond and  
 483 handling end-of-life issues, such as humane killing and bereavement, breaking difficult news,  
 484 understanding that ethics is also about tolerating other points of view.

485 Educators use cases involving financial limitations to illustrate ethical dilemmas in veterinary  
 486 practice to their students.

487 The learning objectives for veterinary ethics are: ethical awareness, ethical knowledge and  
 488 ethical skills.

489 Finally, appropriate professional behaviour, relying on moral values, animal welfare and codes  
 490 of conduct, promotes the development of individual and professional qualities. Taken together, these  
 491 findings may provide a starting point for the development of the essential competencies in ethics for  
 492 European veterinary education.

493 'However, the crucial ethical challenge in euthanizing an animal has to do with the moral  
 494 significance of the animal's quality of life and of animal suffering; and that is usually a welfare issue'  
 495 [59] (p.12).

496

497 **Table 3. Summary of the evidence of veterinary ethics training**

498

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>Herzog, Vore &amp; New, 1989 [58]</b>	Veterinary students	24	Ethics & euthanasia	Qualitative survey	Changes in attitude	Individuals resolved issues differently.	Some teaching practices possibly outdated.
<b>Magalhães-Sant'Ana, 2014 [59]</b>	European vet schools	3: Copenhagen, Lisbon, Nottingham.	Veterinary ethics, including animal welfare & decision making.	Qualitative case study	Vet. ethics teaching	Proposes a model for curriculum development of veterinary ethics.	Assuming similar to all European veterinary universities.
<b>Dickinson, Roof &amp; Roof, 2010 [4]</b>	Veterinary students	28 US veterinary medical schools	Teaching end of life issues.	Survey & comments	Hours spent on end of life issues	End of life issues are an important part of the curriculum	No evidence to support statement that vet. med. is client rather than patient orientated

499

500 4.2.4.

501 In 2010 Dickinson et al studied veterinary student training [4].

502 Veterinary and medical 'Students need to think about their own values and beliefs and  
503 understanding of dying before they can be caring and insightful to others. They need to address how  
504 they feel about the dying process.

505 If veterinary medicine students can recognize dying, and ultimately death, as a natural part of  
506 the life cycle and feel comfortable with accepting care over cure with seriously ill animals, veterinary  
507 medicine schools will have made a major contribution to end-of-life issues in the 21st century' [4]  
508 (p.161).

509

510 **Table 4. Summary of the evidence of attitudes to euthanasia**

511

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>Yeates &amp; Main, 2011 [61]</b>	Veterinary surgeons in UK	58 Responses	Refusing euthanasia	Quantitative & qualitative	Frequency and reasons for & against unethical euthanasia	UK vet practice is more animal focused than client focused.	Too small numbers for a good quantitative study.
<b>Hartnack et al., 2016 [60]</b>	Veterinary surgeons	2478 Austrian veterinarians, only 486 returned fully completed questionnaires for analysis.	Attitudes towards euthanasia	Qualitative & quantitative questionnaire & multivariate analysis	If demographic variables influence attitude	Age, sex, experience & colleagues affect attitudes	This may only represent the 1/5 most concerned vets as answering the questions was time consuming
<b>Folger et al., 2010 [18]</b>	Cats	Position statement of AAFP	End of life issues.	Recommendations.	Ethics of modern medicine	Quality of life most important.	Does not include kidney transplants.
<b>Meier et al., 1998 [20]</b>	USA physicians	1,902 physicians	MAD or euthanasia	Anonymous questionnaire.	PAS or euthanasia requests & compliance	54% of cases of euthanasia were involuntary.	Due to illegality results may be less than actual frequency.
<b>Bachelard, 2002 [21]</b>	Humans & animals	Moral argument	Euthanasia (euth.) to relieve suffering	Philosophical argument	Significance of comparing human beings & animals	Differences limit the power of argument in favour of euth.	Suggests some human suffering sustains moral values of others.

512

#### 513 4.3. Treatment or Palliative Care.

514

515 One narrative review discusses ethical issues surrounding end-of-life care in the United States  
516 for humans.

517 Technologically advanced treatments have a capability to prolong the life of a patient rather than  
518 allowing the natural dying process [63]. Healthcare services should not only target lengthening the  
519 life of people but also improve the quality of life' [64,63], especially when end-of-life decisions and  
520 the costs involved are concerned [63].

521 Healthcare rationing of end-of-life care in futile situations can be considered as greatest good  
522 for society but has to be weighed against patient autonomy [65,63].

523 There are no strict criteria to differentiate a futile treatment; hence it has to be relied on expert  
524 judgment and case prognosis. Rationing of care is present in the current healthcare system. The  
525 increasing expenditure on healthcare in the United States is too much in relation to population size  
526 and outcome and at the same time people are spending more on getting the care they need.  
527 Compassionate care can be less costly and sometimes a good preference when medicine is unable to  
528 restore the patient's health [63].

529 Working towards achieving greatest good for the patient by family members and by the  
530 physician falls into the "virtue theory" of ethics [63].

531 The level of palliative care available to the patient again is dependent on where in the world you  
532 live. On 6<sup>th</sup> October it was reported that Britain was the best place in the world in which to die  
533 according to an end-of-life care index [66].

534 The literature searches outlined in Appendix A revealed numerous articles from around the  
535 world; India [67], Middle Eastern countries [68] and Colombia [69], called for the need for improved  
536 palliative care of the dying and for the availability of access to opioids for pain relief. Some countries  
537 such as Jordan [70], Mongolia [71] and Uganda [72] reported good progress. In Iran the need for  
538 improved quality of care of terminal cancer patients was discussed [73].  
539

540 The level of palliative care available to animals again is dependent on where in the world they  
541 live. In order to have an equivalent of hospice care you are talking about in-home hospice provision  
542 available mainly in the United States, however this is 'a more appealing option for the pet owner,  
543 unable to face the impending loss of their treasured companion'[74] (p.146), rather than the animal  
544 itself. 'The development of a care plan should not be rushed and it must be clearly ascertained how  
545 much the pet owner can contribute to the level of care required, this will dictate how much external  
546 care is required and if, in fact, a home-care programme is a viable option for this pet and owner. The  
547 treatment options included in the care plan need to match the beliefs and values of the owner while  
548 remaining in the best interest of the pet. Incontinence is an issue which should be discussed with the  
549 family members as many terminally ill patients will develop urinary and/or faecal incontinence' [74]  
550 (p.148). 'Educating clients regarding their pet's condition and teaching them how to provide certain  
551 types of care in the home' is essential. 'The veterinary practise should consider offering a district  
552 nursing service to re-assess quality of life and anticipate, prevent, locate and relieve pain in the  
553 patient' (p.149). 'A small number of mobile veterinary hospice and palliative care services do  
554 currently operate successfully within the UK', (p.150), ensuring that 'no aspect of care is being  
555 neglected' [74] (p.151).  
556

#### 557 4.4. Healthcare Policy Implementation

558  
559 'The task of healthcare executives to manage ethical issues surrounding end-of-life care is  
560 challenging'. 'They can guide the patients to make informed treatment preferences by providing  
561 them honest information they can understand, an appropriate prognosis and available options'.  
562 'They can document their preferences', and 'in cases of disagreement' they can 'appoint an ethics  
563 committee to address this ethical or legal issue and document its proceedings'.

564 They 'can compile policies, so as to introduce, promote, and discuss the use of advance directives  
565 as an admission procedure' [75,63] (p. 4).

566 They 'can work towards developing and implementing guidelines & policies for end-of-life care  
567 decision making, so as to avoid ethical dilemmas, especially policies for withholding or withdrawing  
568 treatment options'.

569 They 'can develop resources supporting palliative treatment care choices'.

570 They 'can provide effective support by appointing an employee assistance facility available so  
571 as to address any ethical crisis' [75,63] (p. 5).

572 They 'should take the initiative and discuss each patient's goal for end-of-life care or palliative  
 573 care, as their preferences can differ from person to person'. 'It has a potentiality to change with illness  
 574 hence the health scenario in each specific case has to be renewably evaluated'. Flexibility should be  
 575 incorporated in advance directives [63] (p. 5).

576 'Community standards can work well where the patient's desire for the end-of-life treatment  
 577 choices is not well demarcated' [76,63] (p. 5), 'so that proxies making decisions without guidance  
 578 from the patient can at least know what the majority of people considering similar situations chose  
 579 to do' [76] (p. 1).

580 'As age advances so thus the illness in many cases, hence there is a need to research and  
 581 implement recommendations to relieve the stress faced by people during that critical time and  
 582 optimize quality care to improve and ease the end-of-life journey' [76,63] (p. 5). 'Through research,  
 583 medicine will identify and add to the understanding of the range of wholesome paths to death and  
 584 devise a way of evaluating those paths and those on them. Through training and implementation,  
 585 medicine will improve the journey. It is the core of medical care, a central part of the mandate from  
 586 society and our forbearers in medicine, to relieve suffering and optimize well-being in every part of  
 587 the life cycle. The last phase in a person's life cycle brings a high chance of suffering and of lost critical  
 588 opportunities: it can also offer the potential for important gratification and realized opportunities. As  
 589 the majority of people complete this life cycle whilst in our care, the role of medicine is critical. In  
 590 order to discharge our role-mandate to optimize care near the end of life, including fostering the best  
 591 decisions each individual can make, the medical profession must continue to undertake research and  
 592 training to improve practices' [76] (p.7).

593 In 2007, 63% of Flemish hospitals had an ethics policy on euthanasia [77]. Only Dutch and  
 594 Belgian Institutions dealt with policies on euthanasia, and it was found that in these, significant  
 595 consideration was given to procedures that dealt with conscientious objections of physicians and  
 596 nurses [78].

#### 597 598 4.5. 'More Care, Less Pathway'

600 An Independent Review of the Liverpool Care Pathway (LCP) in England, by Baroness Julia  
 601 Neuberger and 9 others was included because it discusses failings of the palliative care option [79].  
 602 It was requested by Norman Lamb MP, Minister of State for Care Support and was published in 2013.

603 It describes The LCP for the Dying Patient, as an approach to care, including a complex set of  
 604 interventions, that resulted from a desire to replicate within the hospital sector the standard of care  
 605 found in many hospices, for those thought to be dying within hours or days, accepting the difficulty  
 606 of diagnosing when a patient is actually going to die.

607 In the review clinicians expressed their view that in their own last hours they would prefer to be  
 608 treated under an approach such as the LCP, and found that many relatives of people dying whilst  
 609 being treated under the LCP had felt that their loved ones had had good deaths. It would seem that  
 610 when the LCP was operated by well trained, well-resourced and sensitive clinical teams, it worked  
 611 well.

612 However it is clear, from written evidence received and relatives' and carers' input at events,  
 613 that there have been repeated instances of patients dying on the LCP being treated with less than the  
 614 respect that they deserve. It seems likely that similar poor practice may have taken place in the case  
 615 of patients with no close relatives, carers or advocates to complain, or where families had not felt able  
 616 or qualified to question what had taken place. This leads the reviewers to suspect this is a familiar  
 617 pattern, particularly, but not exclusively, in acute hospitals where reports of poor treatment at night  
 618 and weekends – uncaring, rushed, and ignorant – abound.

619 Many families suspected that deaths had been hastened by the premature, or over-prescription  
 620 of strong pain killing drugs or sedatives, and reported that these had sometimes been administered  
 621 without discussion or consultation. There was a feeling that the drugs were being used as a 'chemical  
 622 cosh' which diminished the patient's desire or ability to accept food or drink. The apparently  
 623 unnecessary withholding or prohibition of oral fluids seemed to cause the greatest concern.

624 Preventable problems of communication between clinicians and carers accounted for a  
625 substantial part of the unhappiness reported. Relatives and carers felt that they had been 'railroaded'  
626 into agreeing to put the patient on a one-way escalator.

627 In order that everyone dying in the acute sector, can do so with dignity, the present situation has  
628 to change. It is for this reason that the review made 44 strong recommendations for change.

629 Independent, prospective testing of the LCP had not yet been carried out after nearly 10 years  
630 of its dissemination. Fully independent assessments of end of life care in England are required,  
631 focusing on the outcomes and experience of care, as reported by patients, their relatives and carers,  
632 as well as the quality of dying. Further research into the biology and experience of dying is needed.

633 Some relatives and carers were not told that their loved one was dying. Respectful treatment of  
634 the dying patient and his/her carers requires time to be taken over the difficult tasks of providing  
635 information, delivering the news that the person is dying, understanding the person's needs and  
636 capacity to assimilate bad news and providing the opportunity to reflect on that information and to  
637 ask questions. This should be a non-negotiable aspect of best practice in end of life care.

638 Refusing food and drink is a decision for the patient, not clinical staff, to make.

639 The review heard that, if a patient became more agitated or in greater pain as they died, they  
640 often became peaceful because the right drugs were given to them at the right time and in the right  
641 dose. But there were complaints that opiate pain killers and tranquillisers were being used  
642 inappropriately as soon as the LCP was initiated. Many hospital patients appear to be put on a syringe  
643 driver with morphine as the 'next step' on the LCP, even if morphine is not the right drug, or pain  
644 relief is not what is needed.

645 Any attempt deliberately to shorten a person's life is illegal, but there is no obligation, moral or  
646 legal, to preserve life at all costs.

647 The availability of staff to care for the dying, both in terms of the number of staff and the level  
648 of competence, was found to be of serious concern. There were numerous reports of no access to the  
649 palliative care teams outside office hours and at weekends, both in acute hospitals and in the  
650 community.

651 The review panel strongly supported the work of organisations that promote public awareness  
652 of dying, death and bereavement. There was no specific Nursing Medical Council (NMC) guidance  
653 for nurses caring for patients at end of life or who are dying, this must be provided as a matter of  
654 urgency.

655 The review recommended that use of the LCP should be replaced over the next six to 12 months  
656 by an individual end of life care plan for each individual patient.

657 Unsurprisingly, this review uncovered issues: a lack of openness and candour among clinical  
658 staff; a lack of compassion; a need for improved skills and competencies in caring for the dying; and  
659 a need to put the patient, their relatives and carers first, treating them with dignity and respect. A  
660 need to ensure that guidance on care for the dying is properly understood and acted upon, and tick-  
661 box exercises are confined to the waste paper basket for ever.

662 Many of the elderly patients suffered from cognitive problems, including dementia, and were  
663 unable to express their wishes. Those who do not have close relatives and carers guarding their  
664 interests were by default unrepresented in the evidence submitted to the review panel. The review  
665 panel was very concerned about this, and recommended that each patient on an end of life care plan  
666 that has no means of expressing preferences and views on their care should be represented by an  
667 independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an  
668 appropriate person provided through a voluntary organisation. This also applies to younger people  
669 who may lack capacity.

670 'The review panel strongly recommends a strategic approach to the problem. We need a coalition  
671 of regulatory and professional bodies, NHS England and patient groups, setting clear expectations  
672 for a high standard of care for dying patients – care that will also meet the important and sometimes  
673 neglected needs of their relatives and carers. Working together strategically, such a coalition could  
674 lead the way in creating and delivering the knowledge base, the education training and skills and the  
675 long term commitment needed to make high quality care for dying patients a reality, not just an

676 ambition. As a minimum, this would entail close co-operation between the GMC, NMC, the Royal  
677 Colleges, the Care Quality Commission, NHS England and the National Institute for Health and Care  
678 Excellence' [79] (p.47-48).

679

680 *4.6. We all need food and water to survive.*

681 If medically assisted dying is not an option then many choose to deny themselves the necessary  
682 nutrition and fluids to live. The guidelines provided by The European Society for Clinical Nutrition  
683 and Metabolism (ESPEN), an international multidisciplinary working group, include at least 10  
684 statements which are highly relevant to the terminal patient [19].

685 Firstly it is important to recognise that artificial nutrition and hydration are a medical  
686 intervention, requiring an indication, a therapeutic goal and the consent of the competent patient.  
687 Special consideration is given to end of life issues and palliative medicine; to dementia and to specific  
688 situations like nursing care or the intensive care unit. It is worthwhile to quote from 10 of their most  
689 relevant statements:

690 '5: If the risks and burdens of a given therapy for a specific patient outweigh the potential benefits,  
691 then the physician has the obligation of not providing /withholding the therapy.

692 Commentary: Prolonging of life may never be the sole goal and always has to be put in relation  
693 to the wellbeing of the patient. Prolonging of life may never turn into prolonging of the dying phase'  
694 [19] (p. 547).

695 '11: Every individual is entitled to obtain the best care available. Resources have to be distributed  
696 fairly without any discrimination. On the other hand treatments which are futile and do only prolong  
697 the suffering or the dying phase, have to be avoided' (p.547).

698 '16: For patients with advanced dementia priority should always be given to careful eating assistance  
699 /feeding by hand' (p. 549).

700 '18: Once the diagnosis of persistent vegetative state is established an advance directive or the  
701 presumed will of the patient have to be considered. If there is evidence which is applicable for the  
702 given case it has to be followed' (p. 549).

703 '20: There are no clear criteria to ascertain the beginning of the dying phase. Therefore, a nutritional  
704 intervention in this phase of life should be followed in an individualized manner.

705 Commentary: While death is clearly defined and irrevocable, the end of a person's life is a  
706 process. This process is expandable per se and defining its beginning is subject to individual views  
707 and interpretation. In general the health state of old persons or people with debilitating diseases are  
708 slowly deteriorating. At a certain point, deterioration accelerates, patients become bedridden and  
709 become dependent for most if not all functions to sustain life. Generally these patients suffer and  
710 derive no pleasure or feelings of wellbeing in this situation. This period should be prolonged by  
711 nutritional support if people are predominantly starving and when a gain or preservation of quality  
712 of life is possible. If this is not possible, the intention of this treatment in dying persons is to satisfy  
713 hunger and thirst. An individual's expressed wishes and needs may change in the final phase of his  
714 or her life. In fact, each person demonstrates a different type of behavior until the time of death. The  
715 indication for artificial nutrition should therefore be established at this time after careful and  
716 individualized consideration of the potential risks and benefits with the purpose of providing end-  
717 of-life care. Administration of fluid and energy is not always needed at all times in this phase of life.  
718 Patients do frequently experience dryness of the mouth, an early sensation of saturation, nausea and  
719 an impaired sense of taste, but rarely hunger and thirst. Thirst generally results from unpleasant  
720 dryness of the oral cavity and crust formation and can be frequently relieved by oral care and small  
721 quantities of fluids, less than necessary to relieve dehydration. Parenteral administration of fluid does  
722 not necessarily alleviate the individual's thirst. Besides, dryness of the mouth and thirst may also be  
723 the effect or side effect of medication, oxygen therapy, breathing through the mouth, or anxiety and  
724 depression. Therefore, dryness of the mouth and thirst should first be counteracted by nursing  
725 measures such as lip care and mouth care, as well as repeated provision of small amounts of fluids.  
726 In the rare case that a patient is thirsty despite optimal care or when dehydration is associated with  
727 delirium, the effectiveness of artificial hydration could be reviewed but is doubtful to be of any

728 benefit in the dying phase. At this time palliative sedation is another option and is increasingly  
729 applied' (pp. 549-550).

730 '23: The will of the adult patient who is capable of providing consent and making judgments has to  
731 be respected in all cases' (p. 550).

732 '27: Patients are authorized/encouraged to establish an advance directive or a living will according  
733 to the specific laws in their countries. Certain requirements have to be fulfilled to ensure validity.  
734 Valid advance directives must be respected according to the country's laws and by the treating  
735 physicians' (p. 551).

736 '29: Quality of life must always be taken into account in any type of medical treatment including  
737 artificial nutrition.

738 Commentary: While for oncological patients well established tools to assess quality of life are  
739 available, widely accepted instruments for patients with cognitive impairment, suitable for use in  
740 clinical routine, do not exist in a satisfying way to the present day (2016). Nevertheless, even the  
741 patient whose competence is largely impaired gives clues as to his perception of quality of life by  
742 appropriate expressions or statements. Also the patient who is unable to give consent or make a  
743 judgment should be informed about the proposed measures; the communication should be aligned  
744 to his or her comprehension abilities. The patient's statements or reactions should be taken into  
745 account as appropriate' (p. 551-552).

746 '31: To achieve a mutually acceptable solution or a compromise, one should utilize all options. These  
747 include obtaining a second opinion, a case discussion in ethics, clinical ethics counseling, or obtaining  
748 the recommendations of a clinical ethics committee' (p. 552).

749 '34: Voluntary cessation of nutrition and hydration is a legally and medically acceptable decision of  
750 a competent patient, when chosen in disease conditions with frustrating prognosis and at the end of  
751 life' (p. 553).

752

753 **Table 5. Summary of the evidence of end of life care**

754

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>Karnik, Kanekar, 2016 [63]</b>	Humans	Narrative review	Ethics & end of life care.	Review	Autonomous decision making, rationing care.	End of life care advice & preference should be given priority	A United States based study.
<b>Neuberger et al. 2013 [79]</b>	The dying in England.	723 Responses.	Care under the Liverpool Care Pathway (LCP)	Call for evidence, visits, sought advice, reviewed literature.	Whether the Liverpool Care Pathway was working to the benefit of patients.	44 Recommendations for improvement. & replacement.	It suggests, without any justification, that assisted dying is not good care and is frightening.
<b>Druml et al. 2016 [19]</b>	Worldwide patients	ESPEN guidance	Artificial nutrition & hydration	International collaborative guidelines	Ethics of artificial nutrition & hydration	36 Statements	A very useful guide.

<b>Todd et al., 2016 [1]</b>	Veterinary surgeons	50 Relevant replies, 4,445 views	Medically assisted dying	Veterinary surgeons' forum.	Need for legalization of MAD.	Concerns about human suffering in UK.	Respondents chose themselves.
<b>Maltoni et al., 2012 [22]</b>	Near end of life patients.	1,807 patients from 10 articles.	Palliative pharmacologic al sedation.	Systematic review.	The effect of sedation on survival.	Sedation did not reduce length of survival.	The quality of the studies used ranged from fair to fair/poor.

755

756 *4.7. Other Evidence*

757

758 One review from the Netherlands focusses on the moral problems that nurses encounter caring for  
759 the terminally ill [80]. 'Because of the unavoidable confrontation with the patients' suffering, it is  
760 generally the nurse who takes the initiative to ask for a morphine infusion for those who are  
761 terminally ill' [80] (p.164). They often carry a 'burden of guilt and responsibility'. Other nurses fear  
762 death occurring after the administration of medication so anxiety prevents them from becoming  
763 aware of the patients' situation and their need for medication (p.165). Nurses questioning the  
764 appropriateness of medical treatments can cause conflicts between themselves and physicians.  
765 Nurses are often constrained in following their own moral decision due to lack of authority and 'a  
766 lack of involvement in the decision-making process' (p.167) which can cause the highest stress scores  
767 in situations of ethical difficulty. Negative feelings and professional disillusionment arise when  
768 nurses are unable to resolve the moral problems with which they are confronted, and when they  
769 adopt an attitude of disengagement from the situation. 'Studies on the moral attitude of nurses  
770 describe that qualities such as courage, honesty, the ability to adopt an active attitude, having  
771 confidence, and going beyond rules and conventions when necessary, lead to the resolution of moral  
772 problems and to more satisfaction than an attitude based on disengagement' (p.167). 'Nurses should  
773 be encouraged to develop their moral behaviour by enhancing their sensitivity to the consequences  
774 of their actions, and by being encouraged to place moral aspects above other considerations' [80]  
775 (p.167) in order to defend their personal moral integrity.

776

777

**Table 6. Summary of further evidence of end of life care**

778

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>Beller et al., 2015 [23]</b>	International, terminal patients requiring sedation.	14 Studies, 4,167 patients.	Palliative pharmacologic al sedation.	Narrative review.	Benefits	Insufficient evidence about efficacy of sedation and quality of life of sedated.	Only one study measured unintended adverse effects
<b>Leboul et al., 2017 [24]</b>	Health care providers in palliative care units in France.	28 medical & paramedical providers.	Palliative pharmacologic al sedation.	Qualitative study.	Opinions on the use and effectiveness of end of life sedation & effects on	Nurses who administer the sedation are subjected to moral distress due to the	Only truly representative of palliative care providers in specialist

					patient/carer relationships	uncertainty of their actions. Teamwork helps.	palliative care units in France.
<b>Georges, Grypdonck, 2002 [80]</b>	Nurses caring for the terminally ill	28 Articles	Study of moral problems encountered.	Literature review	Effects on the nurses of ethical dilemmas. How they perceive and react to moral problems.	Skilled nurses cope better. Others try to avoid moral problems and protect themselves, affecting their work and causing a feeling of insecurity.	The researchers drew their results from very varied material not always focused on moral problems of nurses caring for terminally ill patients.

779

780

781 Important differences between physicians' and nurses' approach to moral problems have been

782 observed. Physicians use a more predominantly medical, scientific orientation while the nurses'

783 approach is based more on the patients' and family's point of view [80]. Doctors and veterinarians

784 are trained to dissociate their emotion from their professional skills for the benefit of the patient in

785 most instances and their own benefit when dealing with dying and euthanasia. Nurses are also

786 trained so as not to let their emotions interfere with their nursing skills, however they spend more

787 time with the patient and hence become more aware of the patient's physical and existential needs.

787

788 **Table 7. Summary of the evidence from a Canadian lawyer's perspective & the BMA.**

789

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>Cormack, 2000 [25]</b>	Dutch, American, Australian & Canadians.	Varied	The legal status of euthanasia & assisted suicide.	A review bringing together historical facts.	The possibility of legalization in Canada	The principles of autonomy and beneficence provide the necessary foundation to justify change.	There is damning evidence from the Netherlands, but this is pre-legalization.
<b>BMA 2016 a [26]</b>	UK end of life citizens	Comprehensive overview of reports and situation in the UK & International evidence on assisted dying.	End of life issues & assisted dying.	Literature review	Seeks to set the scene as it stands.	Reviews - accessibility of end-of-life care in the UK & doctor dilemmas in end-of-life care. Assisted dying debate in the UK. International evidence on assisted dying.	Misleading inaccuracies e.g. Oregon's Death with dignity Act was not enacted until 27/10/97. Duplication of references e.g. 552 is the same as 569, 2 is the same as 18, etc.

790

791 This concludes the literature review of papers relevant to end of life issues in human and veterinary  
 792 medicine with particular regard to the comparison of euthanasia to relieve suffering in animals and  
 793 the need for euthanasia to relieve suffering in humans. Some of the topics discussed in veterinary  
 794 papers, such as the ethical dilemmas in making the decision for euthanasia, could help to resolve  
 795 some of the reservations in human medicine currently blocking a move towards euthanasia.

796 The second paper in this series is an ethical discussion of the differences and similarities between end  
 797 of life issues in veterinary and human medicine and whether human medicine can draw from the  
 798 veterinary experience of euthanasia to relieve suffering.

799

800 **Table 8. Summary of the evidence from the BMA continued.**

801

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
<b>BMA 2016 b [8]</b>	UK Public & doctors.	269 Members of the public. 237 Doctors	Dialogue events in 10 geographic locations.	Qualitative research. Not representative of the whole population.	Doctor patient relationship now & if PAD were legalized, concerns about dying, end-of-life care,	The public trust doctors & want a quick painless death. Quality of end-of-life care is inconsistent. Pain is not always completely eliminated. Treating doctors would not want to make decisions about eligibility & fear moral stress.	Recently bereaved (last 6 months) were excluded.
<b>BMA 2016 c [27]</b>	UK public & doctors	269 public & 237 doctors	Reflection & recommendations	Collating a report	End of life care & physician assisted dying (PAD).	End of life care is still failing. Some members of the public were surprised that people with dementia would be excluded from PAD. Oral assisted suicide has complications {most could be averted by the use of euthanasia}.	Some doctors thought relief of pain & suffering would outweigh the negative impacts of PAD. It would have been nice to know how many of the doctors shared this view.

802

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 806 with the search strategy.

807

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809

810 **Appendix A**

Literature search (A1)	
<b>Search query</b>	Should human medicine follow veterinary medicine by including MAD or euthanasia as a legal end of life option in the UK?
<b>Search submitted by</b>	Ruth Eyre-Pugh
<b>Search developer(s)</b>	Clare Boulton
<b>Search strategy</b> CAB Abstracts on the OVID interface	1 ethics/ or law/ or legislation/ or regulations/ or "code of practice"/ or legal aspects/ or legal principles/ 2 (ethic* or law* or legal* or legislat* or regulat* or "code of practice" or code-of-practice or "code of conduct" or code-of-conduct) 3 1 or 2 4 hospice care/ or hospices/ or "death and dying"/ or "end of life" or end-of-life 5 (euthanas* or palliativ* or hospice* or pawspice*) or euthanasia/ 6 (assist* adj5 (dying or death* or suicide)) 7 4 or 5 or 6 8 exp veterinarians/ or medicine/ or physicians/ or veterin* or doctor* 9 3 and 7 and 8 10 limit 9 to (english language and yr="1980 - Current")
<b>Date of coverage</b>	1980 to 2017 Week 05
<b>Inclusion &amp; exclusion criteria</b>	n/a
<b>Summary of CAB Abstracts research results</b>	<b>Date Searched</b> 16/2/17 <b>No of items found</b> 166

811

812 **Literature search (A2)**

<b>Search query</b>	Should human medicine follow veterinary medicine by including MAD or euthanasia as a legal end of life option in the UK?
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<b>Search submitted by</b>	Ruth Eyre-Pugh
<b>Search developer(s)</b>	Clare Boulton
<b>Search strategy</b> CAB Abstracts on the OVID interface	1 ethics/ or law/ or legislation/ or regulations/ or "code of practice"/ or legal aspects/ or legal principles/ 2 (ethic* or law* or legal* or legislat* or regulat* or "code of practice" or code-of-practice or "code of conduct" or code-of-conduct) 3 1 or 2 4 hospice care/ or hospices/ or "death and dying"/ or "end of life" or palliativ* or hospice* or pawspice* 5 euthanas*.mp. or euthanasia/ or (assist* adj5 (dying or death* or suicide)) 6 (exp veterinarians/ or veteran* and (medicine/ or physicians/ or doctor* 7 3 and 4 8 5 and 7
<b>Date of coverage</b>	1973 to 2017 Week 05
<b>Inclusion &amp; exclusion criteria</b>	n/a
<b>Summary of CAB Abstracts research results</b>	<b>Date Searched 17/2/17</b> <b>No of items found 25</b>

813  
814

Literature search (A3)	
<b>Search strategy</b>  <b>PubMed accessed via the NCBI website</b>	1. euthanasia or assisted suicide 2. ethics and medical 3. end-of-life issues 4. 1 and 2 and 3
<b>Date of coverage</b>	PubMed - 1910 – February 2017
<b>Inclusion &amp; exclusion criteria</b>	English Language, 1980 -
<b>Summary of PubMed research results</b>	<b>Date Searched 24/2/17</b> <b>No of items found 204</b>

815

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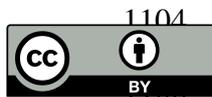
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