

1 **Definitions of terms used in limitation of treatment and**
2 **providing palliative care at end of life**

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4 **Preamble and Purpose**

5 In most of the hospitals in India, patients are subjected to painful inappropriate life sustaining
6 interventions, while in USA and in Europe withdrawal of inappropriate life-sustaining
7 interventions preceded death in up to 90% of deaths in intensive care units (1, 2). In India, it has
8 been reported from very few centres, where withdrawal of inappropriate life-sustaining
9 interventions preceded death in 22%-49% of deaths (3-5). Anticipatory directives and advance
10 care planning are non-existent and patients are not referred to palliative care for symptom
11 management and end of life care (6). Family and caregivers of the deceased patients feel that the
12 patients at end of life have poorly controlled symptoms and distress (7). Health related
13 communication is incompletely delivered and most hospitals do not have trained healthcare
14 providers equipped to provide end of life care (8). Patients are often burdened with impersonal
15 and unwanted health technology at end of life and humanness and comforting touch is lost in the
16 bargain (4).

17 The duty of the health care providers is to mitigate suffering (9). It is “to cure sometimes, to
18 relieve often and to comfort always”(10). There exists no exception to this principle, whether or
19 not there is medical consensus, that the disease is incurable and death is imminent. Death is to be
20 recognized as a natural culmination of life (11). The medical system has the primary duty to
21 improve quality of life all through life which includes the dying phase. In such situations,
22 curative intent must give way to a focus on improving the quality of life of the patient
23 (12). Indiscriminate aggressive interventions in such situations violate the individual’s right to
24 live and die with dignity (13). Medical procedures must thus inevitably be limited, at a point

25 judged by health care providers that continuation of treatment causes considerable harm
26 compared to benefits. Treatment limitation is an integral part of the shift of the goal of care from
27 a cure directed approach to palliative care and end of life care (14).

28 End of life care is a person centered, personalized perception of “Good Death”, which
29 encompasses all aspects of comprehensive care of an individual who is approaching his or her
30 end of life (15). It is applicable to any person, any place and any illness. It involves relief of
31 physical, psychological, social, spiritual and existential symptoms (16). It enables patients to die
32 at the preferred place of choice and receive appropriate care by a trained health care provider. It
33 aims to provide universal access to standard palliative care at the end of life and believes that
34 every individual should have a right to a good, peaceful, comfortable and dignified death (17).

35 To facilitate discussion, preparation of guidelines and framing of laws, these terms relating to
36 treatment limitation and end of life care need to be brought up to date. There has been a
37 considerable evolution of terminology pertaining to this area of healthcare over the past three
38 decades. One fundamental barrier to proper end-of-life care in India is the lack of clarity on
39 several terms that are often mistaken for euthanasia. This consensus document on terminology is
40 prepared under the aegis of the Indian Council of Medical Research (ICMR) towards realizing
41 this goal. The following are the definitions of common terms used in end of life care and
42 palliative care agreed upon by this expert group appointed by ICMR. These are based on review
43 of existing international documents and national consensus on the matter.

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Glossary of Definitions

50 1. Terminal illness

51 Terminal illness is one from which recovery cannot be expected with available treatment and
52 death is considered to be unavoidable in the near future (18).

53 OR

54 An incurable and irreversible condition caused by injury, disease, or illness that would cause
55 death within a reasonable period of time in accordance with accepted medical standards, and
56 where the application of life-sustaining treatment would serve only to prolong the process of
57 dying(19).

58 2. Actively dying

59 The hours or days preceding imminent death during which time the patient's physiologic
60 functions wane (19).

61 3. Life sustaining treatment

62 Life sustaining treatment comprises of any medical treatment that artificially supports or
63 replaces, a body function essential to the life of the person. It includes cardiopulmonary
64 resuscitation (CPR), endotracheal intubation, mechanical ventilation, vasopressor therapy,
65 parenteral or artificial enteral nutrition, dialysis, blood products, antibiotics, and intravenous
66 fluids (20).

67 4. Potentially inappropriate treatment (disproportionate treatment, non-beneficial 68 treatment, inadvisable treatment)

69 It connotes interventions aimed at cure that carry greater possibilities of harm than reasonable
70 possibilities of benefit. There is no general consensus about the use of the related term futility
71 and use of this term should be avoided (21).

72 **5. Cardiopulmonary resuscitation (CPR)**

73 It is an emergency medical procedure that combines chest compression often with artificial
74 ventilation, in an effort to manually preserve intact brain function until further measures are
75 taken to restore spontaneous blood circulation and breathing in a person who is in cardiac arrest
76 (22).

77 **6. Do not attempt cardiopulmonary resuscitation (DNR or DNAR) Not for resuscitation**
78 **(NFR)**

79 A decision not to initiate or perform the CPR, on the background of advanced illness where the
80 patient's chances of surviving in the event that he/she needs CPR are extremely low or the
81 patient fully aware of his/her advanced illness would not like to undergo CPR (23).

82 **7. Withholding life sustaining treatment**

83 On a background of advanced life limiting illness, a decision made not to initiate or escalate a
84 life-sustaining treatment, where the patient's chances of survival after initiation or escalation of
85 life sustaining treatment, is dismal, with the burden outweighing the possible benefit, and the
86 fully informed patient or surrogate if the patient lacks decision capacity, would choose the option
87 not to initiate or escalate the said life-sustaining treatment (24).

88 **8. Withdrawing life sustaining treatment**

89 On a background of advanced life limiting illness, decision made to cease or remove a life-
90 sustaining intervention presently provided, where patient's chances of survival with continued
91 life sustaining treatment is dismal with the burden outweighing the possible benefit and the fully
92 informed patient or surrogate if the patient lacks decision capacity would choose the option to
93 cease or have removed the said life-sustaining treatment (24).

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95 **9. Euthanasia**

96 Euthanasia is the intentional act of killing a dying patient with terminal illness by the direct
97 intervention of a doctor, for the purpose of good of the patient . However, allowing natural death,
98 withholding and withdrawing of life sustaining treatment to limit harm and suffering in a dying
99 patient should not be construed as Euthanasia (25).

100 **10. Active shortening of dying process**

101 An active act intended to hasten death or shorten the life of a dying patient with terminal illness.
102 However, allowing natural death, withholding and withdrawing of life support to limit harm and
103 suffering in a dying patient should not be construed as active shortening of life (2).

104 **11. Physician assisted suicide**

105 Is an intentional act by the physician, on voluntary request of a dying patient with terminal
106 illness, providing the means or methods with an intention to help a person to end his/her life
107 (26).

108 **12. Palliative Care**

109 According to WHO, Palliative care is an approach that improves the quality of life of patients
110 and their families facing the problem associated with life-threatening illness, through the
111 prevention and relief of suffering by means of early identification and impeccable assessment
112 and treatment of pain and other problems, physical, psychosocial and spiritual (27).

113 **13. End of Life Care**

114 An approach to terminally ill patient that shifts the focus of care to symptom control, comfort,
115 quality of life and quality of dying rather than treatments aimed at cure or prolongation of life
116 (28).

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118 **14. Palliative Sedation**

119 Palliative sedation is the intentional administration of sedative substances at the minimal dosage
120 necessary to lower the consciousness level definitely or temporarily of a person suffering from
121 an incurable disease and having a limited life expectancy (days or weeks) in order to obtain relief
122 from one or several refractory symptoms (29).

123 OR

124 “Therapeutic (or palliative) sedation in the context of palliative medicine is the monitored use of
125 medications intended to induce a state of decreased or absent awareness (unconsciousness) in
126 order to relieve the burden of otherwise intractable suffering in a manner that is ethically
127 acceptable to the patient, family and health-care providers (30).

128 **15. Double effect**

129 This principle distinguishes the effects that are intended, from those that are foreseeable though
130 unintended. The principle justifies the appropriate use of palliative analgesia and sedation,
131 specifically to relieve suffering, even at the risk of hastening death as a side effect, which is
132 unintended (31).

133 **16. Death**

134 Irreversible cessation of the heart and circulatory function, or, neurological function of the brain
135 including brain stem (32).

136 OR

137 “Deceased Person” means a person in whom permanent disappearance of all evidence of life
138 occurs, by reason of brain-stem death or in a cardio-pulmonary sense, at any time after live birth
139 has taken place (33).

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141 **17. Best interests**

142 The best interest concept holds that the physicians and other healthcare providers must weigh the
143 benefits and risks of treatments and select ones in which the benefits are maximized and the risks
144 minimized for the patient. This is not based on value judgments but on objective criteria
145 prescribed by professional and societal standards (34).

146 **18. Health care decision making capacity**

147 Health care decision making capacity is the capacity of an individual to make an informed
148 decision after fully understanding the nature of intervention, purpose of intervention, risks and
149 benefits of intervention, risks of not carrying out the intervention and risks and benefits of
150 alternate interventions (34).

151 **19. Shared decision-making**

152 A dynamic process with responsibility for decisions about the medical care of a patient being
153 shared between the health care team and the patient or the patient's surrogates (35).

154 **20. Advance directives**

155 A statement made by a person with the decision-making capacity stating his/her wishes
156 regarding how to be treated or not treated at a stage when s/he loses such capacity. Advance
157 directives include living wills or health care proxies and become operational only after the
158 person loses capacity (36).

159 **21. Surrogate**

160 Surrogate is a person or persons other than healthcare providers who is/are accepted as
161 representatives of the patient's interests. This is a designated/nominated person who may or may
162 not be a family member. If no one is nominated, next of kin are considered surrogates (36).

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164 **22. Autonomy**

165 Autonomy is the capacity of a rational individual to make a free and informed decision.
166 Autonomy, in the context of medical practice, includes the patient's right to full information and
167 to participate in medical decision-making. This includes the right to refuse interventions (37).

168 **23. Beneficence**

169 This principle makes it obligatory on the part of physicians to act in the best interests of patients
170 (38).

171 **24. Non-maleficence**

172 This principle directs physicians to first of all not do harm. The harm also includes harm to
173 patients' whole person interests, expressed as values and wishes (39).

174 **25. Justice**

175 In the context of medical care requires that all people be treated without prejudice and healthcare
176 resources be used equitably (40).

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Explanatory notes

1. Terminal illness

According to International Association of Hospice and Palliative Care, terminal illness is a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and aging. A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise. The terms eventually fatal or terminal condition are used interchangeably. In reference to the patient, language that refers to living with an eventually fatal or terminal condition is recommended (19).

According to American Cancer Society, it is an irreversible condition that in the near future will result in death or a state of permanent unconsciousness from which you are unlikely to recover. In most states, a terminal illness is defined as one in which the patient will die “shortly” whether or not medical treatment is given (41).

According to Mosby’s medical dictionary, terminal illness is an advanced stage of a disease with an unfavourable prognosis and no known cure.

Various authorities have specified a duration of 6 months or 12 months but without any objective evidence and hence the duration is not being further specified in this document.

2. Actively dying

Actively dying has not been well defined in the literature. It is normally described in terms of the last hours or days of life, and presence of unique signs and symptoms preceding death. There is a paucity of studies on the signs of impending death. Further studies are needed to examine specific signs that may signal that the patient is actively dying and to allow clinicians to educate

202 family members and make appropriate recommendations toward maximizing comfort and
203 minimizing aggressive end-of-life measures (19).

204 **3. Life sustaining treatment**

205 According to British Medical Association, this refers to all treatments which have the potential to
206 postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial
207 ventilation, blood products, pacemakers, vasopressors, specialized treatments for particular
208 conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-
209 threatening infection, and artificial nutrition and hydration(42).

210 **4. Potentially inappropriate treatment**

211 According to the official policy statement of the American Thoracic Society, the American
212 Association for Critical Care Nurses, the American college of Chest Physicians, the European
213 Society for Intensive Care Medicine, and the Society of Critical Care Medicine, the term
214 "potentially inappropriate" should be used, rather than "futile," to describe treatments that have
215 at least some chance of accomplishing the effect sought by the patient, but clinicians believe that
216 competing ethical considerations justify not providing them. Clinicians should communicate and
217 advocate for the treatment plan they believe is appropriate. Requests for potentially inappropriate
218 treatments that remain intractable despite intensive communication and negotiation should be
219 managed by a fair process of conflict resolution (43).

220 Justification: The committee recommends use of the term "potentially inappropriate" rather than
221 "futile" to emphasize two important aspects of such judgments. First, the word "inappropriate"
222 conveys more clearly than the word "futile" or "ineffective" that the assertion being made by
223 clinicians depends both on technical medical expertise and a value-laden claim, rather than
224 strictly a technical judgment. Second, the word "potentially" signals that the judgments are

225 preliminary, rather than final, and require review before being acted on. The ethical concerns that
226 may be raised to justify the refusals include concerns that the treatment is highly unlikely to be
227 successful, is extremely expensive, or is intended to achieve a goal of controversial value.

228 **5. Cardiopulmonary resuscitation**

229 According to the International Liaison Committee on Resuscitation, Cardiopulmonary
230 resuscitation, commonly known as CPR, is an emergency procedure that combines chest
231 compression often with artificial ventilation in an effort to manually preserve intact brain
232 function until further measures are taken to restore spontaneous blood circulation and breathing
233 in a person who is in cardiac arrest. It is indicated in those who are unresponsive with no
234 breathing or abnormal breathing, for example, agonal respirations(22).

235 **6. Do not attempt resuscitation**

236 According to American Heart Association guidelines, a Do Not Attempt Resuscitation (DNAR)
237 order is given by a licensed physician or alternative authority as per local regulation, and it must
238 be signed and dated to be valid. In many settings, “Allow Natural Death” (AND) is becoming a
239 preferred term to replace DNAR, to emphasize that the order is to allow natural consequences of
240 a disease or injury, and to emphasize ongoing end-of-life care. The DNAR order should
241 explicitly describe the resuscitation interventions not to be performed in the event of a life-
242 threatening emergency. In most cases, a DNAR order is preceded by a documented discussion
243 with the patient, family, or surrogate decision maker addressing the patient's wishes about
244 resuscitation interventions. In addition, some jurisdictions may require confirmation by a witness
245 or a second treating physician (44).

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248 **7. Withholding life sustaining treatment.**

249 According to Guardianship and Administration Act 2000 and the Powers of Attorney Act 1998
250 in the US, it is the decision to withhold medical treatment prospectively: that is, whether or not
251 to commence treatment for an event/s yet to take place. This may involve a dimension of
252 uncertainty, because there could be unknowns about the future clinical state of the patient, for
253 example, when and if the patient will suffer a cardiac arrest, necessitating CPR(45).

254 **8. Withdrawing life sustaining treatment**

255 According to Guardianship and Administration Act 2000 and the Powers of Attorney Act 1998,
256 in the US, the decision to withdraw a life-sustaining measure implies that a level of acceptance
257 about the benefits of continuing the measures has been reached, both by the clinicians involved
258 and the family. The decision signifies that a stage has been reached where the evidence points to
259 the fact that the patient undeniably and irrefutably is receiving no benefit from the interventions
260 proposing to be withdrawn. Arguably, the consent processes for withdrawing medical treatment
261 may be less onerous than for withholding medical treatment, most likely because the patient 's
262 condition has stabilized to the extent that no further improvement is expected(45).

263 **9. Euthanasia**

264 Euthanasia is defined as direct intentional killing of a person as part of the medical care being
265 offered. The withholding or withdrawing of artificial life support procedures for a terminally ill
266 patient is not euthanasia. Withholding/withdrawing life sustaining treatment taking into account
267 the patients benefits, wish of the patient and family, when based upon the principle of the futility
268 of treatment for a terminal patient, is legally acceptable and appropriate (25).

269 **Passive euthanasia:** Although the term passive euthanasia is used by some people to mean
270 withholding or withdrawing life sustaining treatment, the term is not used in medically advanced

271 countries when the subject is officially discussed. Notable examples include deciding to forego
272 Life-Sustaining Treatment (A report on the ethical, medical, and legal issues in treatment
273 decisions) published by the Presidents Commission for the Study of Ethical Problems in
274 Medicine and Biomedical and Behavioural Research of USA 1983, and the Report of the House
275 of Lords Select Committee on Medical Ethics of UK 1994. The term is also not used in the
276 professional guidelines on the subject in various medically advanced countries (46).

277 Withholding or withdrawing life-sustaining treatment, if done under appropriate circumstances,
278 is ethically and legally acceptable. This is ethically and legally different from euthanasia as the
279 latter is direct intentional killing of a person as part of the medical care being offered. To use the
280 term passive euthanasia to describe the appropriate withholding or withdrawal of life-sustaining
281 treatment may give people the wrong impression that such a decision is ethically and legally
282 similar to active euthanasia. Withholding or withdrawing life-sustaining treatment includes
283 widely different situations, ranging from withholding cardiopulmonary resuscitation in a
284 terminally ill malignancy patient, to withdrawing artificial nutrition in a patient in persistent
285 vegetative state. The former is non-controversial but the latter is very controversial. If the term
286 passive euthanasia is used, people may relate all discussions about withholding or withdrawing
287 life-sustaining treatment to the controversial situations like the latter one (47).

288 The term passive euthanasia may contain the meaning of an intention to kill. We support
289 withholding or withdrawing futile treatment which only prolongs the dying process, but we do
290 not support an intention to kill. Avoiding the misleading term passive euthanasia but using the
291 more neutral term withholding or withdrawing life-sustaining treatment would thus facilitate
292 public discussion on the topic. This would also facilitate discussion with the patients and families
293 in individual cases when such discussion is required (48).

294 **10. Active shortening of life**

295 According to the ETHICUS study, active shortening of the dying process was defined as a
296 circumstance in which someone performed an act with the specific intent of shortening the dying
297 process; these acts did not include withholding or withdrawing treatment although withholding
298 or withdrawing could occur prior to shortening of dying process. Examples included an
299 intentional overdose of narcotics, anaesthetics, or potassium chloride (2).

300 The term "shortening of the dying process" was used instead of active euthanasia because Dutch
301 investigators insisted that the term "active euthanasia" could not include most ICU patients who
302 could not request the action. Several other terms were considered, but shortening of the dying
303 process was accepted by all investigators as it describes the intent, the action that occurs, and is a
304 more neutral term that physicians might more readily record. In addition, as some investigators
305 might still be reluctant to admit to shortening of the dying process, another question was added
306 to evaluate the highest possible incidence of actions that might be considered active euthanasia
307 (although most of these actions were probably not active euthanasia). For each patient,
308 physicians were asked whether any other action (not forgoing therapy) taken to relieve patient
309 suffering may have contributed to the patient's death (49).

310 **11. Physician assisted suicide**

311 According to Hastings Centre Bioethics briefing, Physician-assisted suicide refers to the practice
312 where a physician provides a potentially lethal medication to a terminally ill, suffering patient at
313 his request that he can take (or not) at a time of his own choosing to end his life. It is also called
314 physician-assisted suicide, physician aid-in-dying, and patient administered hastened death (50).

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317 **12. Palliative Care**

318 According to WHO, palliative care is an approach that improves the quality of life of patients
319 and their families facing the problem associated with life-threatening illness, through the
320 prevention and relief of suffering by means of early identification and impeccable assessment
321 and treatment of pain and other problems, physical, psychosocial and spiritual(27).

322 Palliative care:

- 323 • provides relief from pain and other distressing symptoms;
- 324 • affirms life and regards dying as a normal process;
- 325 • intends neither to hasten or postpone death;
- 326 • integrates the psychological and spiritual aspects of patient care;
- 327 • offers a support system to help patients live as actively as possible until death;
- 328 • offers a support system to help the family cope during the patients illness and in their
329 own bereavement;
- 330 • uses a team approach to address the needs of patients and their families, including
331 bereavement counselling, if indicated;
- 332 • will enhance quality of life, and may also positively influence the course of illness;
- 333 • is applicable early in the course of illness, in conjunction with other therapies that are
334 intended to prolong life, such as chemotherapy or radiation therapy, and includes those
335 investigations needed to better understand and manage distressing clinical complications
336 (27).

337 **13. End of life care**

338 According to General Medical Council, UK, patients are ‘approaching the end of life’ when they
339 are likely to die within the next 12 months. This includes those patients whose death is expected

340 within hours or days; those who have advanced, progressive incurable conditions; those with
341 general frailty and co-existing conditions that mean they are expected to die within 12 months;
342 those at risk of dying from a sudden acute crisis in an existing condition; and those with life-
343 threatening acute conditions caused by sudden catastrophic events. The term 'approaching the
344 end of life' can also apply to extremely premature neonates whose prospects for survival are
345 known to be very poor, and patients who are diagnosed as being in a persistent vegetative state
346 (PVS) for whom a decision to withdraw treatment and care may lead to their death(51).

347 **14. Palliative Sedation**

348 According to the position statement of American Association of hospice and Palliative Medicine,
349 Palliative sedation (PS), as defined in this statement, is the intentional lowering of awareness
350 towards, and including, unconsciousness for patients with severe and refractory symptoms(52).

351 PS must satisfy the criteria of having a specific clinical indication, a target outcome, and a
352 benefit/risk ratio that is acceptable to both the clinician and patient. Palliative sedation is an
353 intervention reserved for extreme situations. The use of palliative sedation should only be
354 considered after all available expertise to manage the target symptom has been accessed. The
355 level of sedation should be proportional to the patient's level of distress. As with all treatments,
356 patients, when able, should participate in the decision to use palliative sedation. Treatment of
357 other symptoms should be continued alongside palliative sedation, because sedation may
358 decrease the patient's ability to communicate or display discomfort(29).

359 Palliative sedation raises ethical concerns when it significantly reduces patient consciousness to
360 the degree that the patient is unable to substantially interact with others, does not have the ability
361 or opportunity to change his mind, and is unable to eat and drink (thus potentially shortening
362 survival in particular circumstances). Palliative sedation is ethically defensible when used 1)

363 after careful interdisciplinary evaluation and treatment of the patient, and 2) when palliative
364 treatments that are not intended to affect consciousness have failed or, in the judgment of the
365 clinician, are very likely to fail, 3) where its use is not expected to shorten the patient's time to
366 death, and 4) only for the actual or expected duration of symptoms. Palliative sedation should not
367 be considered irreversible in all circumstances. It may be appropriate, in some clinical situations
368 when symptoms are deemed temporary, to decrease sedation after a predetermined time to assess
369 efficacy, continued symptoms and need for ongoing sedation (30).

370 In clinical practice, palliative sedation usually does not alter the timing or mechanism of a
371 patient's death, as refractory symptoms are most often associated with very advanced terminal
372 illness. Practitioners who use palliative sedation should be clear in their intent to palliate
373 symptoms and to not shorten survival. Because patients receiving palliative sedation are typically
374 close to death, most patients will no longer have desire to eat or drink. Artificial nutrition and
375 hydration are not generally expected to benefit the patient receiving palliative sedation, however
376 questions about the use of artificial nutrition and hydration should be addressed before palliative
377 sedation is undertaken (53).

378 Sedation is used in palliative care in several settings: (1) transient sedation for noxious
379 procedures; (2) sedation as part of burn care; (3) sedation used in end of life weaning from
380 ventilator support; (4) sedation in the management of refractory symptoms at the end of life; (5)
381 emergency sedation; (6) respite sedation; (7) sedation for psychological or existential suffering.

382 **15. Double effect**

383 The essence of the doctrine of double effect is that an act performed with good intent can still be
384 moral despite negative side-effects. In the context of end of life care, this can arise when four
385 conditions are met (31):

- 386 1. Administering palliative medication is not, in itself, immoral.

- 387 2. The intention is to relieve pain, not to hasten the patient's death.
- 388 3. The relief of pain is not achieved through causing the patient's death.
- 389 4. Proportionally, the need to relieve pain is such that it warrants accepting the risk of
- 390 hastening death.

391 **16. Death**

392 According to Academy of Medical Royal Colleges, Death is defined as the simultaneous and

393 irreversible onset of apnoea and unconsciousness in the absence of the circulation (54). Full and

394 extensive attempts at reversal of any contributing cause to the cardiorespiratory arrest have been

395 made. Such factors, which include body temperature, endocrine, metabolic and biochemical

396 abnormalities.

397 In the individual meeting the criteria for not attempting cardiopulmonary resuscitation or

398 attempts at cardiopulmonary resuscitation have failed or treatment aimed at sustaining life has

399 been withdrawn because it has been decided to be of no further benefit to the patient and not in

400 his/her best interest to continue and/or is in respect of the patient's wishes via an advance

401 decision to refuse treatment.

402 The individual should be observed by the person responsible for confirming death for a

403 minimum of five minutes to establish that irreversible cardiorespiratory arrest has occurred. The

404 absence of mechanical cardiac function is normally confirmed using a combination of the

405 following: — absence of a central pulse on palpation and the absence of heart sounds on

406 auscultation. These criteria will normally suffice in the primary care setting. However, their use

407 can be supplemented in the hospital setting by one or more of the following: — asystole on a

408 continuous ECG display, absence of pulsatile flow using direct intra-arterial pressure monitoring

409 or absence of contractile activity using echocardiography.

410 Any spontaneous return of cardiac or respiratory activity during this period of observation should
411 prompt a further five minutes' observation from the next point of cardiorespiratory arrest. After
412 five minutes of continued cardiorespiratory arrest the absence of the pupillary responses to light,
413 of the corneal reflexes, and of any motor response to supra-orbital pressure should be confirmed.
414 The time of death is recorded as the time at which these criteria are fulfilled.

415 **17. Best interests**

416 According to Mental Capacity Act 2005 UK, the act sets out what you must consider when
417 deciding what is in the best interests of your patient. You should take into account: past and
418 present wishes and feelings beliefs and values that may have influenced the decision being made,
419 had the person had capacity other factors that the patient would be likely to consider if they had
420 capacity(34).

421 You must have objective reasons for any decision you make. You must also be able to show that
422 you considered all circumstances relevant to the decision in question. In trying to assess the best
423 interests of a person lacking capacity, you should: Encourage the person lacking capacity to
424 participate in the decision. To do this, it may be necessary to use specific communication
425 methods; for example, simple language or pictures, or by using a specialist to help communicate.

426 Avoid discrimination: The Act specifically states that decisions cannot be based on a person's
427 age, appearance or condition or any aspect of the person's behaviour. The appearance can refer
428 to all aspects of a person's physical appearance, while the condition can include learning
429 difficulties, age-related illnesses or temporary conditions (such as unconsciousness or
430 drunkenness).

431 Try to identify all the issues most relevant to the person who lacks capacity and to the specific
432 decision to be made. These will vary from case to case, depending on the capacity of your patient

433 and the decision needing to be made. If possible, defer the decision if the patient is likely to
434 regain capacity. In emergency situations, it may not be possible to wait for the patient to regain
435 capacity (55).

436 **18. Health care decision making capacity**

437 According to General Medical Council UK, you must assess a patient's capacity to make a
438 particular decision at the time it needs to be made.

439 You must not assume that because a patient lacks capacity to make a decision on a particular
440 occasion, they lack capacity to make any decisions at all, or will not be able to make similar
441 decisions in the future.

442 You must take account of the advice on assessing capacity in the Codes of Practice that
443 accompany the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000
444 and other relevant guidance. If your assessment is that the patient's capacity is borderline, you
445 must be able to show that it is more likely than not that they lack capacity (56).

446 If your assessment leaves you in doubt about the patient's capacity to make a decision, you
447 should seek advice from:

- 448 a. nursing staff or others involved in the patient's care, or those close to the patient, who
449 may be aware of the patient's usual ability to make decisions and their particular
450 communication needs
- 451 b. colleagues with relevant specialist experience, such as psychiatrists, neurologists, or
452 speech and language therapists. If you are still unsure about the patient's capacity to
453 make a decision, you must seek legal advice with a view to asking a court to determine
454 capacity.

455 In making decisions about the treatment and care of patients who lack capacity, you must:

- 456 a. make the care of your patient your first concern
- 457 b. treat patients as individuals and respect their dignity
- 458 c. support and encourage patients to be involved, as far as they want to and are able, in
- 459 decisions about their treatment and care
- 460 d. treat patients with respect and not discriminate against them.

461 You must also consider:

- 462 a. whether the patient's lack of capacity is temporary or permanent
- 463 b. which options for treatment would provide overall clinical benefit for the patient
- 464 c. which option, including the option not to treat, would be least restrictive of the patient's
- 465 future choices
- 466 d. any evidence of the patient's previously expressed preferences, such as an advance
- 467 statement or decision
- 468 e. the views of anyone the patient asks you to consult, or who has legal authority to make a
- 469 decision on their behalf, or has been appointed to represent them
- 470 f. the views of people close to the patient on the patient's preferences, feelings, beliefs and
- 471 values, and whether they consider the proposed treatment to be in the patient's best
- 472 interests
- 473 g. what you and the rest of the healthcare team know about the patient's wishes, feelings,
- 474 beliefs and values(57).

475 **19. Shared decision making**

476 According to General Medical Council UK, the exchange of information between doctor and
477 patient is central to good decision-making(58). How much information you share with patients

478 will vary, depending on their individual circumstances. You should tailor your approach to
479 discussions with patients according to:

- 480 a. their needs, wishes and priorities
- 481 b. their level of knowledge about, and understanding of, their condition, prognosis and the
482 treatment options
- 483 c. the nature of their condition
- 484 d. the complexity of the treatment, and
- 485 e. the nature and level of risk associated with the investigation or treatment.

486 You should not make assumptions about:

- 487 a. the information a patient might want or need
- 488 b. the clinical or other factors a patient might consider significant, or
- 489 c. a patient's level of knowledge or understanding of what is proposed.

490 You must give patients the information they want or need about:

- 491 a. the diagnosis and prognosis
- 492 b. any uncertainties about the diagnosis or prognosis, including options for further
493 investigations
- 494 c. options for treating or managing the condition, including the option not to treat
- 495 d. the purpose of any proposed investigation or treatment and what it will involve
- 496 e. the potential benefits, risks and burdens, and the likelihood of success, for each
497 option; this should include information, if available, about whether the benefits or
498 risks are affected by which organization or doctor is chosen to provide care
- 499 f. whether a proposed investigation or treatment is part of a research program or is an
500 innovative treatment designed specifically for their benefit

- 501 g. the people who will be mainly responsible for and involved in their care, what their
- 502 roles are, and to what extent students may be involved
- 503 h. their right to refuse to take part in teaching or research
- 504 i. their right to seek a second opinion
- 505 j. any bills they will have to pay
- 506 k. any conflicts of interest that you, or your organization, may have with any treatments
- 507 that you believe have greater potential benefit for the patient than those you or your
- 508 organization can offer.

509 You should explore these matters with patients, listen to their concerns, ask for and respect their
510 views, and encourage them to ask questions.

511 Consent: Patients and doctors making decisions together. You should check whether patients
512 have understood the information they have been given, and whether or not they would like more
513 information before making a decision. You must make it clear that they can change their mind
514 about a decision at any time. You must answer patients' questions honestly and, as far as
515 practical, answer as fully as they wish (59).

516 **20. Advance directives**

517 According to National Hospice and Palliative Care Organization, advance care planning is
518 making decisions about the care you would want to receive if you become unable to speak for
519 yourself. These are your decisions to make, regardless of what you choose for your care, and the
520 decisions are based on your personal values, preferences, and discussions with your loved ones.
521 If you are in an accident or have an illness that leaves you unable to talk about your wishes, who
522 will speak for you? You can tell your family, friends and healthcare providers what your wishes

523 and personal beliefs are about continuing or withdrawing medical treatments at the end of life.

524 Advance care planning includes:

- 525 • Getting information on the types of life-sustaining treatments that are available.
- 526 • Deciding what types of treatment, you would or would not want should you be diagnosed
527 with a life-limiting illness.
- 528 • Sharing your personal values with your loved ones.
- 529 • Completing advance directives to put into writing what types of treatment you would or
530 would not want should you be unable to speak for yourself.

531 Decisions about end-of-life care are deeply personal, and are based on your values and beliefs.
532 Because it is impossible to foresee every type of circumstance or illness, it is essential to think in
533 general about what is important to you. Conversations that focus on your wishes and beliefs will
534 relieve loved ones and healthcare providers of the need to guess what you would want(60).

535 **21. Surrogate**

536 According to Illinois Health Care Surrogate Act, "Surrogate decision maker" means an adult
537 individual or individuals who (i.) have decisional capacity, (ii) are available upon reasonable
538 inquiry, (iii) are willing to make medical treatment decisions on behalf of a patient who lacks
539 decisional capacity, and (iv) are identified by the attending physician in accordance with the
540 provisions of this Act as the person or persons who are to make those decisions in accordance
541 with the provisions of this Act (61).

542 (a) When a patient lacks decisional capacity, the health care provider must make a reasonable
543 inquiry as to the availability and authority of a health care agent under the Powers of Attorney
544 for Health Care Law. When no health care agent is authorized and available, the health care
545 provider must make a reasonable inquiry as to the availability of possible surrogates listed in

546 items (1) through (4) of this subsection. For purposes of this Section, a reasonable inquiry
547 includes, but is not limited to, identifying a member of the patient's family or other health care
548 agent by examining the patient's personal effects or medical records. If a family member or other
549 health care agent is identified, an attempt to contact that person by telephone must be made
550 within 24 hours after a determination by the provider that the patient lacks decisional capacity.
551 No person shall be liable for civil damages or subject to professional discipline based on a claim
552 of violating a patient's right to confidentiality as a result of making a reasonable inquiry as to the
553 availability of a patient's family member or health care agent, except for wilful or wanton
554 misconduct.

555 The surrogate decision makers, as identified by the attending physician, are then authorized to
556 make decisions as follows: (i) for patients who lack decisional capacity and do not have a
557 qualifying condition, medical treatment decisions may be made in accordance with subsection
558 (b-5) of Section 20; and (ii) for patients who lack decisional capacity and have a qualifying
559 condition, medical treatment decisions including whether to forgo life-sustaining treatment on
560 behalf of the patient may be made without court order or judicial involvement in the following
561 order of priority as stated in the Human Transplant Act(62):

- 562 1. spouse or partner (including civil or same sex partner)
- 563 2. parent or child (in this context a child can be any age and means a biological or
564 adopted child)
- 565 3. brother or sister
- 566 4. grandparent or grandchild
- 567 5. niece or nephew
- 568 6. stepfather or stepmother

569 7. half-brother or half-sister

570 8. friend of long standing

571 The health care provider shall have the right to rely on any of the above surrogates if the provider
572 believes after reasonable inquiry that neither a health care agent under the Powers of Attorney
573 for Health Care Law nor a surrogate of higher priority is available.

574 Where there are multiple surrogate decision makers at the same priority level in the hierarchy,
575 it shall be the responsibility of those surrogates to make reasonable efforts to reach a consensus
576 as to their decision on behalf of the patient regarding the forgoing of life-sustaining treatment. If
577 2 or more surrogates who are in the same category and have equal priority indicate to the
578 attending physician that they disagree about the health care matter at issue, a majority of the
579 available persons in that category (or the parent with custodial rights) shall control, unless the
580 minority (or the parent without custodial rights) initiates guardianship proceedings in accordance
581 with the Probate Act of 1975. No health care provider or other person is required to seek
582 appointment of a guardian (63).

583 (b). After a surrogate has been identified, the name, address, telephone number, and
584 relationship of that person to the patient shall be recorded in the patient's medical record.

585 (c). Any surrogate who becomes unavailable for any reason may be replaced by applying the
586 provisions of Section 25 in the same manner as for the initial choice of surrogate.

587 (d). In the event an individual of a higher priority to an identified surrogate becomes available
588 and willing to be the surrogate, the individual with higher priority may be identified as
589 the surrogate. In the event an individual in a higher, a lower, or the same priority level or
590 a health care provider seeks to challenge the priority of or the life-sustaining treatment

591 decision of the recognized surrogate decision maker, the challenging party may initiate
592 guardianship proceedings in accordance with the Probate Act of 1975.

593 (e). The surrogate decision maker shall have the same right as the patient to receive medical
594 information and medical records and to consent to disclosure.

595 (f). Any surrogate shall have the authority to make decisions for the patient until removed by
596 the patient who no longer lacks decisional capacity, appointment of a guardian of the
597 person, or the patient's death.

598 **22. Autonomy**

599 According to Beauchamp and Childress; Principles of Biomedical Ethics, autonomy is respecting
600 the decision-making capacities of autonomous persons; enabling individuals to make reasoned
601 informed choices. It is the respect for the right of a mentally competent individual to consent or
602 to refuse clinically indicated medical treatment (including life-sustaining treatment). The choice
603 should be based on adequate information, and the individual takes responsibility for such choice.
604 Respect for patient's autonomy is sometimes extended to include respect for patient's bodily
605 integrity. For example, for mentally incompetent individuals who cannot express preferences and
606 make choice, decisions on life-sustaining treatment should nonetheless take into account their
607 bodily integrity (64).

608 **23. Beneficence**

609 According to Beauchamp and Childress; Principles of Biomedical Ethics, this considers the
610 balancing of benefits of treatment against the risks and costs; the healthcare professional should
611 act in a way that benefits the patient. It also includes duty of care and due regard for patient's
612 welfare and interests (to preserve life, relieve suffering, limit disability). Related professional
613 terms and concepts include patient's best interests and patient's benefit(64).

614 **24. Non-maleficence**

615 According to Beauchamp and Childress; Principles of Biomedical Ethics, it involves avoiding
616 the causation of harm; the healthcare professional should not harm the patient. All treatment
617 involves some harm, even if minimal, but the harm should not be disproportionate to the benefits
618 of treatment. In the context of end of life care, to avoid prolonging suffering by futile
619 interventions, and to adequately consider the risks and harms of interventions(64).

620 **25. Justice**

621 According to Beauchamp and Childress; Principles of Biomedical Ethics, it involves distributing
622 benefits, risks and costs fairly; the notion that patients in similar positions should be treated in a
623 similar manner. Treating all persons according to what is fair or due to them. A related concept
624 often considered is equity. An individual should not be unfairly treated (discriminated) based on
625 disability, age, social status, etc. On the other hand, an individual cannot claim unlimited right
626 (e.g. to be treated at all costs), without regard to the impact on other persons or to scarcity of
627 resources (64).

628

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