Advance Decision to Refuse all Life Prolonging Treatments after three months of very probably irreversible legal incapacity to make my own healthcare decisions; and an Advance Statement explaining some of my relevant values beliefs wishes and preferences

by Dr Raanan Gillon, [date of birth and address]

Brief 'executive summary' for busy doctors !

This document is my legally binding Advance Decision to Refuse any and all Life Prolonging Treatments, including but not limited to attempted cardio-pulmonary resuscitation, respirator or oxygen treatment, renal and other dialysis, fluid and electrolyte replacement therapy, inotropics and vasopressors, pacemakers, any form of systemic antibiotics and any form of artificial or clinically assisted nutrition and hydration, (ANH/CANH), and any other intervention that may prolong my life, if I have for any reason lacked legal capacity for three months or longer to consent to or reject medical or other health care treatments and interventions and the doctor or doctors caring for me consider(s) that I am very unlikely (roughly meaning for me an estimated approximate probability in the region of 10 per cent or less) to regain such legal capacity. Two possible but unlikely exceptions to this otherwise absolute refusal of life prolonging treatment are described below- the first is the possible development of an intervention that would make it *very likely* that I would regain legal capacity to make such decisions and I would be *very likely* to receive it; the second is the possible situation in which I am being kept alive as a potential organ donor and my loved ones accept this prolongation of my life. Those are the only two situations in which I consent to the over-riding of my default position of refusing life prolonging treatment in the circumstances described. This document also outlines, by means of an Advance Statement, some of my relevant values and beliefs and wishes and preferences including for treatments that I would prefer to be given when normal but life prolonging treatments may not be given as a result of this document, and including treatments that I would prefer to be given in order to reduce any antisocial behaviour or condition that I may manifest. I realise that while I have a legal right under the Mental Capacity Act 2005 to have my refusals of treatment met I have no legal right to have my requests for treatments met. However I would like my requests to be considered, as *is* required under the same Act, when doctors are assessing my best interests. This document also considers some specific treatment dilemmas that might arise, reiterates my default position to refuse all life prolonging treatment as summarised above, and states my preferences for alternative symptomatic treatments when such dilemmas arise. The 'bottom line' is that while I am definitely not asking my doctors to do anything illegal such as euthanasia or physician assisted suicide I am absolutely refusing to give my consent and permission for any treatments or interventions that are likely to prolong my life in the circumstances summarised above and further explained below.

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My Advance Decision to Refuse Life Prolonging Treatment (ADRLPT)

If the future situation arises in which I have lacked legal capacity for three months or longer to consent to or refuse life prolonging medical treatment or other life prolonging interventions and my doctor or doctors consider that it is very unlikely that I will recover legal capacity to make such decisions for myself (as a decision aid let me state that "very unlikely" roughly means, for me, an estimated approximate probability in the region of 10 per cent or less) then I Raanan Gillon hereby refuse any form of treatment or intervention that may prolong my life.

Treatments refused

The treatments I refuse include, but are not limited to, attempted cardio-pulmonary resuscitation, respirator or oxygen treatment, renal and other dialysis, fluid and electrolyte replacement therapy, blood transfusions, inotropic and vasopressor medications, pacemakers, any form of systemic antibiotics, any form of artificial or clinically assisted nutrition and hydration, (ANH/CANH) administered in any way other than by *offering* it to me to eat and or drink and my accepting such offers by voluntarily eating and or drinking, anti-cancer treatments unless they are very unlikely to prolong my life, any pharmaceutical treatment unless it is very unlikely to prolong my life, any surgical operation unless it is very unlikely to prolong my life, any form of physiotherapy unless it is very unlikely to prolong my life, **and any other intervention of any sort that may prolong my life** . By 'may prolong my life' I mean that current ordinary medical opinion at the time of their proposed use would judge that their administration would have some likelihood of prolonging my life: only if the medication or treatment or intervention would be medically considered *extremely unlikely* to prolong my life (by which I roughly mean, again to offer a decision aid, that there is no more than an approximately 'guesstimated' one in a thousand probability that it would prolong my life) may it be administered. For the avoidance of doubt I do *not* refuse the administration of pain killers or sedatives including opiates, other psychotropic medications and other pharmaceuticals given to relieve actual or apparent symptoms or signs of suffering or distress.

Types of situation in which this refusal of treatment will apply

The types of situation that may lead to my legal incapacity to consent to or refuse life prolonging treatments include but of course are not limited to severe brain damage resulting from trauma, strokes, infections, neoplasms, autoimmune disease and other forms of brain and neurological damage **and also include the various causes of dementia** such as Alzheimer's disease and vascular dementia, as well as the causes of locked in syndrome. As well as legal incapacity resulting from any form of very severe brain damage that causes coma or vegetative state or minimally conscious state, I also include situations in which less severe brain damage or disorder has caused sufficient dementia or any other mental impairment or disorder to render me legally incapacitous to consent to or refuse life prolonging treatments and interventions. Thus I intend this refusal of life prolonging treatment to cover the complete range of possible clinical states that may have resulted in my legal incapacity to consent to or refuse life prolonging treatments or other life prolonging interventions; at one end of the spectrum I may be in an intensive care bed or other hospital bed, in coma, prolonged vegetative state or minimally conscious state; at the other end of the spectrum I may be at home or in an old age or other care facility affected by dementia. In all and any such circumstances if I have not had legal capacity to consent to or refuse life prolonging treatments for three months or more and am judged very unlikely to regain such legal capacity then this Advance Decision to Refuse Life Prolonging Treatment, made in the full understanding that implementing it may- indeed very probably will- put my life at risk, should be considered as my absolute refusal of any treatment(s) which may prolong my life, with two exceptions specified in the 'Executive Summary' above and again below.

I require this Advance Decision To Refuse Life Prolonging Treatment to be followed even if, in a state of such incapacity or lack of ability to communicate, I appear to be content with my lot, and or to have no preferences or opinions, and or in which my current views are unknown or unclear, and even if anyone caring for me believes that I would wish to revoke any part of this ADRLPT and or believes that circumstances have arisen which had I known about them at the time of writing this document would have caused me not to do so, and or simply believes that it would be in my best interests to ignore any refusal of treatment specified in this Advance Decision. I consider that my own capacitous views of my best interests, as expressed in this document, should, when I cease to have legal capacity, be determinative in the context of refusing, subject to

the two exceptions specified, all and any potentially life prolonging interventions by others. I apologise to any doctors who may find these refusals too emotionally religiously or morally difficult to implement. However I respectfully ask any such doctor: if you really can't accept a legally binding instruction from me when I was autonomous not to give me life prolonging treatment when I no longer have legal capacity to accept or refuse treatment, then please transfer my care as rapidly as possible to a doctor who can. I also expect and hope that the Advance Statement in this document about some of my values beliefs wishes and preferences will inform and be taken seriously by those involved in my care about the types of interventions that I would prefer and would consider to be in my best interests.

The two possible exceptions to my otherwise absolute rejection of life prolonging treatment once I have become legally incapacitous for three months or longer and my doctors judge it very unlikely that I shall recover legal capacity; amazing new treatments and organ donation

First possible exception. A counterargument often offered by opponents of ADRLPTs is that they do not consider possible development of new therapies. I have considered such possibilities and if by the time that I have been legally incapacitous for three months or more to accept or refuse treatment and am very unlikely to regain such legal capacity a new treatment has, by some miracle or otherwise, been developed to a stage that its administration *might* reverse my legal incapacity and thus *might* render me legally capacitous to make and communicate my own decisions, I nonetheless hereby refuse any life prolonging treatment of any sort ***unless*** the doctor in charge of my treatment reasonably believes ***both*** that the new treatment *seems very likely* to reverse my incapacity within six months of its administration ***and*** that I am *very likely* to receive the new treatment within six months of first receiving life prolonging treatment in contravention of this advance decision (by " very likely" I roughly mean, again to offer a decision aid, an estimated or 'guesstimated' probability in the region of seventy percent or greater). In those very improbable circumstances I consent to the administration of life prolonging treatment for up to an additional twelve months. If after twelve months following the over-riding of my refusal of life prolonging treatment in pursuit of this exception, I have not recovered legal capacity to consent to or reject life prolonging treatment this conditional consent to such treatment is withdrawn and all life prolonging treatment including ANH/CANH must be withdrawn and or withheld, unless the following and second possible exception applies.

Second possible exception. If I am being kept alive in circumstances where there is no significant probability of my recovery but in which continuation of life prolonging treatment is recommended in order to maintain my organs and or tissues in as optimal a state as possible in order that they may be transplanted to benefit others, (I am registered for donation on the organ transplantation data base) , and if such life prolonging treatment for the benefit of others is acceptable at that time to my wife and my daughter if they are involved at the time of such decisions, or is acceptable to whichever of them is so involved, or if neither is so involved, then I hereby give permission for my life to be prolonged for this purpose.

An Advance Statement explaining some of my relevant views values wishes and preferences, to guide decisions made by others about my best interests

First , please would my doctors and carers put a prominent notice in my medical and care notes after I have been legally incapacitated to make my own health care decisions for three months and am considered very unlikely to regain such legal capacity, prominently demonstrating my refusal of any and all life prolonging treatment including attempted CPR (cardiopulmonary resuscitation), as specified above, of any other emergency treatment that may prolong my life, and of any ambulance removal from wherever I am residing at the time, unless such removal is for the purpose of complying with this Advance Decision to Refuse all and any Life Prolonging Treatment. Thanks!

My refusal of life prolonging treatment in the circumstances described above of probably irreversible legal incapacity to consent to or refuse such treatment stems from my general view that prolongation of my life should only be carried out if it is likely to enable me to have a life that I would- in my rational and legally capacitous state- consider worth living. For me a necessary condition for my leading a life that I would consider worth living is adequate autonomy at least to be able to make my own deliberated (thought out) decisions about how I wish to lead my life including my own deliberated decisions about what I should permit others to do to me. This includes the ability to decide to accept or reject medical and other health care treatments and interventions including and especially life-prolonging treatments, and to be able to communicate those decisions. If I have lost such capacity or such ability to communicate and am very unlikely to regain either or both then I do not wish my life to be prolonged. I have at the time of writing, already in my 70s, had a good life and I definitely do not wish it to be prolonged in a state where not I but others will be making decisions about my best interests. I particularly dread an outcome such as befell the unfortunate M in the case about which I wrote an editorial in the BMJ of 21.7.12 (and which led me to write the first draft of this Advance Decision) in which a doubtless well meaning judge insisted that M's life be further prolonged after she had been kept alive for eight years in a minimally conscious state. But I also dread having my life unnecessarily prolonged by any life prolonging treatment including but not restricted to all those possible treatments already mentioned in this document, if I am in a state of apparently contented legal incapacity resulting from dementia. I have written at some length about my general approach to prolongation of my life so as to minimise the possibility of quibbles (as I see them) about whether or not in the particular circumstances that may arise this Advance Decision is 'legally valid and applicable'. [For those who might be interested a considerably more extensive account of my reasons for writing this document has been accepted, at the time of revising this document in April 2016, for publication in the Journal of Medical Ethics entitled 'Why I wrote my advance decision to refuse life prolonging treatment….'].

Thus, apart from the two specified exceptions my refusal of any form of life prolonging treatment or intervention in the circumstances described above should be regarded as absolute. As an additional decision making aid I ask that anyone making decisions for me in my best interests concerning life prolonging treatments or interventions should ask himself or herself: 'in the light of the contents of his Advance Decision to Refuse Life Prolonging Treatment would the legally capacitous and autonomous Raanan Gillon who wrote this Advance Decision want life prolonging treatment/intervention in these particular circumstances?' If the answer is clearly and unequivocally 'yes, in the light of his Advance Decisions, Raanan Gillon clearly *would* want

life prolonging treatment in these circumstances' then available life prolonging treatment should be administered**. If the answer is either clearly 'No, Raanan Gillon would reject life prolonging treatment in these circumstances'** ***or*** **if the answer is 'It is not clear to me' or if the answer is 'I do not know in these circumstances what Raanan Gillon would decide' then life prolonging treatment should *not* be administered. My 'default position' is rejection of life prolonging treatment.**

For the avoidance of doubt and as required by the Mental Capacity Act 2005 I make this Advance Decision to refuse life prolonging treatments in the full realisation and acceptance that its implementation would be likely to result in my living for a shorter time than if it were not implemented and that its implementation would therefore , in the words of the Mental Capacity Act, put my life 'at risk'.

I also wish to make clear, however, that I am not requiring or requesting euthanasia or physician assisted suicide or any other illegal act on the part of any of my doctors or other carers or anyone else- I am simply requiring them not to prolong my life in the circumstances described above.

Some treatment dilemmas and how I would wish them to be resolved

Systemic antibiotics

In circumstances described above in which I refuse life prolonging treatment, treatment dilemmas may arise. For example an infection may be causing me obvious or apparent distress which could probably be relieved by systemic antibiotics to treat the infection, but in which the antibiotics would also have some probability of prolonging my life and therefore be legally prohibited by this document. Typical examples would be respiratory infections and urinary tract infections, though of course any infection might produce this treatment dilemma. I wish to make clear that I refuse systemic antibiotics however administered- or any other potentially life prolonging treatments including for example physiotherapy- in such situations. However, I ***request*** that any distressing or apparently distressing symptoms that I may experience should be treated with any available symptomatic treatment that may relieve the symptom[s] or apparent symptoms without prolonging my life. If no such treatments are available I would ***request*** that pain killers and or psychotropics and sedatives, including opiates if these might be effective, should be administered with the intention of relieving the symptoms or apparent symptoms, even if such treatment increases- even if it substantially increases- the risk that my life would be shortened. My overall objective would be to be kept as comfortable as possible- and as apparently comfortable as possible- in ways that do not prolong my life. Once again such treatment should not be given with the *intention* of shortening my life but only in order to ameliorate or prevent recurrence of any distressing or apparently distressing symptoms I may have or appear to have.

Similar reasoning leads me to request symptomatic relief of a non-life-prolonging nature in any other situation where this Advance Decision results in my refusal of what would otherwise be the normal medical treatment.

Discontinuation of any current or future potentially life-prolonging treatments and investigations

If I have been legally incapacitous to accept or refuse treatment (including merely being unable to communicate) for three months or longer and as above I am considered to be very unlikely to recover legal capacity a review of any medications which I am at that time receiving should be made to assess whether or not they may prolong my life. Unless they are very *un*likely to prolong my life I hereby refuse them and they should be discontinued. Thus if I am still taking the following medications I hereby refuse their continued administration; anti diabetic medication, anti hypertensive medication, cholesterol reducing medication and aspirin. On the other hand I would wish to have medications that reduce unpleasant symptoms without being likely to prolong my life to be continued. These include but of course are not limited to my current acid-

reducing medications such as omeprazole. Further investigations for a possible recurrence of my previous bladder cancer should (of course) be discontinued as in the event of such recurrence I would reject any treatment other than palliation of symptoms.

If in pursuit of these requests it were decided that a symptom-reducing medication could only be administered intravenously I would wish no more fluid to be administered than is necessary to keep the intravenous cannula functioning (I thank a doctor at a conference who raised this point after I'd given a medical lecture about my ADRLPT).

Possible prolongation of my life to optimise transplantation of my tissues and organs

See under 'Second possible exception' on page 3 above

Locked in syndrome

If I am diagnosed to be in locked in syndrome and am totally unable to communicate my consent to or refusal of life- prolonging treatment and have been thus legally incapacitated for three months or more and am assessed as very unlikely to regain such legal capacity then my refusal of life prolonging treatment is as definitive as with the other causes of legal incapacity described above. If I should be in partial locked in syndrome but still able reliably to communicate, however laboriously (eg by blinking), then my views about life prolonging treatment should be ascertained (as required by the Mental Capacity Act 2005). If I cannot reliably communicate or if I can communicate but do not have legal capacity to refuse or consent to treatment this advance refusal of life prolonging treatment applies as above. If I am totally unable to communicate but brain function imaging such as fMRI has been performed and has indicated that I am or may be responding to communications by others, then in the circumstances I have described above I would particularly firmly reject all life prolonging treatment, administration of which I would regard as positively sadistic (however unintentionally so)!

Treatments that I would desire where my behaviour or state is reasonably assessed as objectionable to others

In the above described circumstances of probably irreversible legal incapacity to consent to or reject treatment, if I repeatedly behave in a way or ways that reasonable people would consider very annoying or distressing or otherwise objectionable to those around me I would positively wish my carers and doctors to administer medication or other (not very burdensome) treatment that would prevent or reduce such annoyance or distress, provided such treatment would be very unlikely to prolong my life. Examples would include any disorder that causes me to make unpleasant noises such as shouting or loud moaning or uttering abusive comments, or which causes me to behave physically violently or in which my movements (including wandering and walking) are a cause of distress or even merely severe annoyance to others. In such circumstances, and contrary to contemporary care norms, I would positively wish to be sedated or otherwise medicated so as to prevent or reduce my noisiness or any other annoying or distressing behaviour and I hereby consent to such treatments, which I would desire even if they increased the risk that my life would be shortened; of course no such treatment should be administered with the *intention* of shortening my life, which would be unlawful. But I would greatly prefer such 'chemical sedation' to being tied down or tightly wrapped and or to being protected (if I appear to reject such protection) by barriers such as bed bars any higher than those normally provided on hospital beds and or by any other forms of physical restraint, all of which I consider to be far more 'undignified' and against my best interests than 'chemical sedation' and also far more likely to cause distress to those around me, which again I would wish to avoid.

Smelly lesions

A dilemma might arise should I develop a lesion, for example a superficial infection, that is sufficiently malodorous to be offensive to those around me and which might be successfully treated with systemic antibiotics. My refusal of life prolonging treatments applies in such circumstances so that I refuse systemic administration of antibiotics because they might prolong my life. However if local application of antibiotics or any other local or systemic treatment of such a lesion might reduce the offensive odour without prolonging my life (for example local irradiation or even surgical debridement of a smelly tumour) I would wish such treatment to be administered even if it would not normally be the treatment of choice and even if it carried some additional risk of shortening my life- provided that such treatment did not prolong my life.

These last two requests (concerning objectionable behaviour and smelly lesions) are based on my capacitous desire to be considerate to those around me, and, where I no longer have psychological capacity to be considerate, or legal capacity to consent to treatment, I desire to ensure that so far as is reasonably and legally achievable I behave and exist in ways that minimise annoyance or distress to those around me. Honouring these requests by carrying out such treatments would , in my own autonomous and legally capacitous view, be acting in my best interests, as the law requires.

I have written this Advance Decision and Advance Statement, originally on 28.7.2012 and last revised on 16.4.16, with full legal capacity, and I wish to make clear that the Advance Decision component should be regarded as binding even if I have not reviewed it since the last date specified herein or below and even if I survive for many more years with legal capacity to make all my own decisions before it becomes applicable, as I hope will be the case. Although it is possible that I may review and further revise this document following the date of my last signature, this is unlikely as I have no intention of changing my mind about the basic issues nor do I wish to spend additional time on this document; **so unless a later revised and signed version is readily and rapidly available when needed for decision-making, thus superseding this one, there should be no delay in implementing the Advance Decision to Refuse Life Prolonging Treatment component of this document on the grounds that there might be a so far undiscovered revised version.**

I have discussed these issues (possibly in their view *ad nauseam*) with my wife and my daughter [names given in the signed document] and they are both in accord with the contents of this document.

My general practitioners at the time of signature are the doctors at [contact details given in the signed document]. I discussed a draft of this Advance Decision with Dr[name given] who was my personal general practitioner at the practice until she retired [date given] and she told me that she had discussed it with her medical partners all of whom, she assured me, found it to be a potentially helpful document. I am assured that my refusal of life prolonging treatment in the circumstances described above is legally binding under the Mental Capacity Act 2005 and I can only hope that it will in practice be honoured, should the relevant circumstances arise. I also hope that my positive requests for treatments, though they are not legally binding, will nonetheless be taken seriously into account, as is also required under the Mental Capacity Act, when doctors decide which non-life-prolonging treatments and interventions are in my best interests; and I thank my doctors in advance for doing so should the need arise.

Signed by Raanan Gillon [date]

Witnessed by [signature and name and address of witness and date]