End of life planning and decision making:
The involvement of families and doctors, and the questions coroners should be asking

A/Prof Charlie Corke

Barwon Health
University Hospital Geelong

Dying where potentially effective treatment is **not** provided

... would seem to constitute a preventable death

‘Overriding the public interest in preserving life ...

... the law places a ‘very heavy burden’ on those who are advocating a course which would lead to the cessation of a human life’.

W Healthcare NHS Trust v. KH. [2004] EWCA Civ 1324 para 30 per Brooke LJ.

'... treatment and circumstances need to be identified by the patient before loss of capacity ...

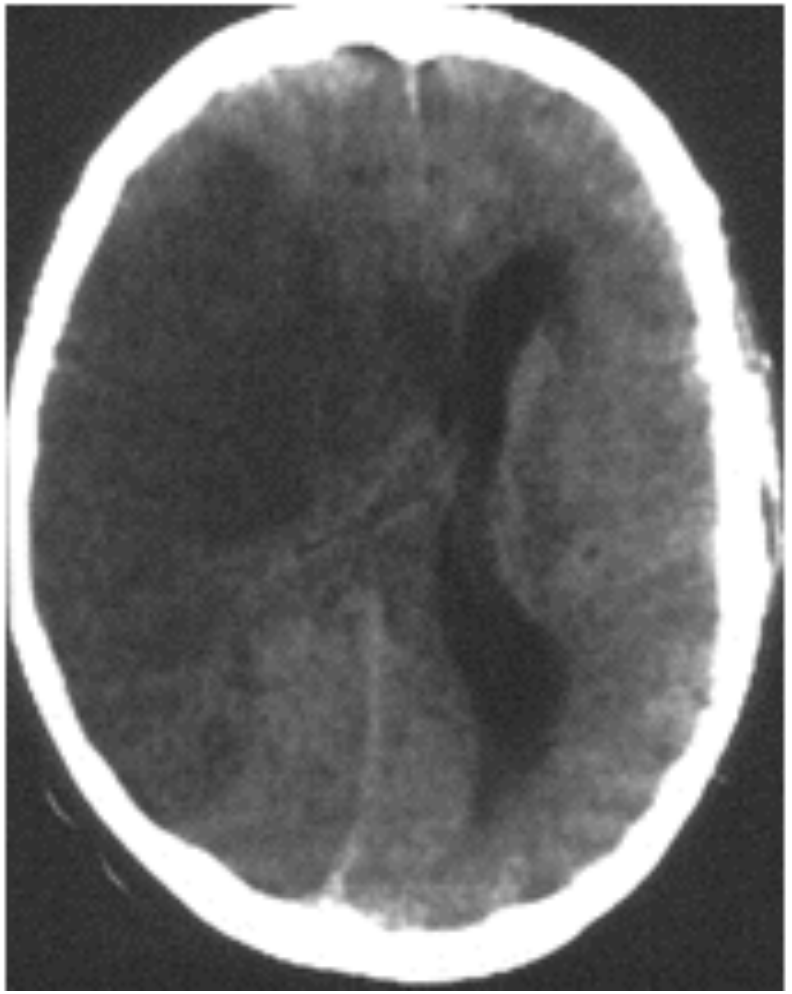
... this degree of specificity is unlikely ever to be achieved

... this renders the patient's values and beliefs an ineffective counter balance to preservation of life in the 'best interests' balance sheet.'

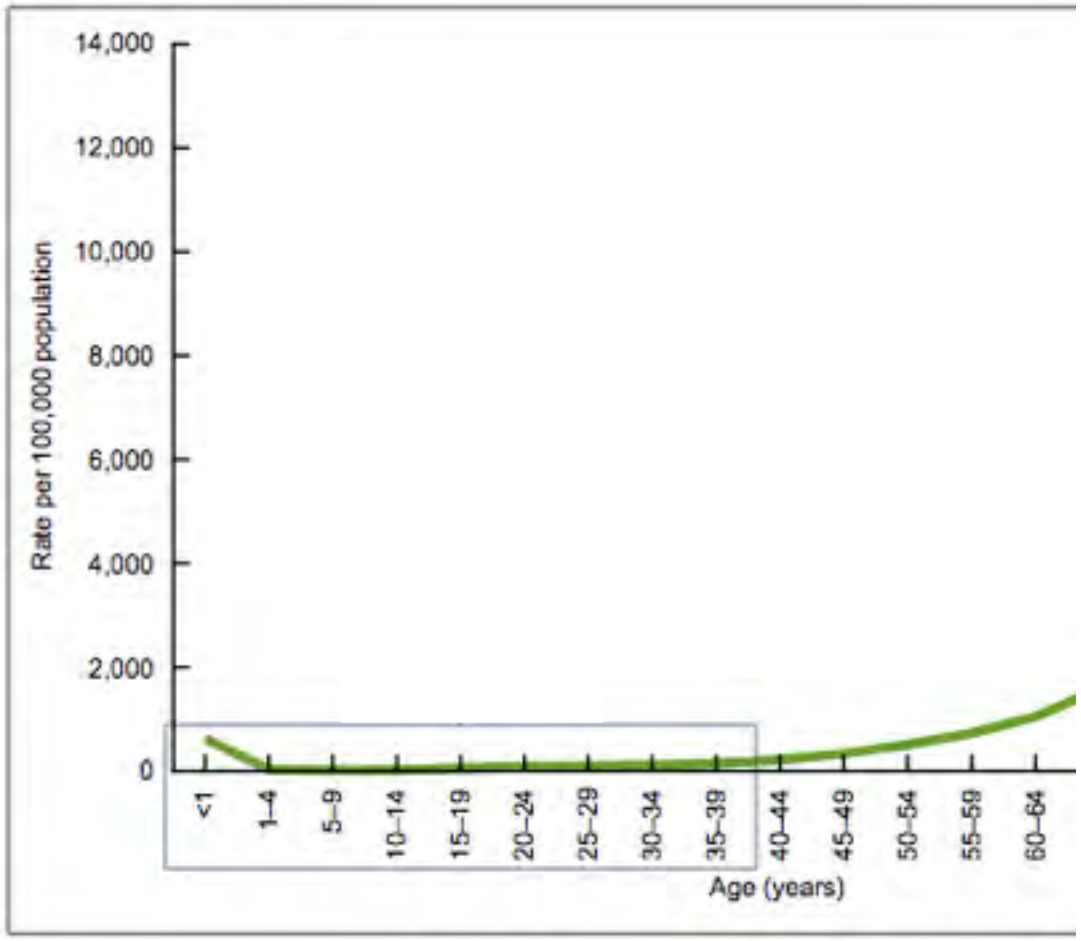
W v. M (2011) EWHC 2443 (Fam).

Johnston C. J Med Ethics. 11 December 2012

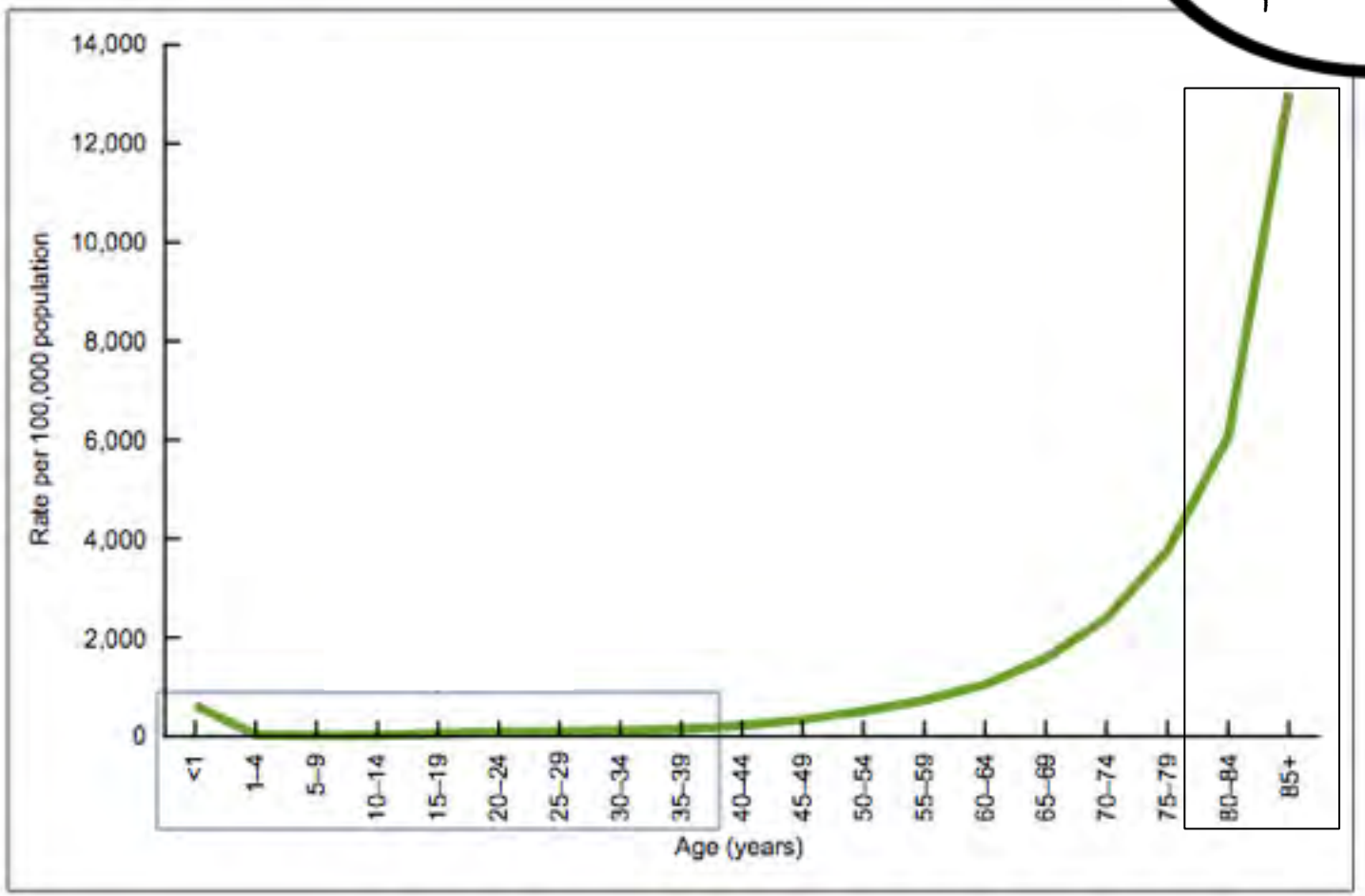
Deciding for Mr W



?

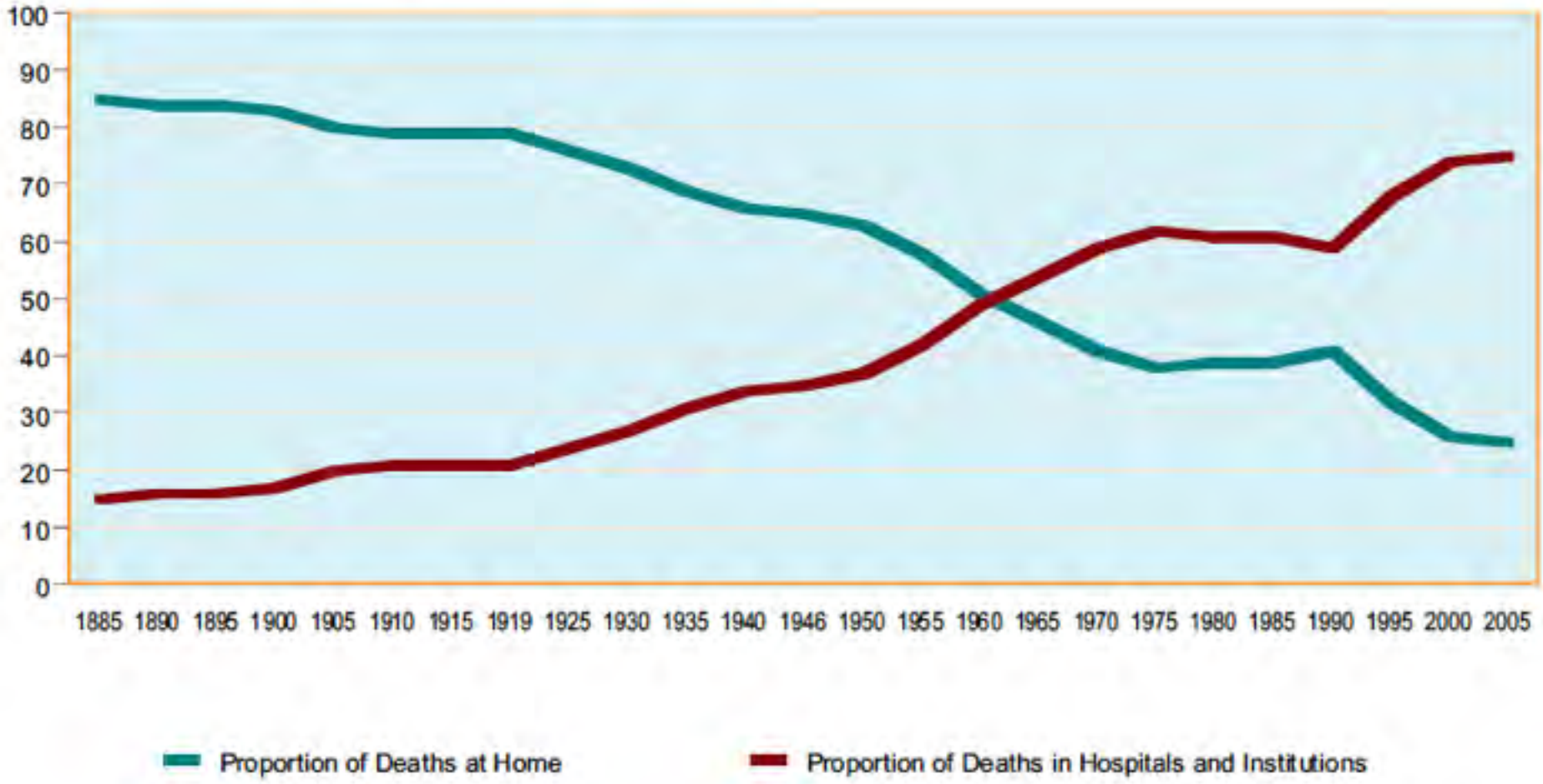

14,000
12,000
10,000
8,000
6,000
4,000
2,000
0
Rate per 100,000 population
<1
1–4
5–9
10–14
15–19
20–24
25–29
30–34
35–39
40–44
45–49
50–54
55–59
60–64
Age (years)

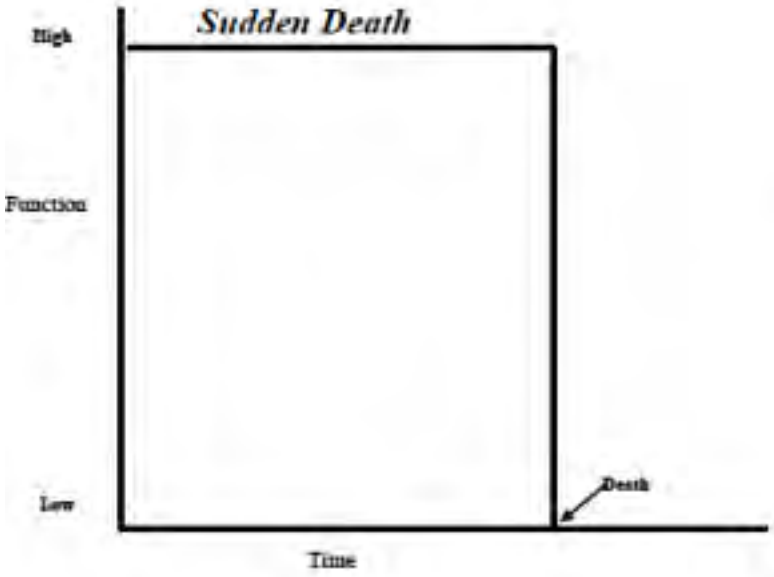
not all death is preventable !

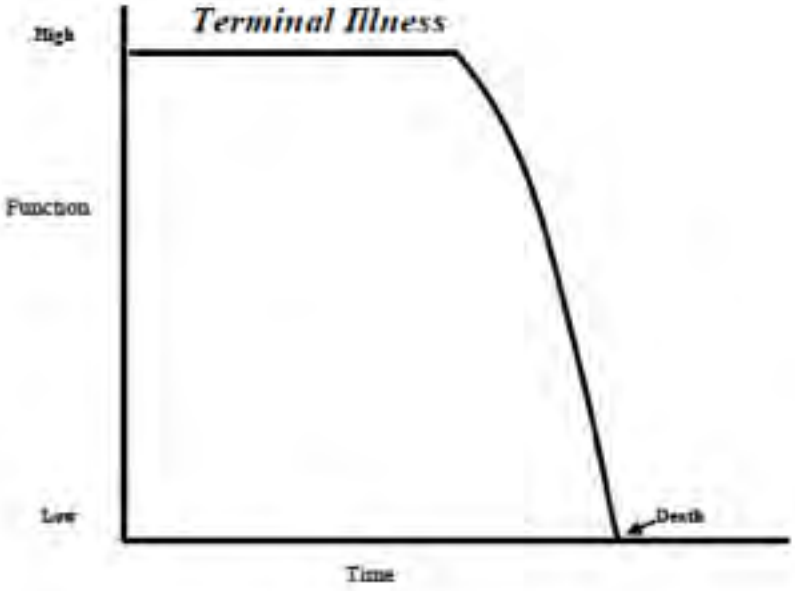


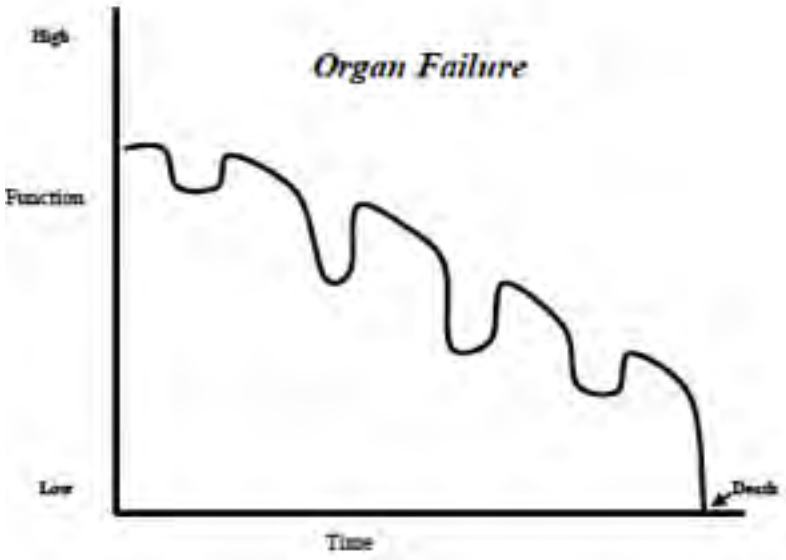
Over 90% of Australians now live to be old

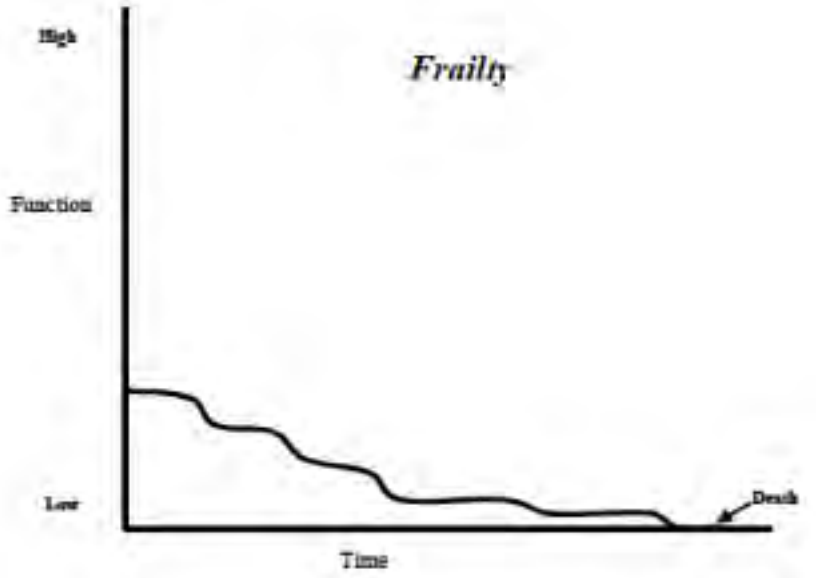
Figure 1.1: Place of Death in Ireland, 1885-2005




Sudden Death
High
Function
Low
Death
Time


Terminal Illness
High
Function
Low
Death
Time


Organ Failure
High
Function
Low
Death
Time


Frailty
High
Function
Low
Death
Time

‘ Death has become optional ‘

Prolonged life support is a reality for us all

How do the different participants see the decision making process?

DOCTORS

Letting someone die ... who could survive with treatment

- **Prolongation of survival is the goal (survival curves)**
- Failure, shame, discomfort
- Not a good doctor
- Incompetence or negligence
- Unscientific (not EBM)
- Censure and criticism
- Coronial investigation

Difficult to get doctors to back off - even for very determined medical families

No matter what.
Fight On.
USC
UNIVERSITY
HOSPITAL

FAMILY

Letting someone die ... who could survive with treatment

- Guilt, abandonment
- Failure of duty
- Failure of advocacy

- Chance of survival is a pivotal concept (gambler's bias)

- **Family have assumed control ... *'Do everything'***

(personal needs and opinions frequently dominate)

Original articles

Choosing Life support for Suddenly Severely Ill Elderly Relatives

C. F. CORKE*, J. F. LAVERLY†, A. M. GIBSON†
*Intensive Care, Barwon Health, Geelong, VICTORIA
†School of Physiology, Deakin University, Waurn Ponds, VICTORIA

(Critical Care and Resuscitation 2005; 7: 92-98)

- 80% surrogates felt treatment 'inappropriate'
- 100% surrogates choose to treat in emergency

CORONER / COURT

Letting someone die ... who could survive with treatment

- Error
- VERY high standard of certainty required to withhold / withdraw

PATIENT

Letting someone die ... who could survive with treatment

- Autonomy
- Best Interest
- Informed Consent
- Human Rights

Understanding the impact of severe illness in the frail, ill, elderly patient

Date of download: 10/12/2014
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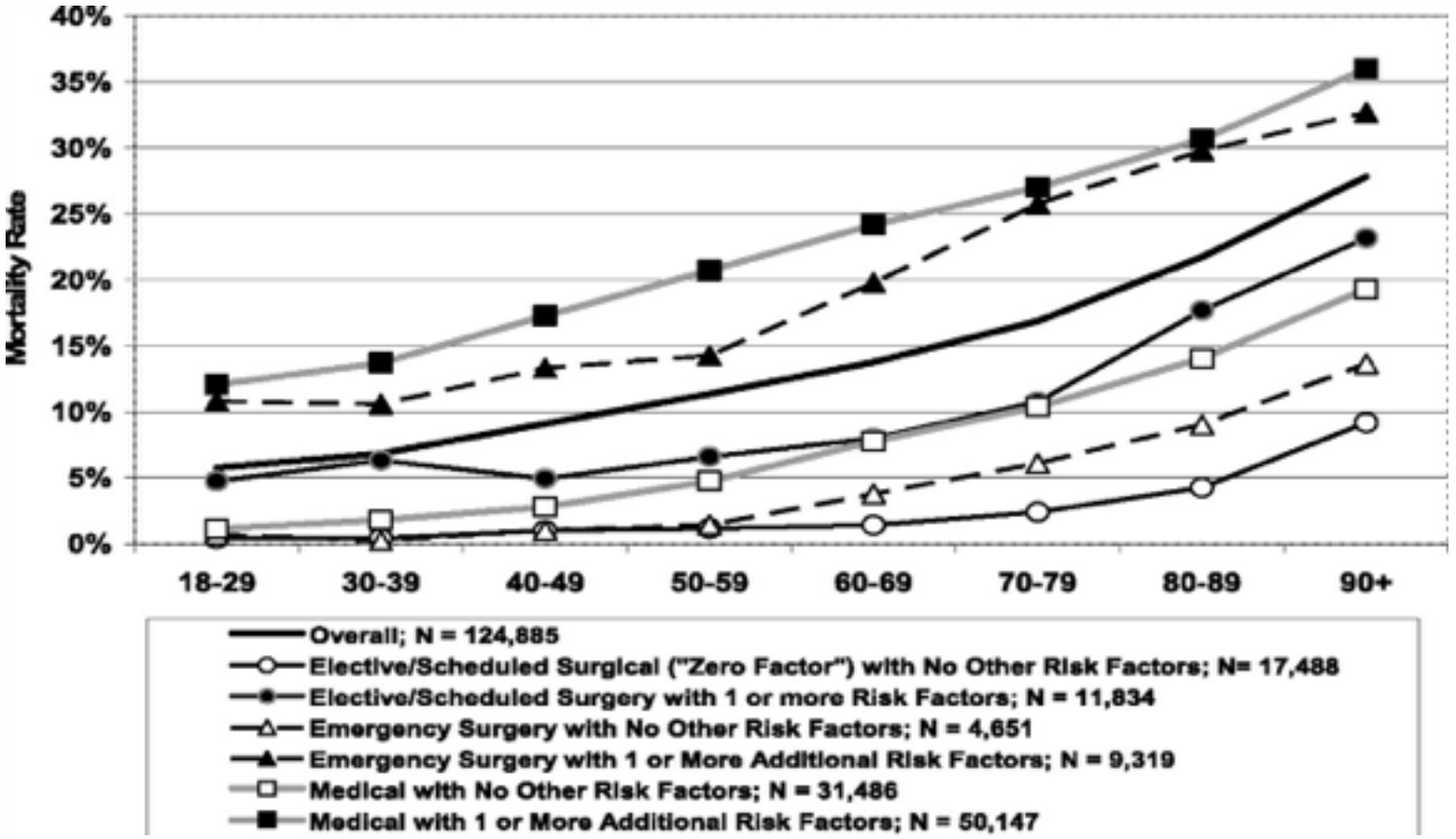
From: Do Elderly Patients Fare Well in the ICU?

Chest. 2011;139(4):825-831. doi:10.1378/chest.10-1233



Mortality rate by age, stratified by patient type.

Association between frailty and short- and long-term outcomes among critically ill patients: a multicentre prospective cohort study

Sean M. Bagshaw MD, H. Thomas Stelfox MD, Robert C. McDermid MD, Darryl B. Rolfson MD, Ross T. Tsuyuki PharmD, Nadia Baig BSc, Barbara Artiuch MD, Quazi Ibrahim MSc, Daniel E. Stollery Ella Rokosh MD, Sumit R. Majumdar MD

- Significantly increased mortality and LOS (ICU and hospital)
- Markedly more complications
- Many more readmissions to ICU
- Marked reduction in ADL with 66% lower likelihood of living independently after discharge

Head injury prognosis

These prognostic models may be used as an aid to estimate mortality at 14 days and death and severe disability at six months in patients with traumatic brain injury (TBI). The predictions are based on the average outcome in adult patients with Glasgow coma score (GCS) of 14 or less, within 8 hours of injury, and can only support - not replace - clinical judgment. Although individual names of countries can be selected in the models, the estimates are based on two alternative sets of models (high income countries or low & middle income countries).

Country	Australia
Age, years	85
Glasgow coma score	6
Pupils react to light	Both
Major extra-cranial injury?	No
CT scan available?	☑
Presence of petechial haemorrhages	Yes
Obliteration of the third ventricle or basal cisterns	Yes
Subarachnoid bleeding	Yes
Midline shift	No
Non-evacuated haematoma	No

Prediction

Risk of 14 day mortality (95% CI)	**84.9% (75.2 - 91.3)**
Risk of unfavourable outcome at 6 months	**96.2% (93.3 - 97.8)**

Reset

Use the Integrated Prognostic Model to estimate 6-month survival for patients on hemodialysis

Age (yrs)	80	
Albumin	20	○ g/dL ◉ g/L
Dementia	No	
Peripheral Vascular Disease	Yes	
Would I be surprised if this patient died in the next year?	No	
	Submit	

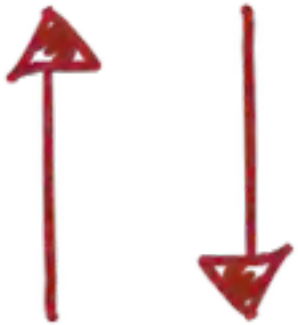
Use the Integrated Prognostic Model to estimate 6-month survival for patients on hemodialysis

Estimated Mortality on Hemodialysis at 6 months: 71.8%.

About this calculator

This prognostic tool was developed by Cohen et al in response to the need for prognostic information on survival in patients receiving chronic hemodialysis care.

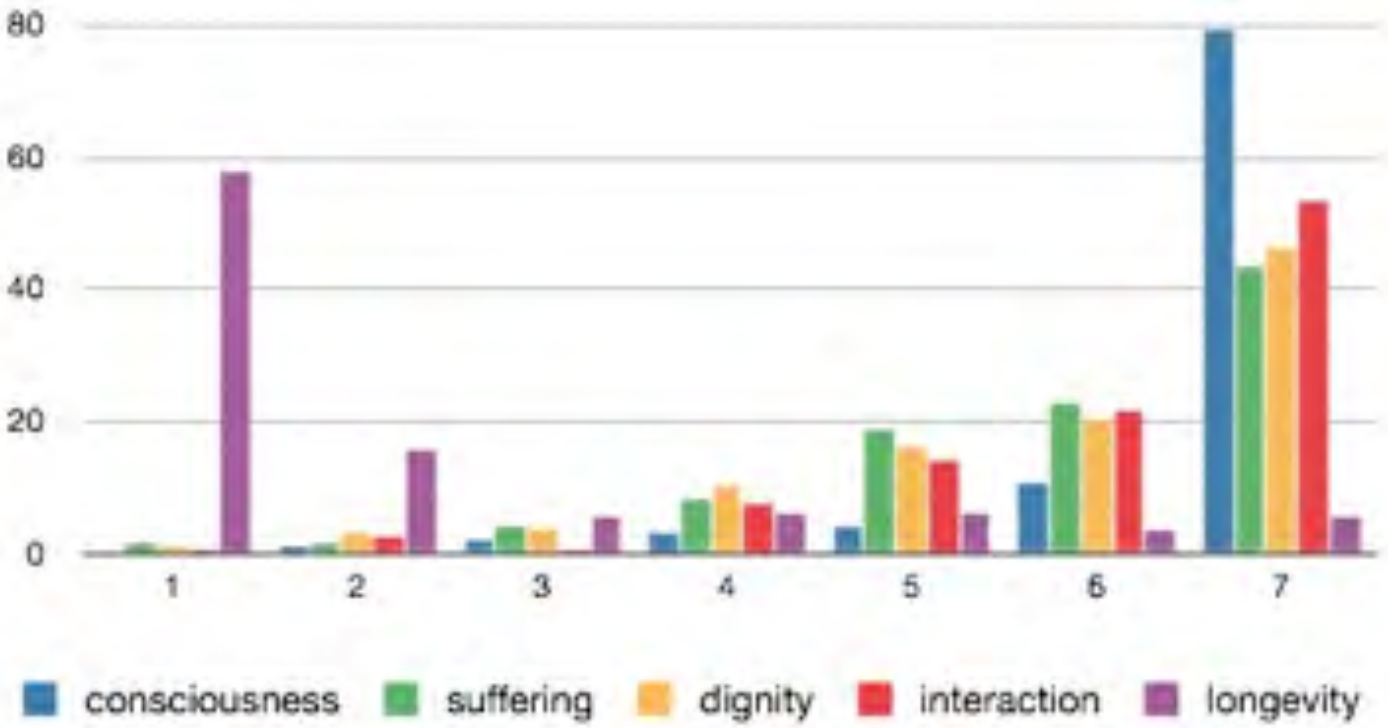
High level acute care



Rehabilitation

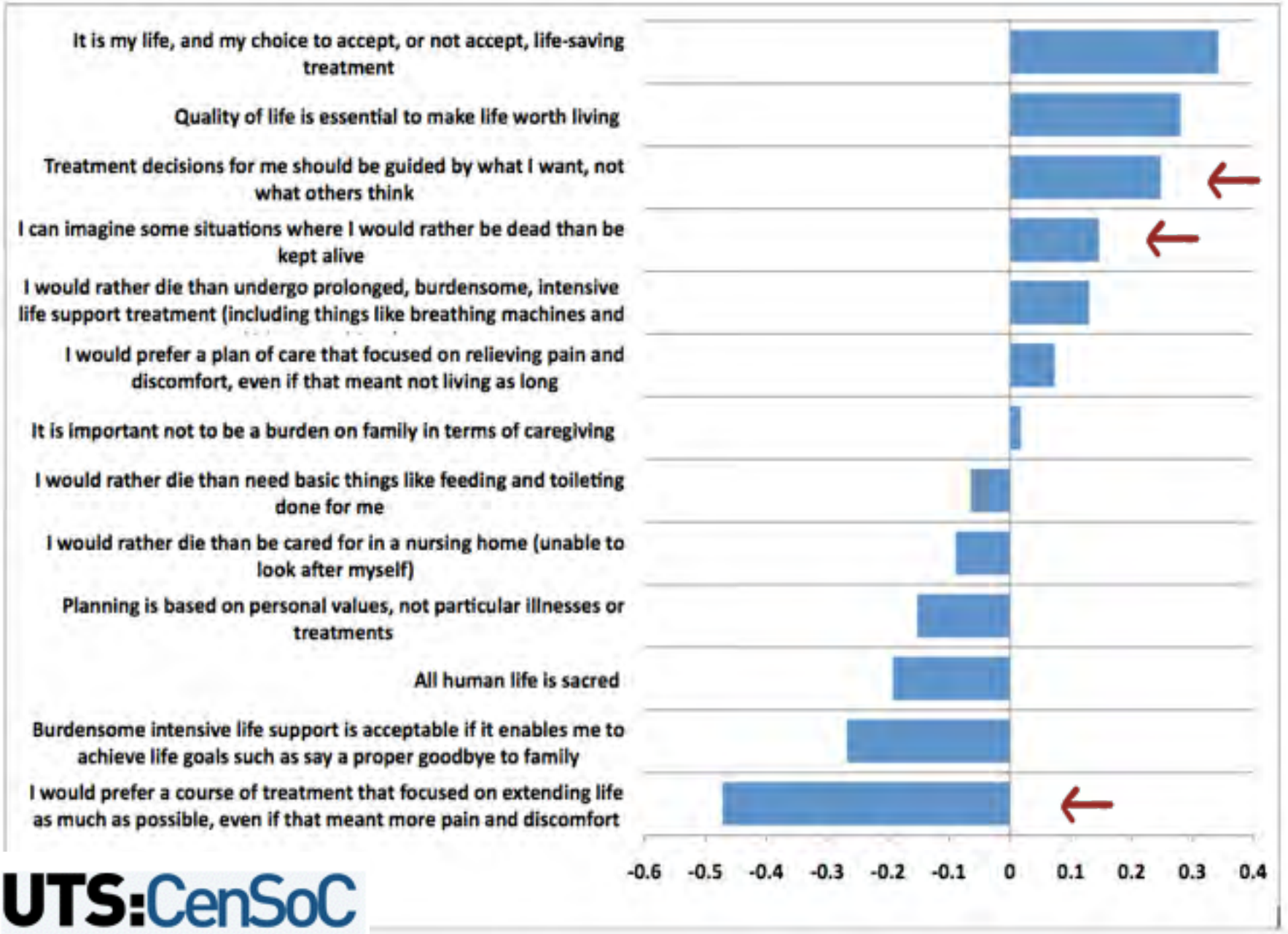
Nursing home

What do people want?



1 – not important

7 – very important



UTS:CenSoC
Centre for the Study of Choice

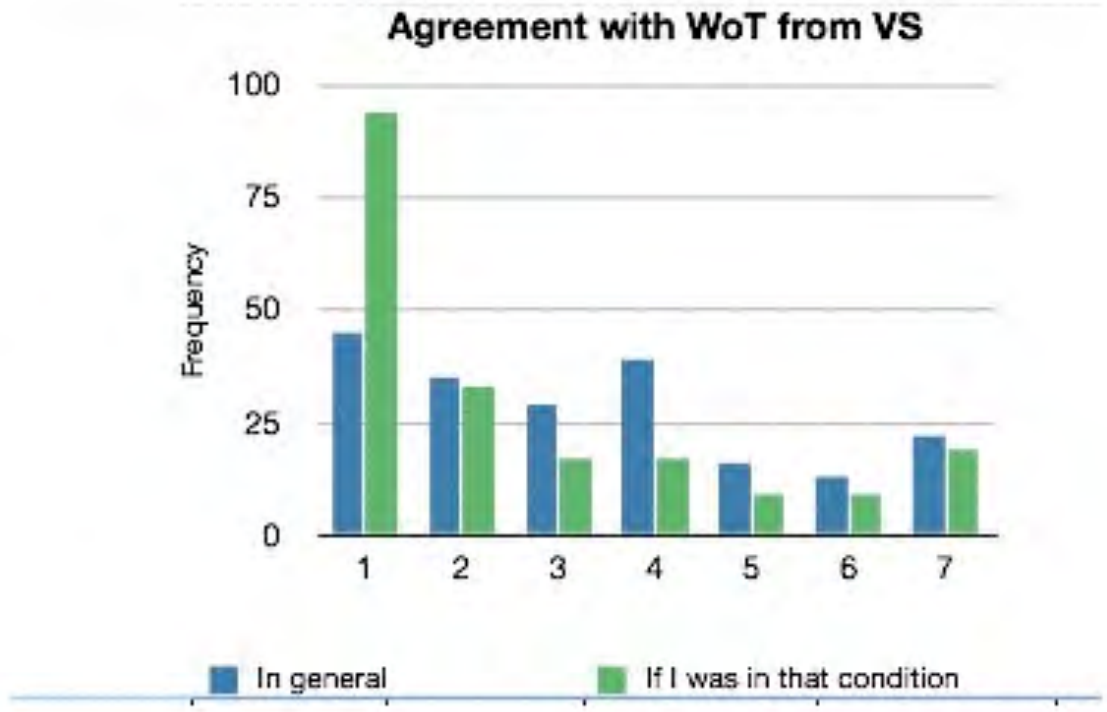
Standard errors all lie between 0.0115 and 0.0142.

UTS:CenSoC
Centre for the Study of Choice

7% believe in extending life no matter what the consequences

32% view quality of life as important but are willing to accept limitations

61% view quality of life as paramount and would rather die than to accept limitations



1 - is completely acceptable

7 - is completely unacceptable

topic	issues	decisions
confronting	complex	vague
scary	contradictory	ambiguous
denied	confusing	unstable

drivers

dignity
suffering
duty
spirituality
burden to family
independence
contribution
sanctity of life
faith in medicine
...

topic

confronting
scary
denied

issues

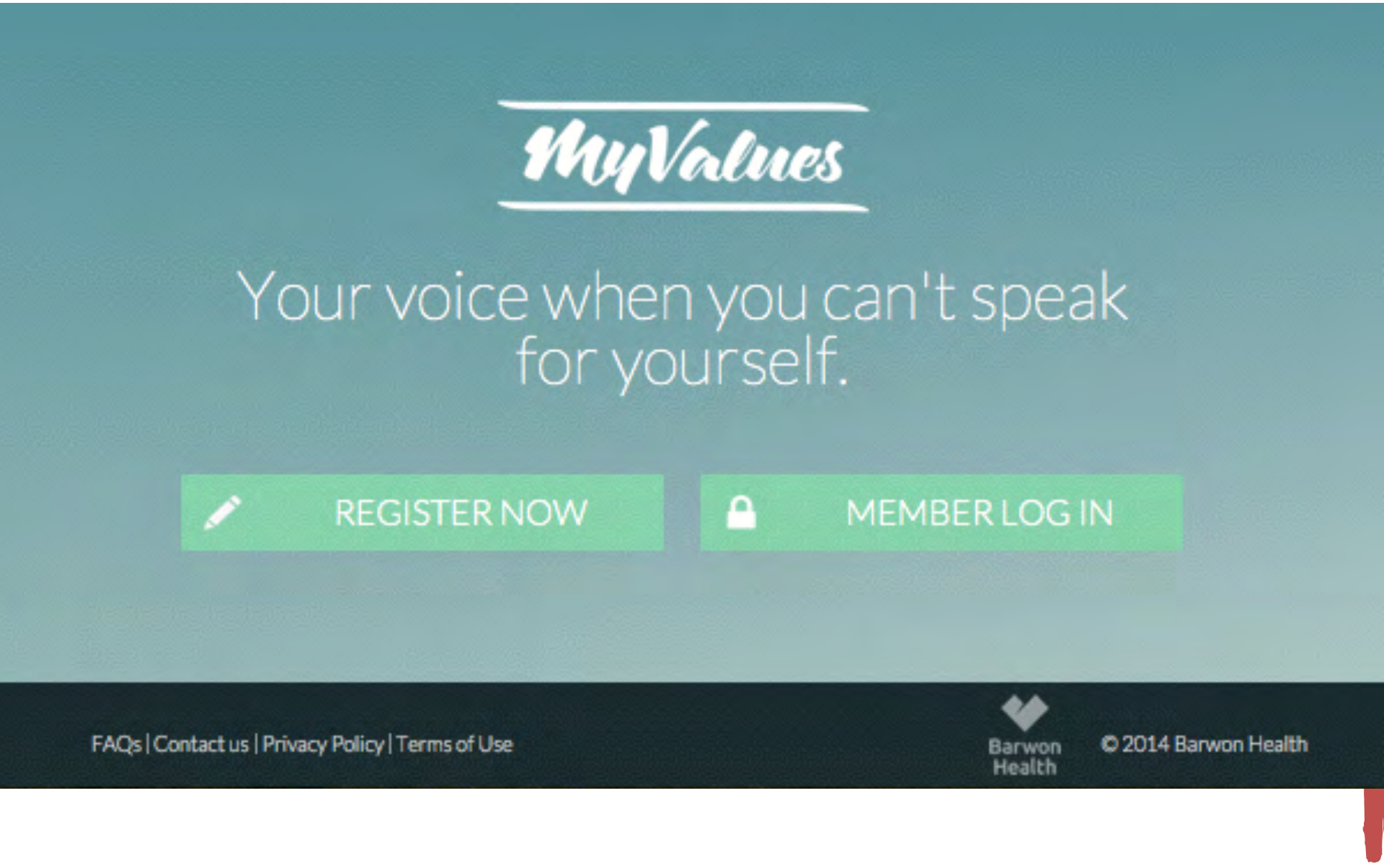
complex
contradictory
confusing

decisions

vague
ambiguous
unstable

drivers	topic	issues	decisions
dignity	confronting	complex	vague
suffering	scary	contradictory	ambiguous
duty	denied	confusing	unstable
spirituality			
burden to family			
independence			
contribution			
sanctity of life			
faith in medicine			
...			

reliable
responsible
stable


MyValues
Your voice when you can't speak for yourself.
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Barwon Health
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The benefits of MyValues

»MyValues helped me speak to my family about a touchy issue.«

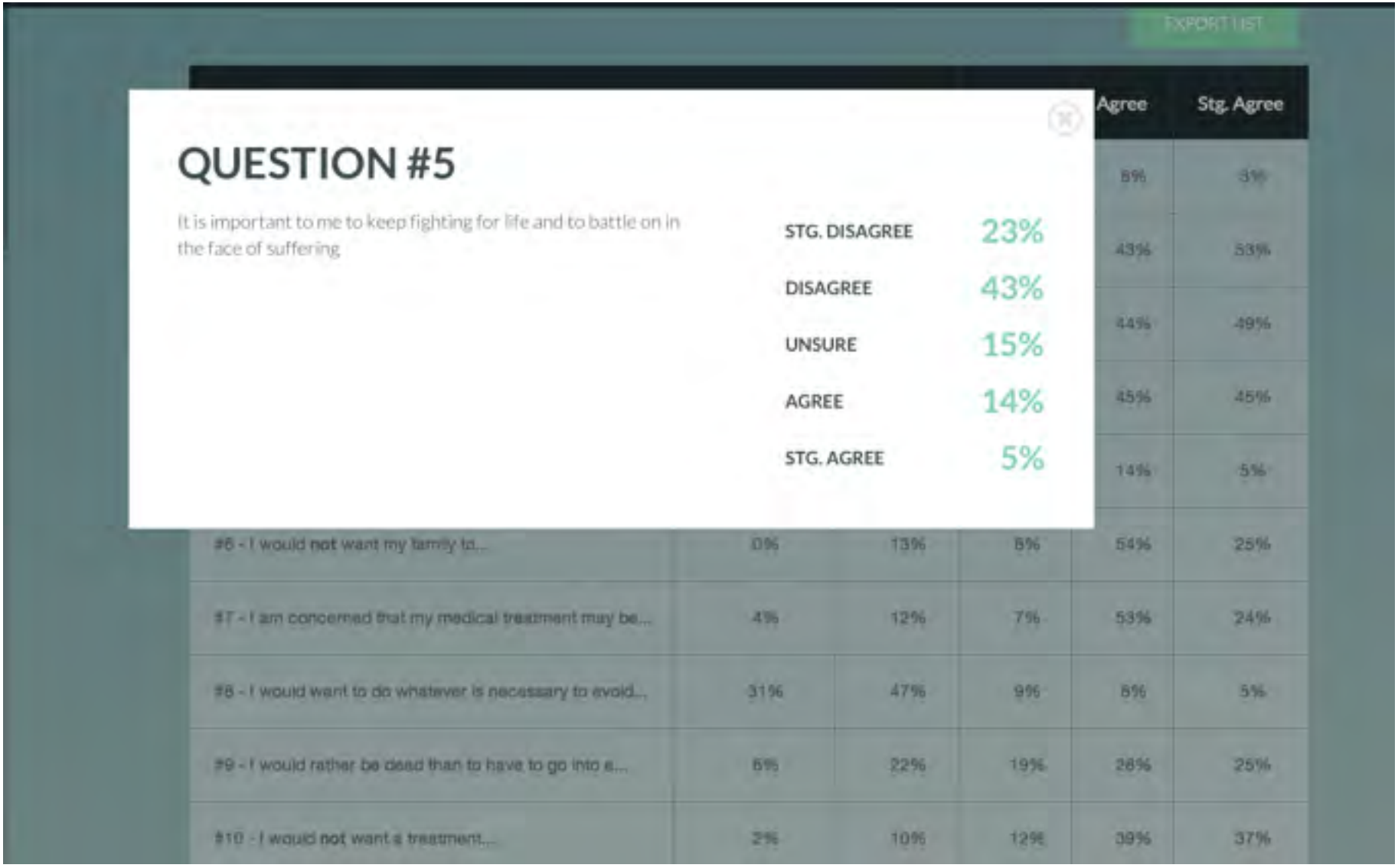
MyValues is a non-emotional approach to what can be a delicate subject. The step-by-step approach not only helps you complete your MyValues report with ease, it also takes the sensitivity out of discussions with your family. Your wishes are clearly expressed and easily understood.

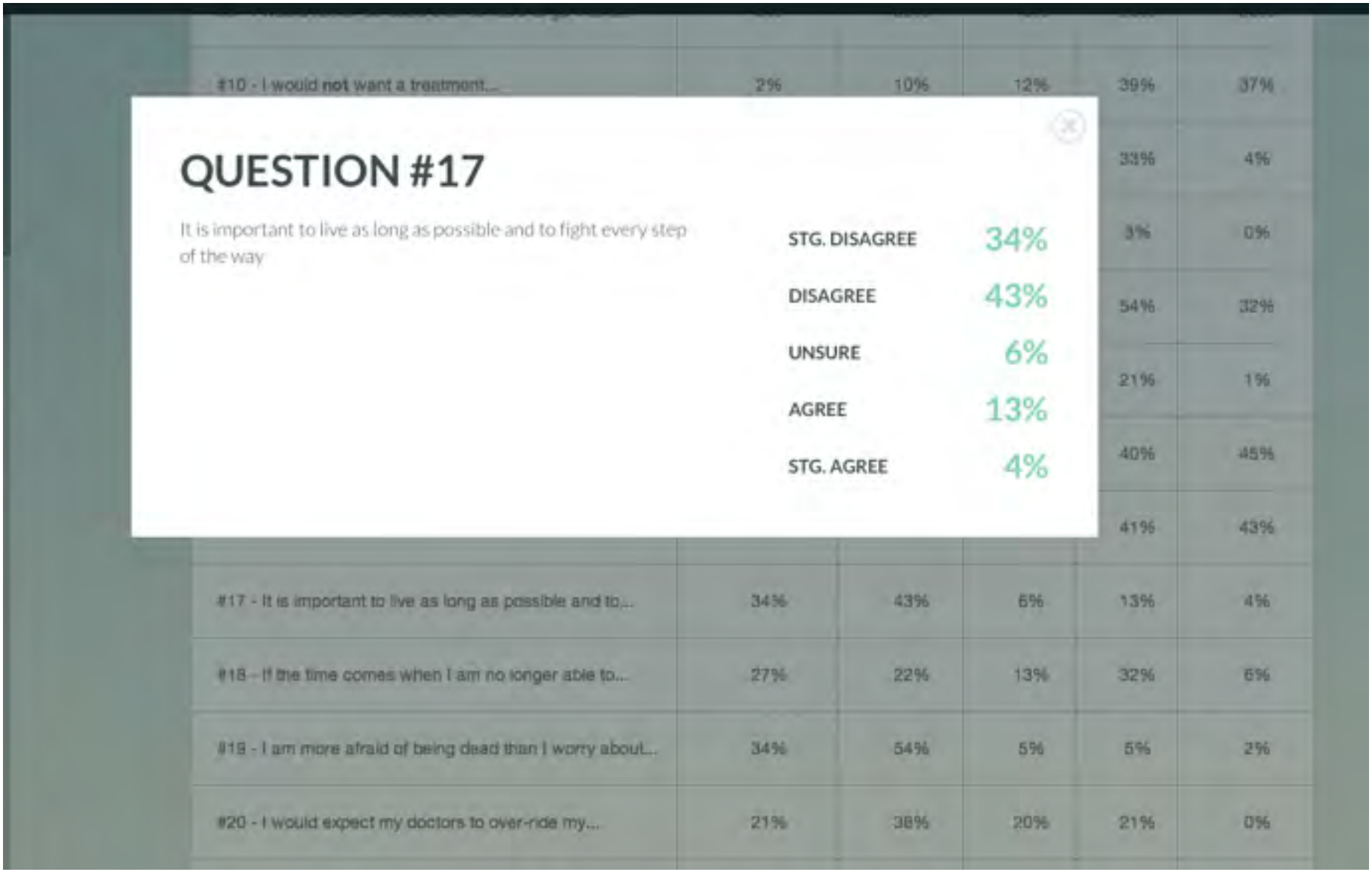
The benefits of My Values

»My Values put the responsibility for my care in my hands.«

Its your My Values, your healthcare and your wishes.

READ THE STORY


EXPORT LIST
Agree
Stg. Agree
8%
3%
43%
33%
44%
49%
45%
45%
14%
5%
#6 - I would not want my family to...
0%
13%
8%
54%
25%
#7 - I am concerned that my medical treatment may be...
4%
12%
7%
53%
24%
#8 - I would want to do whatever is necessary to avoid...
31%
47%
9%
8%
5%
#9 - I would rather be dead than to have to go into a...
6%
22%
19%
28%
25%
#10 - I would not want a treatment...
2%
10%
12%
39%
37%
QUESTION #5
It is important to me to keep fighting for life and to battle on in the face of suffering
STG. DISAGREE 23%
DISAGREE 43%
UNSURE 15%
AGREE 14%
STG. AGREE 5%

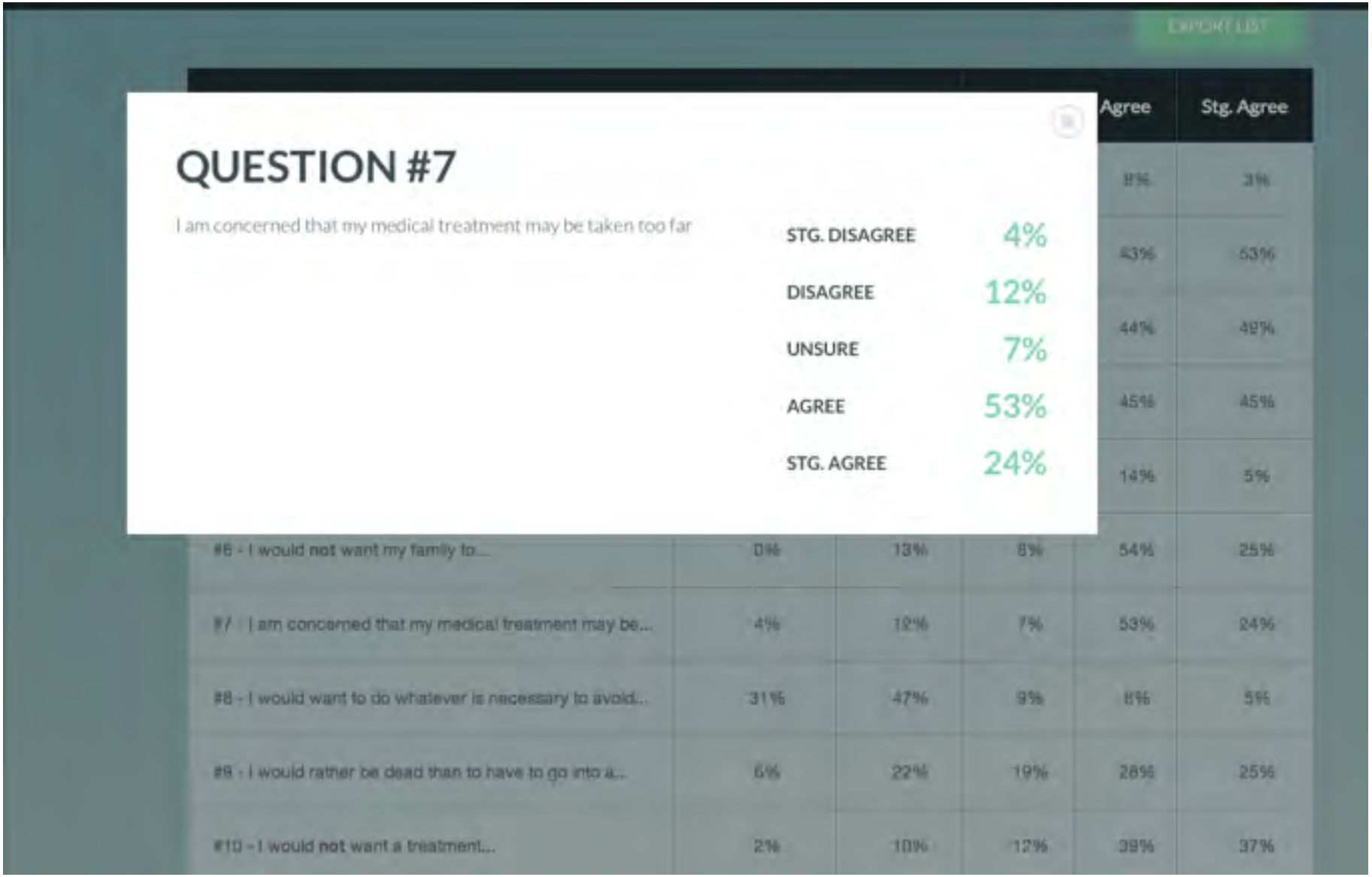

#10 - I would not want a treatment...
2%
10%
12%
39%
37%
33%
4%
3%
0%
54%
32%
21%
1%
40%
45%
41%
43%
#17 - It is important to live as long as possible and to...
34%
43%
6%
13%
4%
#18 - If the time comes when I am no longer able to...
27%
22%
13%
32%
6%
#19 - I am more afraid of being dead than I worry about...
34%
54%
5%
5%
2%
#20 - I would expect my doctors to over-ride my...
21%
38%
20%
21%
0%
QUESTION #17
It is important to live as long as possible and to fight every step of the way
STG. DISAGREE 34%
DISAGREE 43%
UNSURE 6%
AGREE 13%
STG. AGREE 4%

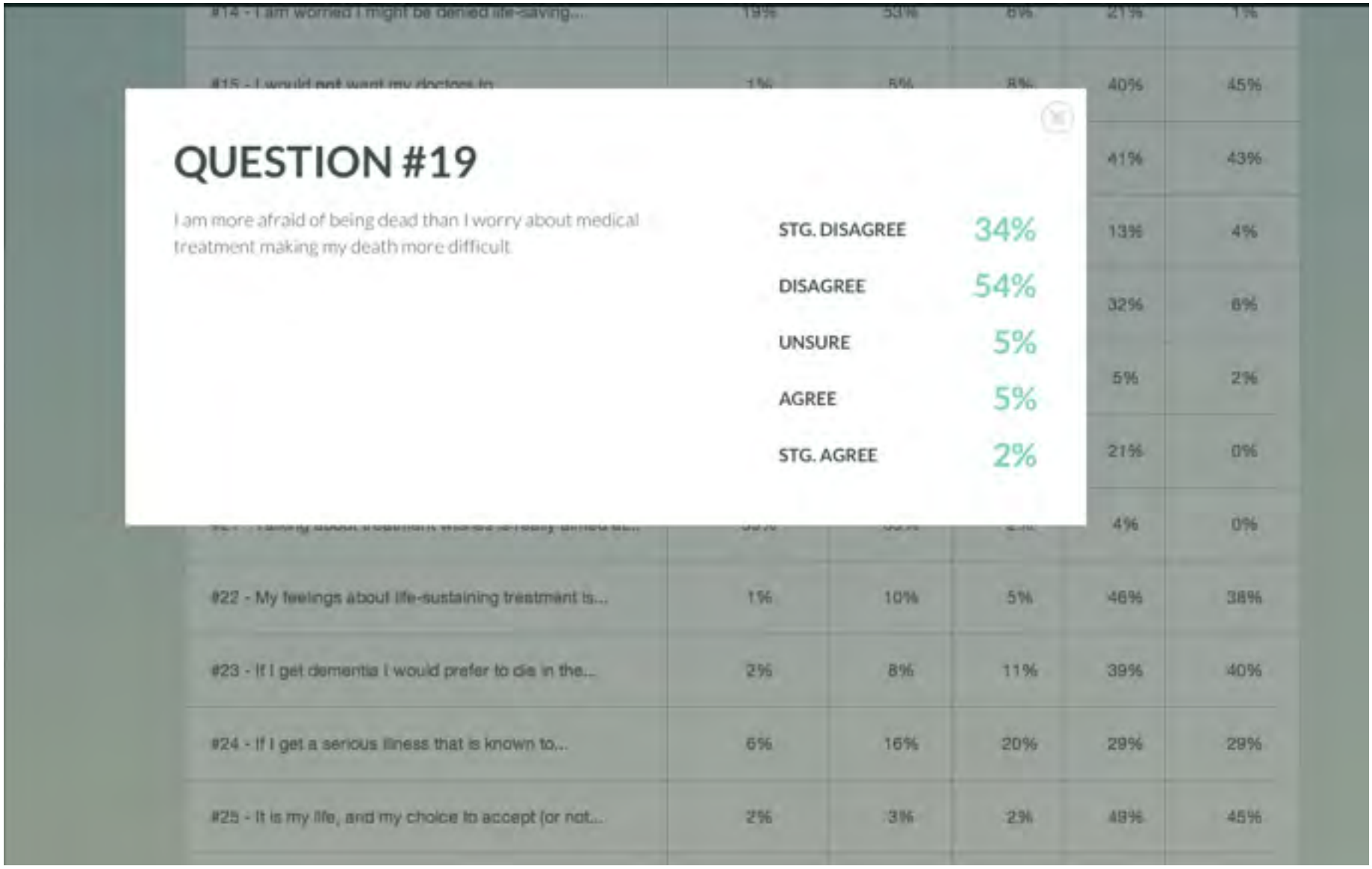
#34 - I feel no religious imperative to...	2%	5%	2%	29%	63%
				61%	34%
				50%	41%
				46%	7%
				6%	1%
				38%	7%
				41%	53%
#41 - Increasing illness and debility would probably...	25%	45%	17%	13%	1%
#42 - I would not want months of...	3%	28%	29%	26%	13%
#43 - If I become unable to look after myself then I...	25%	32%	23%	17%	3%
#44 - If I become very sick and unconscious I would want...	11%	49%	19%	19%	2%
#45 - I would rather die than to need basic things such...	4%	8%	14%	37%	37%
#46 - I can't reasonably plan for future treatment...	18%	49%	9%	21%	3%
#47 - I would want a treatment to keep me alive if there...	20%	40%	19%	18%	2%

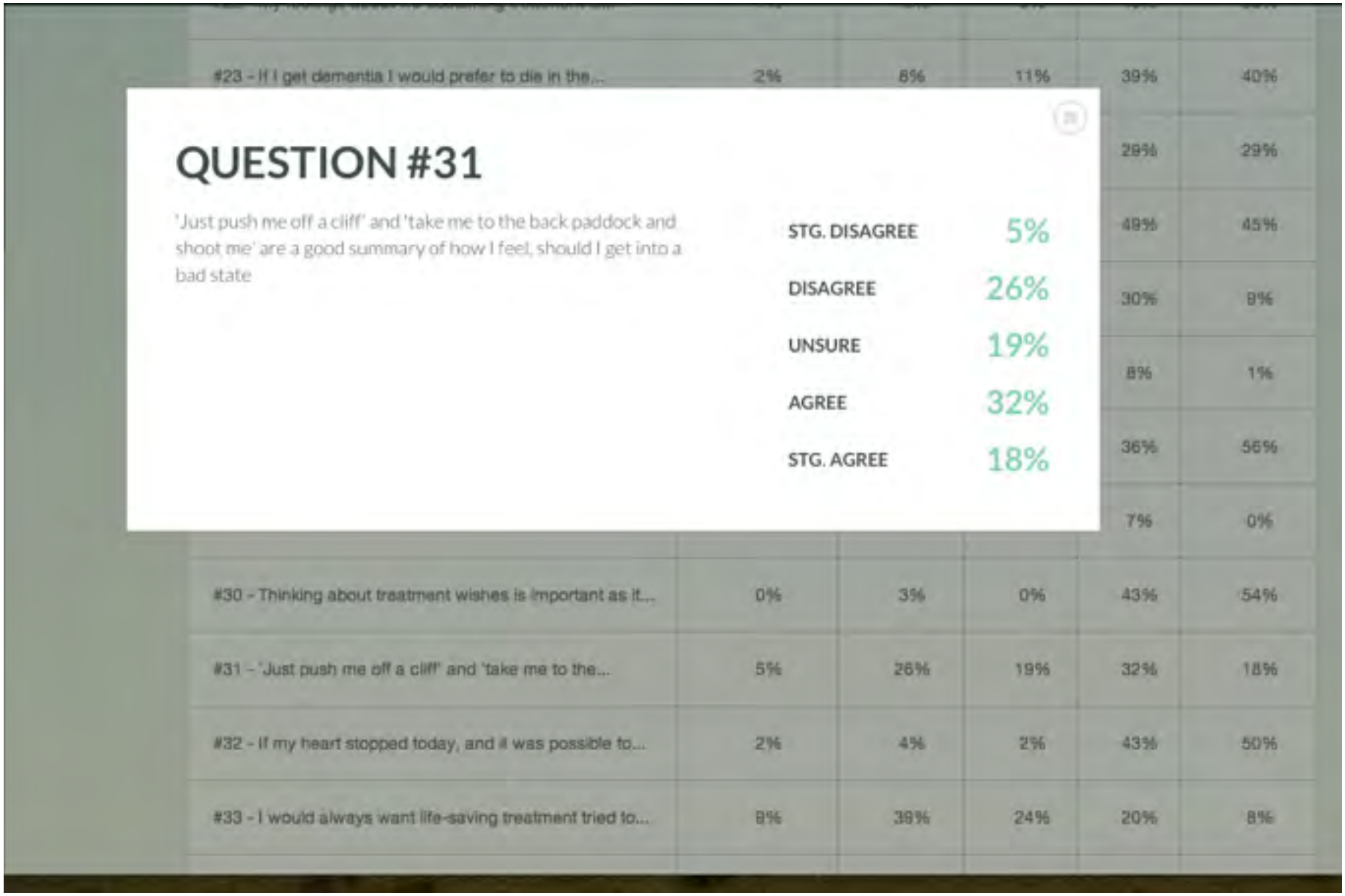
QUESTION #36

I have limits about how far I would want treatment to be taken

STG. DISAGREE	3%
DISAGREE	3%
UNSURE	3%
AGREE	50%
STG. AGREE	41%


QUESTION #7
I am concerned that my medical treatment may be taken too far
STG. DISAGREE 4%
DISAGREE 12%
UNSURE 7%
AGREE 53%
STG. AGREE 24%
Agree
Stg. Agree
#6 - I would not want my family to... 0% 13% 8% 54% 25%
#7 - I am concerned that my medical treatment may be... 4% 12% 7% 53% 24%
#8 - I would want to do whatever is necessary to avoid... 31% 47% 9% 8% 5%
#9 - I would rather be dead than to have to go into a... 6% 22% 19% 28% 25%
#10 - I would not want a treatment... 2% 10% 12% 39% 37%


#14 - I am worried I might be denied life-saving...
19%
53%
6%
21%
1%
#15 - I would not want my doctors to
1%
5%
8%
40%
45%
41%
43%
13%
4%
32%
6%
5%
2%
21%
0%
4%
0%
#22 - My feelings about life-sustaining treatment is...
1%
10%
5%
46%
38%
#23 - If I get dementia I would prefer to die in the...
2%
8%
11%
39%
40%
#24 - If I get a serious illness that is known to...
6%
16%
20%
29%
29%
#25 - It is my life, and my choice to accept (or not...
2%
3%
2%
48%
45%
QUESTION #19
I am more afraid of being dead than I worry about medical treatment making my death more difficult
STG. DISAGREE 34%
DISAGREE 54%
UNSURE 5%
AGREE 5%
STG. AGREE 2%


#23 - If I get dementia I would prefer to die in the... 2% 6% 11% 39% 40%
29% 29%
49% 45%
30% 9%
8% 1%
36% 56%
7% 0%
#30 - Thinking about treatment wishes is important as it... 0% 3% 0% 43% 54%
#31 - 'Just push me off a cliff' and 'take me to the... 5% 26% 19% 32% 18%
#32 - If my heart stopped today, and it was possible to... 2% 4% 2% 43% 50%
#33 - I would always want life-saving treatment tried to... 8% 39% 24% 20% 8%
QUESTION #31
'Just push me off a cliff' and 'take me to the back paddock and shoot me' are a good summary of how I feel, should I get into a bad state
STG. DISAGREE 5%
DISAGREE 26%
UNSURE 19%
AGREE 32%
STG. AGREE 18%

Current situation

Most have nothing documented + family have no idea

No exploration of wishes/values before incompetence

DNR order in isolation (illogical and difficult)

The process is dumped on junior doctors

Much intervention in crisis occurs due to lack of adequate information of what patients want

Solutions for individuals

Get planning happening (patients and doctors)

Good MEPOA and documentation of values

Think beyond CPR and living for ever

Greater focus on narrative

NOTE
'more informed' may be incompatible with human choice

Medical Treatment Act 1988

SCHEDULE 1

Sections 3, 5(2)

Refusal of Treatment Certificate: Competent Person

We certify that we are satisfied—

(a) that ..... (name of patient) has clearly expressed or indicated a decision, in relation to a current condition, to refuse—

*medical treatment generally;

or

*medical treatment, being.....
(specify particular kind of medical treatment);

(b) that the patient's decision is made voluntarily and without inducement or compulsion;

(c) that the patient has been informed about the nature of his/her current condition to an extent which is reasonably sufficient to enable him/her to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) and that he/she has appeared to understand that information; and

(d) that the patient is of sound mind and has attained the age of 18 years.

Dated:

Signed.....(Registered Medical Practitioner)

Signed .....(Another Person)

Patient's current condition

The patient's current condition is ..... (describe condition)

Dated:

Signed: .....

(To be signed by the same registered medical practitioner)

Verification to be completed by patient, if physically able to do so.

In relation to my current condition, I refuse—

*medical treatment generally

or

*medical treatment, being.....
(specify particular kind of medical treatment).

I give the following instructions as to palliative care:

Dated:

Signed ..... (Patient)

NOTICE OF CANCELLATION (*for completion where patient cancels the certificate under section 7 of the* **Medical Treatment Act 1988**)

I cancel this certificate

Dated:

Signed:..... (Patient)

or

The patient clearly expressed or indicated a decision to cancel this certificate on (Date).

Signed ..... (Person witnessing patient's decision)

*Delete whichever is not applicable

NOTE: **"Medical treatment"** means the carrying out of—

(a) an operation; or

(b) the administration of a drug or other like substance; or

(c) any other medical procedure—

but does not include palliative care.

"Palliative care" includes—

(a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or

(b) the reasonable provision of food and water.

The refusal of palliative care is not covered by the **Medical Treatment Act 1988**.

Questions a Coroner might ask

Could ‘balance of probability’ be a more appropriate standard

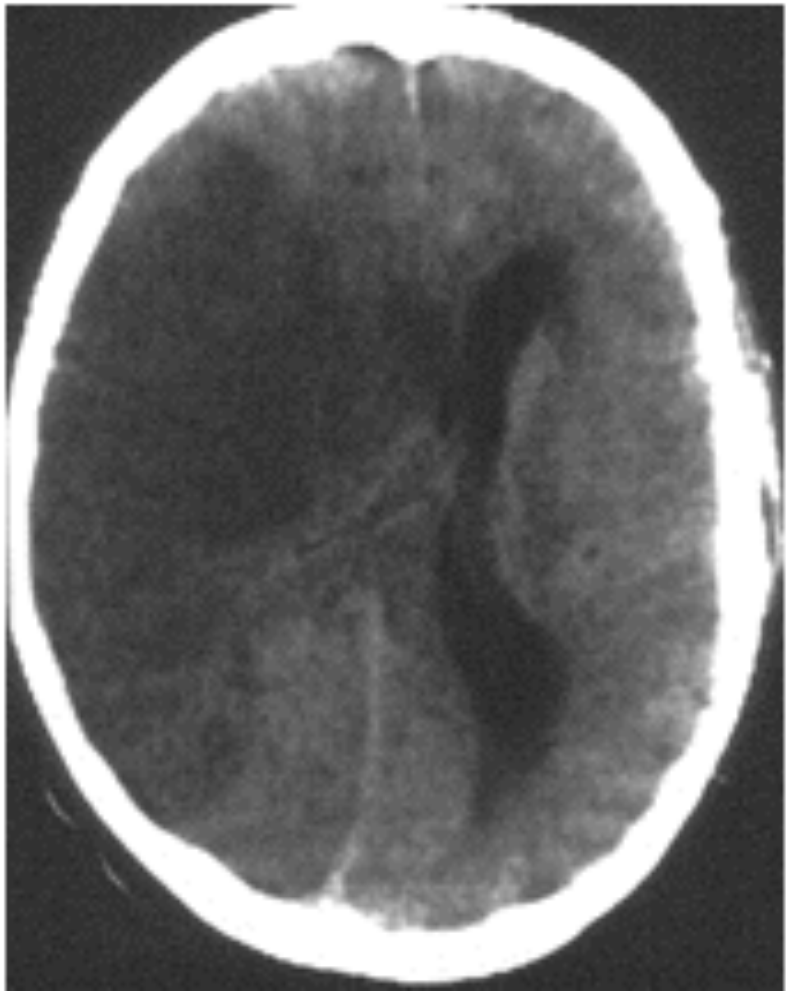
Questions a Coroner might ask

Is there good documentation / explanation of reasoning
and does this suggest adequate authority?

Ask senior doctors

- why no documentation of values, goals, wishes?
- was this predictable? (did they use available predictive tools)
- was poor preparation detrimental for patient and/or family?
- ask what training provided to junior doctors

- Don’t focus too much on the poor junior doctor left to make decisions with inadequate guidance
- Beware making things worse



WHAT DO DOCTORS CONSIDER

- Disease
- Physiology
- Test Results

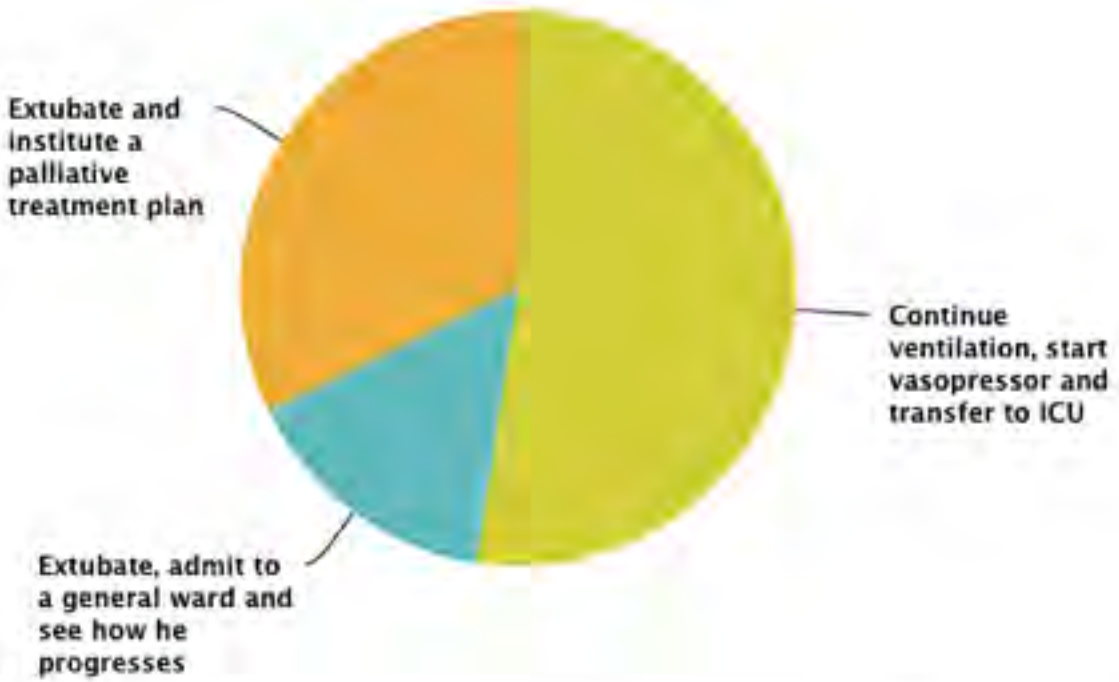
WHAT SITUATION ARE WE CONSIDERING?

- Treatment of no benefit ('futile') so need not be offered
- **Treatment is possible – but can be reasonably declined by patient**
- Treatment is possible – and is so good that it can not be 'reasonably' declined by patient

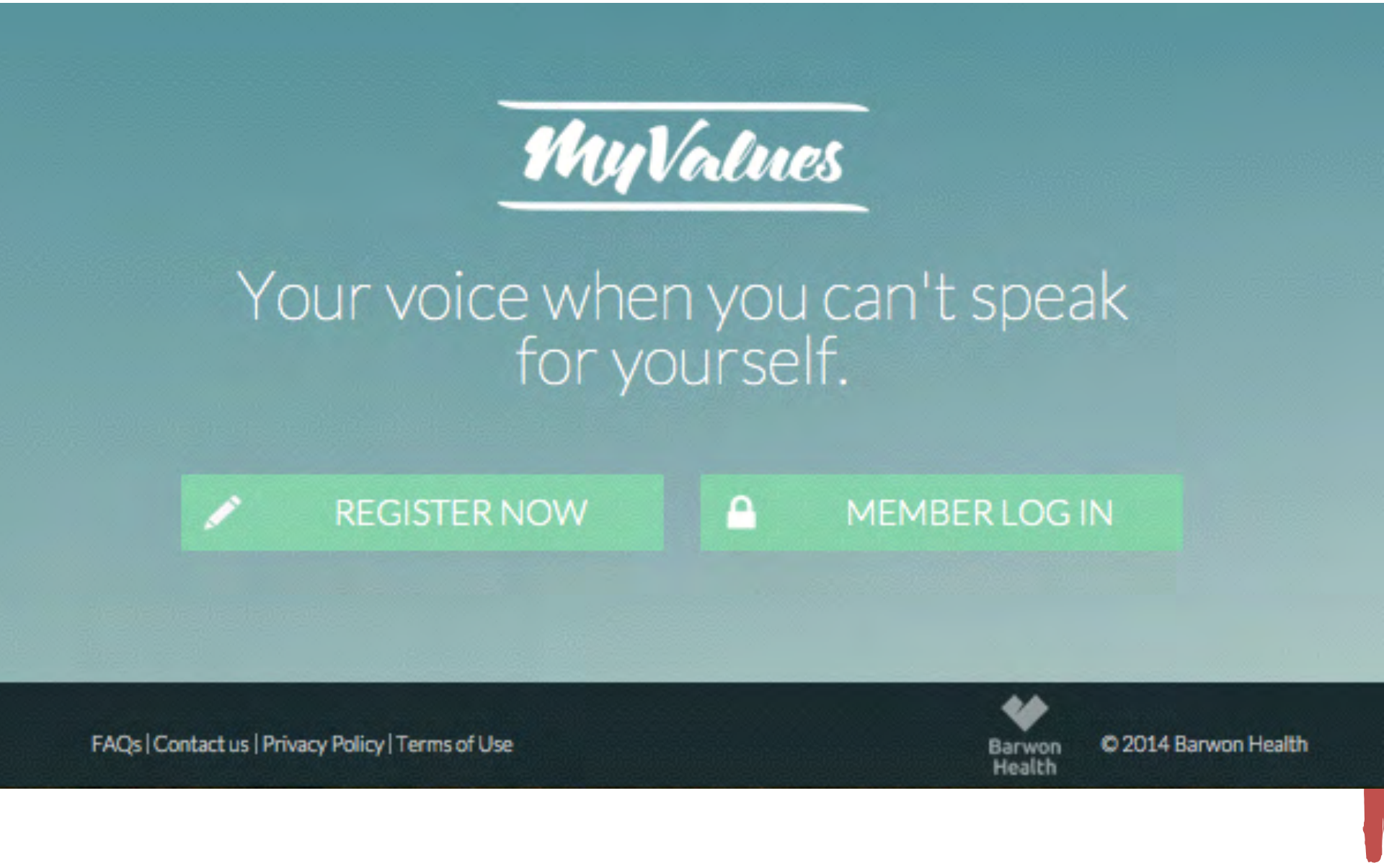
BEST INTERESTS CHECKLIST:

- Consider any advance statements made
- Consider MEPOA's assessment of wishes (if appointed)
- Consider individual's expressed wishes + feelings
- Consider the **beliefs and values** of the individual (including past actions as evidence for same)

- (Take into account views of family and informal carers)



Answer Choices	Responses	
Continue ventilation, start vasopressor and transfer to ICU	52.42%	65
Extubate, admit to a general ward and see how he progresses	15.32%	19
Extubate and institute a palliative treatment plan	32.26%	40
Total		124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Mr W

STRONGLY HELD VALUES

I am concerned that medical treatment for me may be taken too far

'Just push me off a cliff' and 'take me to the back paddock and shoot me' are a good summary of how I feel, should I get into a bad state

The reason to plan in advance is to make considered choices about treatment in a crisis. Any choice I make should be followed in an emergency where I am unconscious

I should rather die than to have to have basic things such as feeding and toileting done for me (long term)

I would rather be dead than to have to go into a nursing home (long term)

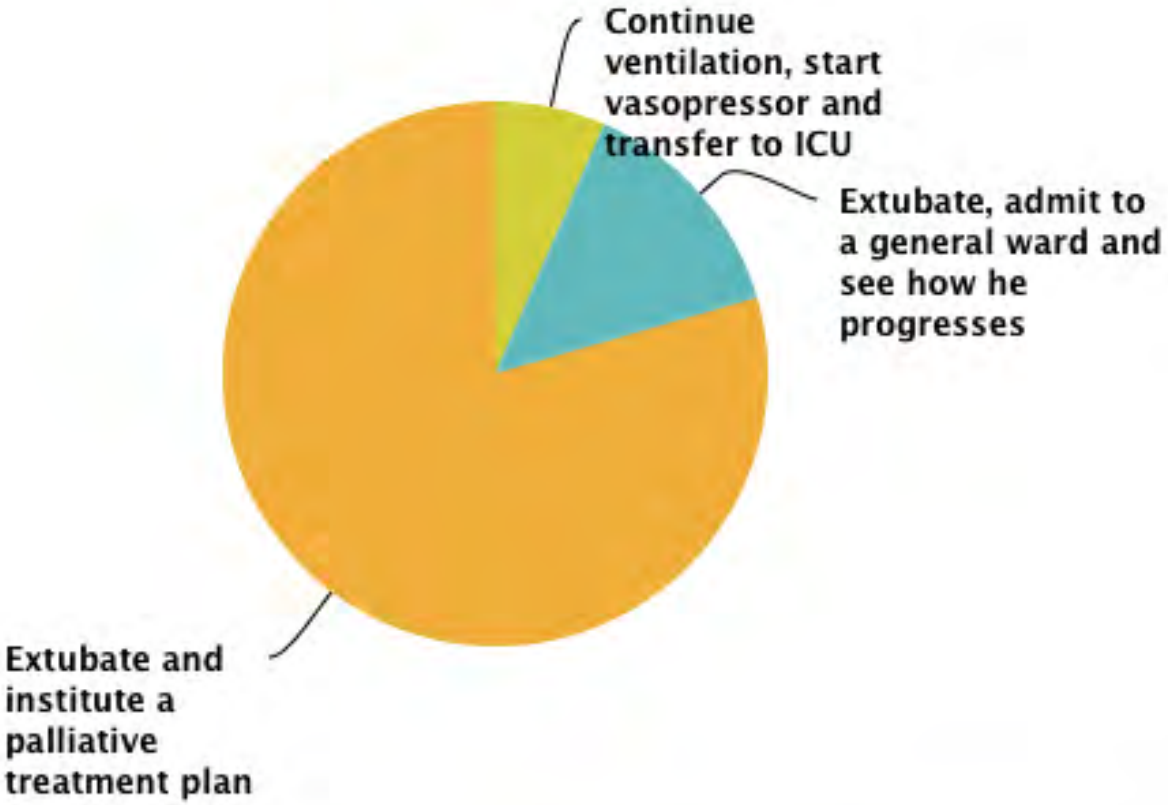
I would not want my family to decide how far my treatment should go - I want to control this for myself

INCONSISTENCY SCORE = 3.33%

Mostly consistent answers suggests a logical, unimpaired thought process. Views in the report are likely to be a reliable reflection of the views of the person completing the survey.

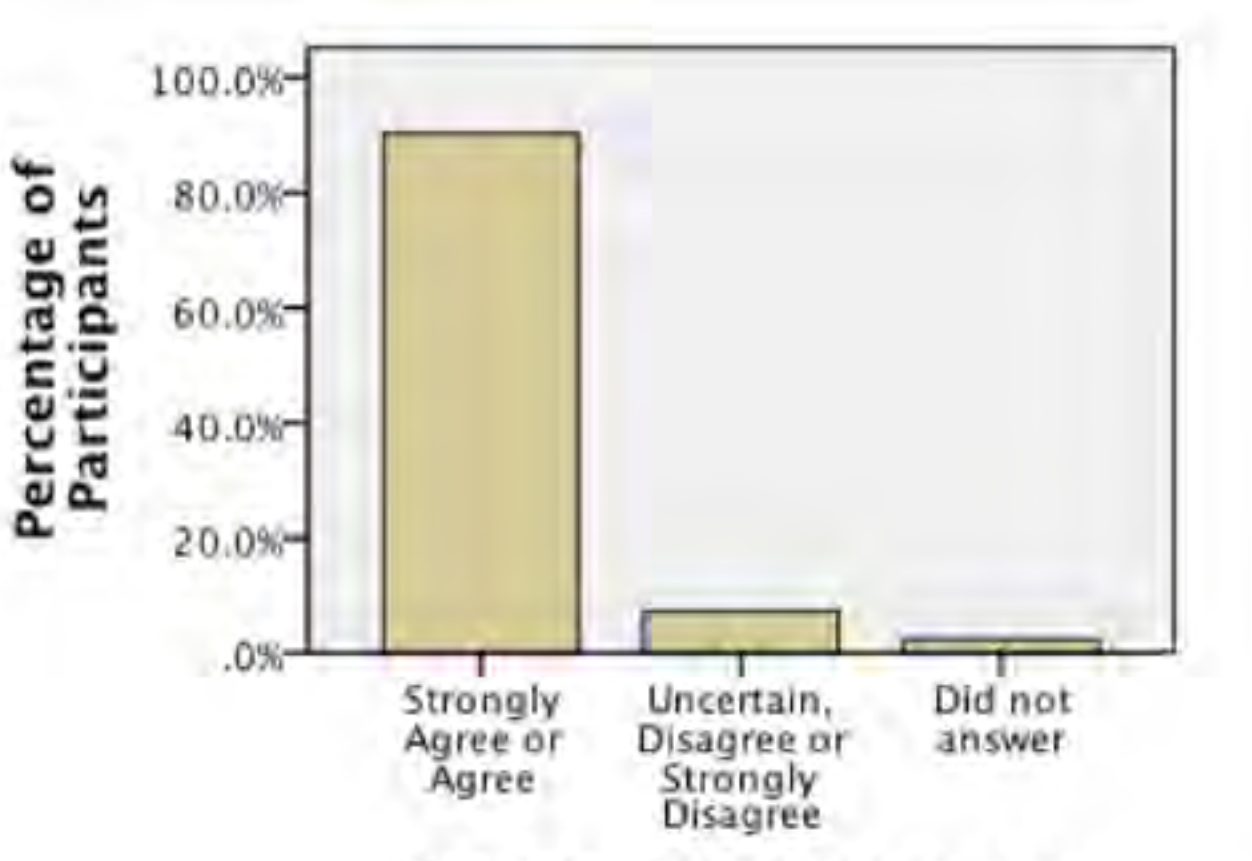
UNCERTAINTY SCORE = 1.67%

Suggests little uncertainty when confronted by the issues, probably already thought about the topic. Views in the report are likely to be held with a reasonable degree of confidence.



Answer Choices	Responses	
Continue ventilation, start vasopressor and transfer to ICU	6.56%	8
Extubate, admit to a general ward and see how he progresses	13.93%	17
Extubate and institute a palliative treatment plan	79.51%	97
Total		122

MyValues gives me adequate information to be confident that I am acting on the patient's wishes



The patient's story has a moral claim to being finished in a way consistent with what has come before and with the values and self-conception with which the person has tried to shape it.

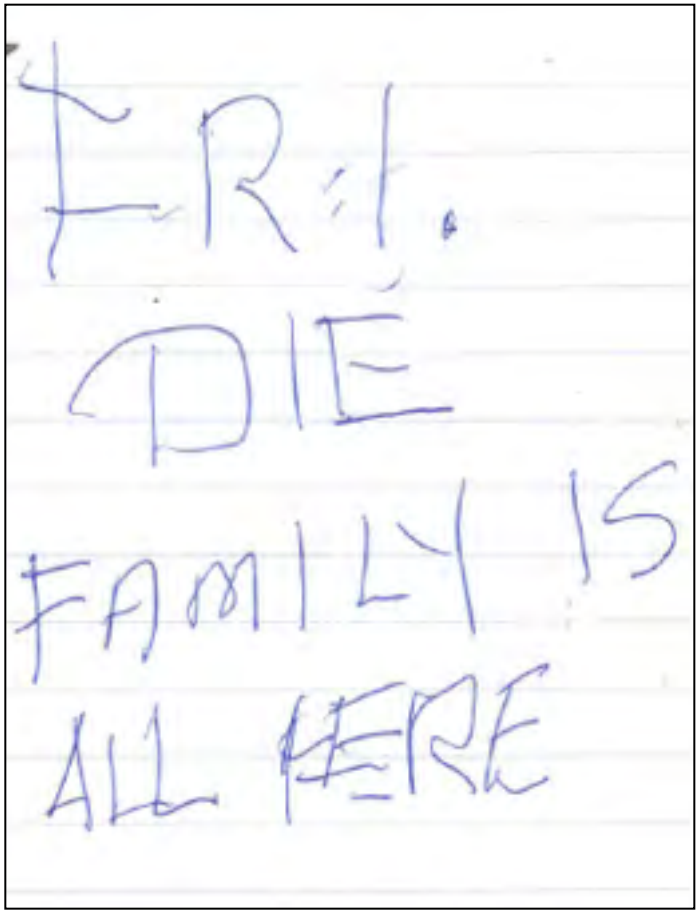
The surviving interests of a person are interests in seeing the story carried out in a way that is meaningfully related to how it has proceeded up to that time.

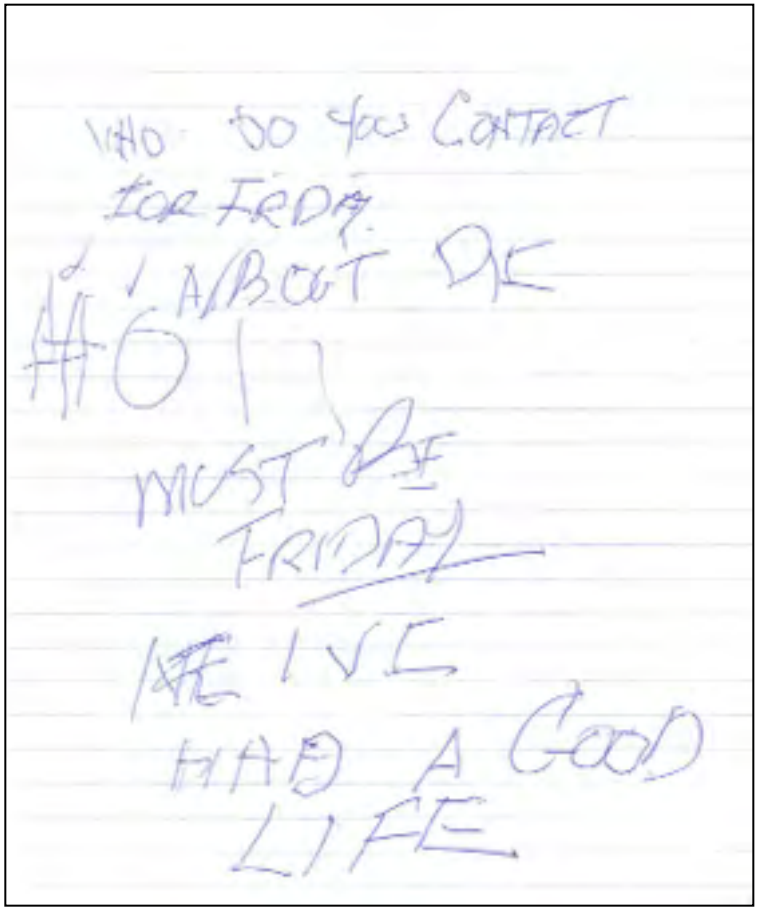
Kuczewski M. Commentary: narrative views of personal identity and substituted judgment in surrogate decision making. J Law Med Ethics 1999;27:32–6, 33.

The test should be, how well a particular decision hangs together with elements of the formerly competent patient's identity-constituting narrative.

Blustein J. Choosing for others as continuing a life story: the problem of personal identity revisited making. J Law Med Ethics 1999;27:20–31, 23.

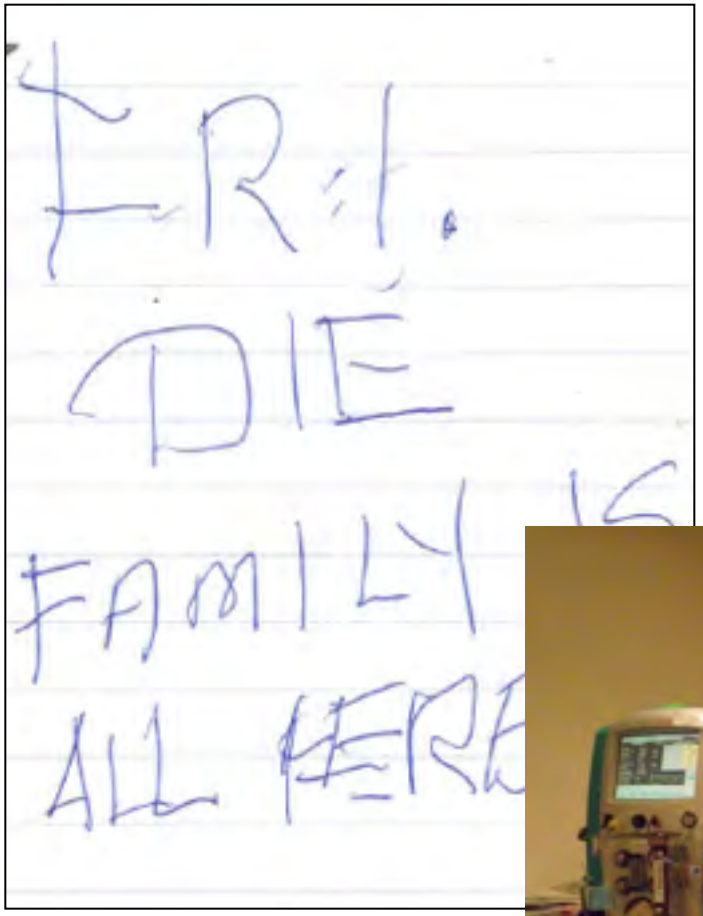
Thank you





FR:1.
DIE
FAMILY IS
ALL HERE

WHO DO YOU CONTACT
FOR FRIDAY
ABOUT DIE
#01
MUST BE
FRIDAY
WE IVE
HAD A GOOD
LIFE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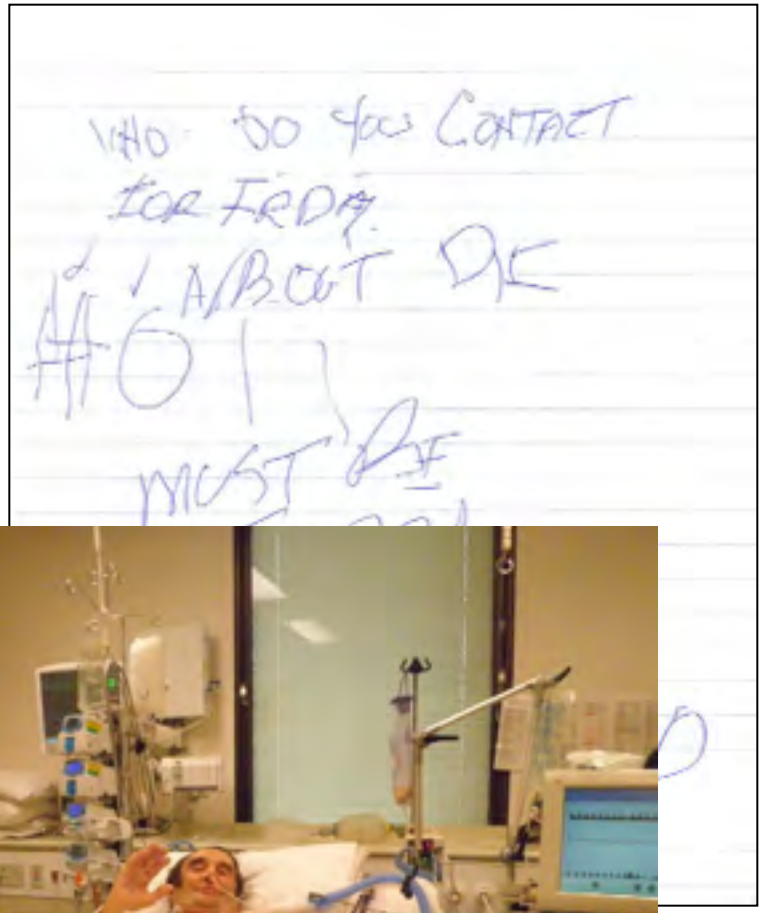
WHO DO YOU CONTACT
FOR FRDM
ABOUT DIE
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Editorial

Expectations as outcome of effectiveness for patients with metastatic lung cancer

Antonio Passaro, Filippo de Marinis

1st Oncological Pulmonary Unit, San Camillo, High Specialization Hospital, Rome, Italy

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metastatic non-small-cell lung cancer undergoing palliative chemo / radiotherapy

384 patients

78% very or somewhat likely to help them live longer

67% very or somewhat likely to help with problems related to the cancer

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metastatic non-small-cell lung cancer undergoing palliative chemo / radiotherapy

384 patients

78% very or somewhat likely to help them live longer

67% very or somewhat likely to help with problems related to the cancer

43% very or somewhat likely to cure their cancer

SPECIAL ARTICLE

CARDIOPULMONARY RESUSCITATION ON TELEVISION

Miracles and Misinformation

SUSAN J. DIEM, M.D., M.P.H., JOHN D. LANTOS, M.D., AND JAMES A. TULSKY, M.D.

60 instances of CPR occurred in 97 episodes

Most cardiac arrest due to trauma; only 28 percent were due to primary cardiac causes.

Sixty-five percent of the cardiac arrests occurred in children, teenagers, or young adults.

Seventy-five percent of the patients survived the immediate arrest, and 67 percent appeared to survive intact to hospital discharge.