What If?......

End of Life Assistance (Scotland) Bill

November 26th 2010

School of Nursing & Midwifery

NHS SCOTLAND

LIVING AND [...]

a national action plan for palliat[...]
and end of li[...]

AIM: identifi[...] assesse[...]

21. Recognised tools are already in place to facilitate the assessment and review of those with palliative and end of life care needs. These include the use of a palliative care register and prognostic indicators in primary care as introduced by the Gold Standards Framework[21,22] and the use of an integrated care pathway such as the Liverpool Care Pathway for the Dying Patient (LCP)[23] in the last days of life. Use of the Scottish Patients at Risk of Readmission and Admission (SPARRA) risk prediction algorithm to identify patients aged 65 years and over at greatest risk of emergency inpatient admission allows NHS Boards and Community Health Partnerships (CHPs) to identify individuals who would benefit from assessment or review and from co-ordinated care in the community to prevent such admissions. The Single Shared Assessment (SSA), carers' assessment and Indicator of Relative Need (IoRN) are important tools in the holistic assessment of needs required at various stages of the disease process. Guidance on the Minimum Information Standards for Assessment and Care Planning for all Adults has recently been circulated to all local authorities, NHS Boards and Community Health Partnerships.[24,25] The Guidance is supported by developments in education and technology which facilitate the safe and effective sharing of data to support the delivery of person centred care. It is expected that all of these tools, as well as the expertise of specialist palliative care and other specialist teams when required, will be used to ensure that the aim of ensuring appropriate assessment and review is met.

healthier scotland
SCOTTISH GOVERNMENT

Review of palliative care services in Scotland

Report supplement: Patients' views

"Utterly hopeless. Not all patients get a heart failure nurse … only those with a hospital diagnosis … generally older people are just not getting any advice, a lot of people don't even understand the medication properly."

Patient interview, chronic heart disease

"It was a lack of care and pure dirt … you're treated like cattle going to emergency."

Patient focus group, cancer

"If a doctor came out to me again and said hospital I'd say no thank-you, I'll take my chances in the house … I would never, ever, ever go back again."

Patient focus group, cancer

"I want to have a quick death without suffering, at home surrounded by my family so that I can say good-bye to them"

Diane Pretty

Currently we cannot offer this opportunity to all.

Will the Bill raise the standard of palliative care?

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What the Bill says…..

" ....assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress"

In general allowing people to die with dignity is not something we are always good at…..now the Bill is law, how will we do this?

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What People said about the Bill….

I have been suffering from neuro-edocram cancer for ten years. I have had 1 major op to my pancreus + a total repluming job. and 2nd a major op to my liver 5 years appart. With the cancer came further infimities. Now 2010 I have inopperable cancer in both my pancreus and my liver. I love and enjoy life, God's greatest gift. I would like to lend my support to your cause in defeating Margo Macdonald's bill. I am in the process of writing a book based on hope against this ticking bomb inside me.

We oppose this proposed bill as we are of the view that it demeans the human person and that improved health and palliative care should be increased. A bill such as Margo MacDonald's would in reality become a threat to the life of all elderly, sick and disabled persons.

What People said about the Bill….

I am writing to express my very strong support for this bill, and for patient choice in general….

…This proud and self-sufficient man, who at the time he began to exhibit signs of Parkinsons was planning a 600-page legal treatise on a subject of great complexity, couldn't turn himself over in bed, couldn't work a television remote control, couldn't wash his own face, couldn't sit up unless propped up, couldn't get out of his chair, couldn't wipe his own bum. He didn't want to live and couldn't understand why he was being forced to continue to live, since his life no longer held any value for him. He was forced to continue to live

considered to have any right to choose

depressed and didn't suffer from any me

I have recently started a chemotherapy treatment for Oesophageal cancer. It is hellish.
The possibility of a cure is 5%, of delaying death by a year or 2 is 65% , of having no improvement and dying within 1 year is 30%.
I do not wish to drag my wife and family through the unpleasantness of watching me die slowly.
I want to die with altruism and courage, without chairlifts, bed baths and hospices.
The doctors have the means: how do I get hold of it? A simple injection like the vets give.

Figure 3: Due care requirements under the Termination of Life on Request and Assistance with Suicide (Review Procedures) Act

- be satisfied that the patient's request is vo considered
- be satisfied that the patient's suffering is that there is no prospect of improvement
- inform the patient of his or her situat prognosis
- discuss the situation with the patient and c conclusion that there is no other reasonabl
- consult at least one other physician with r the case, who must then see the patie writing that the attending physician has sat for due care
- exercise due medical care and attention ir patient's life or assisting in his or her suicid

(Source: Tiedemann and Valiquet (2008, p 11

Table 2: Estimated frequencies of medical end-of-life decisions and continuous deep sedation in the Netherlands in 2001 and 2005

	2001		2005	
	No	%*	No	%*
Medical decision on end of life:				
Active Voluntary Euthanasia	3500	2.6	2325	1.7
Physican Assisted Suicide	300	0.2	100	0.1
Ending of life without explicit request of the patient	950	0.7	550	0.4
Intensified alleviation of symptoms	29000	21.0	33700	25.0
Withholding or withdrawing life-prolonging treatment	28000	20.0	21300	16.0
Continuous deep sedation:				
With medical end-of-life decisions	8500	6.0	9700	7.1
Without medical end-of-life decisions	-	-	1500	1.1

* Of all deaths

Source: Onwuteaka-Philipsen et al (2007)

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Table 3: Rates of AVE or PAS and ending life without an explicit request by the patient, in 2001 and 2005, by characteristics of patients

Characteristic	Deaths in 2005 studied (No.)	% of all deaths	AVE or PAS		Ending of Life without Explicit Request by	
			2001	2005	2001	2005
Age:						
0-64 yr	2583	19.2	5.0	3.5	1.0	1.0
65-79 yr	3462	32.4	3.3	2.1	0.4	0.3
≥ 80 yr	3920	48.4	1.4	0.8	0.7	0.2
Sex:						
Male	5371	49.7	3.1	2.0	0.7	0.4
Female	4534	51.3	2.5	1.5	0.7	0.4
Cause of death:						
Cancer	2760	28.8	7.4	5.1	1.0	0.3
Cardiovascular	4882	31.9	0.4	0.3	0.6	0.2
Other or unknown	2323	39.3	1.2	0.4	0.5	0.6
Type of physician:						
General practitioner	5135	41.3	5.8	3.7	0.6	0.2
Clinical Specialist	2891	32.3	1.8	0.5	1.2	0.7
Nursing home	1458	24.5	0.4	0.2	0.4	0.3
Total	**9965**	**100.0**	**2.8**	**1.8**	**0.7**	**0.4**

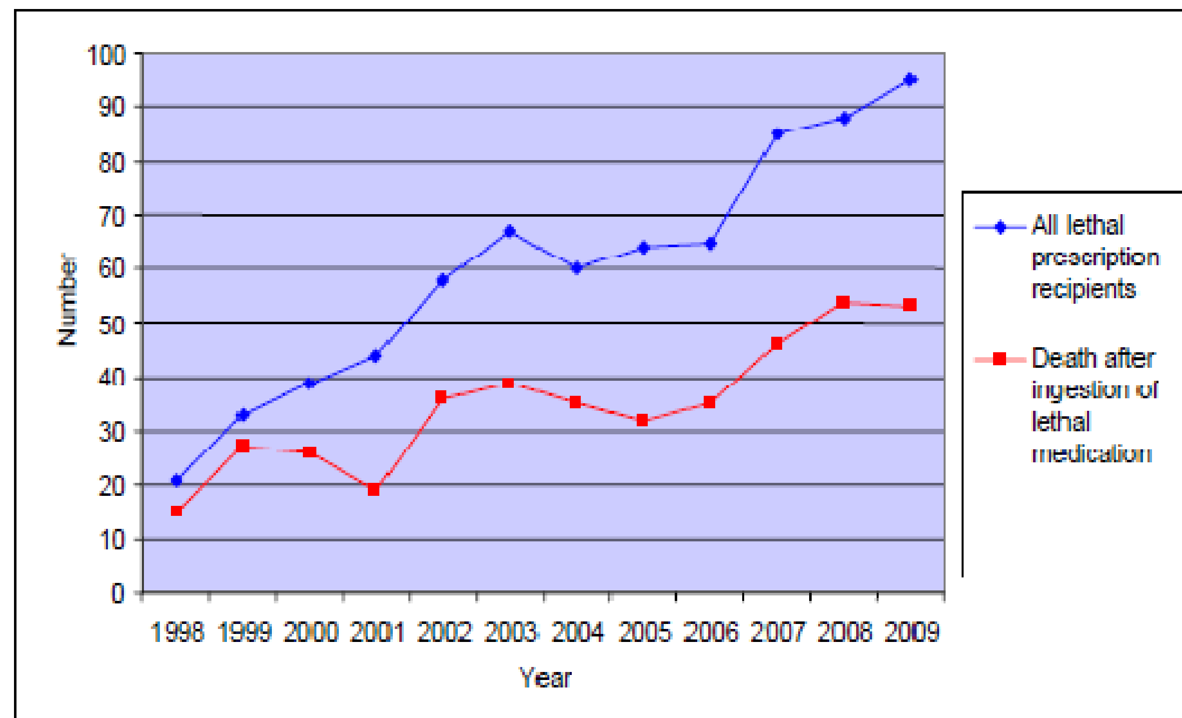
Source: Van der Heide et al (2007)

Figure 5: Process for dispensing prescription under the DWDA

- The patient must make two oral requests to his or her physician, separated by at least 15 days.
- Following the second oral request, the patient must provide a written request to his or her physician, signed and dated in the presence of two witnesses.
- An additional 48 hours must pass before the physician can write a prescription, though the patient can revoke the request any time by any means.
- Neither of the witnesses can be: a relative by blood
owner or operator of a healthcare facility that the pe
a witness must also not be the prescribing physicia
- The prescribing physician and a consulting physicia
- The prescribing physician and a consulting physicia
- If either physician believes the patient's judgment is
disorder, the patient must be referred for a psychol
- The prescribing physician must inform the patient o
care, hospice care, and pain control.
- The prescribing physician must request, but may no
kin of the prescription request.
- Once the prescription has been accepted by the ph
what manner with who present to self-administer. N
can administer the medication.

(Source: OSG: DHS (2006b) and Patel (2004))

Figure 6: Number of DWDA Prescription Recipients and Deaths by Year, Oregon, 1998-2009



Source: OSG: DHS (Online) 'Death with Dignity Act Annual Reports'

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Table 5: Characteristics of persons who died after ingesting lethal medication, Oregon, 1998-2008 and 2009

Characteristics	2009 (N=59)		1998-2008 (N=401)		Total (N=460)	
	N	%	N	%	N	%
Sex:						
Male	31	52.5	213	53.1	244	53.0
Female	28	47.5	118	46.9	216	47.0
Age:						
18-34	2	3.4	4	1.0	6	1.3
35-44	1	1.7	11	2.7	12	2.6
45-54	2	3.4	32	8.0	34	7.4
55-64	9	15.3	85	21.2	94	20.4
65-74	13	22.0	114	28.4	127	27.6
75-84	24	40.7	112	27.9	136	29.6
85+	8	13.6	43	10.7	51	11.1
Median years	76	-	70	-	71	-
Underlying illness:						
All cancers	47	79.7	326	81.3	373	81.1
Amyotrophic lateral sclerosis *	5	8.5	30	7.5	35	7.6
Chronic lower respiratory disease	3	5.1	15	3.7	18	3.9
HIV/AIDS	0	0.0	8	2.0	8	1.7
Other ^	4	6.8	22	5.5	26	5.7
End-of-life concerns #:						
Losing autonomy	57	96.6	357	89.9	414	90.8
Less able to engage in activities making life enjoyable	51	86.4	347	87.4	398	87.3
Loss of dignity	54	91.5	228	83.8	282	85.2
Losing control of bodily functions	31	52.5	233	58.7	264	57.9
Burden on family, friends, carers	15	25.4	152	38.3	167	26.6
Inadequate pain control or concern about it	6	10.2	95	23.9	101	22.1
Financial implicaitons of treatment	1	1.7	11	2.8	12	2.6

NB:
* A form of Motor Neuron Disease
^ Includes: alcoholic hepatic failure, corticobasal degeneration, diabetes with renal complications, hepatitis C, organ-limited amyloidosis, scleroderma, Shy-Drager Syndrome, multiple sclerosis, meningioma, chronic heart failure and Huntingdon's disease
\# Affirmative answers only ("Don't know" included in negative answers)

Source: OSG: DHS (2010)

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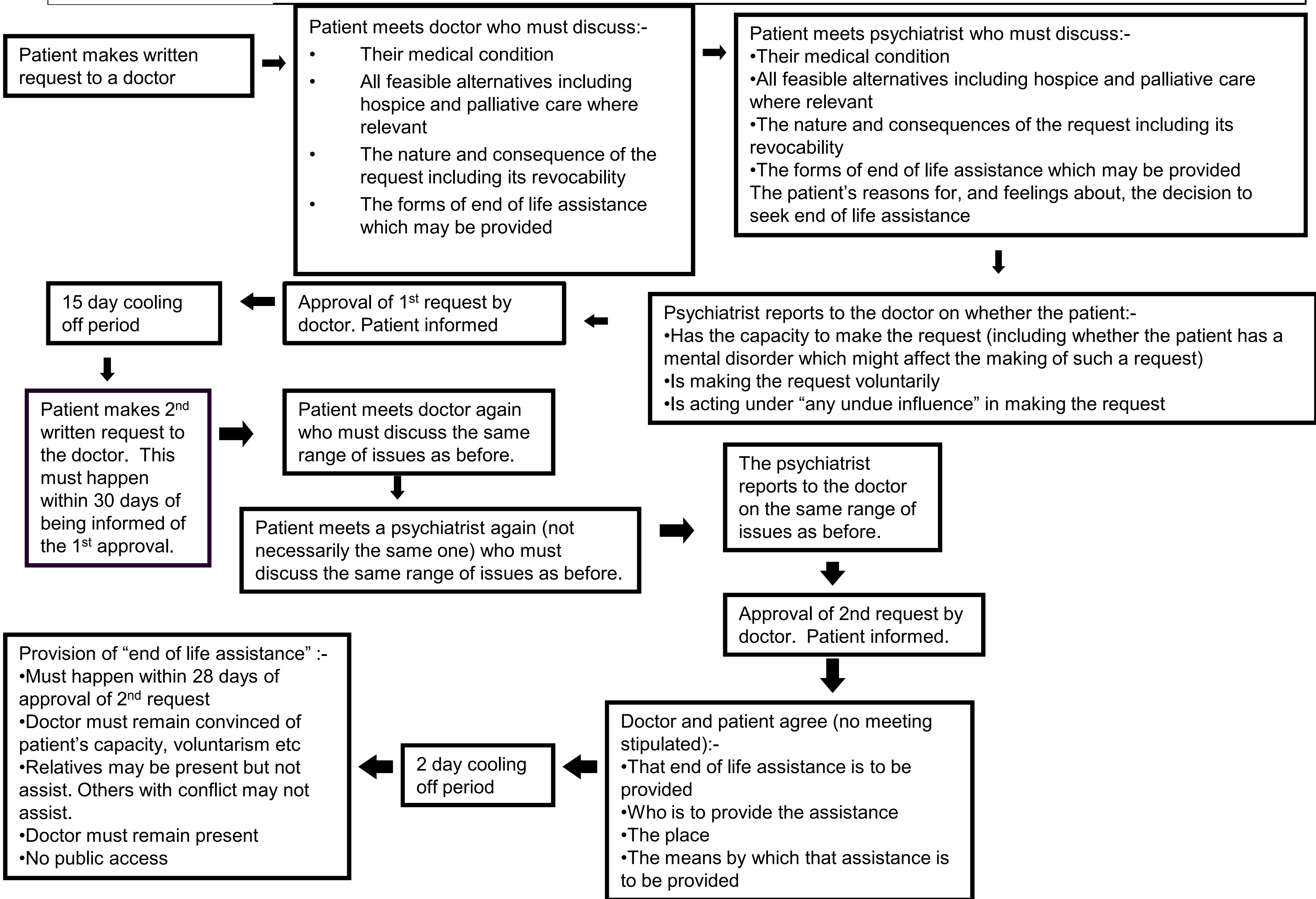
The Scottish Parliament
Pàrlamaid na h-Alba

End of Life Assistance (Scotland) Bill
November 25th 2010

- 16 years or over
- Registered with a medical practice in Scotland for at least 18 months
- The person has been diagnosed as terminally ill and finds life intolerable
- The person is permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable


The Scottish Parliament
Pàrlamaid na h-Alba
End of Life Assistance (Scotland) Bill
Patient makes written request to a doctor
Patient meets doctor who must discuss:-
• Their medical condition
• All feasible alternatives including hospice and palliative care where relevant
• The nature and consequence of the request including its revocability
• The forms of end of life assistance which may be provided
Patient meets psychiatrist who must discuss:-
•Their medical condition
•All feasible alternatives including hospice and palliative care where relevant
•The nature and consequences of the request including its revocability
•The forms of end of life assistance which may be provided
The patient's reasons for, and feelings about, the decision to seek end of life assistance
Psychiatrist reports to the doctor on whether the patient:-
•Has the capacity to make the request (including whether the patient has a mental disorder which might affect the making of such a request)
•Is making the request voluntarily
•Is acting under "any undue influence" in making the request
Approval of 1st request by doctor. Patient informed
15 day cooling off period
Patient makes 2nd written request to the doctor. This must happen within 30 days of being informed of the 1st approval.
Patient meets doctor again who must discuss the same range of issues as before.
Patient meets a psychiatrist again (not necessarily the same one) who must discuss the same range of issues as before.
The psychiatrist reports to the doctor on the same range of issues as before.
Approval of 2nd request by doctor. Patient informed.
Doctor and patient agree (no meeting stipulated):-
•That end of life assistance is to be provided
•Who is to provide the assistance
•The place
•The means by which that assistance is to be provided
2 day cooling off period
Provision of "end of life assistance" :-
•Must happen within 28 days of approval of 2nd request
•Doctor must remain convinced of patient's capacity, voluntarism etc
•Relatives may be present but not assist. Others with conflict may not assist.
•Doctor must remain present
•No public access

GROUP A: Clinicians and managers responsible for delivery of palliative care

How will this work within the framework of current palliative care?

Develop a protocol for PAS for your organisation taking account of all involved in this care pathway.

GROUP B: Patients and carers facing end of life decisions

What do you want to have in a care pathway for PAS to ensure the best care for you?

GROUP C: Palliative care professionals who objected to the Bill

The Bill is law so what challenges and/or opportunities now exist for palliative care clinicians?