ROYAL
PHARMACEUTICAL
SOCIETY

1 Lambeth High Street
London
SE1 7JN
T: 0845 257 2570

Dignity in Dying
181 Oxford Street, London W1D 2JT

Safeguarding Choice A draft Assisted Dying Bill for consultation

The Royal Pharmaceutical Society (RPS) is the professional body for pharmacists in Great Britain. We are the only body which represents pharmacists in all sectors of the profession. We lead and support the development of the pharmacy profession including the advancement of science, practice, education and knowledge in pharmacy. In addition, we promote the profession's policies and views to a range of external stakeholders in a number of different forums.

We thank you for the opportunity to respond to this consultation which has important implications for all sectors of the pharmacy profession.

Our members have a spectrum of opinions on this subject and we therefore remain neutral and neither support nor oppose the draft Bill. We have answered the consultation questions from the perspective of the implications for patient care and the role our members would play if the legislation was passed.

We are pleased to see a conscience clause included in the draft, exempting anyone from the necessity to be involved in assisted dying if they have a conscientious objection.

The RPS has an ambition to establish Great Britain as the safest place to take medicines and patient safety is at the heart of all pharmacy practice. An assisted dying procedure is a unique situation but this does not detract from the need to have appropriate clinical governance procedures and guidance in place as with any other prescribed medicine. As the experts in medicines pharmacists have an important role to play in ensuring that any regulations or guidance associated with the proposed Bill is appropriate and suitable for those pharmacists who would provide the service. This is a very sensitive issue and we are happy to discuss this further with you if our response raise further questions or needs clarification on any point.

Mair Davies — **Chair Welsh Pharmacy Board**

Shilpa Golpie — **English Pharmacy Board**

Consultation Questions

Q1. If adequate safeguards can be found to allow assisted dying (assistance to die for terminally ill, mentally competent adults only) and no healthcare professional is obliged in any way to assist a patient to die, would you support a change in the law on assisted dying?

As a professional body whose members have views both for and against any change in the law we must remain neutral and neither oppose or support the bill. However if there was a change in the law we would expect the pharmacy profession to be consulted early in the process of drafting regulations and in any national guidance and protocols.

2 Do you think upfront safeguards before an assisted death (as set out in the draft? Bill) or retrospective safeguards after an assisted death (under the current law) are most effective for protecting patients?

This question is really asking the same as Question Number 1 .Are we for or against the proposed bill? Therefore again we must remain neutral on this point as our members are divided on whether or not they support a change in the existing law .

3*.* Should any other additional eligibility criteria be added?

We agree that any proposals should be applicable only to terminally ill people but in addition we would stipulate that while a decision about how a person wishes, or thinks they wish to die could be taken at any time (and rescinded at any time) the carrying out of an assisted dying procedure should only be possible when the person has decided for themselves that their life is intolerable. The criteria should include that all the palliative care options have been made available to them and explored before a final request is made.

4 Would you prefer assisted dying to be available to people with a prognosis of:

As stated above we think the concept of life being intolerable for the individual is more useful than an exact time frame. Different disease states will lead to a wide variety in quality of life at different stages and this individuality should be accommodated to provide a person centred approach.

5. Mental Capacity
Are you satisfied with the arrangements proposed in the Bill for assessing? these eligibility criteria? (We would welcome any suggestions for additional arrangements for assessing these eligibility criteria).

We question the statement regarding the requirement of the nurse or doctor to assess mental capacity when delivering medicine. How could this be done and assessed? Does that one professional make that final decision? What would happen if this was queried by relatives at a later date? This seems like an additional barrier if someone has already made the declaration with a witness and been assessed twice by doctors.

6 Should it be a requirement that one of the two assessing doctors has a certain level of knowledge and experience of end-of-life care?

We would expect all patients to have had the opportunity to explore all the palliative care or end of life options available to them. It would not be necessary for the doctor themselves to have this specialist knowledge but would be essential that they could refer the person to someone who had. This could be a multidisciplinary approach as both palliative care

pharmacists and specialist nurses would have this expertise. We would also expect close working relationships with hospices to be the norm.

7. Are you satisfied with the proposals for the waiting / 'cooling off' period?

The principle of a cooling off period seems a sensible approach. It is difficult to be precise about the best time frame for this as each person would have individual requirements. Prognosis can be difficult to predict even at the latter stages of life. What would be the situation if a person's deterioration was much faster than anticipated?

8 Are you satisfied with the proposal that two doctors, acting independently of each other (and referring the patient for further assessment by other professionals where necessary), assess the patient's eligibility for assisted dying?

We agree that two doctors should be required to give an independent assessment of whether or not the person fits the eligibility criteria. One of these doctors should be known to the patient and know their medical history. This would normally be the patient's General Practitioner, although may be a hospital specialist who has been caring for the patient in their terminal illness. We also support further referral when necessary to other appropriate health professionals.

9 Should the doctor or nurse remain on the premises until the patient dies?

We expect that the time and place for an assisted dying procedure would be pre –planned and as such it would be possible for a doctor or nurse to be present and to certify the death afterwards. If a doctor or nurse was not present then someone who was trained and competent in all aspects of the procedure should be present. If the date and time the person has chosen for their assisted death is known, then it should be possible to have a doctor alerted of the need and estimated time required to attend to confirm death. It should not be necessary for the doctor to be present at all times.

While the approach of having a suitable nominated person to collect the medicine (with an appropriate audit trail) and stay on the premises is sound, there appears to be no logic in restricting this to doctors and nurses. This could lead to allegations of euthanasia if a healthcare professional was as closely involved as to potentially assist the person to take the medication. The proposed Bill in Scotland suggested that an independent facilitator, who was not necessarily a healthcare professional, be used to pick up the medicines and be responsible for returning any unused medicines to the pharmacy. We support this model and suggest that this concept be explored further.

10. Would you prefer a doctor-led or legal-led (or another) assessment and safeguarding model for assisted dying?

We believe a doctor led model would be the most suitable and a legal led model would be overly bureaucratic, and would in any case involve using health professionals as expert witnesses for the final decision making process.

11 Do you have any suggestions for how the process could be made less onerous for patients whilst maintaining their safety

We must avoid the situation where a prescription for assisted dying can be presented over the counter in a community pharmacy by a person or their representatives, without the pharmacist

having prior knowledge of the proposed action. This could cause extreme embarrassment, inconvenience and distress for the person concerned and the pharmacist if the pharmacist had a conscientious objection. In some instances signposting to another health professional is also contrary to someone's moral or religious beliefs and this needs to be addressed.

The pharmacist must be considered a core member of the healthcare team. As well as dispensing and supplying medication pharmacists are legally and ethically obliged to ensure that the medication is right for the patient. Responsibility for the prescription is shared between the prescriber and dispensing pharmacist. The pharmacist must have access to all the documentation necessary to ensure all legal aspects of the process have been correctly addressed and all criteria met in full.

This should be a well planned procedure and as part of the planning a care plan should be drawn up to accommodate all the person's wishes. The time and date should be decided upon and who will be present.
We think the involvement of an independent facilitator could be advantageous in the process and help with administrative tasks as well as witnessing the death .We envisage a triangular link between the doctor, pharmacist and a facilitator, if used, to make necessary arrangements and thereby avoid any unnecessary stress or anxiety for the person and their family.

12. Should it be the patient's responsibility to find a second doctor, should the attending doctor be able to refer the patient to an independent doctor or should there be a clear mechanism for patients to find an independent doctor

The attending doctor should refer the person to a second doctor for assessment as they would with any other referral process. What would the options be for the patient if one of the doctors does not agree that the patient is suitable for an assisted death?

13 Are you satisfied that the functions of the Monitoring Inspectorate are appropriate?

There is not enough detail in the consultation to be precise about satisfaction with the monitoring process. We agree there needs to be a monitoring process and would wish for the detail of this to be explored further before regulations were approved.
The monitoring process should include governance around clinical issues and this should also form part of the appraisal / GMC revalidation process for any doctor involved in assessment or prescribing.

14 Do you have any suggestions as to any existing organisations that Would be better suited to take on these functions than the proposed Monitoring Inspectorate.

The Accountable Officers presently have a remit to monitor the prescribing and use of all controlled drugs in their area. This provides information on quantities and patterns of use in all sectors of healthcare and they would therefore have a role in any monitoring process.

15 The Bill also proposes that alongside the monitoring and evaluation of the Monitoring Inspectorate (based on the analysis of evidenced declaration forms and other paperwork required from pharmacists and doctors), the Registrar General should produce an annual report on assisted deaths based on the cause of death recorded on death certificates. This would provide important information on the underlying illnesses, and other characteristics, of those choosing assisted dying. Are you satisfied with this proposal?

Yes we approve of an annual report which should be comprehensive, informing of practice nationwide and ensuring transparency of approach. It would inform of any necessary changes in the regulations and flexibility should be built in to allow these changes to occur in a timely manner i.e. not requiring to wait for the sunset clause. It will be of public interest to see the statistics around any new legislation to provide reassurance that the criteria are being adhered to.

16 Do you support the inclusion of a 'sunset clause'?

We approve of a sunset clause and would advocate that in the first instance 10 years might be too far ahead and that initially perhaps a 5 year clause would provide more public reassurance.

17 Do you have any comments on the suggestions of areas to be covered by the Code of Practice?

We would like national guidance and protocols to eliminate any postcode discrepancies and give consistency across England and Wales on procedures, training and the use of evidence based medicines. There will be implications regarding the use of medicines in either an unlicensed or off-label capacity. It is important that all parties are informed and understand these implications. There will be a role for pharmacy in the development of guidance, protocols and educational resources to ensure that all medicine related aspects have been properly considered before implementation.

Some clarity should also be provided on any legal implications for anyone nominated by the terminally ill person to be present in order to avoid confusion in the 'assisting 'process. No one who is a family member, friend or beneficiary of the estate of the deceased should be involved in preparing the medication in any way or assist the person to consume the lethal dose .

18 What training and support should be available to doctors and other healthcare professionals in the event of a change in the law on assisted dying?

Any doctor, pharmacist or facilitator should be trained in the legal requirements and the criteria required for eligibility; the paperwork and administration required before and after procedures, including consent requirements, national guidelines and protocols. All training should be multidisciplinary to ensure a coordinated approach and common understanding of the process. The training should be holistic nature and encompass some of the sensitive issues anyone involved might encounter. This might extend to the provision of a peer support network or signposting to a listening friends resource.
We believe participation in the training would be optional for all concerned and would be the entry point for 'opting in'. Successful completion of the training would be mandatory for anyone involved in the assisted dying procedure.
Organisations such as the Centre for Pharmacy Postgraduate Education (CPPE) and the Welsh centre for Pharmacy Professional Education (WCPPE) and their medical equivalents would be key participants in delivering the national training modules required.

19 Do you have any other comments on the draft Bill?

We believe that any assisted dying procedures should not be subject to commercial interest and should remain within the NHS. One of the reasons for any change in legislation would be to reduce inequalities as presently only those with financial means are able to travel to Switzerland to avail them of the different legal system there.
Has the proposed legislation taken into account that choice at the end of life also means dying in different settings and any legislation should allow for assisted dying in other settings such as care homes and secondary care?

Consideration may also need to be given to accommodating requests at particular times or dates. This will involve close cooperation between the doctor, pharmacist and any appointed facilitator. The process to be followed if the person changes their mind or wishes to delay until another day needs to be clear to all.
Consideration will need to be given to how the service is provided with respect to contractual requirements within the NHS.

20 Do you have any comments on the Declaration form (Schedule 1)

The declaration form as shown is a good starting point but as indicated in our answers throughout this response it should be expanded to cover all the criteria required

- It should incorporate or be attached to the patient care plan.
- It should indicate that palliative care options have been explored and exhausted rather than merely informed.
- It should indicate that the person now finds life intolerable