

Written evidence submitted by the Royal Pharmaceutical Society (ADY0403)

We are the professional leadership body for pharmacists in Scotland, England, and Wales.

We promote pharmacy in the media and government, lead the way in medicines information, and support pharmacists in their education and development.

We are responding to this call for evidence is to highlight professional and ethical considerations that would have to be made regarding pharmaceutical input around this issue. We want to ensure that the views of pharmacists are considered and that the content of any bills brought in the future reflects pharmacy practice.

Assisted Dying

The RPS takes a neutral stance on this topic, it is neither for nor against assisted dying due to the wide-ranging nature of our members views. The information here has been extracted from our policy on this topic which can be found [here](#).

If legislation was passed in any of the GB countries every pharmacist would need to make a personal decision on whether or not they would wish to be involved in providing or supporting such a service.

If legislation is passed, pharmacists will have a key role in developing suitable protocols and guidance for prescribers. Policymakers need to recognise and be aware that the role of pharmacists goes far beyond supply of the required medication.

Proposals for changes in the law have sought to address solely the situation of a mentally competent person suffering from a terminal condition, whose quality of life has deteriorated to the extent that they now determine it to be intolerable and that they wish to end their life at a time of their choosing, rather than by the natural course of their disease. It is therefore in this context that we are specifically examining the issues around assisted dying from a pharmacy perspective. We have not yet addressed the wider issue of either euthanasia or broader patient groups.

Professional and ethical considerations

Conscience clause - It is a pre-requisite that a conscience clause is incorporated into any legislation. There must be no obligation for any pharmacist to participate in any aspect of an assisted dying or similar procedure if he or she feels this is against their personal beliefs. The framework we are proposing allows pharmacists to 'opt in' by completing the necessary training, rather than 'opting out'. It also avoids the need for anyone ethically opposed to assisted dying to signpost to another pharmacist as this can also pose an ethical dilemma.

Legal protection - There must be explicit protection in place in any legislation for pharmacists, pharmacy technicians and other health care professionals to be protected from prosecution when participating in the approved process for an assisted dying procedure. We would not anticipate any non-regulated pharmacy support staff to be involved in any of these procedures.

Protection from coercion

Criteria - All safeguards initially agreed in any prospective legislation need to be effective and rigorously applied. The criteria for eligibility should be steadfast and unable to be altered without proceeding through the primary legislative process. Comparisons have been drawn to the parallel with the 1968 Abortion law where there has been criticism that the criteria for eligibility have not been upheld as was originally intended.

Pre-registration - We advocate that there be a legal requirement for patients to pre-register their wish with their own GP to have assisted dying as an option at a later stage in their lives if they fit the legal criteria. Their wishes should be recorded in their health record. This differs from an advance directive which gives instructions for withholding a treatment which might prolong life and thus cannot be used for requesting specific treatments. This pre-registration process should be in a nationally agreed format.

Capabilities required to consent to assisted dying

Mental competence and eligibility - A person must be capable of making an informed decision i.e. have the mental capacity to do so. We recognise that this will exclude people with Dementia or Alzheimer's disease which are also terminal illnesses. However, this is a different situation from someone requesting assistance to change the timing of their inevitable death from a physical illness.

The involvement of another person in the decision to end someone's life would mean the process was not assisted dying, but euthanasia which is not currently being addressed.

Assessment - Two doctors should carry out a full assessment of the patient, which carries the responsibility for ensuring that the patient fits the necessary eligibility criteria before a lethal prescription can be issued. Whenever possible the patient and patient history should be known to one of the assessors.

Assistance - A person must be able to self-administer the lethal prescription and be able to change their mind and halt the procedure at any point to differentiate between assisted dying and euthanasia. A person's physical state might deteriorate between making their decision to end their life and the date planned for the procedure. This should not be a barrier to carrying out their wishes and therefore a flexible approach to the practicalities of assisting someone is required.

Mechanical devices might be required to overcome physical disability as some people by nature of their illness will not be able to swallow solids, or drink from a cup without a straw or without spilling. This aspect should be discussed in the care plan.

Information, advice and guidance needed for informed decision making

Alternative options - It must not be assumed that when a person presents with a request for assistance to end his/her life that this is indeed their actual first choice. People may present with a request for assisted dying when they are not aware of all the alternative options available to them. It is imperative that the best possible standard of palliative care is provided and that all options have been fully explored in a multidisciplinary, holistic approach to care.

It should be a pre-requisite that counselling and advice on all the alternative options be provided to anyone contemplating assisted dying.

Patients should be given the opportunity to discuss the alternative options available to them, to give a clearer understanding of the scope and range of the best practice available in palliative care, including pain management, as well as fully explaining the assisted dying procedure, covering risks and expectations.

A medication review to discuss polypharmacy issues including minimising the risk of side effects towards the end of life would be advantageous.

We would expect all suitable alternatives to be pursued and exhausted before returning to the prospect of an assisted dying. It is the experience at Dignitas in Switzerland that information and advice can encourage people to pursue alternatives to assisted dying [12](#). Pharmacists have a key role in this aspect of patient care.

Facilitators - We support the concept of an independent facilitator of the person's choosing who would not necessarily be a health professional but would be present to witness the death and aid in all administrative tasks as required. They would complete the multidisciplinary training along with health professionals and be competent in the requirements around safekeeping, storage, security and disposal of the medication being used.

Other factors

National approach - National guidance and protocols would be expected to be in place to ensure that best practice for the procedure is consistently applied across GB with limited variation and based on a sound evidence base for the prescription. We would look at the experience of other countries in developing protocols.

Similar protocols and procedures should be in place no matter in which setting the patient is being cared for. This would include hospital, hospice, care home, the patient's own home and any other domiciliary setting. The protocol should also cover the issue of prescriptions, supply, documented use and return and disposal of any unused medicines.

A robust audit trail is required. Pharmacists from primary and secondary care must be included in any multidisciplinary working group to develop national guidance for all settings. The group membership should also include representation from the controlled drugs accountable officers' network, particularly, as controlled drugs are being considered for use.

Registration with a GP in the country where the procedure is lawful and is to be carried out would also be required.

Commercial interests - One of the drivers for groups lobbying for a change to the existing legislation is that people currently travel to other countries to avail themselves of an assisted dying procedure and this is felt to be an unnecessary burden on patients and their families.

If assisted dying procedures were to be available outside the NHS then there would still be an issue of affordability and accessibility. This form of care is unique and must not conflict

with the commercial considerations of a private sector organisation and therefore we feel strongly it should stay within the NHS.

Patient Care

Having pre-registered their wishes with their GP at some point in the past a person would make a formal request to their doctor at a later stage to indicate that they wish to use the legal process for assisted dying now available to them.

The procedure would require forward planning and the documentation should include a care plan drawn up with the patient to ensure all their wishes are accommodated. This should include planning of all aspects on how the procedure will be carried out, who will be present and any consent required.

Arrangements should be made for access to information and advice on the alternative options available. If the person still wishes to pursue the assisted dying option after exploring and /or making use of the available options, then a final request would be made which would trigger the issue of a lethal prescription and arrangements commenced as per the care plan with a pharmacist and facilitator being approached by the doctor.

Close cooperation between pharmacy and medical colleagues would be required to facilitate all the necessary arrangements and ensure all documentation is in place before any final prescription is presented. The timing and administration details require careful consideration to avoid patients requesting a procedure ahead of their own particular need to satisfy protocol and administrative requirements.

A person-centred approach is crucial for all aspects of assisted dying and people may change their mind from their initial decisions as life becomes more precious to them despite worsening health. It is vital that the person can indicate their wishes until the final moments of their life.

A person's wishes, around confidentiality and the number of people party to the process needs to be accommodated. There should be flexibility in arrangements, to allow either primary or secondary care pharmacists to be involved depending on locality, with consideration given to remote and rural situations.

Families and carers should not be subjected to any unnecessary pressure and stress at such an emotional time. They may or may not want to be involved in the practicalities of arranging a procedure.

The presence of an impartial facilitator would be useful for all practical aspects of the procedure including being an independent witness present at the death. The facilitator would not necessarily be a health professional and should not be a relative or anyone directly involved in the patient's healthcare.

A confidential database, available to doctors when discussing assisted dying procedures with patients, with a list of the pharmacists and facilitators who have opted in would allow patients a choice in whom they involve in this very personal experience. It would allow forward planning, including contingency planning if any of the original personnel were to be unavailable for any reason.

Professional and ethical considerations in Prescribing and Dispensing

It must be remembered that in dispensing a prescription a pharmacist assumes a proportion of the responsibility for that prescription and therefore must be assured that all legal requirements are in place and that it is entirely appropriate for the patient.

The same principles apply for prescriptions for an assisted dying procedure but these do present as a unique situation. Although pharmacist independent prescribers could sign a prescription, we consider in this instance the link to the clinical assessment of eligibility criteria is essential and therefore the prescriber should always be one of the assessors. In addition to the usual practice of checking that the prescription fulfils the necessary legal requirement, pharmacists must have full access to the patient's diagnosis and assisted dying care plan.

Consideration needs also to be given to the handling of all paperwork to ensure a full audit trail, and facilitators will be bound by the same confidentiality requirements as currently apply to healthcare professionals. All paperwork would be seen and processed appropriately before the designated dispensing day. Close liaison between the doctor, pharmacist and any facilitator would be required to ensure everyone involved is kept fully informed.

For arrangements relating to the dispensing, supply, pick up and potential return and safe disposal of medication, it is expected that the pharmacist and doctor would liaise to make all necessary arrangements between them and any appointed facilitator.

Consent issues would be clearly documented in the care plan. Stock of the appropriate medicinal products may not be routinely held in stock but ordered as required for the individual patients. We anticipate that the forward planning required would allow adequate time for the pharmacist to ensure the prescription was available on the due date.

The prescription would be written when the patient makes their formal request (having previously pre-registered) to their doctor and has fully considered all agreed alternative options. As the prescription would be for a controlled drug there would be a 28-day window of validity ensuring time to activate the patient's care plan and make the necessary arrangements.

Thought should be given in planning as to when the prescription will be picked up to allow the pharmacist adequate time for consultation with the facilitator to ensure all pharmaceutical care aspects are considered and that any remaining questions can be answered.

The drugs used for this procedure will either not have a marketing authorisation (MA) in the UK for human use or will have an MA but will, by necessity, be being used off label rather than for the licensed indication. While this should not present any difficulties, the doctor, patient and pharmacist should be aware of this.

Training and Education

In order to balance the needs of confidentiality and access to services, we advocate that pharmacists indicate their willingness to be involved by "opting in" to training and then be listed on a database with access restricted to doctors and those pharmacists and facilitators who have similarly opted in to participate in the scheme.

Doctors would then be able to access the information and identify registered personnel to start proceedings at a patient's request. Pharmacists who do not wish to be involved would not be listed and therefore would not be approached.

Pharmacists would require to be fully competent in the legal requirements of an assisted dying procedure and have knowledge of the necessary paperwork, consent requirements and protocols. Joint training with other disciplines involved would be necessary to give a coordinated approach and common understanding of the process.

It would be advantageous for any training to be holistic in nature and encompass some of the sensitivities pharmacists may encounter in practice. This might extend to the provision of peer support for colleagues or signposting to the Pharmacist Support resource of Listening Friends if required.

This training would also be available to pharmacy technicians. Training would always be optional aligning with the conscience clause but successful completion of the training would be mandatory before any involvement in an assisted dying procedure commences.

Organisations involved in the education and training of pharmacists and technicians namely, NHS Education Scotland (NES) Pharmacy, Centre for Pharmacy Postgraduate Education (CPPE) and the Welsh Centre for Pharmacy Professional Education (WCPPE) would be key participants in supporting the development and delivery of educational packages whilst ensuring a coordinated national approach is adopted across GB.

Palliative and End of Life Care

Palliative care services have traditionally focused on cancer care but there are other therapeutic areas where illness can be terminal and end of life care can be distressing for patients and carers. These include heart failure, chronic obstructive pulmonary disease (COPD) and several neurological conditions.

Hospice beds are not always available and patients die in hospital when their preference is often a hospice or supported home option.

In the other countries where assisted dying has been established, distinct improvements in the quality of palliative care have been recognised and we commend and support this approach.

As a result of the information and advice which anyone requesting assisted dying would have available to them, and in keeping with a patient-centred NHS, we would both support and expect improvements in palliative care to allow equitable access for all patients diagnosed with a terminal illness.

It is however recognised that there are times when even the best palliative care provision fails to give patients an acceptable level of symptom control and the dignified death they would wish for. For these few patients assisted dying, if it was available, may be their preferred choice.

Whilst palliative care specialists have specialist knowledge which will be useful in formulating the protocols and ensuring the use of evidence-based medicines, it must not be

assumed that they would want to be involved in assisted dying procedures, and indeed it could be a conflict of interests in some situations.

Hospice pharmacists might not want to participate in case this raised anxieties among patients and their families or carers around hastening a death. Anecdotally, hospice care is acknowledged as excellent and the pathways already used in palliative and end of life care will, for the majority of patients provide a route to a peaceful death with support available for both patients and their families to come to terms with this end-stage of life.

Established treatment pathways at the end of life should remain quite separate from a formal assisted dying procedure.

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